

## **EFORTT Ethical Frameworks for Telecare technologies for older people at home (Deliverable 3)**

### **WP 2 Ethnographies of Telecare Interventions**

#### ***Work progress and achievements during the period***

**Introduction** – the report below details the telecare applications being examined in detail in each partner country with progress on the ethnographic data collection. In some cases the start of the ethnographies was later than expected due to delays in obtaining ethical committee approval. While this has not resulted in any major deviation from the timetable in the first reporting period, it is possible that we might need to request 1-2 extra months for delivery of the final report of WP2 due in month 27 ie D2). Fieldwork has finished at the time of reporting, analyses are in full swing (see data clinic report).

#### **Ethnographies in Spain**

Fieldwork has been organised in collaboration with the Red Cross-Catalunya and the Red Cross-Castilla La Mancha. 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. Both studies take into account all the places and agents involved in these services. This means that the fieldwork takes place in the alarm centre and offices but also follows the workers' day and the users' home and daily life. Additionally, we decided to carry out some extra in-depth interviews with users, carers and workers from private home telecare service companies. Most of these were carried out in Madrid. These interviews helped us to in comparing public and private services.

In the end, the **SIMAP Service** (Personal Location Service on Intelligent System of Monitorisation of Personal Alarm) had to be ruled out as an object of study because it was a very new system which suffered some delay in starting and there were insufficient users existing in time for our fieldwork phase. Nevertheless, ethnography of the SIMAP Service (in Catalunya) had been developed at its documentary stage. As the SIMAP Service in practice

was delayed due to political agreements between Red Cross and Generalitat (Catalonian Government), ethnographic research could not be realized in time.

Our ethnography of **Home Telecare Service (HTS)** (in Catalunya and Castilla La Mancha) is designed in six different methodological stages and techniques: documentary analysis, observations of the alarm centre, observations with installers, observations with volunteers, focus groups and in-depth interviews. In both places, Catalunya and Castilla La Mancha, 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 funded city councils or users), different health situations and ages of users. In Castilla La Mancha we have only used focus-group methodology with users, users and non users' carers, volunteers, tele-operators and Red Cross workers and also coordinators.

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 compiled and analysed documents about legal issues, design and testing, and we continued observing the work of the Red Cross Organization. We observed the process of contracting with the user, installation of the service and then we researched how it was 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 that will subsequently be interviewed. We have collected field notes and also some photographs and graphical documents.

Observations in Catalunya: we have attended 10 installations, 10 breakdowns, 3 follow-up visits, one change from private to public service, 1 discharge because of decease, 1 track-telephone line test and 1 keys return.

### *Interviews*

We have finished the stage of interviews with Red Cross' workers: coordinators, managers, installers, volunteers, designers and other academic people who work on this field.

Going with installers and volunteers and observing their daily work, we have got in touch already with those users that were interviewed in-depth. This way, volunteers operated during observation as 'key informant' for meeting users and relatives. Once we made the contact through volunteers and technicians, we arranged 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.

In Catalunya, we have carried out 10 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 couple, with relatives or formal carers). These 10 interviews are 6 in-depth interviews users with volunteers and 4 in-depth interviews to users with carers, relatives or living alone.

Related to extra-interviews carried out with users and carers from private HTS companies, we have made 8 in-depth interviews with users, 2 mixed interviews with users and their relatives, 1 interview with a user's relative and 3 interviews with HTS private companies' workers. We also made 2 interviews with technical designers from TECSOS and another one with an academic-engineer, professor in EUITT.

### *Group Discussions*

In Catalunya we have carried out group discussions with two groups of users, one group of volunteers and technicians, two groups of professionals carers (nurses, doctors, politicians/policymakers, social workers), two groups of tele-operators, one group of formal and informal carers (relatives) and two mixed groups (one of them composed by volunteers, users and relatives, and the other one composed by volunteers, users and technicians). In Madrid we have planned one group of users, one of volunteers and technicians, one of tele-operators, one group of carers and relatives and another mixed group.

In Castilla La Mancha we have carried out group discussions with one group of informal carers (relatives) of elder people (not users) in a rural context, one group of informal carers

(relatives) of users in urban context and another one in rural context, one group of users in urban context and another one in rural context, and one mixed group of Red-Cross professionals (volunteers, technicians, tele-operators and coordinators).

Most of the interviews are transcribed verbatim and ready for analysis. Detailed fieldnotes were made. Afterwards, 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 Castilla La Mancha) 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 couldn't start the observation stage of the fieldwork. As this set up depends on the political agreement between Red Cross and the Catalanian Government and this was delayed, we focused on the Home Telecare Service and made a wider analysis of it. That is one reason why we are working in two locations: Catalunya and Castilla La Mancha.

