The EFORTT-project Work Package 4 report: the Data Clinic

Introduction

The EFORTT data clinic (Work package 4/ D2) took place in Rondane, Norway, 9 – 11 February 2010. The objective of the work package and data clinic was to produce a coherent comparative analysis for the four ethnographies and the four pairs of citizen panels. The intended outcome was to develop analytical themes and highlight issues that can become organizing strands or topics of discussion at the international conference in Barcelona in September 2010.

Before the meeting data material and preliminary analyses from each participant country was distributed, for everyone to read. These data included extracts from the ethnographic material, transcripts from the citizen's panels and quotes from policy documents. The data were selected, organised and analysed according to three questions, developed on from the EFORTT 'Description of Work' document, as well as previous discussions at EFORTT project meetings.

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

Representatives from each project country were present: three from Spain, two from the Netherlands, two from the UK and two from Norway.

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

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

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

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

In this report we bring together a selection of the 'clinic' data from each partner country and present our preliminary analyses and findings, as well as discussions at the meeting. The report is divided into four parts. In the introduction we present the aims of the work package and a summary of the preliminary findings that were discussed during the Rondane meeting. The remaining three parts will present excerpts of data plus commentaries and preliminary analyses on each of the three main questions guiding our work in the data clinic. Each of the three questions represents a theme for one or more publications/articles. During the meeting each partner took the lead on one of these, to be developed further in collaboration with a group consisting of members from each partner country.

Summary 1: New care arrangements with telecare (pp 5-19)

Telecare does not offer a 'technological fix' to replace either traditional health care services or informal care networks, and so make an easy solution to care crises, personnel crises, and budget crises in aging societies. Telecare does not *perform care* by itself, or on its own. Instead it creates a lot of new work; it introduces new tasks, skills, responsibilities and actors. These include installers, tele-operators, instructors, service providers and service workers, in addition to drawing on family carers, neighbours, friends and volunteers. Accordingly, telecare does not work independently of a large system or network, and it does not work effectively if the user has no social network.

Telecare either brings along and sustains a network that is already in place, or needs to mobilise and install a new network if there is no existing one. In the latter case, relatives, friends, neighbours may become part of a new network in which relations become more functional, qualified and formalised. Indeed, relations become tested, defined and qualified. Some relations may become intensified, some relieved, some both intensified and relieved. Many actors and figures, old and new, are involved in this work of relating, organizing, negotiating, adapting, smoothing and tinkering, in order to make the system or package work, and work better. But, crucially, one has to provide a system or network together with the technologies, because otherwise the technology is seen to be useless. There are clear limits and limitations to what telecare systems can do – they can for instance not help people to the toilet or clean the house. The aim of telecare policy, then, that telecare will be effective for people living alone and lacking social networks, is not grounded in practice. It needs to be acknowledged that telecare rests upon and is dependent upon networks, and that either these are already in place or they have to be made anew by bringing actors, including volunteers and informal carers, into the system. In this way, telecare makes visible multiple caring practices, many carers, and the care networks they sustain.

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

Summary 2: Normativities and visions (pp 19 – 28)

28What *normative visions and programs* do these technologies embody? To answer this question, we have been looking not primarily at normative visions as they are expressed in policy documents (although we do sometimes use those, of course), but at their incorporation and embodiment in technological practices. The advantage of this 'bottom-up' approach is that it may give a more realistic view on the ethics of telecare than simply analysing policy documents and ambitions. In our work articulating practices, the question then becomes not how to define good care once and for all, but how to prioritise 'goods', to show the situatedness of what is good and bad care. We found six such situated visions of good care present in different degrees:

i) Good care is care that engages its users. Advanced telecare that is not closely identified with the activities of the user could place older people in a completely inactive role.

ii) A version of good care as embodied in almost all telecare programs is that care should allow for 'ageing in place': staying 'at home' as long as possible. This vision of good care may, however, also oblige people to stay at home longer than is appropriate for them. Telecare may be continued even when care in a collective setting would be better. As a result alternative, collective settings may disappear as a consequence of the 'success' of telecare.

iii) Good care is also care for the carers, but this is understood differently in different sites. For example, carers' rights are currently taken to be more important in England than in Norway. In England, carers' consent may be as important as that of the 'user'.

iv) One of the 'goods' revealed in our material could be called reciprocity, which can be seen most clearly in more medically related examples. This is when the telecare technologies not only assist formal and informal carers in caring for the older person, but when these enable the older person to help the carers.

v) Good care sustains privacy; the material shows that telecare may be a way to increase privacy and personal continuity. However, in some situations privacy may also be threatened, for instance by practices using GPS tracking. This also applies to, for instance, health monitoring telecare. Some clients using telecare for health monitoring feel that it sometimes comes 'too close', as it confronts them with their disease too much. In this form of medical monitoring the patients were required to answer a set of questions about their disease on a daily basis.

vi) A last vision of good care that came out of the data concerning several of the telecare arrangements we studied was the provision of 'peace of mind'. This is particularly noticeable in the use of alarm pendants: even if the pendant is never or hardly actually activated, it is however still an important part of good care because it provides reassurance for the older person and her or his family.

Summary 3: Creative reshaping (pp 29 – 38)

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

Our research material demonstrates a wide range of different forms of telecare usage: refusal, intermittent use, misunderstanding, target driven installation, 'misuse', adaptation, creative use, customization and supplementation. All of this research data about the creative use of telecare and the non-use of telecare raises questions about what 'proper use' is thought to be in each context. The empirical material shows that this is different in different contexts and that telecare should not be understood as a universal solution, but a situated one. We argue that people's creativity in customising systems is actually essential to the 'ethical' use of telecare and that this customisation process should be respected. In this way telecare systems (in design and implementation) can avoid becoming totalising and coercive.

Data Section 1

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

Five overlapping main issues were drawn out of the data material and the data clinic discussions on this question - for the purpose of this report they will be dealt with separately.

Telecare does not work without a network.

A first conclusion to be drawn is that telecare does not care on its own- it cannot take the place of care or a care network. Quite the contrary, the empirical material shows that it takes a lot of negotiation, thought and organisation to live with these technologies. The point is that telecare either brings along or mobilises, formalises or sustains a care network or collective. This is done by drawing friends, relatives, neighbours, installers and (telecare) operators into the care network. Telecare doesn't come with a ready made social network. In Spain, for example, in order to contract this service, users need to show that they have a minimal support network. The form users have to complete for contracting the telecare service asks for some ‘contacts’. If they don't have any, service doesn't work (e.g. someone to look after the user's keys in case Red Cross need to enter their home, someone to phone and warn in case user falls down).

The ethnographic material from each of the countries gives many examples of the negotiations involved in establishing, mobilising and sustaining these care networks.

Spanish material (Interview with a remote telecare officer):

> **P:** *Basically what we do is keep them company, they need someone’s company; we listen to them and encourage them a little. Sometimes you go to their homes, spend half an hour with them, they tell you their troubles, you tell them a few things and (...)*
>
> **E:** I see. How long do you usually stay at someone’s home?
>
> **P:** *Well, if they have fallen, the time we need to wake them up and make sure he/she is fine. If you have to wait for the doctor, then you can spend 3 hours. That’s why you can watch TV, talk to them.*

English material (from an observational interview with a monitoring centre worker, describing her interactions with a telecare user):

> Operator: *You know a lot of the Alzheimer’s, things like that where their memory’s going… I mean we’ve got gas detectors in and that and you go through and you’re talking to them and you say ‘Can you smell any gas? Can you check your cooker for me?’* [They say] ‘*I haven’t got a gas cooker’ and they have, you know… So you just have to get someone* [to go out]*… I’ve always said, telecare is only as good as the contacts we’ve got. If you can’t get somebody to go and check on that, you know, you’re really struggling, because the police don’t want to know every few minutes* [or] *to be going. So the more contacts we can get with the telecare the better, because that’s what we have to rely on you see.*
>
> Researcher: So it’s about the network –
>
> Operator: *it is*

> Researcher: - around that person?
>
> Operator: *Yes. Then we've got one or two that have gone in that have got nobody.*

The data does also reveal some tensions between policy and practice on the issue of the necessity of social networks in order to make telecare work.

> There is a very interesting contradiction in our (UK) material: I'm asking people at this call centre, the providers of this telecare service, 'what about these social networks?' And they say 'Oh, telecare only works if the person has a social network, has neighbours, has relatives and so on. Then for us – at the call centre – it works.' So I asked the social work manager. I said 'in a call centre they say that telecare only works if you have a social network', and she is going 'NO! That is not the aim of the policy. Why wouldn't you have telecare if you live alone and have no networks? It is FOR these people'. So here you have two different perspectives on what this means – to have a functioning telecare system. (MM/18-0010 data clinic discussion).

