EFORTT

WP3:

Citizens’ panels, older people and new technologies of care

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Introduction

The EFORTT project was designed around two axes of investigation: deliberative and ethnographic. This document reports on the deliberative axis, which consisted of two rounds of citizens' panels in each of the four partner countries (The Netherlands, Spain, England and Norway). The citizens' panels were constituted of older people and carers who were not otherwise involved in our research project.

Over the course of two meetings (approximately 22 months apart), panel members reflected on the issues at stake in the field of telecare for older people living at home and they provided critical and engaged reflection on the findings of the EFORTT ethnographic work (reported for WP2.) The aim of this deliberative axis was to provide a set of *citizen responses*. We conceptualize these panels more as policy forums than user forums: they offer independent critical views on issues of significance to EFORTT and to those working in related policy fields.

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

Panel members, as the more detailed discussions below indicate, were also very aware that the introduction of telecare systems may have profound social effects: not only for individuals and their families (what might it mean for an adult son or daughter to be contacted in an emergency, or for them to be able to view or track one's movements on a screen?), but also for communities and societies.

Our panels were adamant that ethical and social questions should be considered in tandem with technical, political and economic ones, and were very keen to be involved in *all of these discussions*. Indeed, many stated that they welcomed the opportunity to be involved in the panels and to be recognized as citizens who had the time and the desire to make a meaningful contribution to these debates.

Table 1 briefly describes the citizens' panels convened as past of the EFORTT project. The panels were arranged in two phases: a) Introductory: to familiarise groups with the aims of the project and the changing nature of care and potential role of new care technologies, b) Follow–up panels: to outline the preliminary findings from the EFORTT ethnographic work, to obtain feedback on those findings and to develop principles for the development of an ethical framework for telecare technologies.

INTRODUCTORY PANELS

COUNTRY	DATE	PARTICIPANTS	COMPOSITION
England	14/07/08	8	Older people
England	11/08/08	10	Older people in independent assisted accommodation
England	26/05/09	8	Informal carers
England	11/09	6	Older people/ informal carers
England	12/09	6	Older people/ informal carers
Netherlands	10/11/08	8	Older people
Netherlands	24/11/08	5	Informal carers
Netherlands	02/12/08	7	Informal carers
Norway	08/09/08	6	Older people
Norway	10/09/08	8	Carers
Norway	29/10/08	8	Older people/carers
Spain	19/07/08	7	Older people
Spain	19/07/08	4	Carers

FOLLOW-UP PANELS

COUNTRY	DATE	PARTICIPANTS	COMPOSITION
England	10/06/10	15	Older people in independent assisted accommodation
England	10/06/10	5	Older people/ informal carers
England	18/06/10	14	Older people/ informal carers
Netherlands	12/05/10	7	Older people /informal carers
Netherlands	17/05/10	8	Older people /informal carers
Norway	16/06/10	5	Older people
Norway	17/06/10	3	Carers
Spain	26/07/10	9	Older people
Spain	26/07/10	9	Carers

This report details the process and outcomes of the panels in each country and a brief analysis of the strengths and weaknesses of the citizens' panels as a research method in this particular context. Although we sought to replicate the same process in each country, there were some local differences in the constitution and running of the panels which have a bearing on the findings: hence our decision to start with country-specific reports.

The Netherlands

Organisation of the Introductory panels

The panels started by asking for the participants' notions of good care and problems they anticipated or wanted to see solved. This was to foreground needs rather than technologies. Telecare 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.

A 50 euro book token was given to all participants and a lunch was served at the start of the meeting. The meetings were digitally recorded, a report was written on the spot and the recordings were transcribed by the project assistant.

Significant findings

Introductory panels

- A first conclusion is that citizens' 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 on *medical* technology (which is the main 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 rule.
- Some participants were really 'hungry' for *any* kind of telecare, although most argued for telecare that was flexibly tailored to individual needs.
- *All* participants 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 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 current policies and ideals of staying at home for as long as possible. Wearable alarms were the forms of telecare that got most enthusiastic responses, although people detested the design (the devices are ugly and should be shower proof). People felt they needed someone to turn to for support when there was trouble.

- Privacy considerations were often superceded by this fear of being alone and having an accident. One respondent said: “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 older and new forms of privacy were made. Some participants expressed a reluctance to be looked after by many different persons in their house, and would then rather be watched over by a web cam, not having to meet their various observers. They would see this as a reclamation of their privacy. Or with Geographical Positioning Systems following people with dementia: the possibility to go out alone, being tracked by GPS, is traded off against having to be accompanied all the time, which is experienced as much more intrusive.

- *All* participants were concerned with 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 much 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 the house 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 families

- The informal carers expressed the fear that the persons they cared for would not be able to use a computer/ICT technology.

- Dependency on technology is sometimes experienced as unreliable: what if the electricity supply 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 in their care work, should the information transmitted be unreliable. Likewise, the reliability of internet based information is questioned.

