



DELIVERABLE 6.4

Report on data analysis aspect of ethics evaluation

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Short description

In this deliverable we report the results of 21 focus groups run in three different countries (UK, France and the Netherlands) exploring the views of older people and formal and informal carers of older people on ethical issues arising from the potential use of the ACCOMPANY care-robots. Specifically we sought views on how to resolve potential tensions in practice between the principles proposed in the ethical framework outlined in our previous deliverable (D6.2), and also whether

there were further principles to be added to this framework.

Participants (n=122) were recruited, and focus groups convened, by four different consortium partners (MADoPA, ZUYD, UH & UB). We believe that this is the first study exploring specifically and in detail the views of older people, and informal and formal carers of older people on the ethical dimensions of the use of care-robots in the homes of older people.

The results are reported by group - older people, informal carers of older people and formal carers of older people - according to the main themes that arose in each. The limitations of the study are outlined. The implications of these results for the framework, and their potential impact on how care-robots are integrated into the homes of older people, will be discussed in our next deliverable.

This deliverable reports activities specifically under T6.7 and user evaluations being run for T6.6. This deliverable will ultimately feed into T6.8.

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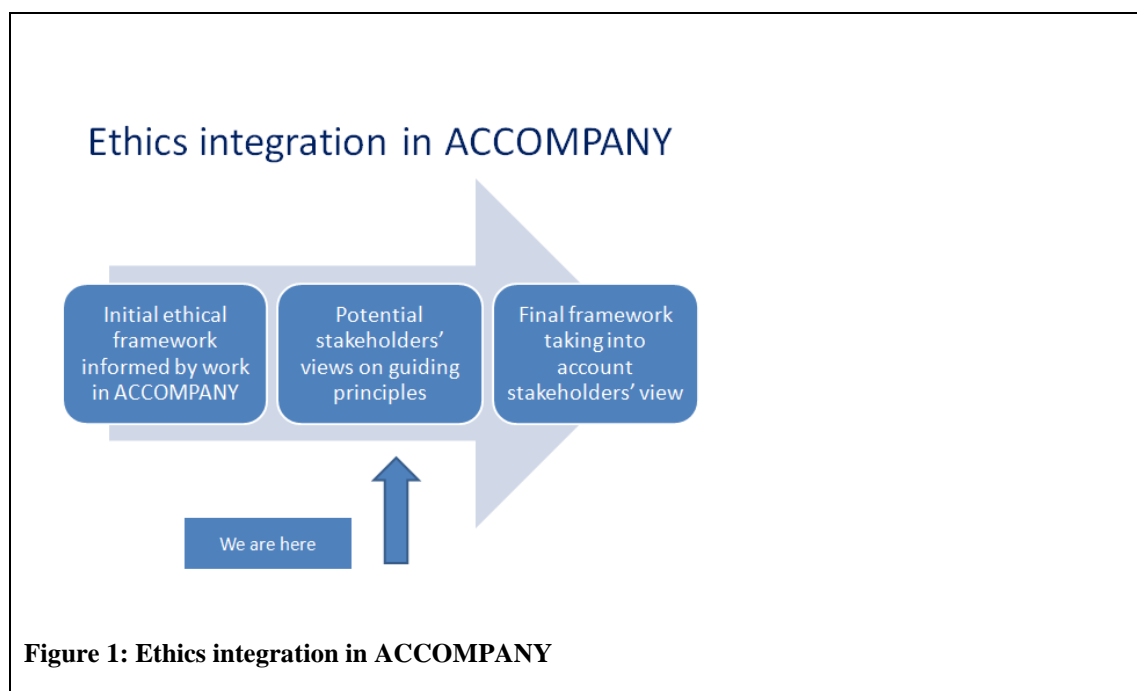
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REPORT ON DATA ANALYSIS ASPECT OF ETHICAL EVALUATION

1 Introduction

An ethical evaluation has been integrated into the work of the ACCOMPANY project. Figure 1 provides a diagrammatic account of how this has been done:



In our earlier deliverable, D6.2, we suggested some values that could be used to guide the design of social robots of the kind being developed in ACCOMPANY. We concluded the deliverable by suggesting a set of scenarios that could be used to expose and discuss some of the fairly predictable tensions between the values if they were applied in practice. We proceeded as if users - especially the older people for whom the Care-O-Bot was designed, but also those who help to support and care for them - were authoritative regarding which values or principles should have priority in cases where they conflict. We sketched out a brief method for eliciting these views on the basis of specially designed scenarios. We also intended that the scenarios be used to expose other ethical values that were important to stakeholders. In this deliverable, we report on the results of consultations with users. We were pleased by the rich data that we were able to collect. In cooperation with our partners at UH, ZUYD and MADoPA, we were able to present the scenarios to user panels running in three different countries: the UK, the Netherlands, and France. Interactions were conducted in native languages. We were also fortunate to be able to increase the number of UK focus groups (henceforth FGs), thanks to the interest expressed in the project by an intercalating medical student at UB, Helena Lee. Supervised ACCOMPANY Deliverable D6.4

by Professor Draper, she convened and transcribed a further three groups of older people living locally to UB.ⁱ We were able to convene these groups thanks to the adoption of our project by the Birmingham 1000 Elders (henceforth B1KE). This is a panel of healthy (self-defined) older people (aged 65+ years) organised by Professor Janet Lord, of the University of Birmingham, who have expressed an interest in participating in health-related research.ⁱⁱ

ⁱ Lee also wrote up her results for her dissertation but this is not part of the deliverables for the ACCOMPANY project.

ⁱⁱ More information about the B1KE can be found on the following website:

<http://www.birmingham.ac.uk/research/activity/mds/centres/healthy-ageing/elders.aspx> We gratefully acknowledge both the input of Helena Lee and of Professor Janet Lord in assisting us to add value to this part of the T6.7. We also, of course, continue to acknowledge the help of all of those who participated in the ACCOMPANY users groups in UK, the Netherlands and France.

2 Method

The aim of this study was to explore perceptions of the ethical principles that should guide the design of social robots for older users and their carers. Specifically, the study aimed to explore participants' thoughts on how to resolve potential tensions between principles proposed in the tentative framework in D6.2, and whether, in considering interactions between social robots, older people and their formal and informal carers, other principles would emerge that had not been taken into account by the tentative framework.

The study design was qualitative, using focus groups as a means of collecting data to inform ethical 'theory-building' (in the social science sense of this expression). The methodology was therefore aligned with the 'Changing Ethical Norms' category of empirical ethics described by Kon (2009), the 'theory-challenging' critical bioethics approach described by Hedgecoe (2004), and the symbiotic empirical bioethics approach described by Frith (2012). In this case, the data from the focus groups will be used to refine the framework proposed in D6.2, and the process of refinement will form the basis of T6.8.

Focus groups were chosen for two reasons. First, the user-panels consulted were already established for ACCOMPANY (see *Report on User and Systems Requirements and First Outline of System Functionality*, deliverable D1.2 and *User Acceptance Over Time*, deliverable D6.5 (forthcoming)), providing input to the project on interactions with the robot. It was therefore convenient to gain stakeholders' reactions to the development of the ethical framework using groups that were already established (though three additional groups of older people were added to these – see below). Second, qualitative methods generally are the preferred way of exploring issues in depth (Kitzinger 2005). FGs are a useful way of doing this, as they also enable participants to react to each other's comments (Carey and Smith 1994; Lindlof and Taylor 2011). This can sometimes result in views being modified to find consensus or can be a way of highlighting and exploring areas of tension between participants (Myers 1998). Scenarios (see Table 1) were chosen to prompt discussion, as it was felt that exploring ethical principles at a more abstract level would not be feasible or meaningful to typical participants in the user groups. Given, however, that the groups would be facilitated in four different sites by four different facilitators, a detailed topic guide was produced to ensure consistency (see Appendix 1). The topic guide was discussed in advance with the facilitators to ensure a shared understanding of the purpose and goals of the scenarios.

Scenario 1

Marie, who is 78 years old, has lived alone since her husband died ten years ago. She has ulcers on her leg, the dressings for which are changed by a nurse once a week. It is important for the healing of these ulcers that she moves around as much as possible to encourage circulation to her legs and avoid further swelling. Her Care-O-bot® knows that she should be encouraged to move about, and suggests several times a day that she walks with it to look out of the window at either the garden or the street below. Marie is reluctant to get up from her chair because she is afraid of falling and walking is uncomfortable. She also uses the Care-O-bot® to get drinks for her from the kitchen, even though the nurse has suggested that she should go to the kitchen with the Care-O-bot® but let it carry the drinks back to her chair for her. Also the Care-O-bot® can only bring bottles of water to her and the nurse suggests that she would feel warmer if she made herself hot drinks. The Care-O-bot® reminds

her to take her antibiotics and to keep her leg up on a stool when she returns to her chair after, for example, going to the toilet. She is grateful for the reminders about the antibiotics but feels irritated about the reminders to elevate her leg as she hardly ever forgets to do this but she likes to get comfortable first. She sometimes put her leg down so that her cat can sit on her lap more comfortably. Her ulcers are slow to heal but when the nurse asks if Marie is moving around more she always says that she is, even though she ignores the prompts to come to the window and doesn't go to the kitchen with the robot.

Scenario 2

Frank is 89 years old and generally frail. He lives alone and needs assistance from a Care-O-bot® to live independently. He prefers the Care-O-bot® to having the neighbours or carers helping him because he thinks they are inclined to be intrusive and interfering. He uses his Care-O-bot® interface to talk about fishing with a friend he has known since childhood. Neither of them can go fishing anymore, but they enjoy talking about when they did and discussing items in a fishing magazine that they both subscribe to. They talk about once a month. Frank really looks forward to these conversations and they put him in a good mood for days afterwards. He becomes quite miserable if his friend is in hospital and unable to talk to him. Frank's daughter has suggested that the Care-O-bot® should be used to encourage Frank join a virtual fishing forum on the internet. She is worried that he only has one friend who is older and poorly and may die leaving Frank with no one else to talk to about fishing. Frank says that he is too old to be making new friends.

Scenario 3

Nina who is 70 years old had a stroke two years ago but has now recovered the use of her arm though one side of her face droops slightly. She is self-conscious about this, but it does not affect her physical functioning. She is supported at home by a Care-O-bot®. Since having the stroke she has become quite irritable and impatient. She often shouts at her daughter when she visits and complains angrily about her condition. Her daughter finds this very upsetting and has come to dread her visits. Nina has been so rude and demanding that two cleaners have already refused to work for her anymore. She is usually polite with her friends. Her Care-O-bot® has been programmed so that it will not do things for her if she asks sharply or in a demanding tone. It encourages her to say please and thank you and will withdraw help until she does so. Nina finds this infuriating and insists that the Care-O-bot® is reprogrammed to do what she asks no matter how she asks for help.

Scenario 4

Louis, who is 75 years old, is determined to continue to live in his own home, which is in a small town in which two of his sons live. He is regularly visited by his daughters-in-law, who bring him food, help with his cleaning and do his laundry. Louis was left with some weakness in one of his legs as a result of an accident in his 40's. He is becoming frail and is finding it increasingly difficult to get up from his chair and walk with his sticks. Louis is supported at home by a Care-O-bot®. The Care-O-bot® is programmed to help support him when he gets up from his chair and can be summoned to help if he falls. Louis has discovered that he can use the interface on the Care-O-bot® to visit online gambling sites and enjoys playing poker in the evening. He also uses the interface to give his doctor his blood pressure measurements, and sometimes his medication is adjusted as a result of the measurements he gives. Louis falls over about once a week on average. On the whole he is able to get up again with the help of the Care-O-bot®, but he recently was on the floor for several hours unable to get up and developed a bladder infection from lying in the cold unable to reach the toilet. He was in bed for several days as a result. This placed an additional burden on his daughters-in-law, who took turns to stay with him during the day until he was well enough to live alone. It was during this time that his daughters-in-law realised that he used the Care-O-bot® to play poker on line. They are very unhappy about this as he often loses money. They want access to the poker site to be blocked. They have taken away his sticks so that he has to use his walking frame, which means that he is less likely to fall. They want the Care-O-bot® to be programmed so that

it alerts them as soon as he falls. Louis insists that it is up to him what he does with his own money and says that he doesn't want them to come rushing around every time he falls because he can usually get himself up.

Table 1 – scenarios used in focus groups

ACCOMPANY has three types of user panel: (1) healthier, cognitively unimpaired older people; (2) older people who need some support to remain independent in their own homes; and (3) formal and informal carers of older people (who in some cases are carers of the older people participating in the panels i.e. the MADoPA triads). Those in the additional focus groups conducted at UB had no previous experience of working with ACCOMPANY, or previous exposure to the robot being developed. They were shown a short clip of the robot under development as a basis for discussing the scenarios. The FGs were run according to the topic guide (see Appendix 1); the scenarios were circulated in advance to those who expressed an interest in attending the FG. On arrival written consent was obtained. Once the participants were ready, the facilitator announced that recording would commence and typically the participants first introduced themselves and then the facilitator addressed the scenarios one at a time, starting with the first and using the prompts as necessary. The facilitator read the scenario out loud before proceeding unless the participants indicated that they had read it, in which case a synopsis was provided. The only difference in the UB FGs was that the clip of the robot was shown before the discussion of the scenarios commenced. A total of 21 FGs were run; 9 with older people, 6 with formal (paid/professional) carers, and 6 with informal (unpaid) carers. Participant characteristics are reported in the results section below. We aimed to run groups with between 5-8 participants in each, to facilitate organisation and maximise potential individual participation (Krueger 2009).