This issue of the role of social networks in telecare can also be linked to fears about telecare being used to replace human (i.e. face to face) care. This was a fear that was voiced by participants in the citizen panels in the different countries:

English material (Citizens Panel 3):

> Panel member 1: *Again there's a line isn't there, because we want to increase the freedom and we also want to ensure that whatever that technology is it isn't simply replacing the person that is currently giving the care. Because one of my huge anxieties about this is that the more we can do with technology by way of keeping an eye on somebody being in the right place, however it's done whether it's internal room monitors or whether it's something like an electronic tag, the huge danger is that if we go down that road to any great extent it is so easy because of financial implications to then reduce the personal input and if you've got… I mean the example was… if relatives are worried about Mum they might call in every day and if there was some other technology was available they might only call in when they wanted to have a much better visit. But goodness me, it is so important to not replace that human contact! And having been a person who's been at home and not seen anybody, not talked to anybody for days and days, and sometimes weeks and weeks, the desperate need for a person to physically be there to do something… And just because some IT innovation has happened, if that in any way reduces the amount of carers going into a person's home, or whatever it may be, I just feel that would be absolutely against the whole ethos of trying to improve the care of people whether it be in community or care homes.*

> Researcher: which links back to your earlier point about care being more than a practical issue - the carer coming in might be able to provide emotional care, spiritual care, you know that kind of human -
>
> Panel member 1: *human contact.*
>
> Researcher: - *human contact, it isn't just the meal or the bath being run or whatever.*
>
> Panel member 1: *it's holding the hand. I mean my next-door neighbour this 95 year old, when somebody goes in - she's also got dementia so she thinks she's been alone for a long time, she doesn't realize that actually the last carer went 2 hours ago and you know another carer's coming in another 2 hours - she'll grab your hand and this physical contact, this desperate need for physical company, just to feel somebody to love them, that they matter etc. So you know, something on the ceiling or the door so that somebody else can be reassured that person is alright is no substitute for somebody going in.*

Excerpts from the discussions at the data clinic:

> It was the same in our (Spanish) panels. If telecare is for people who live alone … if they are more independent, then they are more alone than before. … The solution is the same as the problem (BC/3-0012).
>
> It somehow connects to these sensors in homes. (…) The idea that someone looks into your house… You cannot see them, you cannot contact them. It is this specific technology that brings out these fears. Our Dutch people had the same worries (JP/3-0012).

Norwegian material (citizen panel):

> *First and foremost I think it has to be about human care. And not so much about the technical stuff. I think of those sitting at home and are not well and then they are supposed to become attended to or themselves to attend to this kind of technical equipment instead of having contact with a human. I think this is difficult to accept.* (CPMB)

At the data clinic we discussed whether these fears (of technology replacing human care) voiced by the panel participants could be considered as warranted in light of the empirical findings. The fears of technology replacing human care were discussed in relation to policy rhetoric. The following are extracts from the discussions at the data clinic, and point to the discrepancies in policy rhetoric:

> In the … panels, WE don't suggest this … that technology will replace the human care. So this is a fear that comes out rather spontaneously. And they get that from a context of cuts, recession … cutting costs, this kind of things. They pick that up from the context in which

> they are talking. So in a way they are coming out with this replacement idea. But officially the story is that it is not a replacement. It is complementary. (MM/2-0012).
>
> There are different official stories I think. The other official story is that it is a compensation for workforce shortage. And there is no way of doing this than by replacing … (DW/3-0012).
>
> Yes… on the one hand it is in the documents that 'we cannot afford to carry on the same way as today', but also they say 'and it's complementary' (MM/3-0012).
>
> Yes, so 'we are going to do more', which is quite contradictory I think. (DW/3-0012).

There are a number of different actors and figures involved in this network

Telecare involves a number of different actors and figures; including the technologies, installers, instructors, service people and service providers. These actors have different roles and responsibilities. The notion of 'care collective' is a useful term to conceptualize the ties between the different actors involved in this network of relations, as it draws attention to the boundaries and composition of these relations:

> The introduction of telecare becomes a trial or a test or … of the relations and price. And the actors, what their capacities are or not. The different roles. So one way of thinking about this – it is not just care arrangements but care collectives. Something new comes into this collective and the boundaries as well as the composition of that collective gets opened up and very strongly actualizes these ties: who is close and who is not? What is nearness? What is distance? Something is near or distant – what does that mean in terms of living nearby or being responsible in different ways. So somehow all of that has brought up and had to be negotiated when these things come in. And affective ties as well. (IM/7-0010).

Telecare makes care at a distance possible. But it also enables different forms of closeness. The concern with distance and closeness is important as it addresses issues of responsibilities and affective ties within the care collective:

> ….in the Spanish material is the way in which … because (the telecare contract requires) having to put their (friends and relatives) names down, the older people themselves … One older woman was actually trying to use that as a means of ensuring a member of the family who is a long way distant, was aware of her health situation. So she wanted him on the list although he couldn't possibly respond. (CM/8-0010 data clinic discussion).

Spanish material (80BMOTDN p. 6)

> *(...) He tells us that when installing the device problems such as family issues come up (e.g. when it comes to the contact's personal data form). Siscu tells us that, sometimes, the users want them to put all their children on the list of contacts. He explains to us one case: an old lady wanted his son – who lives in Almeria – on the list. She insisted by saying 'he is also my son and I also want him to be there.' (...) [Niza: it seems like the 'contact person' field is sort of a map or a hint about how the affective and care relationships around the user are set up. Telecare workers turn to the family, neighbours or friends. The person who is 'the contact' is a very important issue within the family because it shows who they want to be contacted or called in case of an emergency. Who is going to take care of the user, who looks after her/him, who is the person to be trusted by the user, who is the closest person to the user (...)* Daniel: In that sense, it seems to me that there's a conflict between the contact's nearness – as understood by the telecare – meaning 'how easy is it to move the user in case it is required.' Hence, the contact person must live nearby the user, be involved and worried about the user and willing to collaborate. And from a family point of view, contact's nearness may imply affection and/or responsibility. These criteria do not always seem to match].

The issue of closeness and distance is linked up to the frequency of contact between the nurse and the patient in the Dutch material. Previously, before telecare, the nurses were in touch with the patients once every six months. Now they are in weekly contact. And the material shows that this frequent contact contributes to establish new and different forms of relations and responsibilities between the nurse and the patient.

Dutch material (p. 11-13):

> *COPD patients in homecare answer questions about symptoms over the health buddy daily: Mrs. A: 'I have to answer questions again [over the health buddy] and then it goes to the hospital, and the GP's, and they look at the answers, at what this have to say. And if it is not ok, they call me over the PAL4' [webcam]. (...) The health buddy contacts are accompanied by a weekly webcam conversation. This does something to the relation with the patient, but also with the nature of the conversation. The nurse sings the praises of the webcam contact that allows her to see the patient. This makes it possible to build contact, build trust. You can 'hear' the patient, because you can refer to conversations you had before. The nurse says it is very intense and compares it to an ideal consultation: 'low thresholds, short lines to be at home with the people, friendly for the patient.' But the weekly conversation is also more superficial, she remarks, when compared to the 6 month visit of the patient to the clinic. In the half an hour of the 6 month consultation, a particular list of possible worries are discussed in depth. All these issues are not discussed in the weekly web-cam chat, she says. You cannot ask every day whether the patient has quit smoking. The web-cam appointments rather deal with the day to day problems, the ups and downs. It foregrounds what is of concern NOW, front*

> *stage, not what is a concern always, but backstage. (...) This development was not foreseen at the start of the project. The nurse reflects upon it on the spot and can compare the frequency of the web-cam contact with the 'depth' of the 6 month consultation. Earlier in the interview she had stated that 'attention' for the patient was the most important ingredient in good nursing care. Now she discovers that attention comes in different forms and shapes.*
>
> *Another aspect brought about by the frequency of contacts is that patients may discuss subjects that are never addressed in consultations with their different carers. In one case, the carer using the web-cam becomes a kind of case-manager, having the overview over what medication patients take. They may advise patients not to take some of these, as happened to Mr. V. This effect was never intended.*
>
> *Mr. V: 'Yes, I contact the lung nurse more quickly. Like with the medication, when I think: what is this? Well, then I show it (over the web-cam) and she says: yes, well, you use an incredible lot of medication. I will ask Doctor X about this. And then she calls a few days later and says 'well, this and this, you don't need to take that, and just let these pills be. And when you see the doc at the end of the month, I will discuss this with you. See. These things. If I would not have it [Pal 4] I would go on swallowing.*

Excerpts from the data clinic discussions related to the Dutch material:

> It's very interesting … It's care at a distance. The problem is that it becomes too close. The distance. (DW/23-0010).
>
> I think the frequency does something about the complexity. Because when you become involved in the daily stuff there are different types of complexity compared to when you draw the big lines. So there is much more stuff that becomes relevant and that is brought up, and different types of stuff. (HT/23- 0010).

Informal carers play an important role in the care collective. And the material shows that care at a distance gives informal carers the opportunity to (re)build and maintain social relations and responsibilities, also outside the care collective. But at the same time the material also actualizes the question of the limits of these engagements.