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

- The difficulty for people with dementia to use telecare devices 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 older people to drink was also thought of as helpful.

Organisation of the Follow-up panels

The meetings were organised to discuss the preliminary findings from the ethnographies. Also, the findings from the introductory citizens' panels were fed back to the participants, and some results from the other countries were also presented.

Two telecare projects were discussed in detail:

- a webcam project used by homecare organisations (PAL 4).
- telecare in palliative care for people with terminal cancer (Health Buddy).

The discussion focussed on four ethical issues arising from the material:

1. Should telecare have specific functions, or are general systems better? Related questions were whether people preferred to have their telecare on their home computer, or on their television, and how this would influence one's 'feeling at home'.
2. Does telecare imply more or less work for informal carers?
3. Is technology de-humanizing care and what to think about relations between telecare technologies and care?
4. Telecare and privacy: does telecare disrupt privacy? Or are there different forms of privacy (strangers coming to the house as paid carers, versus strange devices in the house) some of which are more important than others?

Follow-up panels

General remarks

After the presentations the panellists worried that all these devices and data would take an enormous amount of time from formal carers such as nurses. Apart from this being bad for healthcare workers, the panellists worried about the independence of the patients: would this not take their independence away?

If monitoring could be delegated to devices, perhaps people could spend more time with personal contacts.

The PAL4 web based telecare with its many functionalities could be a great antidote against loneliness, and this is an important problem among older people and people with chronic diseases.

Producers of telecare devices should stop thinking that older people are incapable.

1. General or specific?

The more functions in one device the better, especially if people have small houses. It is best to start learning to use this device gradually, and add more functions when the patient needs them. This could be a smart-phone, but there are also concerns that very old people may not be able to use this. It should be easy to carry, wearable rather than hand-held. The television is another option: everyone has one. The difficulty would be to separate health/clinical matters from the latest football match.

A portable e-book might also be a solution. The motto should be: give the people what they need, and don't bother them with other things.

Telecare should provide an alarm function.

Others stress that it is pivotal for frail older people to be distracted from their ailments. One panellist was adamant that a device that confronts the patient with disease is bad.

2. More or less work for informal carers?

Respondents from panel 1 agree that it is more work: but this is just what they wanted! They live at a distance from their parents and want to look after them better. Less worries, more care! (in Dutch this is: meer zorg, maar minder zorgen!). Telecare could help keep track of the medication usage for forgetful patients.

3. Is technology de-humanizing care and what to think about relations between telecare technologies and care?

As in the Introductory round, panellists insisted on the importance of personal care: this should never be swapped for devices. One should be able to touch the other at least some of the time. Telecare could assist these contacts and deepen them. The panellists were not really worried that a nightmare scenario would unfold, and stressed the resilience of the older generation.

Others feel that care is already well on the way to becoming impersonal. They feel they are ‘a number on a list’ already, and they are very concerned about this. They see a problem where it comes to signalling that a person has problems; this can be best done on home visits. There was a concern that telecare might be a way of making nursing staff/healthcare workers redundant.

4. Does telecare disrupt privacy?

Devices may be switched off. A panellist who had experienced dependence on many different carers had felt a great loss of privacy. (If controlled from the house) a webcam may be switched off and does not have to be positioned in the kitchen. There are worries about what will happen to data that are collected. Another great advantage of the webcam or sensor might be that you do not have to tell the same story again to the next carer.

One panellist thinks that ‘obtrusive questions’ such as those asked on the Health Buddy, are a form of invading privacy. Not just anyone should be allowed to read the answers.

Others feel that their privacy is already so much disrupted that it cannot get any worse. Even the supermarket knows whatever you buy! They feel a balance has to be made between safety and privacy: people with dementia should sometimes use devices that ‘healthy people’ would find disruptive.

England

Organisation of the Introductory panels

Following introductions, the facilitators explained the EFORTT project briefly and gave a short presentation outlining the history and uses of telecare to date and examining possible what future developments. 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:

1. How do new care technologies shape, and get shaped by, care practices?
2. How do they define good care and how do they re/distribute tasks and responsibilities?
3. 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 second panel held towards the end of the research period to see and comment on the findings of the team.

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 care costs where these were needed: two participants asked for this help. The meetings were digitally recorded, and the recordings were transcribed by the project officer.

Significant findings

Introductory panels

- Telecare users themselves are usually frail, elderly, and unable to travel far; the carers are often restricted by their caring responsibilities; thus both groups are likely to be excluded from deliberations about new care systems. Telecare users are often also carers or former carers. The over-riding fear expressed by panel members was that telecare might become used to replace ‘human carers’ and that it would lead to increased social isolation and possibly depression amongst older people. 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 there was mistrust that costs would remain affordable. The users and potential users were vehement that they would wish to remain in their own homes and not live in residential care homes.
- 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 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 or understand how the technologies worked.
- 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 health readings, could heighten users' anxieties. 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 e.g. 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 for older people while others thought they might be entertaining and companionable.