Prior institutional ethical review was obtained for each of the participating sites. Written consent was obtained from all participants. All the FGs were either audio recorded (UB) or both audio and video recorded (UH, MADoPA, and Zuyd) and transcribed verbatim. At UH, two different camera perspectives were used. The second camera perspective was used during the transcription process, in cases in which it was not determinable from the first perspective which of the participants spoke.

The analysis of the data had to accommodate the fact that the groups ran in three different countries, each with their own language, and that none of the researchers involved were fluent in all three languages. Accordingly, the following approach was agreed. Each of the two sites not using English (MADoPA & ZUYD) selected a representative example of each of the three types of FGs (one each of older people, informal carers, and formal carers) and translated the transcript into English. A single researcher (Draper) coded all 6 of these transcripts, plus the three transcripts from UH and the three from UB, using a combination of directed analysis and Ritchie and Spencer's Framework Analysis (see Table 2 below). This permitted the data to be searched for views supporting and/or rejecting the proposed tentative framework, whilst also being open to the expression of additional values/principles by participants.

1) Familiarisation - data immersion reading the transcriptions several times.
2) Identifying a thematic framework – coding of data using a combination of descriptive, in vivo and initial coding (Saldaña 2009). Descriptive codes referred to the values outlined in the Deliverable 6.2, hence hybrid between Framework and directed approach
3) Indexing –An approach similar to constant comparative analysis (Glaser 1965) was used in sorting the quotes, searching for correlations and contradictions between quotes.
4) Charting – involved thematic organisation of the quotations which provided a systematic way to manage data directly relevant in answering the research aims/questions.
5) Mapping and Interpretation – involved creating a mind map of the data’s main themes, subthemes and their connections, thereby bringing the data set together as a whole.
Table 2: Use of Ritchie and Spencer’s ‘Framework’ analysis

Draper’s coding was then discussed with the second researcher (Sorell), who had coded the same data independently. The resulting codes were then roughly worked into themes (Draper) and presented to a meeting of all of those involved in running the FGs. This enabled some discussion, refinement and agreement about the emerging data with those who had a working sense of what data was likely to be found in the transcripts that had not been translated. Researchers from MADoPA (Gutiérrez Ruiz) and ZUYD (Bedaf) then coded the remaining transcripts in their native languages. Quotations that may be used to illustrate the resulting themes were double translated for accuracy. Reports were then produced summarising the outstanding data and providing information about the FGs at each site. These reports were then passed to Draper and Sorell to be combined and reported in this deliverable, along with the data from the English FGs and translated transcriptions.

Next, a draft of the deliverable was circulated for comment and refinement from the perspective of each of those who conducted the native-language analysis. Ideally, all of the transcriptions would have been translated into English and a common interpretation agreed but this was not possible given the resources available. The compromise method of analysis is a clear limitation of the study. A further limitation was that two of the translated transcripts were not available for initial analysis when the group met in Heerlen to discuss the coding and themes. This meant that only very partial data was available for two groups (formal and informal carers) at the time of the meeting (June 2013). These were the only deviations from the analysis plan outlined above, though reporting differed between MADoPA and ZUYD. Figure 2 below shows the process of data collection, analysis, and write-up.

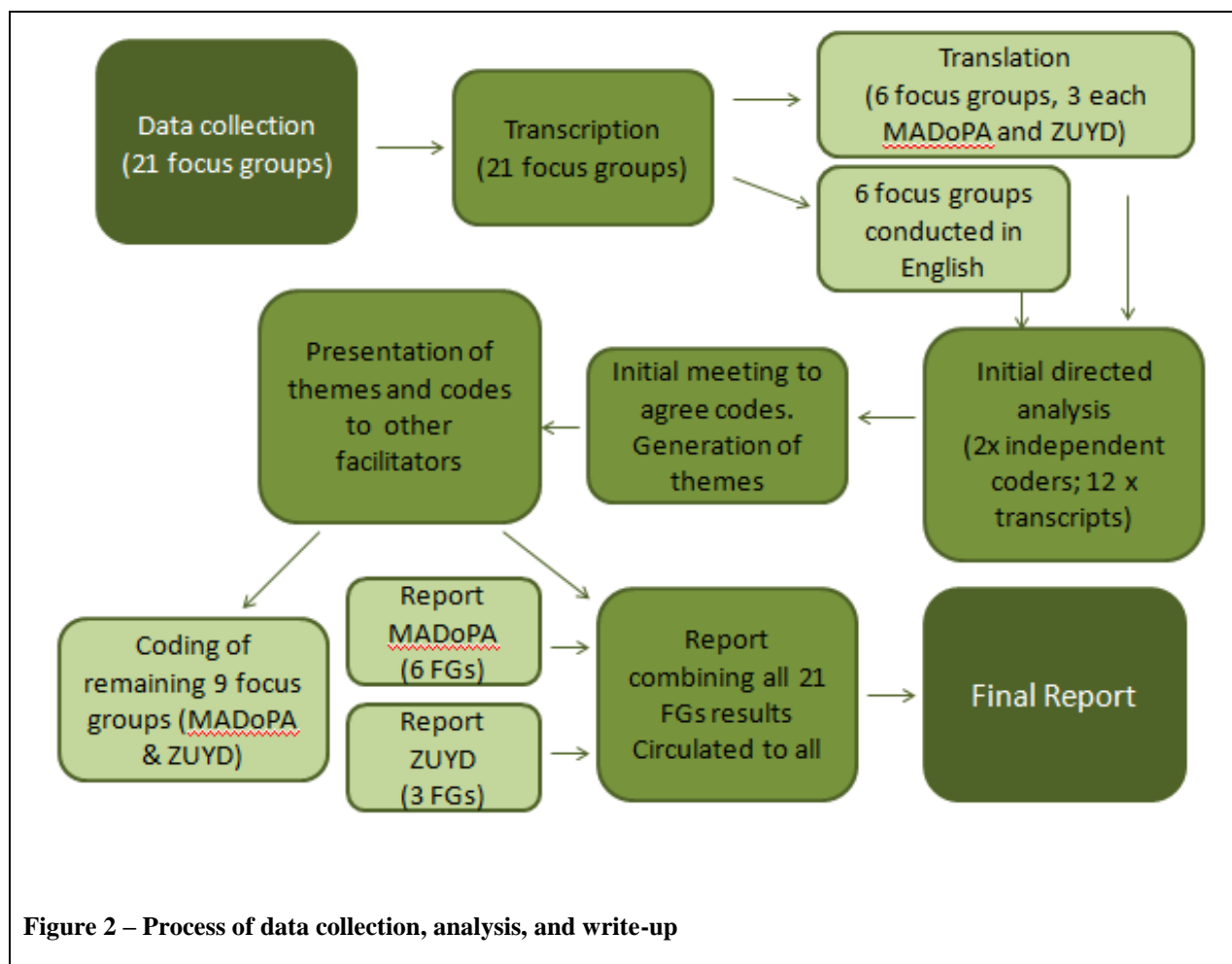


Figure 2 – Process of data collection, analysis, and write-up

3 Results

We have reported the results according to the type of group: user, informal carer; or formal carer. Marked differences between sites will be noted, though cannot be generalised.

3.1 Number, type and timing of Focus Groups

All of the existing panels were run at the three sites (see above) plus an additional three groups at UB. The exact composition of the groups varied, as not all potential participants are able to attend each of the panels. On occasions the number of participants per group was sub-optimal as potential participants were unable at short notice to be present.

	Older people	Mean time (actual) in mins	Informal carers	Mean time (actual) in mins	Formal Carers	Mean time (actual) in mins
MADoPA	3 (7,8,4)	109 (110, 115, 102)	3 (7,5,3)	121 (117, 132, 114)	3 (7,5,4)	113(120, 116, 103)
Dates/place	Nov 2012-Jan 2013/ Ile de France and Champagne Ardenne regions, France		Nov 12-Jan 2013/ Ile de France and Champagne Ardenne regions, France			
ZUYD	2 (7,3)	75 (90, 60)	2 (6,5)	54 (46, 62)	2 (6,7 ⁱⁱⁱ)	55 (55, 55)
Dates/place	February, 2013, Venray March, 2013, Heerlen, NL		February 27, 2013, Veldhoven March 13, 2013, Heerlen		February 26, 2013, Venray February 28, 2013, Heerlen	
UH	1 (5)	Approx. 90	1 (4)	90	1 (6)	90
Dates/place	January 2013, Hatfield, UK		February 2013, Hatfield, UK		August 2013, Hatfield, UK	
UB	3 (7,7,7)	87 (92, 73,95)				
Dates/place	March 2012, Birmingham, UK					
TOTAL	9 (55)		6(30)		6 (37)	

Table 3:
Information about data collection periods, participants per FG and time each ran for

3.2 Participant characteristics

3.2.1 Older people groups

Basic demographic information only is reported. Given the nature of the research methods employed, no attempt has been made to analyse the data with reference to these characteristics. On the other hand,

ⁱⁱⁱ Halfway through the session an extra participant joined the focus group session. This participant is not included in the number of participants.

it is interesting to note that with the exception of the Dutch groups, women were disproportionately represented, even allowing for the age range of the participants. Some of the oldest of older people (defined as 85+ years) participated. The groups tended not to be ethnically diverse. Some of the participants were not living in their own homes. Demographic information was not formally collected from UB but based on observation of the FG participants, the ratio of men to women was noted. All of the non-Dutch participants were >65 years of age. Participants in the Dutch group were >62 years of age, with the exception of one who was 42 and receiving home care due to her illness, and faced similar problems to those of elderly people. All will have self-reported as healthy as this is part of the joining process. All were living in their own home, but not necessarily alone. Several of the participants in the Netherlands went to day care for 2 or 3 days a week. More than half of the older participants from ZUYD (7 participants) made use of CareTV to contact their carers through the television at least once a day. UH did not formally collect demographic information except that which was necessary to determine their eligibility for the study.

	MADoPA	ZUYD	UH	UB
Age range	Average age: 81.53 (68 -95)	Average age: 72.8 (42 – 92)	65+	65+ years
Men: women	2:17	6:4	3:2	8:13
Living independently/living supported accommodation	11/8	All were still living independently and received home care.	All living independently	21:0
Ethnicity (list all)	Not permitted to collect this data in France	White Dutch	White British	White British
Table 4: Basic characteristics of the participants in the older persons focus groups by site				

3.2.2 Informal carers groups

	MADoPA	ZUYD	UH
Age range	Information unavailable	Average age: 65.3 (52 – 79)	Information not recorded
Men:women	4:11	2:9	0:4

Range of informal care experience	Most took care of their mother or father.	Most took care of their father/mother (in law); other relatives e.g. uncle, husband. In 2 cases the person taken care of was recently institutionalized and in 1 case recently deceased. 2 informal carers were also formal carers.	Information not recorded
Table 5: basic characteristic of the participants to the informal carers groups by site			

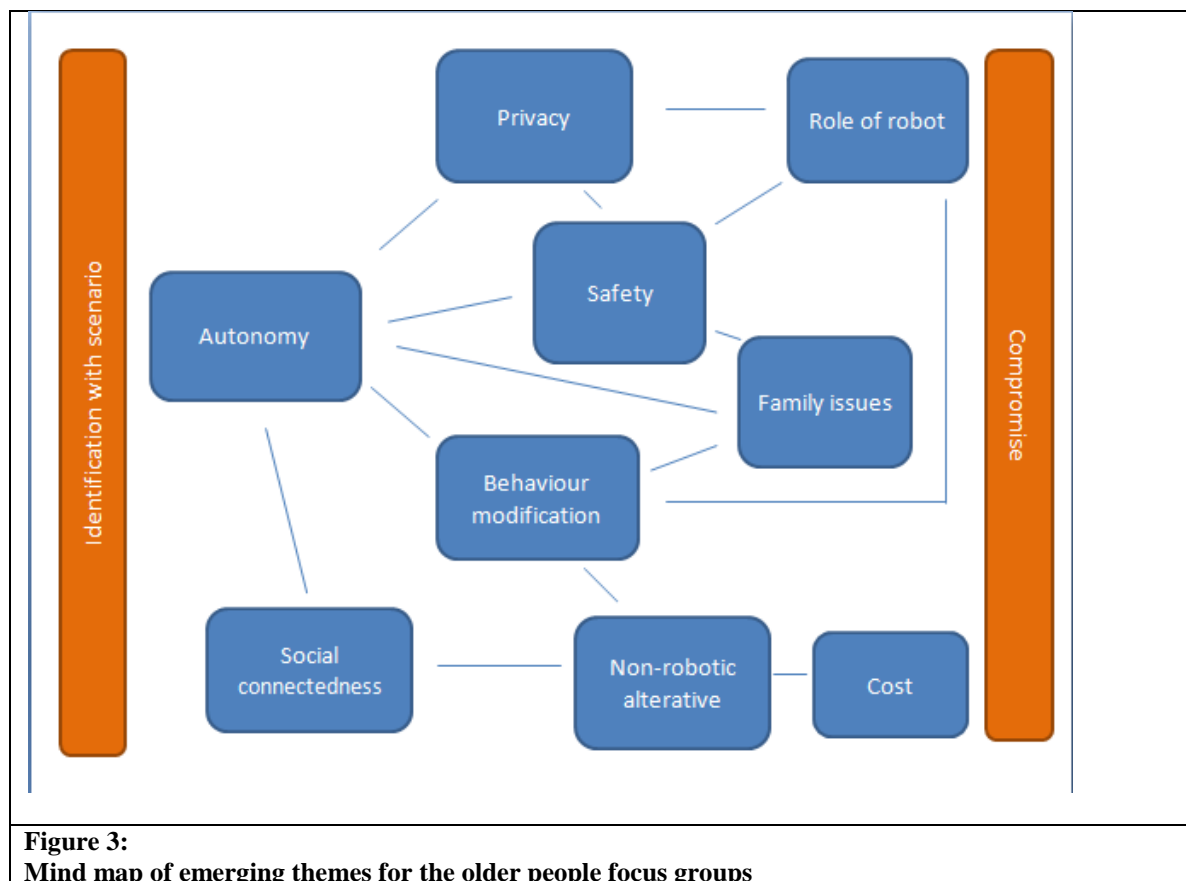
3.2.3 Professional carers groups

	MADoPA	ZUYD	UH
Years of experience	7 years	Information not recorded	Information not recorded
Men:women	1:17	0:13 ^{iv}	0:6
Range of roles	7 personal care assistants 3 nurses 4 nursing auxiliaries	7 day care workers in nursing home. 6 home care assistants	1 GP 1 nurse 1 retired care home manager 1 manager of a