> (…) some of the material said that telecare was important because it gave informal caregivers more possibilities to do what they like. Like in the Norwegian material, there was someone who had taken up singing in a choir because she could leave her husband stirring around without fear. But in the Spanish material some people were scandalized because children wanted to go on holidays without having to care for their parents. … Because they just wanted to be on the beach without being bothered. And that person was scandalized about that

> attitude. So that’s an interesting tension. It is about one of the actors in the collective … what they could do and not do. And that changes accordingly. (DW/7-0010).
>
> In the Norwegian case one more or less explicit aim is to support carers for instance to go on holidays or to have a life that makes them able to care for longer. And not to be burnt out by having to be available 24 hours without any holidays or anything. So having the possibility to sometimes have a relief or … is seen as a part of that somehow. (IM/8-0010).

Norwegian material (interview with informal carer/use of GPS device in dementia care, p. 10):

> *BB: ‘My husband wandered a lot. (...) I don’t think I am exaggerating when I say that I have had 400 searches for him. For a period he walked off every night. So we got this GPS device that we fastened to his belt in the morning. The device was connected to our daughter and me. To our mobile phones, so that we could know where he was. And it really worked very well, I would say. He used it for three years and was a free man. He could go out all he wanted. In the evenings and ... Yes all the sudden I could join the choir again, and I could go exercising and ... I always found him. It [the GPS device] gave me a new life.’*

Spanish material (90MMEGT, p. 4/interview with home telecare operator):

> Interviewer: When you say that relatives ask for the service, why do you think they do it?
>
> Coordinator: *Well, it is a relief. Instead of dialing their number (relatives), they dial ours.*
>
> Interviewer: Do you really think it is a relief for them (relatives)?
>
> Coordinator: *Yes, I do think so. Once, a son even asked me if I could call his mother every day because he was going on holidays.*
>
> Interviewer: And … why doesn’t call her himself?
>
> Coordinator: *That’s the point. Actually, I asked him whether he was going some isolated place with no mobile coverage. He answered me saying he was simply going on a holiday.*
>
> Interviewer: But his attitude verged on …
>
> Coordinator: *I know it, but there are a lot of people like him!*

A lot of work is being done and new tasks, skills and responsibilities are being assigned

> What I got out of reading the materials is that for people using these technologies, it takes a lot of negotiation, thinking, organizing … to get to live with these technologies. (...) To make them work well (JP/4-0010).

The material shows that different actors are assigned new tasks and skills:

> And they have to do new things. Like make these new decisions and distinctions between the medical and the social and these kinds of things. (IM/1-0013).

The extract from the Dutch material shows that it is both *new forms of work*, and *more work* that is involved for the nurses in incorporating medical remote care technologies. But telecare also involves new tasks and responsibilities for the patients/users:

Dutch material (p. 9):

> *Interestingly, the happiness of the patients is not shared by the nurse in the same way. Although she appreciates and values the experiences of her patients, when asked 'what's in it for her?' she is quite frank: a lot of extra work, that is not very interesting from a perspective of specialized nursing on an oncology ward.*
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> *Oncology nurse: 'It's just, it is so much extra work. It's a fax to the GP, making a new file there, noting details about the patients and writing timesheets. And also your research, that again costs time! It's all really small things, but added up, it's a lot. It is all time that is not spent on your patients.*
>
> *The care that is needed to keep the device going is, for the nurse, very different from the care for her patients. It is about providing information to third parties and doing office jobs.*
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>
> *Mrs. A: I have to answer questions again [over the health buddy] and then it goes to the hospital, and the GP's and they look at the answers, at what it is you have to say. And if it is not ok, they call me over the PAL4* [webcam].

For the patients it is easier to contact the nurses. The threshold for contact is lowered, (which is interesting, because the same does not seem to be true for the contact with the GP, who is not contacted more frequently). Part of the explanation is that the nurses may contact the patients. The nurses are ahead of the patients. Other reasons for a lowered threshold to talk to the nurses may be that the frequent visits realize a kind of contact that is not often concerning medical emergencies, but are chats about different topics. There are no confronting consequences or diagnosis or hospital admissions. The contacts are unthreatening.

The discussions at the data clinic were also related to the role, skills and work of the teleoperators and installers as the Spanish and UK material showed that they are key actors of the telecare systems.

> I think the new role, skills and practices of installers, teleoperators and …. That is kind of very visible. We make them visible by doing our empirical study. But they are invisible to policy. (MM/13-0010).

Lancaster material (Call centre observation/interview, p.3):

> Call centre operators have to use their verbal skills to deal with situations e.g. coaxing the older person to get out of bed and to safely reach the toilet on their own.
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> Operator: …*I mean we have a couple* [like that] *haven't we? And you feel so helpless through the night if you get a call and suddenly they'll say 'I want a wee'. Well you can't get the paramedics to go and get them out to have a wee and they might not have any - I mean we've got key safes to let paramedics and that in, but sometimes there is nothing you can do! There isn't, is there? There's nothing you can do, but try and talk them into getting out of bed. I've done that before today.*
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>
> Researcher: So if a call comes through and you’re not sure how the person is - they’re confused - how do you deal with that? Because you can’t see them, you can’t touch them, you can’t - how do you manage?
>
> Operator: *Listen to the conversation and make my mind up what is going on, and then nine times out of ten I would get someone to go and check on them. I would never leave an elderly person, because they’re a little bit like a child. They say things and you can’t really… take it for granted they’ll be all right* - *in case* - *I never leave a call, I always get someone… it’s not worth it.*

This conversation with two monitoring centre workers demonstrates a range of verbal care skills in which operators use language to reassure the client and return them to a happier state of mind. The use of the term ‘we’ is important here in that it produces an alignment with the client, reducing the social and physical space between them.

> Operator 1: …*same with the bed sensor, it tells you when they get out, and you do try and speak to the people just to make sure they haven't fallen … There's one lady, she wanders all night long, just moving herself. She has bad nights, she doesn't sleep very well.*

> Operator 2: *We should sing lullabies to her. I usually say 'It's too early now, get back into bed, night night, God bless' and they like you to talk to them like that, [when]… you're lovely with them. You can talk to her.*
>
> Operator 1: *You say, 'We're having a bad nightmare, let's have a brew!'* [chuckles]
>
> Researcher: Really?
>
> Operator 1: *Yes, she'll go and - because she's capable - make herself a cup of tea.*

This conversation also demonstrates the role of gradually accrued knowledge of clients: both operators know that this particular woman is capable of making a cup of tea, so their encouragement of this as a calming strategy makes sense.

Teleoperators attempt to build relationships via the telephone and computer system. This can lead to emotional attachments, particularly when there is a requirement to make weekly test calls to make sure the equipment is working. This regular, mundane contact allows for a relationship to develop where, as the worker here says, you're 'not just a voice'.

> Researcher: And are there some people that - you get to know them as people in a sense?
>
> Operator: *Yes. You get attached to some of them as well, even from just like doing the weekly test calls. I know when I used to do a lot of helping out in the days, I'd get to know, even down to getting to know the wardens when they come through* [on the phones].
>
> Researcher: Yes, I can imagine. It makes it a nicer thing to do, then, doesn't it, in terms of a job, because you've got relationships with someone?
>
> Operator: *Yes, they like that as well, not just a voice, they send you Christmas cards.*

BUT these weekly calls are now being phased out due to high numbers of clients on the system. This means fewer opportunities for building meaningful relationships with clients, even those classed as 'vulnerable'.

> Operator: Well we had a lot of weeklies - they were the vulnerable ones - but they try to get everyone to test monthly now, we have hardly any on the weekly now.

The ethnographic material shows that the teleoperators, through their everyday tasks of answering and coordinating calls, have a key role in making distinctions between medical and social care. The making of distinctions between medical and social care is important as it determines what kind of response that is appropriate, and hence what kind of service that is given to the person asking for assistance. This issue was discussed in particular with reference to the English material:

UK material (citizen’s panel, p. 9):

> Eileen 2: (…) *I had an unexpected experience with my pendant, about 4 years ago… I’ve had a pendant for must be 7 or 8 years, since my husband died. I didn’t get one in the beginning, I was so much more capable really and thought,’no I don’t want a pendant’ and then eventually I thought, ‘no, you’re in the house on your own, and at nights, in the bedroom you can press it’. But I had an unfortunate experience with mine and I took my waste bin out the front, you know, the trolley thing and somehow or another I got tangled up with this wheelie bin and ended up on the drive. But I managed to get myself up and go inside the house, and I thought ‘what a stupid thing to do’, you know, I was passing the car and tripped over the wheels of the wheelie bin. this was mid-morning and by mid afternoon or late afternoon I thought ‘oh, my arm’s bothering me’ and it really was, and I thought ‘I’m going to press my pendant’ which I did. And XXX Corporation were operating that scheme then, not YYY, and the reception that I got from the person who answered the phone was, ‘well ring for a taxi and go to the hospital’ and I thought, ‘what have I paid you nearly £900 in all this time to be told ring for a taxi and go to the hospital?’ Anyhow, I didn’t, I thought no, so I rang paramedics and they were very good. They came out and said ‘I think we’d better get you to the hospital’. Now if I’d have I’d have rung for a taxi the taxi would have probably come and knocked at the front door or pipped the horn and that would have been it. The paramedics came in and it was in the winter and they said ‘now, have you any other heating on besides your fire, no, is your back door locked?’ and he went through to the kitchen. A taxi driver would not have done that. And at the end of the day I thought oh, I’m not going to take issue over this but really they should have been taken to task for it, because when you’re wearing one of their pendants that they issue, you don’t want to be told by the person answering the phone, ‘ring for a taxi and go to the hospital.’*

Excerpts from the discussions at the data clinic show the redistributions and repositionings around the medical/social care boundary (9/11-0010):

> DW: This brings up the medical use of telecare in your material. Where the person has fallen down and called the telecare and they said just call a taxi and get to the hospital. That was a medical context in which telecare was used.
>
> MM: No, it was social context.
>
> DW: Why was that?
>
> MM: Because that was a community alarm setting. So she was calling for social care.
>
> DW: She is calling because she has fallen down.