Organisation of Follow up panels:

Each of these panels followed a similar schedule to the Introductory panels. Members of the research group gave a presentation giving a brief resume and explanation of telecare devices followed by some of the study findings so far. Panellists were invited to question or comment on the findings in the light of their own experience. After lunch panel members divided into smaller groups (5 or 6) with research team members and were asked for their suggestions for an ethical framework for telecare. The panel then re-convened and each group contributed to the final discussion outlining the suggestions and conclusions they had made. These were recorded and collated.

Significant findings

Follow-up panels

We asked members to develop a list of conditions for ethical telecare, the following is a summary of the three panels' discussions.

- Personal face-to-face care is the most important element of care. Telecare should not be a substitute for this. It runs the risk of increasing isolation and is not a solution for loneliness. There needs to be a balance between telecare and personal care. Telecare cannot perform practical care tasks and is not suitable for people with later stage dementia. The alternatives to telecare (moving to a care home, for example) need to be made more attractive.
- Telecare should maximise the freedom of users: they should be in control/ able to turn devices off (except perhaps in cases of early dementia when this may endanger the user).
- Telecare can provide some peace of mind to carers and can be part of taking care of carers (which is very important). It is seen as appealing by some carers, who reported that they were able to sleep better knowing that the older person had a bed sensor or that the house had a door exit alarm, for example.
- Telecare needs to be individualised and chosen by the user. It must meet the client's needs, not the provider or manufacturer's needs. It must be suitable for older people and must take into account issues around language and cultural differences, disability (including common disabilities like hearing and sight loss,

for example) as well as early dementia. People want to be able to choose where technologies are placed in their homes – they are often put in the wrong place. Installers should be very careful about the placement of ‘key safes’ on the outside of the older person’s home, for example, which can identify an older person as vulnerable.

- Older people should be included in the design process – they have lots of good ideas and plenty of time to contribute. Researchers should speak to designers and manufacturers too.
- The response to telecare alarms must be timely, appropriate and reliable.
- Call centre staff need thorough training and appropriate support.
- The systems need to be explained well to users, (this could be done through dramatised examples). This needs to be repeated more than once and could possibly be done by volunteers from appropriate voluntary organisations (although some participants thought they should be paid). There needs to appropriate follow-up after installation.
- Users must be sure that the information gathered about them will not be misused. They do not want the information to be made available to adult children, but it may be acceptable for data to be shared with medical practitioners. Some were worried that telecare has the potential to disturb families, to cause arguments and rifts. There are strong concerns about the range of carers’ skills and behaviours: they need to be trustworthy and there should be clear procedures to use when things go wrong.
- The use of cameras is not appropriate. Some feel that sensors are also inappropriate, although others can see their value. Some only want technologies that they can control: ‘it has to be guided by me’.
- There was debate about how telecare should be paid for. Some think it is okay for users to make a contribution or fund it themselves, others think the state should provide this care. It was noted that governments may benefit from telecare if it reduces care costs. Participants are concerned that people who have saved money all their lives may have to pay, whilst others, with fewer savings, are not asked for a contribution. Self-directed care (the introduction of personal care budgets) is not appealing, but rather daunting.

Spain

Organisation of the Introductory panels:

EFORTT project introduction: Citizens' Panel program was explained and also a brief introduction to EFORTT and the GESCIT Research Group. At this stage any queries about the process were answered.

Home telecare presentation: A video and power point explaining a telecare example, the Red Cross Home Telecare Service, was shown to participants to introduce them to the research fieldwork.

Presentations and discussions were organized in three different parts. Each of them started with a brief introduction from EFORTT Team and was followed by a round of opinions and explanations about personal experiences. Then, there was a group discussion and a final discussion with conclusions and summary.

Topics and questions discussed:

1. What is your opinion about home telecare systems?

2. Which benefits and risks (limits and possibilities, negative and positive points) do you think this kind of intervention has for users, caregivers and also for the Health System?
3. In which circumstances and cases do you think telecare systems are appropriate or not? In which cases would you recommend it or not (conditions of use, health status, combinations of devices and forms of caring)?
4. In which places and living spaces do you think telecare is appropriate and when would you recommend its use?
5. What should future developments in telecare devices have to take into account? (Commodities, needs, types of users, ethics, economic conditions, access, design...)

Significant findings

Introductory Panels:

Older people:

HOME TELECARE USERS AND CARE RELATIONSHIPS

- The entry of private companies into telecare market is already perceived as a potential threat by some users: devaluation of the “social” part of social-health services and increase of “management” solutions.
- Hiring telecare service doesn't cancel or shouldn't cancel family and personal care relationships but may make the presence of a carer unnecessary. There is a consensus in the ideal/desire of staying the maximum time at home and trying to give the older people autonomy. Even though they may live in an old people's home, participants would value independence (individual rooms) and autonomy, (the freedom to come and go as they please).
- Life together with other older people, whether it is in an old people's home or in sheltered apartments, is not positively valued because it makes people see themselves in a negative way, as “ancient people”.
- About domestic caregivers: it requires an effort of mutual adaptation; there are some difficulties in finding the “appropriate” person (in terms of good connection between cared-for and the care-giver) and a high economic cost.