^{iv} The extra participant that joined the focus group meeting was a male
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	1 social worker 1 psychologist 1 ergotherapist 1 manager		private home care provider 1 care worker 1 carer in a dementia unit
Table 6: Basic characteristics of the participants to the professional carers groups by site			

3.3 Older people groups



The main themes and connections between themes to emerge from the older people groups are represented in Figure 3. It is difficult to present and discuss participants' views under one theme without reference to their views under others. To avoid repetition we will refer to inter-relatedness without elaboration, save where elaboration is necessary to explain nuances.

3.3.1 Identification with the scenarios and the desire to reach compromise solutions in the event of tensions arising.

We made two observations about the scenarios. The first is that they worked well as a vehicle to promote discussion because the participants found them realistic and could relate to them. The second is that participants often tried to work around the problem presented by a scenario. We do not offer these observations formally as themes arising from the data, but only to indicate over-arching influences on the discussion.

The participants related well to the scenarios, which suggests that they found them realistic. They raised and attempted to resolve issues. Many of the participants had experience themselves not only of being elderly but of being informal (and sometimes formal) carers for other elderly people. So they

sometimes related to the scenarios as potential user-hosts of the robot, and at other times as potential carers of an older person using a robot.

You have to remember that ulcers are really painful and I can understand why she doesn't really want to walk about much. One of my neighbours has got ulcers on a leg and her son really has to struggle with her to get her to go outside for a walk. It hurts so she doesn't want to. Robot or no robot, she won't go out (MADoPA OPFG1 P1)

'cause for twenty four years I lived in a block of retirement flats, so I've seen a lot of these situations come and go...carers come and go, people are rude and a neighbour of mine who's just died she fitted that scenario ...so well and she was rude to her carers, so they left. She was rude to her daughters, had her daughters in tears, and yet she was fine with everybody else. (UB OPFG1 P6)

so I can empathize in certain ways. Being impatient is different to being rude. Sometimes you appear to be rude because you can't get the words out because your brain is not functioning with your mouth you know that is frustration rather than rudeness the same person who never been rude before the stroke are going to be now (UH OPFG P4)

I'm also such a person, so I can tell you that I don't always do what they tell me to do. (ZUYD OPFG 2 E3)

Perhaps because they found the scenarios realistic and because they were able to relate well to them, the participants had strong views about which of two values in tension in a scenario should prevail, where one of the two clearly seemed to be the more important. The participants also engaged in problem-solving, trying to come up with creative ways in which the ethical tensions presented by the scenarios could be resolved to the satisfaction of all concerned while giving weight to both of the values in tension with one another.

Yes, if necessary you could program the robot different during the evening, so you still have the time to watch something. Or that you could indicate: "I want to watch this and we can walk over 1,5 hours". (ZUYD OPFG1 E7)

If it [the robot] couldn't [get her a hot drink], she could have a little flask, I mean the robot could carry a little flask and then just take the top off (UH OPFG P1)

O4 : If she really does have to get up and walk around, the robot will have to keep saying things like "Come on, we're going for a walk!!" just like a nurse or a physiotherapist would.

O5 : You can't...

O3 : Perhaps there's the way it's said too. Perhaps the robot should say it gently and kindly rather than as an order. (MADoPA OPFG1)

1: Could we programme the robot so that we took away the stick and added a carrot?

6: Yes

1: So that when she was nice to the robot, asking it properly, that she got some extra reward from that...

6: the idea is that she should say thank you and be polite so when she asks in a reasonable voice for whatever, a drink I assume, y'know like what we've seen on the video, and she says it reasonably then the robot responds by saying 'Thank you very much, I'd be pleased to do that (UBOPFG2)

It is worth noting, however, that even in these suggested compromises values do assert themselves. So, for instance, in the UB example above, the participants seem to accept that the robot can be used to

alter Nina's behaviour. The compromise relates to how this might be achieved, offering an alternative that is at the same time more respectful of her autonomy.

3.3.2 Householder Autonomy

We looked specifically for participants' references to notions of autonomy, as this was clearly a significant value in the framework offered in D6.2. We did not anticipate that participants would necessarily use the term 'autonomy' (or equivalent in translation) so we coded as references to autonomy all references participants made to notions of e.g. control, others doing what older people wanted, letting older people decide for themselves etc. In reporting participants' views on autonomy, we also noted how important they felt this was in comparison to other values (such as e.g. safety). However, even taking this into account as a potential bias in the analysis, autonomy was an important point of reference in all focus groups discussions, and referred to in relation to all of the scenarios. It seemed to us when interpreting our data that autonomy was related to many of the other themes, as shown in Figure 3.

Our participants did regard the autonomy of the person into whose home and for whose benefit the robot was being introduced (henceforth the 'householder') as a significant factor. There was a general presumption that the householder's views about how the robot should behave should be respected. The participants tended to assume that the householder would have been consulted about whether or not to have a robot in their homes. There was often a strong – but not unconditional – sense that householders should be able to live their lives as they wanted to, even where others did not agree with the choices made, and sometimes even if others were inconvenienced as a result. This was a general – but not universal – view in response to most scenarios, except UH, where the older person group seemed to regard paternalism as acceptable in certain cases. Another striking exception was found at ZUYD in the case of the third scenario, where there was very little support for Nina's behaviour, even towards the robot (see Table 7).

Scenario One

You have that thing in your home to receive help, not to get forced. (ZUYD OPFG2 E3)

Elderly people still have their personal freedom and if they say no it should be no, shouldn't it? (MADoPA OPFG1 P1)

I dislike it and I think it's a bit (stronger) than dislike, that the idea that because you've reached a certain age...you have to have something, or you're put in a position where someone's telling you what to do all the time...You have a right to decide I don't want, I don't care what I'm being told to do. I have a right...as as any adult does not to do it. And not have to put up with being nagged at (UB OPFG1 P5)

Scenario Two

E3: No [the daughter should not be allowed to programme the robot]. You should still respect the opinion of that person. I really think that.

R1: Even if Frank really enjoys the internet after a while?

E3: Yes but you can always show it, but he... Yes... [silence] I still think the person himself... You should not

ignore his opinion. (ZUYD OPFG1)

Some people are just like that. They like being on their own at home not seeing anyone. (MADoPA OPFG1 P7)

I know three people who are in their mid and late nineties. Two are very active, very outgoing, they meet, they go out, they meet people and they're very good. One will not. And that's a fundamental difference between them and they've been like that all their lives. (UB OPFG1 P7)

2: It actually says he likes - well they use the word prefer don't they but they but he likes the Care-o-bot cause it does things for him, makes a cup of tea, carries this, does that, and he doesn't want to have people coming in and messing about

6: which is his right (UB OPFG3)

You should still respect the opinion of that person. I really think that. [...] No. It is difficult. Because you shouldn't ignore their opinion. They should be able to tell and decide things. (ZUYD OPFG1 E3)

Scenario Three

P2: One thing that has to be made clear is that it's not her fault

P1: Yes, I say we leave her freedom. The robot isn't going to die just because she insults it. (MADoPA OPFG1)

No I don't think a robot should be able to treat somebody as if they're a naughty child... Not not somebody of seventy, no (UBOPFG1 P6)

I think you don't need to swear the whole day, also not to that robot. (ZUYD OPFG1 E3)

Scenario Four

Concerning the gambling he says he's in charge of his own money and I have to agree with him... (ZUYD OPFG1 E3)

people shouldn't treat all elderly people like children (MADoPA OPFG1 P6)

He is a youngster! [commenting on age relative to his own] How dare they interfere? (UH OPFG P1)

It's his money! (UB OPFG2 P3)

Well if it his gives him pleasure which it apparently does I mean there's not, he's not bankrupting himself with it, it just says he loses, you don't know how much he's staking ... it might be an enormous amount of money, if it does give him - well it's one of these individual freedom things again isn't it ...But then I ask myself, I'm all for him playing poker myself, but then I think what would I say if it was porn he was looking at. You know would I have the same kind of, 'Oh yes let him'. As actually I think I would actually ((laughs)) thinking about it or :: I can't think of a limit but I mean what if it was bridge online say if he played bridge or bingo you know. We mustn't think poker is kind of evil or more evil than other things (UBOPFG3 P6)

Table 7. Evidence of participant support (older people's focus groups) for householder autonomy

Although most participants tended to associate autonomy with being allowed to do what one wants, it was also recognized that autonomy could involve freely *making oneself* do something:

P3: One has to make oneself do things also and cook

P1: Yes, that makes you walk as well (OPFG2 MADoPA)

The participants were aware that not all older people are autonomous, and linked respect for autonomy to having good cognitive functioning and the absence of dementia, some referring to mental capacity and linking this into the potential for family and carers to make decisions for older people who are not able to make decisions for themselves. This was particularly apparent in the Louis scenario, as some of the participants seemed, as a result of their own experiences of being carers, to be aware of powers of attorney in relation to financial matters.

...with these none of them [people in the scenarios] have dementia or going that way when they can't make a decision. They're all of sound mind to make their own decisions (UB OPFG1 P2)

there's no suggestion there that he [Frank] is incapable of making his own decision (UB OPFG2 P4)

It also depends on how someone is mentally. It can be the case that they, when they are in the kitchen, forget what to do. They will forget it. (ZUYD OPFG1 E1)

P6: It depends on her level of awareness

P3: Her degrees of awareness, yes. (MADoPA OPFG1)

he is obviously still 'compos mentis' it's his business (UH OPFG P2)

quite simply we've nothing here to suggest that that Marie isn't of sound mind ... And if she is of sound mind and can know make a decision then it is up to her whether she wants to .. obey (UB OPFG1 P5)

I think this is the hardest one of all three actually, because this lady it looks as if the problems with her are the residual effect of the stroke therefore she can't help herself being impatient and irritable cos this is one of the things that can happen after a stroke, isn't it? Not with everybody but with some people. So it's, I think this is quite hard (UBOPFG3 P3)

Although they asserted its importance, participants did not always consider that respect for autonomy was an over-riding value. They acknowledged that sometimes people do not make good decisions (defined as those that best promoted their own health or other kinds of well-being). Some participants did not feel that this alone was sufficient for others to override decisions, however; indeed some were very clear that people should be allowed to make their own (bad) decisions, and then they (and also their family and carers) had to live with the consequences of these.

Personally I'm not sure that the robot should act like that. Basically it's there to help her, she lives with it. If her daughter doesn't like it, she can just visit her mother less often. (MADoPA OPFG1 P3)

My husband needs to use a rollator. But 9 out of 10 times he walks without that thing. And I can say the whole day: That thing is over there use it. Then I'm the robot. But if you have to say that 20 times a day.... Well... And he falls. Just try to keep yourself together. It's his own fault then. He should have used his rollator (ZUYD FGOP1 E5)

P6: He has the right to choose to be alone

P3: [Yes, yes]

P7: [Yes]

P2: [Yes that's right]

P6: if that's what he absolutely wants, yes we all have that right, yeah

P7: Yes I mean it's his, his, what he wants (.) to be ((laughs whilst talking)) alone and miserable and although you might not want him to be alone and miserable that's [what he seems to be] aiming at. But I, to

go back to the beginning - we have other people have the responsibility to encourage him not to be but not the duty to force him not to be. (UBOPFG3)

Many participants distinguished between making decisions for people and making efforts to get a person to see something differently. They thought that it was acceptable to attempt to persuade people to change their minds. This was particularly apparent in scenario 2, where the feeling was sometimes expressed that Frank might not realise what he was missing, nor realise what possibilities were open to him. It was felt acceptable to suggest using the forum, or other possibilities, to him, though this was on the understanding that he could still refuse. Participants proposed a variety of ways in which Frank's mind could be changed that went beyond persuasion more conventionally conceived as the power of rational verbal argument. They were not beyond employing cunning, or as one participant put it '*fair means and foul*' (MADoPA OPFG1 P4) to get him to try the site. Participants also drew a distinction between pressing changes on householders that that still gave them scope to choose differently, and coercion. For instance, in the case of Frank some of the more devious methods suggested for getting him at least to try the internet site were proposed along with a statement suggesting that getting him to try it could open future possibilities that he hadn't previously appreciated, or that if he once tried it and didn't like it that was then up to him. In this respect the participants seemed to be drawing a distinction between coercion and what might be termed 'autonomy-promoting paternalism'. Likewise, in scenario 3 it was noted that replacing the sticks with the frame didn't stop Louis from getting around (undermine his freedom of movement), it just made getting around safer.