> MM: (…) That's not medical in England!
>
> DW: But then … She wanted the telecare people to react in a proper way (…). She requested help because she had fallen down. So the medicine/social distinction is not made by people who have the problem. I mean we make it and the system makes it.
>
> MM: (…). Empirically, if you look at the story she gets up somehow. She gets into the house and then she calls. And she is calling a community alarm. She is not calling with a medical problem. It might be a medical problem, but she is not calling with that degree of specificity.
>
> CM: They have to make an assessment of whether it is an emergency or not. And in this case they have decided she can get there on her own still. So it is not an emergency.
>
> MD: When we are talking about what is good care … So for the user she is attended to and it makes no difference if it is social or if it is medical.
>
> DL: At the same time in order to get proper care it is important to distinguish. Because otherwise you cannot mobilize a proper response.
>
> DW: Who makes this distinction?
>
> DL: The teleoperators.
>
> CM: The new care arrangements are about teleoperators having to make that distinction.
>
> DW: What it does … It puts in a new figure which has to make this social/medical distinction.

In this excerpt from Spanish materials, a designer coordinator explains that good care (or at least, future care) is that where social and health care goes together. So that tele-health doesn't already mean 'medical'. This means that many different agents now working around care, will be closer and more integrated in a future social-health telecare.

> *That version of telecare which has not a medical approach but a social one, the first social goals are to minimize the risks, reduce vulnerability and give a medical service in case of an emergency. However, telecare has started to converge with the tele-health area, not exclusively medical. And it has started to say, for instance, if I call the users every week and we record their blood pressure, although the Red Cross call agent is not a nurse she knows she has to check it to prevent a blackout. Secondly, if I call them every week and I ask them how they feel, I stimulate their memory…and besides, you tell them 'look, we are going to provide a blood pressure calculator, cheap and easy to use, which is going to be given who might take her/his blood pressure'. Well, despite the fact that you are not responsible for that, I they give me more info because the workers are trained (...) then the next step would be great then: 'Do not worry. I am going to give this information to your doctor or the geriatric centre so as to let them know what your social and health status is'.*

Telecare gives users/ patients the task of being more active; more self-aware, more self-managing

> (…) Telecare give the patients tasks of being more active. (…) And that implies a new definition of care – of good care – as looking after yourself, and being more independent (IM/1- Day 2 discussions).

Our ethnographic material shows that telecare comes with a demand for active and disciplined users/patients. For example, the Spanish and UK telecare users are required to press the pendant in situations when assistance is required. This requires self-insight and awareness of one's own situation and the ability to assess when assistance is required. However, and at the same time, the UK material shows that the telecare users also need to be disciplined as to not using the service inappropriately; for example for social chats.

An issue that was discussed in relation to independence as the aim of care is that independence comes with vulnerability and loneliness. Telecare addresses vulnerability but not loneliness.

And, although the policy rhetoric concerns telecare promoting independence, the ethnographic material shows that telecare also involves new and old forms of dependencies. This double relation between in/dependence was discussed at the data clinic (Day 2 discussions, p. 1- 2):

> JP: Why do you think … Why do you say more independent? Because you have just showed that all these networks…
>
> IM: Yes, it is a both/and. Patients are supposed to be more aware of themselves in new ways. To know and examine and to recognize themselves in new ways and their bodies. And to use their relations. Also their boundaries so that they are being both separated and included somehow. And that means that they have to be relatively fit and able. And at the same time telecare studies also shows that they are not independent, autonomous individuals. It is both/and. They are assigned the task to become more active and independent, and at the same time the practice studies that we do shows that they are not. They are not these independent individuals."
>
> DW: Caring is also about having someone to care for you. It is interesting isn't it, because the rhetoric is all about independence. But what we are doing is making visible new forms of dependence. And not just new forms of dependencies, but also dependencies that already exist.

The issue of in/dependence is also related to gender. The question is whether telecare contributes to maintaining traditional gender relations?

> It came up with a couple of the men that were involved with the interviews. It was really interesting the way in which the men didn't seem to be bothered about seeming to be dependant. Whereas the women were 'no we don't want to'. We were wondering if similar things were coming out elsewhere. Because if it is, it is quite an interesting gender issue. But I think out only came out in a few interviews …I think it would be a real hard case to say that this is how it is everywhere (CM/4-day two discussions).

Telecare makes patients and users active and disciplined in different ways. One example is taken from the Dutch material, where the patients are required to answer questions posted by the health buddy on a daily basis. These questions are then analyzed by the nurses at the hospital. It is the patient's response to the questions which determines whether the nurse is to make a follow-up call. Interestingly, the Dutch material shows how telecare, in making the patients answer the daily questionnaire are made to categorize themselves.

Dutch material (p. 8):

> *Mrs. Jackson: Sometimes you get a question: Are you nauseous? And you can only say 'yes' or 'no', and sometimes it is a little bit, but you cannot answer that. So I say 'no', because if you say 'yes', it looks so bad. If you say 'yes' it looks really bad and the nurse might call you up.*
>
> *The health buddy subtly reshuffles the relation between nurse and patient. It makes the nurse more accessible, and in turn, changes the patients into helpers instead of wailers, posers or people disturbing other people by demanding attention.*

Excerpt from the discussions:

> It struck me … so what telecare is doing here is making users categorize themselves. They are doing all this kind of self-examination in order to cooperate with … or in order to … into the system in a way that they want. (MM/23-0010).

The telecare network may be differently configured – from 'full package' to more loosely related networks or collectives

> (…) these telecare networks may be differently configured somehow. From the full package that you have in the UK, the more systemic integrated thing – to more loosely related or partially related networks like the Norwegian and I think also the Spanish where you have Red Cross with very different services that are more or less related. And then the Dutch cases. So that bridges this thing that is quite different. They configure these networks quite differently. (IM/DC discussions, Day 2).

In the UK, telecare is a part of a ‘package of care’ and its implementation is a part of meeting government targets. This means that there is a strong push to enroll potential users. This push towards telecare is strongly linked to the demographic challenges of the ageing population.

In the Netherlands, Spain and Norway, telecare represents more loosely integrated networks. Telecare in these countries are offered on a limited scale, and partly outside the official provision of care. Telecare is hence not ‘one thing’, but represents a whole spectrum of different technology-care constellations. The ethnographic material expresses this variety.

What normative visions and programs do these technologies carry/embody?

The discussion on normativity issues started with the group beginning to conceptualize the ‘ethical framework’ which is central to the EFORTT project. This discussion was partly related to the SENIOR project, which is another, EC-funded project, with an aim of providing ethical guidance and a dialogue roadmap on good practices of e-inclusion. The question was how the roadmap of the SENIOR project relates to the ethical framework to be established through the EFORTT-project.

A major distinction between the two projects is that SENIOR is based on a classical ethical principle approach. This implies of an understanding of ethics as based on the four principles: respect for autonomy, nonmaleficence, beneficence and justice. The moral practices of telecare are then measured against these principles. The EFORTT-project, on the other hand, is based on an empirical approach to ethics. This implies analysing the normativities of the practices that are being studied. Hence what constitutes good practices are not defined beforehand, but emerge in and through the material. This point contrasts with the approach which is often taken by telecare commissioners and providers:

> *There are no ‘good practices codes’ yet, so to speak. There are written principles, visions, requirements, limitations within the law but there is no a good practice code. Actually, we are trying to deal with this topic from long ago. The last time I told you about the ETSI standards.* (Spanish material p 25)

An ethical framework from the empirical perspective is emergent, and based on the mapping of different norms that arise from the practices, policies and panel discussions involved in this project. The task of the EFORTT project is to identify these issues as well as suggesting relations between them.

In an interview with a remote telecare designer, the notion of ‘info ethics’ appeared as related to the normative visions that technologies use to carry:

> *Yes. I think, first of all, there is a term for that. The European Commission created the word ‘infoethics’ long ago. I remember the first time we heard it: ‘if you search for ‘infoethics’ there, then it is related to several points, isn’t it? That is, the system does not have to damage the user who was not previously suffering; it has to prevent him/her from being insecure; you have to avoid that the person might suffer an electric shock: Imagine that this personal data*

> *could be available to people who should not access to it. I mean, all the possible sources of damage from IT. The system should not raise false expectations. It should not make things worse than they were or make the user feel worse than before, because she/he is lacking something*. (Spanish material, p.24).