BENEFITS AND RISKS OF HOME-TELECARE SERVICES

- General consensus that telecare services are beneficial. The speed in response and device's reliability are positively valued: although calls are usually answered quickly, responses to emergencies take too long. Home-telecare service is good for support and companionship. It monitors the state of mind and user's health by means of, for example, controlling medication. It gives company, protection and security to users and to their relatives.
- Perception of danger from radiation emitted from the terminal, especially from the pendant (over the body or near the bed).

CONDITIONS FOR USE OF TELECARE SERVICE

- Reasons for getting the service are related to a perception of being threatened (by a “fright”), to reducing risk or to isolation, more than because of the advanced age or an illness.
- Resistance to using the devices: some people don't wear the pendant because they are afraid of getting it wet 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” (bothering) the service. They would rather call their families than the telecare service.
- Telecare service would be recommended for any person who lives alone, who is ill or frail, even if young, and for older people who have some help from a career but who are not covered for all 24 hours, especially at night. For older people who live together it is not perceived as so necessary because one of them could alert services to the emergency.

FUTURE DEVELOPMENTS

- Some resistance to the use of technological devices in general
- Although using video-cameras at some buildings' entrances could help as a security device, the use of video cameras as part of telecare-service is negatively valued due to the fear of being controlled and invaded in their personal and private space
- They think that telecare service is really easy to use, although it can be uncomfortable especially if they have to wear the pendant while they are sleeping. If they turn over in bed, the pendant moves and disturbs them.
- They suggest the development of a bracelet that incorporates some location system that could indicate to the user where he/she is at that moment. Because it would be permanently connected to some location network (by GPS), there wouldn't be any risk of getting lost.
- They propose that the earphones and microphones in telecare devices should have enough range to enable talking from any place at home. It could incorporate the microphone “on the pendant” and thus avoid talking from the device's terminal.

- They propose the design of a mobile device with capacity to detect any anomaly. It could integrate several sensors and measures, as happens with universal remote controls.
- They consider that every house, especially new buildings, should have gas and fumes detectors.
- They demand aesthetic criteria for technological design of devices.
- They demand usability, comfort and simplicity criteria: easy-to-use and understandable devices, easy to wear.
- Universal accessibility and social economic criteria: they want devices to be within reach of all kind of income levels.

Caregivers:

HOME TELECARE USERS AND CARE RELATIONS

- Telecare service can be reassuring but can never replace affection and care among human people. Lonely people need other people for company, conversation, help.
- General deterioration of care relationships (for example, neighbours' mutual help and family. Increasing individualization forces society to adopt this kind of measure. There should be research about how to change people's attitudes (for increasing co-operation, mutual help, collaboration...). Instead of promoting social networks, telecare technology promotes individualism. If loneliness has been detected as an actual need/problem and it has been caused by these devices' adoption this situation may increase the very problem that tries to mend.
- Participants ask for the reasons for so much control and security: for prolonging our lives? Our health is so good that when we arrive at old age we are physically healthy but ‘neurologically sick’.
- On the other hand, at certain ages and after accepting that you are in need, security is more important than feeling of control or intrusion.
- The ideal and more useful option is to have some close caregiver, but when this is not possible, telecare service is really useful.

Conceptions about Telecare service

- It is considered as one more caring tool. It can be considered as a compensating tool for lack of health, company or family. It's more valued as a health resource than as a social resource. (This part 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.

Good care definitions

- Good care is that which attends to a frail person's needs (affective, living...) and tries to make them happy.
- Care definition depends on cared people's perspectives about well-being.
- The concept of "care" is something new: 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

- **Risks & Shortcomings:** To be able to use telecare older people must not have any kind of neuro-cognitive limitation. There is also doubt in case of severe hearing problems. There is a "gap" in the service in the case of people with cognitive or hearing impairment. A user needs to be conscious to be able to press the button, people must have some autonomy. Service doesn't work outdoors (not enough range in case of big country-houses). It is difficult for some older people to learn how to use telecare. The service is not promoted enough.
- **Costs:** Economic and social criteria for applying for a financing service are very strict. If somebody applies for the service, it can take a long time. Participants think that private companies' entry into this caring market may deplete quality of telecare services because it is commercialized: it may mean changes in staffing levels, neglecting attention and quality, more relaxation of training requirements. When municipal institutions are diminished and there are a lot of demands, they

subcontract private companies. It makes them lose control, capacity to evaluate and track quality of services (accountability). There are some risks of losing personal information or poor data management. Hiring telecare may result in families giving less care and attention to the telecare user.