I would like to say: "Now it's the proper time to take my medication." I do that now myself as well [as having a reminder]. (ZUYD OPFG1 E4)

But if someone is not interested... I think you should give someone a couple of lessons so maybe this makes him interested in it. (ZUYD OPFG2 E3)

It doesn't mean that he's got to use it, she [the daughter] can just put the programme there for him and maybe he uses it of his own accord. Is that not right? She's not forcing him to do it, it's just if she can just manipulate it and add that to what he's already got well then he has a choice, maybe when nobody's about he'll have a little play and find it by himself, if he hasn't got it he can't do that. So it's not as if she's interfering she's just adding it to his range of possibilities and it's there – he can either do it or not as he wishes presumably. (UB OPFG2 P7)

You could pretend you pressed the wrong button on the robot or something and saw it by chance. By the time he's tried to find out what's happened or you tell him the truth, he'll have seen the channel and may well be interested. Sometimes you have to use fair means and foul to change people's minds... (MADoPA OPFG1 P4)

They don't just take something from him. They come with an alternative. Instead of the crutches they give him a walking frame which makes it less likely for him to fall. It's not like they take away him walking. (ZUYD FGOP1 E7)

people don't always realise that they can improve their quality of life. (UH OPFG P1)

if it was programmed [for] the person that is who's going to be of use to ...they'd asked the person what they would like it to do and per'aps they could programme their particular voice to the robot ... , it'd be like them asking themselves [to do the job] (UB OPFG 1 P2)

I think this case from the other one in that in Frank's case it's simply... we're only meaning more happiness for him in the sense that you're not actually interfering with him in his physical being or his mental [pause] well you are a little bit in his mental state but only to make him happier, whereas the case with the other woman I think that was much more a medical intervention which she didn't want as probably has the right to decline, y'know her own way. But this is a softer sort of issue I think in this one (UBOPFG3 P6)

Changing Frank's mind was not regarded by participants as such big a threat to his autonomy as, for instance, trying to change/prevent behaviour in the other cases. Participants were also sympathetic to Nina, as they felt that her rudeness may be due at least in part to her stroke. On the other hand, some participants noted that she seemed to have some control over her rudeness when it suited her. This suggests that she was at least in part responsible for her rudeness and might, therefore, have to accept the consequences of being a rude person as opposed to a polite one. (Participants' views about behaviour control will be elaborated further below)

The fact is that she is usually polite with her friends therefore she can be, it's not as if something has happened that she is rude to everybody, she isn't. Therefore the control is there she is just not using it she is choosing to be offensive to her two cleaners and her daughter. (UHOPFG P1)

Well I don't see why she can't be as rude to the robot as she wants because it might actually, if she uses [all her rude] up on the robot ...she might be nicer to people, cause she's capable of being, if she's capable of being nice to her friends (UB OPFG3 P7)

it depends whether they can't stop themselves because there is a residual effect of stroke or whether they are just being rude for the:: for the sake of being rude, I don't think anybody should be rude to anybody else. But it can [be] impatience after a stroke can be quite noticeable having had relatives that have had stroke they can become very impatient and when they ask you to do something they want it doing now (UBOPFG3 P3)

she's difficult with the people who come to care for her, not with her friends (MADoPA OPFG1 P3)

it might stimulate a type of behaviour she will display to others as well (ZUYD IF2 M3)

Many of the participants thought that some cooperation with the robot was a reasonable requirement deriving from the initial agreement to have one as a companion in the first place. This suggests that respect for autonomy starts even before the robot is installed in the householder's home (partially due to the fact that the robot is installed by agreement), but also that some agreements willingly entered into should be honoured even when the robot appears to nag.

I'm assuming that this isn't forced on her she agreed to have a robot, so stay at home and have a robot rather than sort of saying 'Right, if you don't have it you have got to go to care' so it's not something she has got to have. It's something that she makes the choice to have the robot and I think you made that choice she has got to pay a little attention to it even if it is a robot. (UH OPFG P2)

To begin with, if someone wants a robot in their home, if they decide to get one, then what's the point if afterwards they actually don't listen to it? ... To my way of thinking, with the robot it's the as when you go to see a doctor. If you don't take the medication he prescribes for you, why bother going in the first place? (MADoPA OPFG1 P7)

You have chosen yourself to have that thing in your house, so you also have to accept the things it does. (ZUYD OPFG1 E2)

what is the point of people having a robot who are going to provide facilities are you going to accept it or not? And if you're going to ignore anything and everything it does except get you your drink of water you might as well save the money and not get her one! (UB OPFG1 P1)

Finally, there were some participants who expressed the view that paternalistic behaviour – even when enacted through the robot – could be justified because it was for the good of the person concerned.

E3: Yes

E2: *It's safer for him. So he won't fall anymore.*

E1: Yes

E4: *It gives him more support.*

R1: *But Louis prefers to use his crutches.*

E3 *Yes [...] but it also happened that he couldn't get up anymore. And then I think, from my perspective, it's better to use the walking frame than the crutches. (ZUYD OPFG 1)*

P2: *Well I think the Care-o-bot has got to be programmed to alert if he falls.*

P1: *Yes, serious falls I think because if he got ill, that is a problem.*

P2: *...somebody can check up whether he has picked himself up or not. I mean probably the robot would only need alert with falls when he stayed down. (UH OPFG)*

Well I think it depends whether he played poker before he became disabled. If he played poker before then he would want to continue playing it, but if he hadn't played it before and he only found out about the sites once that he saw that it was accessible on his robot then that's :: maybe the poker sites shouldn't be there, because gambling can be very addictive... and it become an addiction and then they lose everything, nothing to do with whether the children are going to inherit, but from his personal point of view it would be very demeaning to suddenly find that he'd lost everything (UB OPFG3 P3)

I think it shouldn't be her re-programming the robot because people who have this kind of problem, they sometimes have suicidal thoughts, and it wouldn't be good if they could programme something that might help them to commit suicide, So the robot should be re-programmed by someone else. (MADoPA OPFG1 P5)

3.3.3 Safety

The Louis scenario in particular was designed to draw out discussion on the potential tensions between autonomy and safety. There were safety issues directly related to physical health, represented in the scenario by the falls. Threats to financial security represented by Louis's use of the internet for gambling were also considered. Taking the latter first, some concerns were expressed about the potential dangers of using the internet – and these were raised first in relation to Frank's use of the internet to become more socially connected. When it came to Louis's internet gambling, there were concerns about Louis losing the means to support himself and pay his bills. Competing with these concerns was the view that Louis (and by extension other older people) should be free to spend his money as he sees fit (i.e. support for autonomy).

I agree, there are people who don't realize what they're doing and how fast things can go. And to avoid further problems you could say €5 or €10 per month and that's it... [...] But the moment he's going to make debt, you create a big problem for the society and the bills also need to get paid. If you agree on an amount per month everybody is happy. (ZUYD OPFG1 E7)

E5. *There are so many other sites where you can also lose money.*

E3. *That is the risk these days.* (ZUYD OPFG1)

I would have worries about being on an internet forum because Frank's vulnerable, like children are. I mean Frank might have very expensive fishing rods or antiques or something. And somebody on the forum can pretend they're anybody (UB OPFG2 P6)

Yes, well I was just thinking people on internet forums can indeed be horrible people (UB OPFG3 P7)

Researcher: *So you're saying that he should be left free to play poker but that limits should be set. So who should set those limits?*

Several participants: *Members of his family.*

O4: *Once they've added up the cost of his rent, his food, the people who care for him and everything, they can see how much he has left, can't they?* (MADoPA OPFG1)

That's right, that happened to my mother and you know, we have [...] we got to this [...] I mean she was sending for things, and we are not talking a few pounds, we are talking about a lot of money sending for things I happened to be there one day and this great big parcel arrived I said 'Who is this for?' She couldn't even remember sending for it. We had to alert these companies (UH OPFG P1)

Falls tended to bring concerns about safety into much sharper focus – perhaps because the scenario was organised around the idea that Louis expressly didn't want an alarm to be raised when he fell whereas his informal carers did. Again, the scenario stipulated that Louis had recently experienced adverse consequences from lying for an extended period after a fall and that his walking sticks had been replaced with a walking frame that he had previously refused to use. Many participants were familiar with the benefits and short-comings of fall alarms. In relation to falls, participants tended to think that autonomy mattered less than safety. Even where participants felt it was reasonable for Louis to set limits on how quickly the robot should send an alarm some also felt that a point would come where the robot should automatically summon help. Participants generally felt uncomfortable about older people being left unaided. This concern was also raised in relation to the Nina scenario, where one of the objections to the planned robotic programming was that the robot might ignore Nina when she really needed help.

Well no, Louis doesn't want it. But from my side I say, when he is 15 minutes on the ground let the robot make the alarm signal. (ZUYD OPFG1 E3)

P2: *Well I think the Care-o-bot has got to be programmed to alert if he falls.*

P1: *Yes, serious falls I think because if he got ill, that is a problem.* (UH OPFG)

Now that he gets stuck on the floor and can't get up when he falls, after a certain amount of time, the robot should be re-programmed so that someone can come and help him. After all, he can't stay like that all day. (MADoPA OPFG? P4)

also it seems that the the the Care-o-bot will not actually do something if she's not polite to it, I think it's dreadful that – [the] machine... actually not do what it's supposed to do [4: frightening] [2: I find that quite quite] scary Yeah and I think that's awful to have, to programme a machine that that sort of won't help her (UB OPFG2 P5)

I would have thought the robot could be programmed [that after a certain] time so that if the robot hasn't managed to get him up off the floor or it says it helps him after a certain time-lapse, then it should send out an emergency call (UB OPFG3 P3)

But concerns about safety went beyond the content of the scenarios: for instance one group (MADoPA OPFG1) were quite concerned both that the robot should not open external doors (e.g. to strangers) and that householders should not be allowed outside if they were at risk. Here the concern was not householders with dementia but rather householders prone to falls.

Everything should be done to make sure that the person can't get out of their home. (MADoPA OPFG1 P3)

3.3.4 Privacy

No particular consensus emerged from the groups about privacy. This may be because facilitators across the different sites did not always press the participants for comments on this topic.

Two of the scenarios (scenario 1 Marie and scenario 4 Louis) were specifically designed to elicit privacy concerns. In both, information about existing medical conditions could potentially be shared. In the case of Marie, participants were asked to consider whether the nurse visiting to treat leg ulcers should be able to gain access to information about Marie's adherence to medical advice about movement and leg elevation. In the case of Louis, information about blood pressure was already being shared (using telehealth) but there was a question over whether the robot should alert family members/others in the event of falls.

Some participants addressed privacy concerns by distinguishing between medical information on the one hand – which they felt could be shared with healthcareers – and other, non-medical but personal information. Some accepted that making this distinction might be difficult. For instance, the issue of falls was recognised as straddling medical and personal areas. Attitudes partly reflected the view that healthcareers need information in order to treat conditions effectively, and the robot was regarded as an extension of the healthcareer. Of those participants who expressed this view, some noted that if information was shared with healthcareers it would be treated as confidential (presumably implying that it would not be shared any further). Equally, they regarded information that related to care as being private – the willingness to have information shared extended to healthcareers but not necessarily family members – even those closely involved in providing care such as the daughters-in-law in the case of Louis. This is interesting in terms of the status of informal carers. On the one hand, the norms of medical confidentiality do suggest that information should not be routinely shared with family, but on the other hand, it potentially disadvantages those who provide care informally as they are not part of the care 'team', even though they may have significant care responsibilities.

Yes [the robot should tell the nurse], because otherwise there is no point having the robot doing these things. (UH OPFG P2)

I mean if it if it relates directly to the care of the individual then, yes [the nurse should be able to get information from the robot] (UB OPFG1 P4)

It's arranged that this goes to his doctor and he will take action if needed. That's enough. Why again telling the daughters-in-law? (ZUYD OPFG2 E3)

I think that's more medical but I think, so I don't think the daughters-in-law need to be informed of that, but falls that he didn't get up from, yes... I don't think they should be entitled to know anything that's too

personal. I think his personal life at his age as he is obviously still 'compos mentis' it's his business. They should be entitled to know things that deal with his safety. (UH OPFG P2)

There was not, however, complete agreement on keeping information from other family members:

Well everyone's entitled to their own privacy that's for sure and if it affects other people then it is slightly different isn't it. (UB OPFG3 P2)

I think the only person's who's a right to know is the spouse (UB OPFG2 P3)

I think it is ok when there is an emergency. You need to live with it. (ZUYD OPFG2 E1)

On the other hand, some participants commented (unprompted) that having a robot in a home could lead to intrusive monitoring.