Normativities and telecare: new ways of thinking about good care.

On the basis of the EFORTT data, the issue of normativity was discussed. The aim of these discussions was to identify what normative visions and programs the different forms of telecare technologies embody. It is important to note that from an empirical framework perspective, this implies awareness and foregrounding of the situatedness of the values and norms embedded in the material.

Through the discussions six different, situated visions of good care were identified:

Good care is care that activates its users

The idea of the active user is manifested in different ways in the data material. In the Dutch material, for instance, the idea of the active user is built into the medical monitoring technology. The health care buddy makes the patients respond to a set of questions on a daily basis. And if they fail to do so, the nurse will call the patient:

> Husband: *It is really nice to know that you can call directly and immediately with the oncologist [the nurse]. It makes it all closer*. [..]
>
> Wife/ patient: *There is less of a threshold. Each time you are being told: call the oncologist, phone number so-and-so, otherwise call your GP. With no phone number, because this is different for everyone. So the message is clear: 'Call, call, call. Do not feel shy. Call.' So that activates you too* (Dutch material, p. 7).

The understanding of good care in terms of active users is closely related to the idea of self-management. Self-management is an expressed aim of UK policy on telecare:

> *The role of telecare in supporting different patients groups* [headline*]*.
>
> *(...) [It] provides facilities to self-manage at home but allow patients to stay in contact with carers.* (UK material, p. 13).

Self-management is related to the idea of independence and autonomy; such as living alone, moving freely or going away, and doing whatever you want. This vision about good care as improving autonomy is shared by users and designers:

> Designer: *Of course, when you ask the disabled (person) what personal autonomy means or how it is being improved. Well, reduced mobility people might tell you that he/she can move freely in his/her environment; but a deaf person might tell us –and we learned this thanks to a*

> *sociological research- he /she has the ability to choose whether he/she wants to live alone or at home. I do not know if I'm making myself clear"* (Spanish material, p.23).

Implicit in this is an understanding of good care in terms of 'looking after yourself.' Hence good care is about being responsible and – if possible – to prevent illness from occurring. The notion of 'prevention' is central in the material. The idea is that prevention is the solution for health problems and costs (Dutch material, p. 13). In the Dutch context, where health care services are financed through insurance, this closely relates to the idea that unhealthy living should be penalized with higher insurance costs (ibid).

Also in UK policy materials, there is a strong link to prevention in terms of cost-efficiency. Prevention is cheaper than cure, and early detection of potential risk factors is an expressed aim of telecare:

> *An important contribution of a telecare service is that it has the potential to stimulate better flow of patient information to carers, by informing the response team and other carers of an event, and identifying changes in a user's pattern of behaviour.* (UK material p. 16).

An example of the benefits of early detection is given in the policy documents (UK material, p.15):

> *Mrs. B has a history of falling. Following discharge from hospital she was provided with a basic telecare package that included a bed pressure sensor that could detect when she left the bed during the night and turned on the lighting to her bathroom. It would then trigger an alarm if she did not return to bed within an agreed time. The package was programmed to record how many times Mrs. B left her bed during the night. A few weeks after it was installed it was noticed at the control centre that Mrs. B's nocturnal visits to the bathroom had increased significantly over a three-day period. They alerted a care professional and Mrs. B was diagnosed with a urinary tract infection which was then quickly treated enabling a full and quick recovery* (Building Telecare in England, p.9).

The issue of information and education is central in relation to the active, self-managing user. Here is an excerpt from the data clinic discussion (Day 2):

> IM: Also the information, knowledge and education bit come into it. Because many of these things come with the idea that if you educate or have information or have knowledge of things then …
>
> DW: (…) I suppose it is close to the activation issue. How do you activate? By educating people.

The Norwegian project SecurityNet, which forms one of the fieldwork sites of the EFORTT project, started out with an explicit educational aim. However, this strong focus on education has later been reframed in terms of a stronger focus on information:

> *The project has a preventative purpose where the intention is, through the use of ICT, to contribute to give patients and next-of-kin increased knowledge and competence to manage everyday life. The aims are to prevent or delay admission to an institution for the patients, to prevent burnout of the next-of-kin, and to assist in establishing social networks.* (excerpt from policy document, Norwegian data material, p. 12).

The implicit aim of the education and information is for the patients to change their (risk) behavior. The Dutch material gives one interesting example of how this might not be the case:

> Mr. V has a connection with the COPD nurse via a webcam and a Health Buddy for monitoring his symptoms.
>
> Mr. V: *Well, I typed that in a few times, that I was out of breath. And then they phone me up, because I could be in the red [meaning the nurses get a red alert, demanding their action]. This means you are in the danger zone. And then, they call at once, really. And then they say: 'Yes, you need to see the* doctor. *'But I am not the type to run to the doctor. And then they call the next day and then they say: 'Mr. V, what did the doctor say? And then I say: 'No, I did not go.' 'Yes, but you should learn to listen 'because you know, when we* [CODP patients*] get inflammation, then it is for us, of course, really fatal [*funest*]. Because every inflammation we get, is at the expense of your lungs. The alveolus* [part of the lungs] are destroyed.
>
> Interviewer: and this cannot be repaired.
>
> V: *No, that's what I am saying. When you have COPD, you keep it like it is, or it gets worse. See, you have diseases that get better. Bu this, cannot, it will never get better. That's just it.*
>
> I: So that is why they push you like this.
>
> V: *Yes, yes. And then they say: Yes Mr. V, you should learn to listen.*
>
> How to change people's behaviour and make them behave in healthy ways? The answer is often: provide them with good information. But Mr. V in the fragment is very well informed. He knows very well he should go to the doctor. He even knows the consequences of not going, and understands the grimness of not going. He knows he should go, he is being told he should go, being nagged to do so, *but he still does not go*. The telecare system made it easier for him to contact the nurses, but not to go to the doctor's.

Care should allow for 'ageing in place'

An obvious version of good care as embodied in almost all telecare programs is that care should allow for 'ageing in place'. This implies of staying at home as long as possible, which is what most elderly people would want when asked.

In the UK material (p. 14) ‘ageing in place’ is framed by policy documents as something which old people deserve and will expect:

> *... The number of people requiring community based health and social care support, and the levels and complexity of those needs, is expected to increase considerably over the next decade… And people will have higher expectations and want a future where they have greater control over their own lives including being able to manage their own risks. They want independence, and after a lifetime’s work, they want and are entitled to, dignity for life. Telecare is vital to unlocking this future* (Dept of Health 2005, Building Telecare in England p3).

In this discourse, the growth of the ageing population creates a burden of care which can only be managed if there is a technological solution. Telecare will be one method of alleviating the ‘ageing time bomb’:

> *Telecare has huge potential to support a diverse range of individuals to live at home. It can also give carers more personal freedom, meet potential shortfalls in the workforce and complement the work of clinicians and social care and housing providers to achieve outcomes that improve the health and well-being of people using services* (Building Telecare in England, p4).

This vision of good care, however, may work out differently in various situations. It may, for example, oblige people to stay at home longer than is appropriate for them. Telecare may therefore contribute to continued care at home, when care in an institutional setting may be better. Another issue is that alternatives – collecting living settings - may disappear as a consequence of the ‘success’ of telecare.

Good care is also care for the carers

Another form of good care that can be drawn out of the data material is care that takes the carers into account:

> This is a form of good care that is not only focused on the person; on the individual that is walking around with a GPS or a pendant, or communicating through the health buddy or whatever. It is also for the carers. Some practices are more related to supporting the carers than other practices (DW, Day 2 data clinic discussions).

One example of this form of good care is taken from the Norwegian material and the use of Global Positioning Systems in dementia care. Through the use of the GPS device, the carers expressed that they had got ‘a new life’ as they were able to resume social activities and hobbies. One next of kin was clear that the GPS device made it possible for her to still be in employment, as she was able to detect her husband’s whereabouts through the GPS device

(Norwegian material, p. 10-11). Another example, also taken from the Norwegian material is SecurityNet, where the next of kin are the target of the service. Here is an excerpt from the data clinic discussions:

> In the Norwegian case I think that the technology make visible the other carers. (...) because they address the carers as well as the patient. The SecurityNet is explicitly addressing carers, who care for their patients as a part of this collective. So it's not yourself as an individual (IM/22-0010).

Good care as reciprocity

One of the 'goods' revealed in our material could be called reciprocity. It could be seen in two forms, and mainly linked to medical examples. The use of GPS devices in dementia care, for example, provides an opportunity to find a person who is wandering. This is made possible because the GPS device provides detailed information of the whereabouts of the person being monitored. Having this information is on the one hand crucial in enabling family carers to be able to be engaged in employment and other activities. On the other hand, and this is where the reciprocity comes into it, the GPS device can also be used to start the process of bringing the wanderer home. Reciprocity is also seen in the data in a slightly different form, as an element of good care as performed by telecare. The Dutch material shows how the patients, through their use of the health care buddy, help the carers to care.