- **Benefits:** It can (sometimes) control users' medication better than “present” caregivers (because of computerized dispensers). It gives peace to users because they are afraid of falling and not being helped. It provides company. It provides security. In relation to the Public Health System, offering this kind of service could involve a big financial outlay initially but then, it could probably mean saving money.

CONDITIONS FOR USE OF TELECARE

Telecare service would be recommended to:

- Autonomous older people living alone. Caregivers whose dependants and relatives need constant attention but they themselves need to go out for short periods. It could mean some change in women carers lives because it may give them more time, may give them peace of mind,...it is helpful because it lets them have their own lives and makes compatible different aspects of carers' lives. Older people with caregivers because it can also be useful for carers in case they have to call for an emergency (they can get faster attention than trying to get it on their own). People who need constant care. Older people who don't want to live with a domestic caregiver.

Telecare service would be recommended in case of:

- Cases of emergency, falls, isolation. - In rural contexts, it can also work as a security service, especially in relation to emergency and transportation. The ideal situation is being able to choose those devices that can respond specifically to each person's needs.

Telecare service would NOT be recommended in case of:

- In case of loneliness: the most advisable option is to take up time with activities. Another option is calling the “Hope Telephone” (similar to the Samaritans in the UK), but not hiring telecare services. -People who live in an old people's home; they are assisted by health staff.

Possible resistance:

- Generally, when first confronted with change, older people reject any kind of innovation. Technology is perceived as cold and distant. Resistance to using telecare services may be due to the fact that it is difficult to accept the loss of autonomy and privacy. The requirement to hand over the keys to their home can be perceived as a hurt or loss of identity because this object (also money and ID card) are thought of as a symbolic representation of identity. It must be difficult to give something that belonged to you for so long, even more so when you don't know exactly who is behind the service. They know they are going to be safer but they distrust custody of their keys by someone else.

About hiring the telecare service:

- It should be the users themselves who decide to install it or not, even when the service is already included in social rented apartments. If that is not possible, relatives should do it. They think that most of people prefer to live alone while they are healthy and autonomous, even if they have enough money. In these cases, they prefer to hire a cleaner rather than a caregiver.

FUTURE DEVELOPMENTS

- Smart homes don't need users' intervention to be activated and so this widens the possible range of users.
- If the user is able to decide whether to use this kind of system, there is no ethical problem. However if users are unable to make this choice themselves they may also need a carer. In this case, if they need a carer's services, they are no longer independent and autonomous so, the use of this kind of telecare makes no sense (is not appropriate) for them.
- One participant thought it would be sad to live in a “smart” house.

Suggestions

- Improving research about “emotional” technology: a mobile phone can be thought as an “emotional device” because it makes it possible to maintain social networks.

- Easy-to-use criteria: devices should not require a lot of changes in the user’s habits and daily life.
- Technological developments addressed to clinical/medical needs are better valued than those designed for social fields.
- It would be necessary to protect personal data used by informational devices.
- When users sign the contract for telecare services (especially those where health and personal data are constantly monitored) they should be informed about all conditions and consequences. To what extent is somebody accepting technology without knowing everything it implies? To what extent is the decision of adopting a technological device the users' decision or family's decision?
- The use of video-conferencing (webcams) in telecare systems is positively valued because it can be perceived as more personal by older people. But it might confuse dementia sufferers.

Organisation of follow-up panels:

EFORTT project introduction: Citizens' Panel program was explained and also a brief introduction to EFORTT and the GESCIT Research Group. At this stage any queries about the process was answered.

Home telecare presentation explaining Red Cross Home Telecare Service and other kind of telecare devices (alarms, ambient sensors, tele-health and smart homes) was shown to participants in order to introduce them to all EFORTT research fieldwork.

Preliminary findings from the ethnographies were presented, using pieces of fieldwork data to illustrate them. After explaining these, we asked about ethical questions in group discussion: Is it good or bad? In which cases and circumstances? How should it be?, etc...Then we asked for some proposals and recommendations, taking into account the available information and their experience.

Synthesis and conclusions: during the lunch, UAB team worked on summing up the principal ideas from older people’s and caregivers' panels. We tried to express and translate these ideas in some ethical principles and recommendations. These were then shown to both panels, debated and clarified in order to end up with a proposal for ethical telecare.

Nine ethical principles were obtained from the Follow-up Citizens' Panels. They are a synthesized summary from discussions of the older people and caregivers' groups.