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 8 people in one group. Because of this delay fieldwork progressed more slowly than planned.

### *Results*

Although the analysis is 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 this 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 ‘installed’ (configured) 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.

### **Ethnographies in Norway**

Ethnographic fieldwork has been conducted in four 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.
4. The use of GPS tracking devices in dementia care

Trygghetsnett (SecurityNet) is an internet-based service provided 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 staff from the municipality. This base is open three hours a day, Monday to Friday. The participants, which 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. The use of web-cameras is central in the individual contact, allowing for a different form of interaction than ordinary telephone contact. Two discussion forms are established within the network. These are written forums which members only have access to.

TrygghetsNett was established in 2003 as a time-limited project by the municipality of Nøtterøy in the south-eastern part of Norway. However, due to the overwhelming positive response from the participants, the service was from January 2009 extended to 12 municipalities in the same region. As a part of this expansion two more base stations were established in the region. However, due to technical and organizational problems, this extended service was not fully operative. As of January 2010, Security Net has reorganized again, with only one operative base station at Nøtterøy, coordinating the services for the whole region.

### *Observations and interviews*

Observations has been done by being present at the base station of Nøtterøy, following the (electronic) written discussions of the forum, as well as listening to the conversations the base-staff have with the individual participants. Six field visits have been conducted at this base. Repeated requests for field visits to the new base-stations established in 2009 were made. However, due to technical problems and other practical issues, these requests were never met. Interviews have been conducted with participants, the base-station staff, the project leader, a representative from the administration and ICT developers. Also contact was made with a researcher involved in a formal evaluation of TrygghetsNett in 2006.

Most of the interviews with the participants were conducted over the TrygghetsNett, which implied that it was possible to have face-to-face contact through the webcam. In addition one interview was conducted at the base and one over the telephone. The interviews with the base-station staff were conducted at the rehabilitation centre where the base-station is situated. The other interviews were conducted at the work sites of the respondents. Participation in two

group interviews with participants organized by the local University College as a part of a new formal evaluation of the expansion of the project was planned. However, due to the unsolved technical and organizational issues, this formal evaluation has been postponed.

#### *Other sources of data*

Transcripts from the discussion forums dating back to 2003 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. Interviews were also conducted with the local coordinator of dementia care services, who was directly involved in the trial, and the home-based nurse responsible for the day-to-day follow up. In addition, the project coordinator and responsible technician were interviewed.

Also one field visit was made to the city of Grimstad, which represented a second potential field site for testing out another, slightly modified version of the ICT-based calendar. This field visit involved attending to the kick-off meeting, where all key actors involved in the project was present, and where the new hardware was displayed and tested. In addition a formal interview was conducted with the technology developer. More interviews and field visits in Grimstad was planned, but due to problems with the hardware solution, the project was stopped shortly after. The MPower project was finalized in May 2009.

### 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 alarms and monitoring technology in care of persons with cognitive impairments. The process of compiling the new guideline was expected to be completed in 2010. However, the process has been delayed due to unforeseen circumstances. It is now expected that the guideline will be completed in 2011. 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 completed.

### 4. The use of GPS/tracking devices in dementia care

In Norway, GPS tracking devices in dementia care are primarily used as a private solution; i.e. that the GPS device is a commercial product that is bought on the open market, often by a spouse or close next-of-kin, who is doing the monitoring. The use of GPS/tracking devices as a part of formal care provision is strictly regulated, and such monitoring is subject to extraordinary procedures and the approval of the Regional Health Authorities. However, over the past 1-2 years, there has increasingly been a media focus on the potentials of such monitoring, also as a part of formal care. Hence, increasingly, some municipalities are starting to implement GPS/tracking devices as a part of their care-services.

#### *Field visit and interviews*

Interviews with next-of-kin who have experience with GPS devices in dementia care have been conducted. In addition, two interviews and one field visit involving formal care providers have also been done. Another four interviews with formal care providers are planned, and will be conducted over the next few weeks. Finding municipalities who have experience with GPS tracking devices has been challenging and very time consuming.

#### *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 December 2008. Another major reason for delay has been difficulties getting access to the 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 about services, advice 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 and mainstream solutions (which both SecurityNet and MPower is based upon) make such a difference for the individuals involved, has been most surprising 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.