Don't you find it un- well - unethical I suppose to find that you're being watched all the time, that you're being fed, recorded all the time that you are... (UB OPFG1 P5)

I've got a slight problem with this nagging if you're saying that that it could go on prompting you because it knows you haven't moved. Presumably it's recording that. I've got a slight problem that this is very Big Brother-ish we're going to catch you out if you try and lie to us about what you're doing (UB OPFG2 P1)

Well the issue really here with the robot is that whether the robot shops him to his daughter, his daughters, you know that's the robot link really isn't it because otherwise it could be a robot free story but if the robot is able to keep a record of his activities online, which I presume it can and it could then, the daughters could then check up on him on a regular basis and then we'd have a sort moral issue really about the robot should be doing that (UB OPFG3 P6)

3.3.5 Behaviour modification

The scenarios presented many opportunities for us to gather the participants' views on whether the presence of a robot in an older person's house could be used to change their behaviour in some way. Change of behaviour matters because reablement is an aim of the ACCOMPANY robotic design and enablement is one of the ethical values proposed in the ACCOMPANY ethical framework. 'Enablement' is helping someone to do something, and in the context of ACCOMPANY the 'something' in question is promoting their independence or general wellbeing. Reablement is helping someone to regain the ability to do something for themselves.

In the first scenario, Mary is encouraged by the robot to adhere to her medication and also a treatment regime of keeping her legs elevated and generally moving about to increase her circulation. Frank, in the second scenario, is being encouraged to become more socially engaged, whereas the robot is being used in the third to modify Nina's tendency to be rude to her carers and daughter. In the final scenario, Louis's gambling is being facilitated – though not deliberately encouraged by the robot – and his family would like to prevent the robot being used in this way. The scenarios thereby elicited views from the participants about quite a wide range of behaviour changes.

Reminders to adhere to medical treatment or advice were generally regarded as useful, whereas altering characteristic behaviour was not. We can speculate that this difference is due to the fact that reminders are very familiar forms of help, and sometimes self-help, and that when they are provided

by machines, or even people, they facilitate the execution of, rather than determine, a person's plans. The participants were mindful that memories might begin to fail as people become older, so that prompting specifically in relation to medication was regarded as useful. Participants did express concerns about how reminders were given – they were concerned about being nagged, reminders being given in a robotic voice becoming irritating and also the timing of reminders (e.g. not being interrupted by the robot when doing something they particularly enjoyed).

Yes, but if it is programmed to push you every 30 minutes and you're watching a thrilling movie. You don't want to get up and then it stands next to your chair: "You have to get up, you have to walk." (ZUYD OPFG1 E3)

That's the glory of it actually is to remind you of things that's very important cos that's so easy to forget isn't it? (UH OPFG P5)

Perhaps there's the way it's said too. Perhaps the robot should say it gently and kindly rather than as an order. (MADoPA OPFG1 P3)

Yeah, because medication is a major problem for people [5: That's right] Not remembering what they've taken, if they've taken too many, and so on... But people find even that [using pill boxes] doesn't work and whereas if the robot actually knows what's happening and records it, then I think that provides a very useful function (UB OPFG2 P2)

Prompting health-promoting behaviour was less welcome though not entirely unwelcome. The mixed response here seemed connected to the fact that cooperating with physical therapies can be uncomfortable, and participants felt sympathy for that discomfort. Also in play was the view that people are not normally forced or cajoled into cooperating with health-promoting behaviours: they are, for instance, relatively free to smoke tobacco and drink too much alcohol. But no clear boundary emerged between adherence to 'prescribed' actions (recommendations of the 'do this in order to recover more quickly' kind) and adherence to health-promotions messages (advice of the 'do this to avoid damaging your future health' kind).

The participants reacted most strongly against interventions designed to change what might be termed 'characteristic' behaviour – behaviour that reflected the person's personality. The Dutch focus group participants were, however, more inclined than other groups to take the view with respect to Nina that being impolite was unacceptable: R1: *Does it make a difference if they tell you Nina can't change any more, it's her personality? Does she then still need to try to be nice?* E3: *Yes.* (ZUYD OPFG1). Their positive views about politeness seem to outweigh their concerns about behaviour modification and respect for autonomy in this scenario. One participant in this group, though, felt that "*nothing will change her [Nina]*" (ZUYD OPFG1 E2) and others accepted that it was better to take out frustration on a robot than family members. However, these views about politeness were shared by other individual participants elsewhere, even though the groups as a whole did not seem to arrive at the same consensus view on this as the Dutch groups.

It may not be easy to comply with advice

I think the robot could sort of be more forthright if you say. Sort of tell her to do it more often. Because I know sitting in a chair as I have been for 4 months that you need a lot of persuasion to get up from that chair to do something... It is very difficult, you really got to have somebody to prompt you to make you get up and do

something. If you are comfortable in the chair and you know it is gonna hurt when you get up. (UH OPFG P2)

The robot doesn't know whether she's [Mary] having a good day, bad day, if she's had other problems is the leg feeling more painful today, or has she got an upset stomach or a hangover (UB OPFG2 P1)

On trying to encourage politeness

I would keep that [the robot programme] permanently because I don't think that being ill mannered or rude to anybody is the right way for people to live (UH OPFG P5)

But I don't think the robot should be reprogrammed to do whatever Nina wants. She could be a bit nicer, even though it is a machine. I think you still need to be polite...even if it is a machine... If she walks around the whole day grumbling and swearing to the robot, she will do it to her sister, her daughter, the girls from the home care that come to do the cleaning. And then just being nice to her friends and not to the rest, no, that is not right. (ZUYD OPFG1 E3)

R1: *Do you think Nina is allowed to yell to the robot?*

E1: *For certainly not (ZUYD OPFG2)*

P4: *I'm on Nina's side on this one*

P5: *Yeah*

P4: *Well it's this this gadget, this washing-machine thing telling me to be polite to it*

P5: *Yeah – it's a machine!*

P4: *Yes, absolutely.*

P2: *What in effect that is happening is that this machine is almost trying to reprogramme Nina*

...

P4: *In fact, it's quite a good idea that she can have a machine that she can be rude to. Might be nicer for the cleaners and her daughter (UB OPFG2)*

O2: *They should hold a referendum: "Should she be polite? Vote yes or no!"*

O7: *But a robot doesn't care whether you say thank you to it or not!*

O2: *The problem goes deeper than that.*

O3: *I don't think it's the robot's place to intervene!*

O7: *No, nor do I.*

O5: *But it's to make her get the...*

O3: *No, it won't do any good.*

O7: *No it won't.*

O3: *I can't believe it! How can it be that people become rude and agitated and everything, when they didn't used to be like that at all? What are you supposed to do if her mind's affected in some way (pointing to her head)? You can't tell people like that off!*

O6: *But you can ask them to be nice. (MADoPA OPFG1)*

Other attitudes to changing behaviours

I think I agree with blocking the website....If somebody gets into debt you should do that first (ZUYD OPFG2 E3)

If it's small amounts and he gets fun out of it, it's his money he does what he likes with it. (UH OPFG P1)

And I suppose being able to say 'Look you will be better if you do this' and persuade them, I suppose it's part of the art of medicine is it? (UB OPFG1 P3)

But I mean we're all told that we'd be better if we didn't, I don't know, eat so much, drink so much or whatever

[3: *Smoke so much, yeah*] *We all know that and it's up to us as individuals whether we choose to act on it* [3: *Of course so*; 4: *Mm, oh yeah*] *And I don't think by the time you get to, seventy, seventy-eight, or whatever it is you suddenly become] in a different category of individual who has to be told (UB OPFG1 P5)*

I think it's deeper than that...I know three people who are in their mid and late nineties. Two are very active, very outgoing, they meet; they go out, they meet people and they're very good. One will not. And that's a fundamental difference between them and they've been like that ALL THEIR LIVES! ... ! So it isn't a function purely of age (UB OPFG1 P7)

I think if they're constrained to the physical assistance then that is fine as it's when they stray into this kind of behaviour modification and all the rest of it, it starts to get a bit worrying (UB OPFG2 P4)

P7: *having found out that it's there I mean I think there is a genuine potential for a quite serious problem there*
 P5: *If this were alcohol, instead of gambling would we feel, we'd probably feel the same way as we do about the gambling*
 P2: *It's more of a health issue though, isn't it if it's alcohol.*
 P5: *Yes*
 P7: *Mm yeah (UB OPFG3)*

I have the feeling it [force Nina to be polite] would work contrarily [have the opposite effect]. (ZUYD OPFG1 E2)

O1: *If another person re-programmes it like her daughter asks, and she doesn't like it, she could easily change it back again as soon as the other person's gone.*

O7: *Yes precisely! That's exactly what I said, it won't make any difference if someone else does it. (MADoPA OPFG1)*

Table 8 Older people's views on robots being used to change or modify older people's characteristic behaviour

3.3.6 Social connectedness

Although some participants wanted to draw a distinction between loneliness and being alone, there was a general concern that robots should not and could not replace human contact.

I'm alone the whole day for over 8 years now. And you can't replace that empty hole. Also not with a robot. (ZUYD OPFG1 E2)

P7: *One of my daughters-in-law is a domestic help and she says that doing the housework is not really what some people she works for really want her to do*

P3: *They want her to talk to them*

P7: *Exactly! They want someone to chat with, especially if they don't go out much anymore. (MADoPA OPFG1)*

I suppose a robot is not like a human you can interact with really...It will do requests and what you need, or it's programmed to, y'know remind you of things. But it's not the same as having person who you can talk about anything to. (UB OPFG1 P2)

I think the more friends you can make, I mean the more people you got to talk to the more keeps you more lively and keeps you interested in doing things (UH OPFG P2)

Even where they accepted that there was a useful role for the robot, participants wanted clear human input into how the robot was used and programmed. Many participants drew attention to the limitations of the robot when it came to cajoling individuals into trying something new. They tended to think that the robot was only capable of very primitive interactions (see comments in relation to reminders, which they assumed would become tedious repetition) and thought that human contact was necessary if persuasion was going to be effective.

I mean presumably a human being, it's not going to beat a human being is it? (UB OPFG1 P3)

Or maybe his daughter could take a look together with her father. So the father can look if he likes it. Maybe after 1 or 2 times he will like it and will use it himself as well. (ZUYD OPFG1 E5)

In relation to the Frank scenario, many participants were not convinced that virtual relationships were a substitute for 'real' relationships, and some suggested that these real relationships could be encouraged. One group's (MADoPA OPFG1) discussion of Frank shed some light on why older people might get less out of on-line fora, namely that they wanted to *share* memories with people. Here, importance was clearly being placed on interactions with other who were there at the time, and of course, this may not always be possible – as the scenario of Frank was intended to illustrate. Some participants were, however, themselves involved in e.g. Skyping and internet fora and found these enjoyable.

to me that's impersonal, in a way if he was put in with a local fishing club so he knew where the people went fishing, you know that means more to him than a ... as you say somebody you've no idea where they are, what they're like, [what they've done or anything... He might have more contact with somebody who he knew where they were, where they went fishing and maybe ...if he did get, y'know, some contact – even if the contact's over the internet to begin with – if it was a local club it might lead on to some real contact (UB OPFG2 P5)

But actually, shouldn't more be done to encourage contact with real human beings? Because with a machine things are always going to be virtual. (MADoPA OPFG1 P6)

3.3.7 Family issues

The participants expressed a range of views about relationships within families. Clearly these relationships were viewed as important, and many participants either took it for granted that family *were* involved in the care of older householders and in some care-related decisions, or felt that they *ought* to be (more, in some cases) involved. At the same time, views about family involvement were not always positive. There was sympathy for the efforts of the daughters in the scenarios of Frank and Nina, but rather less sympathy for the daughter-in-law in the case of Louis. This was partly a function of the construction of the scenarios: Nina's daughter was described as being upset by Nina's behaviour and Frank's daughter as being concerned by her father's potential social isolation and future loss of a longstanding friendship. On the other hand, even though more details were provided about the care being given to Louis by his daughter-in-law (which was on the face of it more extensive than that provided in other scenarios) there was some hostility to the daughters-in-law. This was in part

provoked by their disapproval of his gambling, which was sometimes assumed to be motivated by a selfish fear that they might be losing their inheritance (to which participants were not sympathetic). But the disapproval also had to do with the fact that they were 'in-laws' rather than genetic children. Some participants were also concerned about gender issues – feeling that sons, being male, could more appropriately provide some kinds of (presumably intimate) care for a father than female relatives.

Concerning the gambling he says he's in charge of his own money and I have to agree with him, but on the other hand it is also more something for his sons to discuss than for his daughters-in-law... And then I think it's not up to his daughters-in-law. You discuss these kinds of things with your children and not with... (ZUYD OPFG1 E3)

So the children are not behind this, but his daughters-in-law (ZUYD OPFG2 E1)

The daughters, the daughters-in-law, those dragons-in-law (UB OPFG3 P7)

P1: That's different and I think it should be his sons taking actions not them [the daughters-in-law] trying to control him. It doesn't say (...)