1. Telecare systems must consider the users as the focus of the service and take into account their regular care and support network:
    - Evaluation of needs (personalized service)
    - A decision reached by consensus with relatives
    - Active participation in service and its design, implementation and evaluation.
2. Telecare systems must promote aging in place while that is possible, but always accompanied by the promotion of establishing new ties and the reinforcement of previous ones.
3. Telecare should be accompanied by an awareness of gender and age diversity on caring provision.
4. Telecare development should promote security and autonomy, and at the same time the capacity to decide about their own care and conditions.
5. Every telecare service should assume that care relationships are reciprocal and mutual support exists between carers and cared-for people.
6. Telecare must acknowledge other caregivers' responsibilities and abilities and offer them support and help in case of need and emergency.
7. Telecare establishment must include a clear basis of usage guidelines and also give sufficient information about them to every agent involved in care.
8. Telecare's implementation must not turn care into a routine, mechanical and fragmented obligation.
9. Telecare should not give a response only to welfare and health emergencies, but it also should offer response to the need for social support and companionship.

Norway

Organisation of the Introductory panels:

Each panel started with a welcome introduction, and a presentation of each of the participants. The EFORTT project was introduced using overheads. The presentation and structure of the panel meeting used the English PowerPoint presentation as a model. This presentation included an introduction to telecare. The main emphasis of the panel meetings was on the following questions:

1. How would you define good care?
2. What are your views about the introduction of remote care technologies?
3. What benefits and risks do you think telecare interventions pose for patients, carers and health care providers?
4. Are there circumstances in which telecare is particularly appropriate (or inappropriate)?
5. Are there locations in which telecare is particularly appropriate (or inappropriate)?
6. What principles would you wish to see underpinning tele health care developments?

All panels were recorded.

Organisation of the Follow-up panels:

Prior to the Follow-up panel meetings a six-page summary document (derived from the EFORTT ethnographic work) was sent to all the panel participants.

1. Telecare implications: new tasks and changed care relations

    - Telecare does not work without a network
    - New forms of care?
    - Telecare produce new tasks
    - New roles?

2. Making telecare work in everyday life involves creativity, adjustments and surprises

- People decide themselves when they want to use telecare
- Some people do not understand the devices
- Some people feel pressured to accept telecare
- Some people ‘misuse’ telecare

Relevant quotes were translated and included in the document. In addition a brief introduction of the EFORTT project was given.

The first part of the meeting was spent going through the summary document, discussing each of the findings in detail. This culminated in a discussion of the three main questions:

1. What kind of society are we making with telecare - what kinds of things would make a telecare system ethical or unethical?
2. Can telecare contribute to the provision of good care for older people living at home?
3. What kinds of limits, conditions, regulations, consultations, agreements are needed?

Significant findings

What benefits and risks do you think telecare interventions pose for patients, carers, healthcare providers?

All panel members (both Introductory and Follow-up) agreed that the use of telecare technologies involve both potential benefits as well as risks.

Benefits

In particular at the Introductory panel meetings (older citizens and carers panels) much of the discussions were oriented on the potentials of telecare technologies on patient safety and security.

- Providing the necessary safety also has potential benefits for next of kin and formal carers.
- The issue of safety as a potential benefit of telecare was also discussed at the second panel meetings (both older citizens' panel and carers' panel).
- One participant of the Introductory carers' panel also mentioned increased social contact as one of the potential benefits of telecare technologies, as patients may be able to get in touch with others in the same situation. There are examples of how telecare technologies link groups of patients through an internet-based service.
- One of the participants of the Introductory carers' panel had hands-on experience with telecare as her husband, who is suffering from dementia, was a part of a trial project with GPS technology. According to her, the GPS device gave both her and her husband freedom and a new life.
- More efficient services were considered by both the older citizens' and carers panel participants as a benefit of telecare for the formal carers. This issue was discussed at both rounds of panels. In particular it is expected that the use of telecare technologies may replace some of the 'mundane duties', such as checking and control tasks.
- An expected benefit for health care providers which was mentioned in *all* the panels was cost-efficiency.

Risks

The issue of potential risks of telecare technologies was discussed at all panel meetings. At the introductory panel meetings, this issue was discussed broadly, whereas the Follow-up panel discussion was more specifically related to the findings presented in the summary document.

- The Follow-up panel was in particularly concerned about the role of informal carers (next of kin, friends and neighbours). This concern was seen in relation to the UK and Spanish ethnographic material; of the responsibilities imposed on the informal carers as responders of the alarms.

- Many people in Norway live in a different part of the country than their family members. This also put some restrictions on the involvement of family it was pointed out.
- The issue of user friendliness was also a main concern at both rounds of panels: Poor user-friendliness is seen as a potential risk for carers, both formal and informal.
- The high turnover of health care workers poses another challenge/potential risk in ensuring proper training in how to use the equipment the panel members agreed.
- In the different panels there was also considerable concern about the huge amounts of data that will be accumulated about the patients/users through the use of telecare technologies.
- The panel members (Introductory and Follow-up) discussed a number of circumstances where telecare technologies may be appropriate, such as in dementia care where the patient is wandering (1st carers panel), and in care for persons with chronic diseases, such as COPD. Telecare may also be appropriate in circumstances where the person feels unsafe and anxious. In these discussions the needs of the next of kin were also taken into consideration. Hence telecare technologies may also be appropriate in order to reduce anxiety and burdens experienced by next of kin.