The key position of lawyers and legal experts is very 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 which is made possible by the GPS device is considered as 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. And for 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 vulnerabilities. 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 maps and complicated technology.

## **Ethnographies in the Netherlands**

Two telecare technologies have been researched in practice; a practice of palliative care using a ‘health buddy’, and a practice for home care where a webcam based system called PAL4 was used.

### **1. Health buddy**

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 as it was used in palliative oncology care. The patients were getting 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 complaints. The aim was to achieve this without extra cost.

#### *Interviews*

With patients, 15 interviews were done. Six of the interviews were with couples rather than the patient alone, and one widow was interviewed. All respondents were over the age of 50. The oncology nurse was interviewed several times: twice face to face, frequently on the telephone. Also, members of the project team were interviewed, such as the responsible specialists in the hospital. The interviews are typed out 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 asking her to 'think aloud'. Also, the project team was regularly attended. Detailed fieldnotes were made. A report will be written for the hospital, which may use this in its discussions with financial partners.

## **2. PAL4**

A second fieldwork study was conducted into the use of the web based system for video communication (with nurses and informal carers), PAL4. The system also hosted a range of other services (short clips, shopping, entertainment, information about the neighbourhood, etc). The aim of this project was to enable older people to assist each other and to lower the threshold to ask for care by 'wrapping it' with other kinds of services. The system is used in several homecare institutions spread over the Netherlands. The fieldwork took place in collaboration of three homecare institutions mainly in the Midwest and south region of the Netherlands (Utrecht, Woerden, Delft, Breda and Schiedam).

### *Interviews*

We interviewed 13 individual users. One interview involved a couple and one involved mother and daughter. All the users were over the age of 50 with one exception of a 15 year old patient and her mother. Of the 13 interviews, five interviews with Pal 4 users were with patients with severe Chronic Obstructive Pulmonary Disease (COPD). Most of the other users were patients as well, but PAL4 was given to them to prevent social isolation. The users belong to 3 different homecare institutions. Four professionals were interviewed: one nurse for COPD patients, a neighbourhood nurse together with a screen-to-screen care consultant, and one program manager with background in nursing.

Four meetings with Pal 4 producers were arranged. During the meeting intentions and progress of the producers were discussed, and results of the research were fed back to the producers. One meeting hosted the producers as well as the participating homecare institutions. All interviews are typed out verbatim and ready for analysis.

### *Observations*

Observations were made during interviews with the Pal 4 users at home. Screen contacts were observed between Pal 4 service desk employees, one COPD nurses and one other Pal 4 users.

### *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 to cause no harm or distress in their work. For this study a privacy protocol was devised and implied that patients 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. In the Pal 4 research site users were contracted in agreement by the producer and homecare institutions.

### *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 progressed somewhat longer than planned. Fieldwork in Friesland was conducted between January 2009 and July 2009, with a presentation of the results to be done in June 2010. Fieldwork in the PAL4 site took place between November 2009 and April 2010.

### **Results**

Results of the ethnographies and the analysis of the interviews is extensively reported in the document for WP4: the dataclinic. Below we highlight some of the results specific for the Netherlands.

### **Health Buddy**

What was interesting in this project 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 seems particularly ambitious.

The 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. By some, the questions asked over the HB were experienced as ‘too confronting’. It is pivotal for a proper working of the device that people should be able to refuse its use.

#### **PAL4**

In the Pal 4 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 an enormous increase in the frequency of the contacts, which would have been once every three-four months before the use of PAL4. The patients were happy for having their questions answered fast, and by having solutions suggested to them to deal with their complaints. Generally, patients felt safe and secure because of the system. Most users appreciated the distraction offered by Pal 4, 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 along 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.

<b>Ethnographies in England</b>
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The Lancaster University 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, either in group or individual interviews: county-level managers; project leaders; county and local telecare 'champions'; social workers; leaders of local carers' and older people's groups; and technology providers (23 interviewees). We have interviewed 7 older telecare users and/or their carers. We 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); home visits by social workers to older people in connection with telecare (5 visits); telecare installations (3 visits); regular meetings of the county's Telecare Steering Group (8 visits); a promotional event hosted by a key telecare provider; a telecare project evaluation conference held by Northshire; and a training day promoting telecare to social workers. We observed a national policy forum on telecare. We have visited three 'Older People's Forums' in the Northshire area and an Asian Carers' Forum, and have had guided tours of two local 'Smart Homes'.

### *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 deviations from the work plan as stated in the proposal and we have met our stated objectives.

#### *Results*

We are in the process of analysing and writing about our results and presenting these at conferences. In publications 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.