Excerpt from the Dutch material:

> Mr. Klaasen: *You have this thing [health buddy] that makes it easy to pass information on to the nurse. The step to fill out the questions is much smaller than actively calling the nurse or a doctor. You know these people are busy, they have patients, meetings. You always feel if you call that you would disturb, and I don't have that with the health buddy. Because they can read it when it suits them. And then I still have passed on my information and that is nice.*
>
> Mr Klaasen: *Well, I don't rush to the phone so quickly, and now you don't have to call. [laughs] I think that is the advantage. I am not the man for long stories over the telephone. And then I think: Hi, there he is again, that buddy wants to ask me something. It more or less has become a friend of me, so to speak. Like you may have a dog or a little cat, I have my health buddy.*
>
> Mrs Williams*: I think it is really great. We always say: there's Tania [*nurse*] winking again. You see, when the light starts flashing [*to announce new questions have arrived*]. We say: Tania is winking at us.*

Good care sustains privacy

Telecare may be a way to increase privacy and personal continuity. However, in some situations privacy may also be threatened, for instances by practices using GPS tracking. This may also apply to, for instance, health monitoring telecare. Some clients using telecare for medical monitoring feel that it sometimes comes too close, as it confronts them with their disease too much. Excerpt from the Dutch material:

> *The project manager tells that 'There weren't many refusers, but those who were there, handed their Health Buddy back in the first week they had it. They either found the use too strenuous (they were to ill), or too confronting, meaning that they did not want to think about questions of death and dying, possible symptoms or the impact of the disease on their lives.' The quitters, who are the non-users, give it up within a week. Others [among my informants] stop when the chemo therapies are over. The project manager tells that so far, there has been much flexibility in how long people could keep the device. This had to do with the budget that was costed for more patients than were actually included* [Minutes of project group meeting, 4 December 2009].

In the Dutch material a distinction is made between new and old forms of privacy. Old forms of privacy involve having different persons coming to the house assisting the patients in various ways, whereas new forms of privacy is linked to the monitoring of patients through telecare solutions.

Excerpt from the Dutch material (p. 10):

> Panel member: *I love my privacy too, and I think telecare is a great initiative. Otherwise there will be Mary, then John, then Sophie. But for washing they would still have to come.*

Interestingly, a trade off between old and new forms of privacy seems to have been made here. Nobody appreciated different persons every day to assist them in their house, nor would they want to have many different caring staff to attend to them.

The new forms of privacy address issues of surveillance. When asked how they felt about being monitored by telecare technologies, the Norwegian older person's citizen panel expressed a positive attitude. Surveillance is here related to safety:

> OCRR: *I think many consider it to be quite ok. I have read about web cameras placed out in the city. On bus stops and such places where people are being mugged. I certainly think that many older people often consider this to be very positive. That it is ok, as it is reassuring. Some people feel safer when they are being watched over.*
>
> (Everyone is talking at the same time, saying yes, they agree)
>
> Question: *With cameras also? (*referring to the care setting)
>
> OCRR: *Yes I would say that.*
>
> OCSN: *Yes, if I could switch it off when I wanted to.*

> OCGL: *I believe a lot in having a tag on your wrist. So they can find you anywhere. It would not make it as personal in a way. Well, I suppose it will be personal, but you're not being watched over. But so they can read what your condition is at any moment. So they can tell me that 'now it is such and such'.*

The excerpt shows that the positive attitude of the panel is particularly related to health monitoring technologies. In Norway policy on the use of monitoring devices in care is very restrictive, and is regulated by the Punishment Act:

> (...) [A] number of considerations will determine whether alarms- and monitoring devices can be used in the private sphere. (...) [T]here are big differences in the different technical aids infringement of the person's privacy. (...) The Punishment Act sets limits to what is permitted. (Norwegian material, p. 7).

Good care as peace of mind

A last vision of good care emerging from the data was the provision of peace of mind. This is clear for the use of the alarm pendant: even if it is never actually used, it is still an important part of good care because it provides reassurance for the actual user and her/his family.

Excerpt from the Dutch material:

> Mrs Norden: *And you go home for three weeks. You see no one, not a doctor, nobody. Well, you could go to the GP, but he knows nothing about these chemos and things. That put me very much at ease: there is something in the background that keeps an eye on you, or maybe that is too big a word, but there is a connection one way or another.*

Excerpt from the Spanish material:

> Old lady: *No, for the people who don't have children. We have children and they are wonderful, wonderful. But, also at night…my son lives close to Guadalajara, my daughter around. It is true, if something happens to you at midnight, you press the button. They (telecare workers) call your son because they have his number, the keys and everything. It's very useful and comfortable.*

Tensions and struggles between different forms of good care

> DL: … We were thinking about the struggles between the different kinds of normativities. We were thinking about what is good care and we found different definitions of what is good care. (…) These are normativities – that care should be like this. And we talked to the manager and he thought that good care is another thing. So it is like a battlefield. The normativities are struggling. And maybe there is one

normativity that tries to impose on the others. And maybe we can describe this battlefield …

CM: So these are at micro, meso and macro levels.

JP: And the tensions between … who can define what telecare is and how it is going to work to bring some good things, and what are these good things…

CM: Like I said at the macro level you have got policy that … where care is …, and then if you want to take it at the miso level where you've got practitioners, local government and so on constructing it as this. And at the ground level you've got the individuals. All that stuff that goes on.

<u>Are normativities necessarily about goods or bads?</u>

MD: But actually, normativities … do not necessary have to do with good and bad (…) it can be because it is the easiest. They use this idea, the managers. It is normative because of this, not because it is good or bad…

JP: Functional is a good.

DW: Yes it is. It is because it is common. That is what you're saying. Or because it is average, or …

MD: … the best is the enemy of the good. You know, it is not necessarily good and bad we are talking about. It works (…) but it isn't necessarily good. Or it is not necessarily the best.

JP: There is some kind of solidified idea … There has been one time when we have been thinking shall we do this or shall we do that. Because you think it would be more efficient or more effective or you would think it will bring a better life for the patient.

MD: What about if it is just the easiest?

JP: Yes, that could also be a good!

MD: When they put the machine in a home, many times it is just the easiest.

CM: Or cheapest, and that is certainly a good.

JP: Yes it is an important good – for the government.

CM: Yes for the government but not necessary for the …

….

DL: There is always implied a value. A good or bad, so if it is efficient it is another way to say that it is good. It is good by other means. So … like giving support to something … you are promoting something that is efficient. So there is a value behind it.

DW: And even if someone is saying it is the norm, because it is the most common. Statistically the most common. The value is that this makes it the best thing too.

MD: For the telephone in Spain …we were told a story. There was a change in provider in …a county, and they had to buy new 30 000 devices. This was not the best. Or even good. And they did it because the new provider had a different system and the old system did not work. And, I mean …what’s going on there? They had to buy 30 000 new devices! The old system worked very well. The new provider has a new system so they had to remove all of this. Just because they changed it.

The understanding of values in terms of norms that is inscribed

IM: What we are trying to focus on is … What are values then or norms that are inscribed, embodied, carried by these technologies or these sociotechnical systems? And that is what we are trying to tease out.

MM: That’s great. But the other thing is … just to confuse everyone even more … is that the sociological approach to this might be what is fair and what is unfair. The sociological approach is about distribution and equality and you know …

IM: Yes but if it is a battle. (…) At least there are many different scripts there, and they partly overlap and they are partly different … and fairness or justice is perhaps a part of one of these scripts. To bring these out and to also show that they are part of different practices. Policy practices, care practices and bring those out. And then we see in the end if we come out and say that we have an opinion.

MM: Yes. A task is probably to show that these technologies are not value free. That they are value laden. And therefore we are showing where these normativities are.

IM: And show the difference between policy and practice. Why do they [end users] want them? That they have different reasons than what policy has for why they should be used.

MM: And maybe the opinion part is to say that you must take responsibility for these values. That this is part of government and EC responsibility. And not to be blind to the values that are inscribed.

IM: Maybe the users don’t want independence and self-management. But they want the technologies for some other reason. Social chatting or whatever.

JP: We have to look at all these kinds of aspects. (…) You get different definitions of what a machine is, what it should do and what it does.

To what extent, and how actors negotiate and creatively reshape these technologies/visions when they effectively become integrated in their daily lives?

> So what it means to work - what workability means is very much creatively shaped by the users. (MM/data clinic discussions, Day 2).

In data from all four countries, it is clear that all kinds of actors involved in telecare negotiate and creatively reshape telecare technologies and visions as they integrate these into their daily lives. Five different issues related to this theme of creative reshaping were identified:

Some older people refuse to use telecare devices or use them only occasionally

We found in each country that the targeted users of telecare systems – older people living at home – often used the technologies in unorthodox ways. Most simply (but also profoundly), this involved refusal to engage with the technology in the prescribed way, as in clear in the following data extracts, older people refuse to wear their pendants (or are selective about when and where they put them on), never use their falls monitors , or ask to have the Health Buddy taken away.