P5: direct relatives really (UH OPFG)

This differentiation between children 'in-law' and actual children may also have coloured participants' views about how much information should be shared by the robot – as there was some resistance to the daughters-in-law being told about Louis's falls. This resistance may also have been related to the fact that it was regarded as medical information. So, even though many participants were uncomfortable about the robot doing nothing in the event of Louis being unable to get himself up, it was not clear that daughters-in-law were the right people to alert.

He obviously couldn't cope on his own without he couldn't cope on his own with just obviously the robot, he needs the extra help of the daughters-in-law obviously. It's a fine line on how far the daughters-in-law could intrude into his personal life. (UH OPFG P2)

P2: Helps him get up if he falls. But only if it can't get him up then the alert should go out.

P1: It should go to the sons.

P5: You are actually saying that the daughter-in-laws are at his care if you do that. I mean I think it is a bit imposition (...) our arrangement is (...) we have got two sons we have got two daughters-in-law. It all goes through our sons.

P1: Yes

P5: We don't put any demand on our daughters-in-law. I think that's unfair to (...) just because they are, traditionally the people who are not at work. I think that would be wrong. But I think that should be something we should still be keeping the Care-o-bot looking after his physical health.

P1: But it should be the sons because apart from anything else it's quite difficult gender wise. You know if he is fallen, I mean Frank fell, you fell once didn't you? Getting in the shower. He had nothing on. You know. ...

P2: I think it would be easier for the son to come and pick him up then for the daughter-in-law.

P1: Exactly (UH OPFG)

I think the other thing we need to say is that the daughters-in-law have taken away his sticks so that he has to use his walking frame. Well I would have thought that should have been a medical decision, not for the daughters-in-law to decide whether he uses his sticks or his walking frame... I think it should be looked into if he is safe to have his sticks or if he needs a walking frame – it sounds like they're both in this house. Well if you have them both there and he doesn't know which one he should be using and why he should be using this particular one, that's why I think it needs to be a medical decision as to

what he has, it's not up to the daughters-in-law to suddenly decide he's falling we'll take away his sticks (UB OPFG2 P5)

R1: *Are the daughters-in-law allowed to decide this [replace crutches with walking frame]?*
E3: *Wouldn't it be better to ask their doctor to decide on this? If it would happen to me I would consult my general practitioner for this. (ZUYD OPFG2)*

Several participants did however assume that family involvement was positive, and recognised the potential difficulties for family members of caring responsibilities. There were mixed views about the extent to which family can influence the behaviour of older householders. In some cases, like that of Frank's daughter, it was felt that interaction with the daughter would be more beneficial than interaction with the robot. But in other cases, participants seemed to suggest that householder do not take advice from family members that they might take from other sources, including the robots. The potential beneficial role of the robot as a 'whipping boy' was highlighted by several participants who thought it much better that a Nina (or other householders) could take out their frustrations or anger on a robot than a family member/spouse.

Well they're bringing him food, helping him, with his cleaning and doing his laundry so they're actually doing quite a bit and when he was in bed they took it in turns to stay with him during the day ...So I think they've got quite a lot invested in this and so::: to some extent I think there's a bit of a quid pro quo there (UB OPFG3 P7)

You can't make people do more than they can take (MADoPA OPFG1 P3)

And also if she's rude to her friends they won't come back perhaps ... family will come back no matter how rude you are (UB OPFG1 P6)

It's her [sic] daughter that's really going to be the lead person in the encouraging bit (UB OPFG3 P3)

it is coming from his daughter from family, she obviously knows him better than most people (UH OPFG P2)

A person's close family knows them well. They know what the person's thinking (MADoPA OPFG1 P1)

But when I look at my parents. My mother had multiple strokes and my father was there to take the first hits. And if we came by she really tried to be nice (...) You help each other. You are there for each other. This person is alone, so you don't have anybody. So what do you do? What your children come you start yelling to them. You have to get rid of your anger. (ZUYD OPFG1 E7)

Or by the home care. Because people believe them. If the home care tells them to try this or that they will accept that. But from their children or partner they will say: "No." (ZUYD OPFG1 E5)

P6: *Yeah the other thing is his sons never turned up to look after him, according to this is it was his daughters.*

P4: *Daughters-in-law*

P3: *Yep*

P4: *so they (.) in law yeah, his daughter-in-laws only turned up.*

P7: *But they're still very supportive as a family aren't they? They're there for him. (UB OPFG2)*

Some participants thought that the householders' interests were intertwined with those of family members, especially in relation to financial responsibilities. If financial irresponsibility meant that

relatives became financially liable, then relatives had a legitimate interest in resisting or preventing that irresponsibility.

Everyone has to be considered, because the children are the ones who have to pick up the pieces afterwards, aren't they. (MADoPA OPFG P3)

he could end up with a huge debt you know that's gonna cause problems in fact doesn't it. I don't know where he lives, let's assume that he is in his own house and he gets into a huge debt and the house has to be sold and he's got to go somewhere else. All these things follow on you know if you got drink problem you get into debt, drunk or you get into debt, he could lose thousands and thousands of pounds. I think then it does become a family problem. (UH OPFG P4)

3.3.8 Perceptions about the role of the robot

The participants had different ways of framing the ethical issues raised in the scenarios, and sometimes it was by reinterpreting the role of the robot that they were able to resolve tensions. For instance, one way of resolving the desire on the one hand to respect Louis's right to spend his own money while protecting him from gambling losses was to criticise the robot as the means through which Louis was accessing gambling sites. This was seen as an inappropriate use of a healthcare resource. Here the robot was being clearly identified as a kind of extension of the health carer (much as it was in relation to medical information – see privacy above). But participants were also, as we have seen, open to the possibilities that the robot has with respect to extending healthcare in the home.

I think I rather agree with that because it's, because it is a bit like the nurse coming in and saying 'Shall we have a game of poker?' isn't it. And you wouldn't expect that (UB OPFG3 P7)

I mean the scenario I could see would be like the virtual doctor, the virtual nurse using the robot as more like a telephone... the robot's telephoned by the professional and it comes through on the i- the Pad and they say, 'Alright George, can I speak to you now? I'd like you to take your blood pressure, or your temperature, or how are you getting on with the new pills' or whatever like that, and then record that and say, 'I've recorded that and I'm handing it, I'm putting it in your notes and handing it on to the doctor' whatever the appropriate thing is, so that there's that human interaction but there's also they're very aware at that moment what's happening because I think sometimes when you're not very well or you've got a hundred and one things to do, like we all do these days, you can forget why that person's doing that thing. 'Why's that helping me?' y'know, it can be very disturbing afterwards. I mean you've lost that bit of information y'know because working in a care home that used to happen, 'Well why are you doing that?' y'know, 'Why are you weighing me?' or y'know 'We want to know have you gained weight or lost weight', 'Oh yeah, I forgot.' Y'know (UB OPFG2 P6)

That's a good use for a robot I think, a very good use. As an alarm, a monitoring device. (UB OPFG3 P2)

R1: *And concerning the data the homecarer could get from the robot. [...] Isn't it personal?*

E7: *No. Homecarers do the same. (ZUYD OPFG1)*

Researcher: *And what about if there are tricky or sensitive issues, for example relating to the person's health? Who should they be decided with? The family? The medical team?*

O7: *And with the person's doctor as well! He should be able to express his opinion about such things as well.*

O1: *If it were me, I don't know who could come and programme it.*

O7: *To my way of thinking, with a robot it's the same thing as when you go and see a doctor. If you don't take the medication he prescribes for you, why bother going in the first place?* (MADoPA OPFG1)

On other occasions the participants point out that the robot is a machine. In the case of Nina, this point is made both to emphasise the point that she should not need to be polite to it (it has no feelings etc) and also to associate it with equipment that should be passive and not refuse to do what it is supposed to. In this respect, participants liken the robot to a servant that should do as it is told.

The robot is there to do things for us...It can't refuse to do things: it can't refuse the person's wishes, although there may be exceptions to the rule... (MADoPA OPFG1 P7)

The robot isn't going to die just because she insults it (MADoPA OPFG1 P1)

It doesn't hurt the robot if she shouts at the robot does it? It has no emotion, so she could shout as much as she like at the robot. (UH OPFG P4)

I don't think it deserves respect y'know, just a quick wipe over with a damp cloth or something y'know (UB OPFG3 P6)

Perhaps it's an outlet for her to be able to get it [Nina's aggression] out on the robot! (UB OPFG1 P6)

At other times the participants recognise the possibility that the robot may be more of a comfort or companion than a passive receiver and implementer of orders.

I think his [Louis] relationship with the robot is the best one. He actually looks on it as a [5: friend!] helping with his life and supporting him, and they're [daughters-in-law] sort of trying to take that away and use it as a weapon against him almost (UB OPFG2 P2)

I said, 'Well I'd want a robot which would put its arm around me. But not help me' (UB OPFG3 P5)

I'd want to know if it would sing me a lullaby, I think that would be rather nice (UB OPFG2 P6)

I say people, human beings if you like, are do not usually spend twenty-four hours a day with a person do they if they have visitors [unlike the robot]. (UB OPFG3 P1)

I mean he seems to be able to respond and relate to the robot to some extent in a way that he obviously wouldn't want to with the neighbours or carers. Some people genuinely don't like strangers in their house interfering with what they see to be their own lives and and but he's accepted the robot because it's not one of those things which is - can be - a positive I guess (UB OPFG3 P6)

2: *Yes call it Sid, probably*

3: *If my mum had it in her house, she would give it a name*

2: *Give it a name mmm*

3: *She would give it, y'know. I mean the sat-nav's got a name, y'know, it's y'know*

5: *To make it more friendly*

3: *Yes, yeah*

2: *I don't think that's a bad thing, really in some senses. She's not giving it money though, she's only giving it a name. Or we can all do that can't we. We give dogs and cats a name don't we?* (UB OPFG3)

R2: *So the relation is similar...*

E5: *With those of a husband or wife.*

R2: *Do you agree?*

E4: *Yes.* (ZUYD OPFG1)

3.3.9 Cost and non-robotic alternatives

We have grouped together participants' comments or concerns about the cost of the robot with their mentions of non-robotic alternatives. Sometimes, but not always, potential alternatives were mentioned by participants because they were clearly cheaper than robots or already acceptable and available alternatives to robots.

I'm not sure how much this has anything to do with the robot, actually does it. I think you could do all this just on an iPad (UB OPFG3 P6)

Oh, like an ipad...it's just a straightforward computer (UH OPFG P1)

If you are seventy-five, you should be allowed a computer not a robot really because [there is] a computer for that (UB OPFG3 P7)

Oh, so it's just an extension of the present technology where you can, you got your mobile phone, you can ring up, you can ring a number and by pressing certain keys you can switch your central heating on and things (UB OPFG1 P4)

I mean, even my television, crafty devil that it is, if I don't move falls asleep it switches itself onto standby (UB OPFG1 P3)

Well yes but you can summon help just by having those things around your neck (UB OPFG3 P7)

I'm sure the cat has a therapeutic function as well (UB OPFG3 P7)

There are also some gimmicks for those already, boxes with names of the days on it (UB OPFG2 P3)

There's a whole lot of other ways of achieving that [access to the internet] ...without trying to build it into the Carobot and i think that you are probably beginning to make that, the Care-O-bot, making it over complicated for no...reason (UB OPFG2 P2)

You haven't got a computer but you might get a robot? So why not get a computer, between you and me a computers probably much cheaper than a robot! (MADoPA OPFG1 P7)

But did he have a computer [refers to emergency button necklace]? (ZUYD OPFG1 E3)

At other times, alternatives were used to supply familiar norms through which to work out issues in relation to the robot. Wearable alarms, for instance, were frequently mentioned in relation to the Louis scenario. Here participants pointed out that the wearer decides when to sound an alarm and can attempt to get up before sounding it, or that the alarm goes to a help-desk rather than relatives, meeting the concerns of Louis about keeping some information from intrusive or over-anxious carers.

If you fell over and you were on the floor there, OK if you were still physically able to move, if you got it round your neck you can press the panic button and away it goes. (UB OPFG1 P4)

P7 If with one of those things, if with a robot you're left lying on the floor then you still need your round the neck buzzer don't you

...