Most of the time the panel members spent discussing circumstances where the use of telecare technologies may be inappropriate. The 1st carers' panel mentioned two circumstances when telecare was considered as unsuitable, the first being psychiatric illness. The second circumstance that was mentioned as particularly inappropriate was situations where the person lives with others. In such situations the person's needs for monitoring may conflict with the need for privacy of the other members of the household.

Also, the use of telecare technologies is inappropriate if it is in opposition to the person's expressed wishes, the panel members agreed (introductory and Follow-up panels).

The following principles are extracted from transcripts of all the panel sessions. Six principles were identified:

1. “The basic principle must be humanity; that the needs of the individual is considered, and that the technology is adjusted according to these needs” (GL/OP/P1).

This quote is taken from the 1st older citizens’ panel sessions, but reflects also the discussions of the other panels (both Introductory and Follow-up). According to this principle the basic needs of a person needs to be met before telecare is to be considered. From the discussions it is somewhat unclear what is meant by ‘basic needs’, but the main point is that telecare technologies are a supplement and not a replacement of necessary human care. Some of the panel members pointed out that telecare may also increase the possibilities for human care.

2. The need for telecare should be continually assessed

This principle is closely linked to the issue of humanness, and must be seen in relation to the very restrictive policy on telecare in the Norwegian context. The panel members pointed out the need for flexibility in deciding on whether or not to make use of telecare technologies. It should be possible to change one’s mind. The assessment itself needs to be based on principles of user involvement, they all agreed. And, preferably, it should involve different professionals. The provision of adequate information is a part of this.

3. Training of formal carers

Many of the panel members voiced a concern about the high turnover among (formal) carers, and about the large number of non-qualified workers. This was in particular an issue in the older citizens’ panels (both Introductory and Follow-up), and involved the exchange of stories based on own experiences. Ensuring proper training of formal carers in how to use telecare equipment was hence considered as an important principle. This training should include not just the technical aspects of the telecare devices, but also the ethical component.

4. The technology should be accessible to everyone

This is an issue that was first and foremost discussed at the Follow-up panel meetings, and involved both the carers' and the older citizens' panels. In Norway there is a State financed system for distribution of technical aids for disabled people. However telecare technologies are not defined as technical aids, and are therefore not accessible through the State system. Today it is the municipality that has to finance telecare installations, and it is not widely used (which is also related to the strict regulations).

5. The technology must be user friendly and flexible

The need for user friendly and flexible technology is another principle that the panel members broadly agreed. The technology must be simple enough for patients and informal carers to use. The issue of flexibility is related to patients and informal carers feeling that they have some influence over the technology; over how it is used. This is particularly important when web- cameras are in use. So it should be possible to control the use of cameras and other forms of surveillance from the patient's (client's) home.

At the same time it was also recognized that being able to switch the system off may also compromise the feeling of safety for some of the patients and next of kin, as some patients/users may forget to switch the system back on again.

6. Formal agreements must be in place to secure patient safety

A final and important issue in the discussion of principles was the need for procedures relating to the storage and use of information that is accumulated through the use of telecare technologies. This principle is closely linked to the issue of information and user involvement.

A brief description of the panel members' reaction to the ethnographic data presented in the Follow-up panels

A summary of the main findings of the ethnographic material was sent by e-mail to all the participants approximately a week before the panel meeting. Most of the participants did therefore arrive well prepared for the Follow-up panels. This made it possible to get very fruitful discussions at these meetings.

Most of the panel members had no hands on experience with telecare technologies, and getting an insight into the details of the ethnographic material opened up some of the complexities related to the use of these technologies. Compared to the Introductory panel meetings, the Follow-up round was therefore less dominated by discussions of the pros and cons of these technologies. Hence the discussions were less polarized.

Some of the EFORTT findings clearly surprised the participants, such as the amount of (predominantly administrative) extra work involved in the Dutch example of the Health Buddy.

A BRIEF REFLECTION ON THE CITIZENS' PANEL PROCESS: HOW IT WORKS AS A WAY OF RESEARCHING WITH OLDER PEOPLE

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

Benefits of citizens' panels

Deliberative panels of older citizens facilitate a more 'horizontal' approach to research. They create spaces in which participants can not only learn about a specific topic, but also question, express doubts, agreement and differences. Unlike research designed to use more traditional interview or group discussion techniques, research which involves citizens' panels creates both the time and space for greater dialogue between the researchers and research participants. In our specific research project, citizens' panels proved highly effective as a means of getting older people and carers to engage in discussion around their wants, needs and aspirations for care – both now and in the future as well as some of the ethical issues surrounding the implementation of telecare. The panel also gave participants an opportunity to explore their opinions, understanding and experiences of the topic; and an opportunity to engage with the fieldwork and data. This enabled participants to become actively involved in shaping the emerging research themes. In sum it entailed a more participatory form of research and a levelling of traditional ‘hierarchies’ between researcher and researched.