Dutch case study: (fieldnotes re project group meeting, 4 December 2009)

> The project manager tells that 'There weren't many refusers, but those who were there, handed their Health Buddy back in the first week they had it. They either found the use too strenuous (they were to ill), or too confronting, meaning that they did not want to think about questions of death & dying, possible symptoms or the impact of the disease on their lives.' The quitters, who are the non-users, give it up within a week. Others [among my informants] stop when the chemo therapies are over. Yet others want to keep using the device, interestingly, also users with little complaints: they thought they might find the device useful if their condition would deteriorate. The project manager tells that so far, there has been much flexibility in how long people could keep the device. This had to do with the budget that was costed for more patients than were actually included.

Spanish material (p. 28): Mixed discussion group (volunteers, users, and call centre agents).

> P8: …*My point is that they trust that we wear them. And instead we, or at least It has happened to me that I dress up, I bring it to the bathroom while I'm taking a shower and I think "well, what if something occurs while I'm in the shower? / and maybe after I get out of the bathroom and I forget to use it again, and of course… Because you can only hear it when you are wearing it, right?*
>
> P5: *Yes, when I get up, I have it in the small night table.*

> P4: *I mean, I use it over night too, because sometimes I have to wake up and, if I happen to forget to wear it, for example, I put it on the night table. Waking up over night is a high risk of falling situation.*
>
> P4 Yes. *I actually think wearing it during the night is more important than during daytime*.
>
> P2: *No, I don't wear it as much as I should've while I'm at home, because if I fall in the living room and it's on the other side... That's bad!*
>
> P2: *But when I take a shower then I do wear it, you see, and I never forget to. But I don't wear it because of this, it's because sometimes, while I'm cleaning, working, I've touched it. And you know what I do now? Oh but I wear it some days, eh! I wear it here, under my bra. By doing so it doesn't move all over that much. But you see, when I take a shower, I never forget to have it with me! And when I dry myself, no! I try hard not to touch this thingy, because I'm afraid that just by touching it I'd have everyone here at my house (laughs). So well, I dry myself with fear, but this hasn't happened yet.*

'Non-use' is sometimes determined by failure to understand the system

UK materials: Fieldnotes of an observation of an annual review of client's needs and telecare service by a RASO [unqualified social worker]

> [After a fall and serious accident, the client] now wears her alarm all the time, except in the bath. She has pull cords in her rooms, a falls monitor, carbon monoxide monitor and extreme temperatures monitor. She seems only to know anything about the alarm – the falls monitor is sitting next to her on the shelf, next to the china dogs, pills, little tin pill box and books. She tells us that it goes off if it tilts and says that she's worried about it going off – she tells the cleaner to be careful. She doesn't seem to understand it at all. The RASO asks her if she wears it and she doesn't seem to understand the question. The RASO asks her if it has a belt and she says yes. Later I ask her again if she ever wears it –she doesn't. The RASO, (amazingly), doesn't try to instruct her about the device or tell her to wear it. She seems to be happy enough with the alarm round her neck. I later talk to RASO about the falls monitor – but she seems to be quite disengaged. I don't think she thinks it matters much to the client, who has not ever had another fall.

UK case study: Transcript of an interview with telecare user (Peggy who has early stage dementia), her son (Fred) and two daughters (Sadie and Helen).

> Researcher: you've got the falls monitor that you've just brought down…

> Fred: *I've just realised, there it is by the side of the bed and we've never touched it since the day it arrived 18 months ago. I think we just decided, I don't know I just had this feeling that it would… you know, it wouldn't necessarily work… I don't know if it's working. I don't know, maybe it has to lie down for a time, it doesn't seem to be… sort… I don't know why we haven't followed that up*
>
> Sadie: *Does it have to be switched on*?
>
> Fred: *No idea*
>
> Sadie: *Is that a switch on the front to switch it on?*
>
> Fred: *No that'll be to call, that's an emergency call thing, but I don't want to do it because I don't want to keep calling them constantly, but we could do, we could try it.*
>
> Sadie: *Well you can ask her when you…*
>
> Fred: *I'll just try this now should I?*
>
> Sadie: *Try the pendant*
>
> Fred: *although we don't use it. Shall we try it or just use the pendant one to try now?*
>
> Sadie: *We'll try the pendant then ask her about that one*
>
> Fred: *Okay. If you push that.* [sound of soft bleep] *Yeah, that one works fine, that's okay, and then I'll try this one while we're at it. Okay, so I'll be back in a minute* [leaves room to get closer to the hub to speak to the operator,]
>
> Helen: *Don't think that one's ever worked, doesn't seem to have.*

Non-use is also related to a self-perception of the healthy, energetic or even brave user. In this excerpt from a Spanish interview, a user thinks that her friends wear the pendant because of some 'weakness':

> Old lady***:*** *No, no. In winter when I get up and get washed in the morning and everything, I wear on the pendant. Even when I am cooking I wear it because anything could happen in the kitchen. And also with this 'thing'* [her dog*], I always have it…I always think about it now. If I wear it now more it's because of the dog. It's a little dog, always around me. Where I go, it follows me.*
>
> *[…]*

> Old lady**:** *Well, when I go to bed I do not use it, but I put it on my night table. My friends wear it all day long. Some do it, others don't. I have to tell the truth. Some do it, others don't.*
>
> Interviewer: And the friends who wear it…why do they do it?
>
> Old lady: *Because they are very….!!!*
>
> Granddaughter: *Because they are very cowards…aren't they? You were about to say that. Because they are more insecure, worriers…aren't they?*
>
> P1**:** *Because they are clumsier, let's say, eh?*
>
> Old lady**:** *Kitty [her cousin] has the service since the very beginning, when it started. They call her a lot as well. But she is very delicate, she is scared of everything. I am not a hypochondriac".*

The following excerpt from the material gives another example of a person who perceives herself as active and independent, and hence as well enough not to use the pendant. Spanish material (p. 28):

> User: *I have to wear it all the time, yes. But the issue is that wearing things on my neck has always bothered me. Rings and earrings, yes, but things on my neck bother me. And well, bad luck.*
>
> Interviewer: What if it was something else other than a necklace? In other places I've heard there are bracelets available…
>
> User: *I don't know. I don't know. The thing is that I installed the system as precaution, thinking that I'd already have it installed by the time my health worsened. The fact is I don't think I really needed it now. I did it for precaution. I'm really well right now, I swim, do tai-chi, constantly up and down, going out… And well I don't know, look, if I fall and I can't get up well bad luck!*
>
> *And well once a month you test this thing to see that it's working. And of course, the first day that I called, about a year ago, they asked me if I was wearing my necklace, and since they got me off guard I didn't lie! Then they preached on me, they told me 'oh, but you have to wear it!' And now, every time they ask me weather I'm wearing it or not I say: 'Yes, yes, yes!'. But please don't go telling on me! At least I leave it next to me when I take a shower. You can get it wet and it's alright, they told me that. But I put it on my hand because it's so easy to slip and fall. In a blink you can be on the floor. And well I use it only in the shower, because as they say, the bathroom's one of the most dangerous places. The rest of the time I have it hanging*

> *on the kitchen. And to be honest I don't want to wear it. My neighbour does though, and two others that I know of, but they are older.*

Consequences of non-use

For service providers, this may mean spending time and resources removing services, which may be perceived as failure (certainly this is the case in England, where local authorities have been under pressure to install telecare in specific numbers of homes to meet local targets).

> I think the interesting thing about the UK context – and that's where context is important – is - a lot of the telecare that is being put in because it is Government targets. So they are being put into people's houses and then maybe not being used. Which is different from somebody saying 'I really want this' and I need to negotiate all the arrangements". (CM/6-0010).

But service providers in Spain acknowledge that older people must be given a choice not to use the pendants, and so prefer to remove the service than run the risk of litigation if that person has an accident which they cannot respond to (because the client is not using the pendant).

Spanish material (interview with service co-coordinator, p. 29):

> **Interviewer:** And some people who refuse to wear it…isn't it just because their children force them to do it?
>
> **Coordinator:** Yes. *At the end, you have to cancel the service.*
>
> **Interviewer:** Are they cases in which this happens? How do you notice that the service is not being useful?
>
> **Coordinator:** *Yes, there are cases like that. You ask them to press the button once a month, because the machines could not work properly. Anyway, when the telecare workers call them every 7 or 10 days, they remember everything they have to do. 'You haven't press the pendant for a long time, can you check it?' And when some old lady answers: 'I don't want it, I have kept it in a drawer and I will never use it!' Then, they communicate it to us, so if they do not want the service, we take the service out.*

Some older people use telecare to meet other needs

We also found that some older people used telecare to meet needs that the service was not designed to meet. Most notably, in the UK case, these were social needs: some clients 'over-used' the service to get social contact with monitoring centre operators. Such 'over-use' was considered problematic by the social care managers, who suggested that such people should have the technology removed from their homes.