P2 *Telecare that's right. Well that would be useful think for a robot to do wouldn't it?...not just let him lie there for hours...* (UB OPFG3)

Cos we all know what rubbish there is on the internet. I mean if he can get on one thing, he can get on another (UB OPFG3 P2)

I suppose like a kind of electronic diary kind of thing, I mean I've got it on my computer...y'know on Outlook that kind of reminded me to come here and all that, that doesn't bother me cause I've put it in. There's nobody else kind of coming along and telling me to do it so maybe if Frank had the ability to set it up to do these things he might feel more comfortable with it. (UB OPFG2 P4)

Or he could ring up the bookies up and putting bets on horse (UB OPFG2 P4)

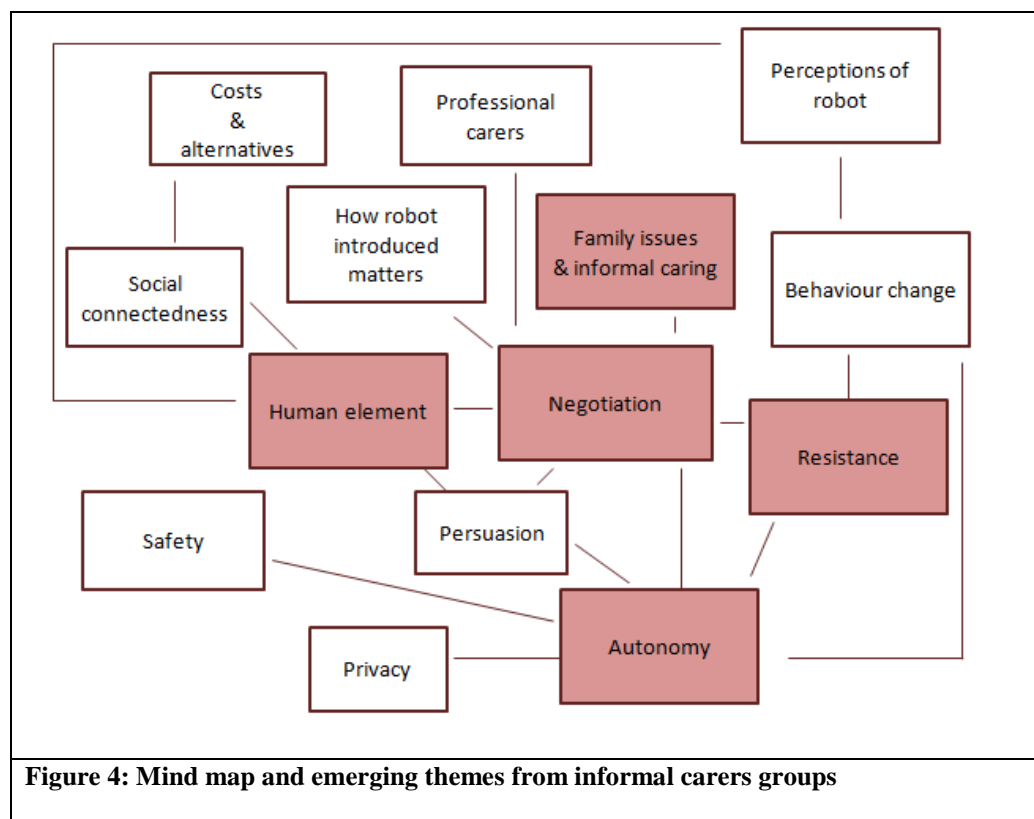
Participants seemed aware that robots were likely to be expensive, and might not, therefore, be available to everyone. One participant worried that robots might be used as the cheaper alternative to actual human support, highlighting the rising costs of good human care for older people.

I was wondering about the whole this if if they're going to be used, who's paying for them and where are they, and would you get to a situation where you had a society that the poor people got the robots and the rich people got the people? (UB OPFG3 P7)

You'll have to work out who'll be able to enjoy the benefit. I'm sorry but it's an important issue, especially the way prices are these days. (MADoPA OPFG1 P3)

3.4 Informal carers groups

There was less of a tendency in these groups to 'problem solve' the scenarios – resolve the tensions they presented without treating a single interest or value as outweighing others completely. Participants related well to the scenarios and did provide examples along similar lines from their own experience.



The main themes to emerge from the informal carers' groups and their relations between the themes are represented in Figure 4. To avoid repetition in reporting the results we will refer to inter-relatedness without elaboration, save where this is necessary to explain nuances. Quotations have been assigned to the most relevant group in the reporting.

3.4.1 Respecting the autonomy of older persons

The same principles were used to code for autonomy as were applied to the coding of the older people groups – and rarely was the term 'autonomy' actually used in discussion.

The participants were clear that the autonomy of older people in general and also that of those they [had] provided care for, was an important consideration. The need to respect the wishes of older people with decision-making capacity connected quite strongly to other themes, such as the importance of how the robot was introduced into someone's home, the general need to negotiate with older people when providing care, and the protection of privacy.

P1: *..but that his stick was taken away and the walking frame put in its place. That's rather a process.*

P5: *A rather arbitrary process.*

P1: *A bit arbitrary, authoritarian and rather harsh, in my opinion.*

P5: *It's not very ethical. (MADoPA IF1)*

I wouldn't ban him from doing it, if it's his diversion it's fine by me. But I would keep an eye on it so he won't get into debt (ZUYD IF2 M1)

R1: *Do you think the daughters-in-law have the right to do that to take the sticks?*

P4: *No, they should have discussed it.*

P2: *No, should have discussed with the medical staff.*

P1: *You know they are taking a parental role treating him if though he is a child, or 16, you know. And although one talks to a child and he may actually be quite advanced, but if we have the right to do that.*

P2: *Yes, a lot of people think they can do it. You know. Tell their elderly parents exactly what they can and can't do. (UH IF)*

The distinction between merely respecting the wishes of older people and actually respecting autonomous wishes again emerged in the groups, with the participants agreeing that there was less of a need to do what people wanted or to give them the freedom to behave as they wished if they were cognitively impaired.

you're bound to face a certain amount of opposition from the individual you are treating or taking care of, because the prison created by illness or a lack of good health, is going to make them unhappy and irritable (MADoPA IF1 P1)

These people are all mentally healthy. It would be a different story if they would have Alzheimer disease or something. In that case the information should be given to the children, but that is a different story. But they are still capable of making their own decisions. (ZUYD IF1 M3)

it is not like a person with dementia or similar eh (ZUYD IF2 M2)

I don't see him mentally incompetent, even if he was mentally incompetent he'd still need to try and discover what is it that (UH IF P1)

As with the participants in the older peoples' groups, there was some sympathy among the informal carers for Nina's behaviour, based on their suspicion that it resulted from her stroke. Equally, some participants felt that because she was able to be polite to her friend meant that she did have some control over her behaviour, and therefore some responsibility for it, when she was impolite to others.

There are also illnesses where you just have to accept things. There comes a point where you realise that you have to overlook and forgive certain things, because age and illness come into the equation. ... So, there comes a time when, to help you get through things that aren't going well and when circumstances aren't normal, you have to say to yourself, OK, that's just the way things are. You have to keep a low profile when faced with things that can't be changed (MADoPA IF1 P6)

M5: *The first thing that comes to mind is that people may display a change in personality post-stroke. So if she reacts aggressive it may be out of her control. That as a first response*

M3: *That's right, but she is friendly to her friends (ZUYD IF2)*

P4: *And it can affect the part of your brain that makes you change your personality.*

P2: *Yes, it might be that you are physically in pain, or discomfort or something, you know. Yes, exactly... Sometimes it's not that they want to be like that, they can't help it. (UH IF)*

Respect for autonomy was not, however, regarded as an absolute. As with the older people's groups, safety was a consideration (see below) that could outweigh autonomy but paternalism was also thought to be justified in other, unspecified circumstances described as getting into problems or difficulties. The tension between thinking that Louis should be free to spend his money as he wished and concerns about his getting into debt if given free rein to gamble were also found in the informal carers groups.

He can't live completely withdrawn into himself even if it's all he wants for now, at least that's how I feel (MADoPA IF1 P5)

R1: His daughters-in-law also replaced his crutches with a walking frame so it is less likely he will fall.

M1: I think that is good. That is what happen in real life but that has nothing to do with the robot. (ZUYD IF1)

What if he is losing money, what's the knock on effect? (UH IF P4)

The participants also draw a distinction between coercion and persuasion, with the latter being regarded as compatible with autonomy and justifying not immediately doing what someone seems to want in the hope of changing their mind. Persuasion, which was closely related to negotiation (see below) came across as common-place as well as acceptable.

P5: I agree with the lady who said you needed to use suggestion, and say things like "I think that it would be a good idea, what do you think?"

P6: With cards it's the same thing as the internet, it's almost like you have to drop hints, but not go any further than that.

P5: Because often, you have to put the idea of doing something into their minds without seeming to. It's the same with everything, whether you want them to eat, wash or have a shower. It's quite an art and you have to learn how to do it.

P6: You do indeed

P5: And sometimes, you mess it up completely (MADoPA IF 1)

Yes, for trying I would say yes. That he will try it a couple of times with his daughter so he knows how it works. Maybe he will like it after all. (ZUYD IF1 M1)

I think with his agreement, when he is in an amiable mood to discuss it, to discuss it and try to get him to [try] perhaps, what he could possibly lose. (UH IF P3)

3.4.2 Older people can be resistant

The participants reported that, in their experience, older people could be quite stubborn and fixed in their views and attitudes. This could make dealing with them difficult, leading to the need for negotiation and persuasion, but in some cases the participants seem to think that it was not worth trying to change their minds about things, so great was their resistance. Some participants expressed the view that older people might also be resistant to technology, including a robot. There was less evidence of this reluctance in the views expressed by the participants from the older people's groups.

No, he really is very set in his ways. He can't see things from a broader perspective, not any more, and there are things that he cannot accept any more. He has become very backward-looking recently, since the illness set in and he lives in his past. (MADoPA IF1 P5)

R1: And can the daughter decide to reprogram the robot in order to do this?

M1: I don't think so. If that program isn't on the robot and he doesn't want it. Also after trying it. If he doesn't want to use it he won't do it. (ZUYD IF1)

I think that these older people, they will not go with the robot, really! From the experience with my father... He would not say something like, 'OK I will walk', more like: 'switch that device off' (ZUYD IF2 M3)

they don't like change, they are reluctant, they feel fearful of new things, and this thing about being able to make new friends. (UH IF P4)

3.4.3 The need for negotiation

What came through strongly in many groups is that the informal carers felt they have to negotiate carefully, not just with older people but also with professional carers. These negotiations are not just attempts to persuade older people of things that are in their own interests (see persuasion above) but are also the means by which older people can (and should) be brought to understand the perspective of other people. Negotiations are also required to balance what older people want with what informal carers are able or willing to give, and are also in part a response to the stubbornness the informal carers reported encountering. Some participants reported how they had altered their perspectives as a result of discussions, as well as using discussion to make their own feelings clear. That said, the participants did not always think that it was worth even trying to change things (see resistance above).

Like most children, I used to be a pain in the neck, with "you should do it like this, you ought to do it like that". It wasn't nice of me. So now, I tell my mum, "if I'm bothering you, just tell me to go away and leave you alone, I won't mind." Between parents and children there are mutual feelings of guilt. I mean, if you tell your mum to go away and leave you alone, you feel guilty and hate yourself, even without considering the lack of respect aspect. Then again, my dad tells me to go away and leave him alone as well. So, the kind of thing I say to them is "do you want to play cards today, I've got two hours free". You have to say how much time you can give, because if you have four hours, they take four hours! (MADoPA IF1 P7)

discussion is between him and the daughter-in-law as to what he is willing to have you know, and they can make strong statements about 'You're making your life lot more difficult and we would find it easier if this and this and this (...) and we would stop worrying so much and your sons would stop worrying so much.' (UH IF P1)

I give this robot two weeks, and this effect will be gone. My dad and being active..... When the doctor says something like that it will be effective for two weeks and then it will wear off (ZUYD IF2 M5)

3.4.4 The human element

Against the backdrop of the perceived need to negotiate and use coaxing and persuasion, it is perhaps unsurprising that so many of the participants in all of the groups doubted that robots could replace humans in the caring role. They tended to think that the robot could only play a limited role, which also coloured their views about whether the robot could or should be engaged in attempts to modify the behaviour of older people.

A robot can't understand a look. If she frowned or expressed some kind of suffering, a robot wouldn't understand anything. (MADoPA IF1 P5)

but it cannot judge this [when to press a point and when not to] like a human, this will be always the difference (ZUYD IF2 M5)

it still requires a person to explain this to her and model it to her and to see if she can actually do it because she might not be able to do it (UH IF P1)

Some participants, especially in the MADoPA groups, also seemed concerned that human interaction was important in its own right and that humans should not (as opposed to *could* not) be replaced with robots. Views on the importance of social contact more generally are reported below.

nothing can replace the presence of another human being (MADoPA IF1 P6)

Well, I do see some advantages, but they are limited. But I do think that the contact between humans is really important (ZUYD IF1 M1)

3.4.5 How the robot is introduced into the homes of older people matters

In each group some participants had views about how the robot should be introduced into the home of an older person. There was some expectation that its presence in someone's home would have been agreed and discussed in advance. This agreement in part reflected views about autonomy (see above) in that people shouldn't be forced to share their homes with a robot or bow to the robot's 'demands' but it was also related in some cases to the 'ground rules' which would govern aspects of interaction with the robot – like the need for cooperation. Some participants thought that if the older person did not make good use of the robot (which in part meant cooperating with it in ways that would be beneficial to them) the robot could be withdrawn and placed with someone else.