In the EFORTT Project we separated the citizens’ panels process from the ‘ethnographic fieldwork’. This made visible how, as a research technique, the panels process acknowledges research participants' agency. As such, citizens’ panels proved a useful supplement to the ethnographic data, with the level of engagement of our panelists being very high.

We acknowledge, of course, that (unlike the ethnographic work) citizen panel discussions are framed by the aims and objectives of the research, nevertheless, we maintain that they are of direct benefit to participants as they offer a very rare opportunity to deliberate collectively a topic of serious concern, and to researchers who gain information about a subject that is directly related to the participants’ lives. For the research team this requires some “pedagogical” effort in both preparing and giving information to participants about then topic for discussion.

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

A particular benefit of the follow-up citizens’ panels is that they allowed researchers to relay back the results of ethnographic fieldwork and data analysis in a participative and productive way. Participants could thus reflect on much more concrete projects. In our research, the second round of citizens’ panels also enabled members of the research team to draw a contrast between their own country-specific findings and those of other partner countries. In some instances, these comparisons facilitated panel members' ability to refine or modify early findings. They also enabled us to take the discussion out of the sphere of 'what do we think will happen?' to 'what do we think about concrete applications?' thus facilitating our understanding of what forms of care and telecare older people can and will support, and the policy recommendations that flow from that. Citizens' panels can thus be said to provide an opportunity for participants to express their opinions and understandings of the research and emergent data, giving them a sense of 'ownership' of the findings and recommendations.

Challenges of citizens' panels in telecare research

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

Across all four countries, telecare is primarily used by frail older people who have limited ability to travel, hence it is difficult to involve them in group discussions requiring their presence at a specific location beyond the home/institution. As a consequence not many panel members had hands-on experience of telecare technologies. This was exacerbated in the Norwegian context where telecare (as opposed to telemedicine) is not widely used. Where panels did have one or more participants who had experience of using telecare it proved a significant advantage in that they were able to describe the everyday use and challenges of telecare, moving discussion away from the more generalist issues of the 'pros and cons' of care technology. One way that the English researchers sought to address this problem was to run a panel for older users of telecare within a communal sitting room in assisted living accommodation. This worked effectively for both the introductory and follow-up panels. However it has to be acknowledged that assisted living in the UK is quite an expensive option, hence those living in such settings tend to be amongst the more affluent of our older people. It was more problematic to engage the least affluent of older telecare users in Citizens' Panels. In England we had to rely on individual interviews to ascertain their views.

Despite the difficulties of engaging older telecare users in citizens' panels, it should not be overlooked that whilst many of those participating were not current users of telecare, they are nevertheless *potential future users.* Their views are thus of importance in learning what form of care older people want in the near future and what role telecare should play in the provision of that care.

Due to their caring responsibilities, informal (family) carers can also find it difficult to participate in group discussions of this kind. For them, the key issue is ensuring there is support/funding to 'cover' for them whilst they participate in the panel.

In many instances formal carers were unable to obtain leave from work in order to attend the citizens' panels. In Norway, the research team sought to address this by rescheduling panels from day-time to the evening. However, getting people to attend panel meetings in their spare time was also an issue. This was particularly true in relation to the second carers' panel meeting which was held in mid June, which is a very busy time. As a result attendance at the second carers' panel meeting in Norway was very low. Unlike the English example, the Norwegian team did not offer any payment for attendance, and it is possible that this would have made recruitment easier.

As a consequence certain groups are likely to be excluded from deliberations about new care systems, so real efforts need to be made to find alternative ways of ensuring their views are heard.

Finally, whilst the second round of panels provided some extremely useful data, all research partners found it difficult to 'retain' the same people for both rounds of panels (about 18 months apart) resulting in a mix of continuing and new participants being recruited to this phase. Clearly this has an impact on the dynamic of the panels, with newer participants being unable to reflect back on their experiences first round. There were many reasons for this: some older people were experiencing ill-health, some of older participants were not available at the times organised, and some carers were unable to find relief from their caring role to allow them to attend.

In Conclusion

Overall, it was pleasing to note that many participants became very engaged in what were quite lengthy and intellectually demanding discussions, and were keen to see a copy of the EFORTT final report. To us, this indicates the success of the panels in stimulating and engaging older people and carers in deliberating these significant social issues. The quality of debate in the panels, only served to confirm that older people have a critical and indispensable role to play in the future shaping of policy and practice around telecare development.

This report was produced by the EFORTT research partners in England, The Netherlands, Norway and Spain, and written by Maggie Mort, Celia Roberts and Christine Milligan, with thanks to Josephine Baxter, EFORTT Project Officer.