UK material (fieldnotes of Northshire telecare steering group 5/12/08):

> A discussion followed about the ‘misuse’ of the pendant amongst some older people. It was noted that the alarm calls to the monitoring centre were often triggered by the older person rather than by one of the sensors, indicating that it was often the older person them self who wanted someone to talk with or visit them. The Project Leader suggested that perhaps one response was to take the pendant away, but others argued that this was not a good idea as there was a need to acknowledge that pressing the pendant for someone to come out was an important part of social care and they needed to acknowledge this response….
>
> Another suggested that where older people were ‘misusing’ the service social care needed to review their case and assess what people’s real needs are. If this issue is driving the cost up, this needs to be acknowledged nationally with some assessment of what can be done about it, but evidence was needed first.
>
> One service provider gave an example of a medication dispenser that was not used by an older person and which was later found in another site in the same building but not linked to the response line [i.e. the older person had passed it on to a neighbour].
>
> It was emphasized that there was a need to assess the costs of escalating ‘false calls’ that had the potential to ‘clog up’ the call centre and put other ‘genuine’ users at risk because they can’t get connected.

This was in stark contrast to the Dutch case, in which social interactions were encouraged through the Health Buddy and in which ‘over-use’ was not seen as a problem.

Some informal carers ‘customise’ devices to suit the particular needs of the individual or setting. Carers looking after older people also tinkered with the technologies in order to customize them for their family member’s particular situation. One Norwegian carer talked in detail about using matchsticks and tape to ensure that her husband with dementia did not accidently set off his alarm.

Norwegian materials (transcript of interview with carer. p.17):

> CHB: *Technical aids come with an extra demand. That I as a next of kin will manage this. That I am able to sort it out and manage it, and follow it up and maintain it.*
>
> CHB: *It is a challenge to get him to take it with him. I found a small pouch for a mobile phone with a key-ring. He still remembers to lock the door. It was a routine I knew he still had. And he takes the GPS with him 80% of the time. But then the pouch was too thin I found. Because when he had it in his pocket he pressed the button by accident, so it switched itself off. So I bought a new pouch with a key ring. And then I made this home-made solution of placing match sticks and tape in a frame around the off button so that the button is sheltered.*

> CHB: *We had this very serious incident recently. It was late autumn and quite cold. And he* [her husband] *walked into the nearby forest. And in this area the GPS is very unspecific. In the forest there are tracks only. I searched for him several times and became very anxious. And then the battery stopped working! In the end I got hold of him on the telephone. But he was unable to tell me where he was. And he was very scared. I called him later and then he thought he knew where he was. 1 ½ hours later he got home. Then he had been away for 7 ½ hours without food or drink. He was soaked and had panic. And his shoes were full of water.*

Again, some health and social care workers find it necessary to modify systems in order to make them work (either in cost or function terms). Workers associated with telecare also engaged creatively with telecare systems, tinkering with both social and material technologies in order to make them work more efficiently, to make them affordable, or to make their own jobs more manageable. In one of the Norwegian case studies, for example, people had had to make changes to the piloted technologies in order to make it feasible to roll out the service at reasonable cost.

Notes from Norwegian case study: SecurityNet started at first as a pilot project in 2002. For the first three years it was based on a Swedish solution (developed as a part of an EU-founded project):

> GH (coordinator/administration, municipality of Nøtterøy): *The background* [for the project] *was that our Director was at a World Congress, where she saw information about this project, where Sweden was coordinators. (..) And the Swedes [the University College of Borås] were positive to share. But they were very particular about things, and everything that was to be done and developed had to be approved by them. (...) We soon realized that the material was not quality assured. It was old. And it became very expensive. They charged 1600 NOK for each participant for each month, and hire for server on top of that, and so on. We experienced them to be very rigid. They made this big business concept where they had a 75% ownership. And we did quite soon realize that we could not continue with this. So when the pilot project was over, the municipality* [of Nøtterøy*] took over the project. (...) The technical solution was home made. The server was at the VVV University College and could go down any time. The technical collaboration between the Swedes and UUU, the Norwegian company delivering lines for us, was not good. It was my fault that things didn't work. We tried out a picture telephone from Germany. And we realized that it was not compatible with the old.*
>
> *So we made a demand that the new* [locally based*] solution had to be based on so called free software. So we made a temporary solution for Nøtterøy.*
>
> *(...) I don't think the Swedes had been thinking of the practical workings of the solution they developed. It was not supposed just to be a project, but a part of the everyday running of the municipality. I don't think the* implementation *was done well enough. Here it is a need to be*

> *down to earth and to the basic. It was too expensive. The costs were too big for the municipalities. I suggested 100 NOK for each month and then a small increase after some time. In Sweden two municipalities were involved. And none of them followed through.*

From 2005, as the pilot project period was completed and SecurityNet was established as a project-based service by the municipality of Nøtterøy, a small and newly established (local) company (ZZZZ) with strong ties to the local University College, were given the responsibility for the development/maintenance of technical aspects.

> MB (ICT developer): *In the beginning we had a good deal of contact with the elderly participants. It was then we got the feedback that the video picture was too small. And there was too many buttons. So we did quite a bit of development-work. (...) I have met all of them.*

<u>*Some telecare workers go beyond their 'technical' role parameters to adapt telecare to the particular situation*</u>

In the English case study, we came across two key forms of creative engagement with telecare systems: firstly, in observations of installations of telecare we found that unqualified technicians were making decisions about which devices to install (going against the decisions of qualified social workers), based on what they perceived as the practical issues involved in the installation and the likelihood that the client would use the service as prescribed by the social worker.

UK material (fieldnotes: observation of telecare installer, Northshire, p. 23):

> I met Kevin on Tuesday afternoon, to go out with him in his van to do an installation in X. He carries all his stuff in a clear plastic box. He wears nice clothes and his council badge around his neck. He looks professional and carries a small step ladder.
>
> We chat in the car about how he got into this work. He has had no (formal) training – just applied for the job because he thought he could do it. He 'knows one end of a hammer from another.' He is 'used to the public' because he has another job, selling handmade objects at fairs. He was not given any training as an installer – just went out with someone else a couple of times and then was 'thrown in the deep end'.
>
> We talk about him making decisions about what to install. It amazes me how much power he has in this situation. He takes the social worker's notes/ instructions (which he has printed out from the computer as a one-sheet form) as a guide only, really. He reads through this sheet before he goes, sees what the social worker is recommending, then puts in his van what he thinks might also be needed. Kevin is very thoughtful about what is being recommended by the social worker and what might be better for the client. Sometimes he makes no installation at all: he tells me a story about going to install a pendant and falls monitor for a woman who had a friend of 50 years living nearby. When he went to do the installation, the friend was

> there and said to the client ‘But you wouldn’t ever press the alarm, would you?’ and the client agreed. The friend also said ‘But you’ve never worn anything around your neck, have you? So you wouldn’t wear the pendant.’ Also, it turned out that the woman’s carers come after she was out of bed and had already come downstairs. It seemed to Kevin, then, that there was no point in giving her a falls monitor, as she would have needed the carers to put it around her waist and by the time they were there, she was already through the most dangerous part of her day in terms of falling (coming down the stairs). So he ended up not installing anything (contrary to the social worker’s instructions, which he is supposed to follow).
>
> Kevin tells me he will only install if the client is happy and understands enough about what the technology is and how it works. He could, he says, pressure them to accept, but he doesn’t. He is making big judgments, in my view about the clients’ understanding, with no training. He jokes later that if was on commission it would be different!

We also found that workers in the monitoring centre used creative strategies in dealing with telecare clients. As mentioned above, such work involves using language to produce a kind of co-presence that is calming to the client, and which can avert a need to send someone out to check on the older person. This work involves going ‘off protocol’: workers must be inventive in the ways they talk with older people and their family members.

UK material (interview transcript: two call centre workers (Anita and Bev), p.4)

> Anita: *same with the bed sensor, it tells you when they get out, and you do try and speak to the people just to make sure they haven't fallen interveningly. There's one lady, she wanders all night long. Just moving herself. She has bad nights, she doesn't sleep very well.*
>
> Bev: *should sing lullabies to her, I usually say 'it's too early now, get back into bed, night night, God bless' and they like you to talk to them like that when you’re lovely with them. You can talk to her.*
>
> Anita: *You say 'We're having a bad nightmare, let's have a brew!'* [chuckles]
>
> Researcher: Really?
>
> Anita: *Yes, she'll go and - because she's capable - make herself a cup of tea.*

All of this research data about the creative use of telecare and the non-use of telecare raises questions about what ‘proper use’ is thought to be in each context. The empirical material shows that this is different in different contexts and that telecare should not be understood as a universal solution, but a situated one. We argue that people’s creativity in customizing systems is actually essential to the ‘ethical’ use of telecare and that this customization should be respected. In this way telecare systems (in design and implementation) can avoid becoming totalising and coercive.

Concluding remarks

The above report is the result of initial analysis carried out by each partner based on local data, then brought together and discussed across all four partner countries. It will be further refined after being used as a basis for presentation to the second round of project Citizen Panels in June 2010. As such it forms part of an iterative process and represents ‘work in progress’ towards the final EFORTT project report and publications.