Operating the machine implies the need for training, for it to be installed. That means you need someone who can show the person how things work and monitor the way they use it for a while. You need someone who can keep an eye on relations between the machine and the person cared for. Perhaps we need to go further on this, look into it more deeply, to enable the machine to be installed in the right conditions. (MADoPA IF1 P1)

But when you take the benefits, see the advantages of this right away and it is introduced stressing the benefits then I think it is possible (ZUYD IF2 M1)

I think you should take something as a starting point. And with that you should also have a certain policy in which you state: "If this is your care need and this is your situation we can help you, but you should also be motivated." I think you need to evaluate the situation after a certain period. You should take a look at what it brought to the user, but this doesn't need to be in the controlling way, because you're still dealing with humans (ZUYD IF1 M1)

I think one of the problems that P4 was talking about relationship with the robot, in programming it you actually need to have somebody spending a day or at least half a day with the person who is going to have the robot to see what they actually do and how they do it so you could have some idea of kind of a time elapsed should be built in before the reminder was given. And maybe a bit like a sat nav discussion about what tone of voice, male or female? (UH IF P1)

They're signing away their privacy for certain things. The gambling isn't exactly a health issue. It could have a knock on effect that slightly defeats that point, or the speaking rudely, you know, you don't really want the robot (...) you could understand that the elderly person wouldn't want this recorded how often they are rude. But when it's like they didn't put their legs up and therefore their health is at risk. That they

actually sign that they agree to having this robot instead of going into a care home because the function of this robot is not just to be useful but also for health and safety. (UH IF P4)

3.4.6 Using the robot to change behaviours

On the issue of reminders, the participants – like those in the older people groups – expressed contrary views, some holding that reminders were useful and others that they would be irritating.

And look at my mother, every day she asks what day it is. The robot can remind her. Reminders are automatic things, it could do that without any difficulty (MADoPA IF3 P3)

If it senses that she has taken the legs down for a given period of time. Say if 40 minutes has elapsed and the robot has sensed that she hasn't put it back up again it could give her a gentle reminder, not something every 5 minutes like when you are in the car and you haven't put the seatbelt on. (UH IF P3)

R1: *So the role of the robot should be more passive? Something that gives reminders but no orders. An inferior.*

M several: *Yes.*

M2: *For instance a signal for activities and nothing like "you should go to the toilet now" or anything like that.*

R1: *And what about users that need to do exercises for physical therapy. Also only a reminder for that and nothing more?*

M2: *Nothing more (ZUYD IF1)*

With regard to the robot being able to effect any change in behaviour, there was general scepticism tied to their view that older people could be stubborn (see above). One recurring point was that, if people did not want to change, it would be virtually impossible for the robot (or anyone) to bring change about.

If someone doesn't want to take their doctor's orders on board, they're not going to take much notice of a robot either (MADoPA IF1 P6)

If the person is genuinely hostile, the robot would be good for anything. If she doesn't want to take her medications and puts her tablets into the toilet....(MADoPA IF3 P1)

Views on whether the robot ought to be used to change behaviour were mixed. There was the sense already referred to (see 'how the robot is introduced into the homes of older people matters' above) that cooperation with the robot was part of what was agreed to in receiving the robot, but this tended to be restricted to health-related interventions rather than those intended to modify characteristic behaviour. Sometimes participants favoured passive and obedient robot behaviour. Another recurring view was that trying to make people change was patronising (which connected to views expressed on respecting autonomy).

In response to the Nina scenario, there was much more of a consensus that Nina should be able to speak rudely to the robot or even yell at it because the robot is only a machine and has no feelings to hurt.

M3: *I think when you do have a robot why should you not be allowed to speak unfriendly to it*

M1: *yes and it won't be unfriendly back as a reaction to it (ZUYD IF2)*

I won't consider it a big problem, it she want to speak in an unfriendly tone, that's fine. The robot won't suffer from it (ZUYD IF2 M5)

because that takes a character which it will never have (ZUYD IF2 M2)

3.4.7 Perception of the robot

The idea of the robot as a mere machine was also thought to be an advantage by some participants, in the sense that some of them – perhaps because they had been on the receiving end of older peoples' frustrations – thought it was good that the robot did not have feelings, and that the householder would be able to vent their feelings on it.

it is not a person (UH IF P1)

To me a robot will always be a machine (MADoPA IF1 P2)

That is the advantage of the robot. If I'm correct that thing doesn't have any feelings (ZUYD IF1 M5)

But the participants, for all their concerns about the loss of the human element, were fairly positive about some aspects of the robots. For instance, one participant noted that the robot would be in a position to provide 'non-stop care' that it may be difficult carers to give, but again in the context of the robot not replacing human care. Another recognised that there might not be enough human carers to provide all the care that is required, so that machines might fill this gap.

It can't replace a human being, but it could be used in addition, as an extra, to provide a certain number of services. Maybe in cases when non-stop care can't be delivered by humans (MADoPA IF1 P7)

The advantage of a robot, it's, you were talking, you had a home-help two hours, three hours per week, the robot, once it's there and equipped, can work 10 hours a day. That doesn't bother it (MADoPA IF3 P1)

Yes, but we can't offer that [human assistance] anymore because there aren't enough people (ZUYD IF1 M1)

The framing of the robot was also discussed. For example, the type of machine it is was a significant factor. Here there were echoes of the discussion in some of the older people groups where the expectations of the robot were coloured in part by it being regarded as an extension of the healthcare provider. The UH group, for instance, seemed to reach a consensus that access to the robot would need to be controlled – even if the potential users had the means to buy it from personal resources. The MADoPA IF1 group felt that the robot had a care role and suggested that the older householder should have control over the programming.

R3: So you don't think people should be able to buy them outside of that context? It's very definitely, a care package it is not a life style choice.

P3: Well, it could be a lifestyle choice. You can, I mean there could be (...) but I think it should be rolled out initially as part of a health service care package.

P2: Surely each robot should need to be programmed to its individual patient. It wouldn't be, you wouldn't have a multi-purpose robot (UH IF)

P7: Is it like a household appliance, for example like a food processor you use to slice tomatoes because you don't want to cut your hand? In that case, is it just there to go and fetch bottles? Like a vacuum

cleaner is just there to vacuum? Or does it have a job as a carer, is its role to care for a person and give them something more? How do we really define this robot?

P1: For me, its role is the second one you described, it's not a Moulinex mixer!

P7: Then if its role is as a carer, isn't it supposed to do what the individual cared for asks it to do, not what other people might ask it to do?

Several people speak all at once

P1: It's also supposed to do what the person needs (MADoPA IF1)

If that program isn't on the robot and he doesn't want it. Also after trying it. If he doesn't want to use it he won't do it (ZUYD IF1 M1)

3.4.8 Family issues

The experience of the participants as informal carers was often referred to during their discussions. It also came up in themes related to negotiation and the resistance of older people. The participants tended to be sensitive to the effect that caring for an older person can have on family relationships. Although the participants referred with clear affection on occasions to those they were caring for, they also spoke of the strains that caring created.

when we, her four children, told her doctor, who was our family doctor, that we were willing to take her in, he strongly advised against it. He told us that if we didn't want to break up our homes and marriages, we should put her into a good old people's home for the time she had left, but not take care of her ourselves as it would be too much to take on. And indeed, towards the end, mentally it became hard. (MADoPA IF P2)

But he [M3's father] didn't want to push it [his alarm] because he thought I would be there shortly. So he laid on the floor for 1.5 hours. You feel guilty at that time, but you can't be sitting all day long right next to him (ZUYD IF2 M3)

P3: Regardless whether the daughter is 15 or 65 the mother is still the mother and therefore she considers the daughter should be (...) following her lead rather than pushing around placing orders herself. 'I'm mum you do as I say so (unclear 05:38)

P1: I can remember my mother telling me she knew best when she was an old lady (..) best for me, it wasn't just her own behaviour. (UH IF)

This meant that they tended to identify with the carers in the scenarios and were sensitive to the implications for the carers that behaviours and choices of the householders in the scenarios might have.

I don't want to go as far as saying he treats his daughters-in-law like slaves, he does rather take them for granted. (MADoPA IF1 P3)

In everyone's best interests actually; in his best interests and in the best interests of his family, who won't have to make unnecessary journeys. Who'll come round if he falls? (MADoPA IF1 P1)

R: And the daughters-in-law also replaced the crutches for a walking frame what causes less stumbling.

M1: that's a good thing.

M2: Yes because imagine that he gets a pneumonia again. Then they have to call in again to solve those problems. (ZUYD IF2)

R3: *So are people obliged to take into account the effect on others?*

P1: *Really, Louis should. But you know legally (...)* (shrugs her shoulders) (UH IF)

At the same time, these views were balanced against the participants' sense that older people's autonomy should be respected, and also that they should have proper and dignified care.

It's a good thing children can't put their parents in the care of a guardian just so as to protect their inheritance. (MADoPA IF1 P7)

P6: *My dad, when I go and see him in the evening, which since the summer has meant every evening because he's been very ill, I stay with him while he gets ready for bed, and all the time I get "thank you, thank you, thank you". It can be quite embarrassing, and I try to tell him to stop because after all, he was the one who used to help us*

P5: *It's harder for an adult to accept ...*

P6: *At the moment, things are fine, but even when things aren't going too well, I can still handle it. When I think of P4 though, how she must feel when things aren't going well it's true that it must be quite tough* (MADoPA IF1)

in all the scenarios written here you should always think from the care need of the client and you should always keep patronising and privacy aspects in mind. (ZUYD IF1 M1)

There was some sensitivity to genetic relatedness in response to the daughters-in-law in the Louis scenario, though this was not as commonly commented on as in the older people's groups.

M1: *But I don't think that, how it's situated here, that the daughters-in-law are responsible. The sons should interfere in this, not the daughters-in-law.*

R: *And that's a clear difference?*

M3: *Yes, I think so.*

M1: *Yes, it also feels totally different.*

M3: *Yes, I think so* (ZUYD IF2)

3.4.9 Interaction with professional carers

Some of the participants seemed to see a clear role for professional carers that was distinct from that of informal carers. Participants also sometimes seemed to feel that older people might cooperate more with professional carers than family members.

And the woman Mary should know that the nurse has access. Cos I was thinking if Mary had a good record with the nurse even more than with the Care-o-bot she would feel a sort of reward that the nurse says 'Oh well done, I can see that you have gone to the window, yes maybe you have missed that time but you have gone much more often than last week'. (UH IF P4)

The doctor has a big impact, a really big impact. (MADoPA IF1 P5)

I think that a doctor needs to be involved because the doctor has the professional magic (MADoPA IF3 P1)

M1: *In my opinion that's a task [monitoring blood pressure information] which belongs to the general practitioner. When he doesn't received any information in a whole week, he should sound the alarm.*

M4: *Yes he will sound the alarm.*

R: *But should it be possible for the daughters to have a look through the information if it truly was right? Or is that something between them? The general practitioner and...*

M3: *Yes I do think so.*

M5: *The general practitioner and the patient.*

M1: *And the robot just have to alert the general practitioner. (ZUYD IF2)*

I think it's funny, because at the day of the informal carer at the house of my mother we had a discussion with the professional carers. And the care staff said: 'The client is the King. If the client refuses something we won't do it'. While the children, the informal carers, often have the tendency to say: "Can't you do this or that with my mother, because that is better for her. (ZUYD IF1 M5)

3.4.10 Safety

The participants generally expressed views suggesting that the safety of older householders was important. They tended therefore to be resistant to the robot behaving in ways that put older people at any risk of harm (e.g. refusing to fetch Marie drinks or to do as Nina asked). Getting older people to see that their safety was a worry for family members was highlighted in discussions about how care needed to be negotiated (see 'negotiation' above) and was sometimes felt to justify paternalism (see above).

The problem with letting others decide for the person is the loss of that individual's personal freedom, and the fact that different parties have different interests and motivations: the family wants to be reassured, and care workers want to care and keep the patient safe even though the patient may not necessarily want to be kept safe. (MADoPA IF1 P7)

M5: *Or the robot should only warn his daughters in law when he is unable to get up.*

M1: *When he is on the floor for a certain period.*

If the robot could do anything it should be able to do this.

M4: *Well, if he is still on the ground after 10 minutes that it's time to send the alarm.*

M1: *Because if you're on the ground for 10 minutes he won't be able to get up. I think.*

M4: *Maybe there is a certain time they can all agree on. (?) that if you're not up after 15 minutes someone should be warned.*

M6: *Would you like it if there is still someone warned?*

M4: *Most people who experienced being on the floor for hours never ever want to experience that again. They will do everything to prevent it from happening again.*

M4: *They are in need. (ZUYD IF1)*

R: *Should the robot be programmed to refuse to get these drinks for Mary unless she goes to the kitchen with the robot?*

P3: *No, she might be incapacitated.*

P4: *It might be a bit dangerous to do. (UH IF)*

Some participants, however, seemed unwilling to accept that just anything could be described as a safety concern. In the Louis case, for example, some distinguished between the danger of getting into debt and threats to his physical wellbeing of lying unaided after a fall: *Because it is not as [if] his life is in danger. (UH IF P4)* But as this exchange between ZUYD participants showed, not everyone agreed with this kind of distinction.

M1: *Yes, at least for my own safety. And when thinking of the playing poker it's about his safety not to end up in debt. Now it is about the physical safety not to break anything or not getting an infection. But when it comes to the debt repayment I would take action on playing poker before he got into debt.*

M3: *In my opinion sons can interfere with that. (ZUYD IF2)*

One participant (UH IF P4) expressed the concern, however, that “*wrapping them in cotton wool all the time*” may actually erode the quality of life of older people.

3.4.11 Importance of older people being socially connected

The value of being socially connected was often referred to. This was closely related to the human element (see above) but was not identical. The human element tended to refer to something distinctive and inherently valuable about human contact, whereas the importance of social connections tended to be regarded as a valuable means to something else. For instance, if someone is well known in the community any changes in their patterns of normal behaviour will be noticed and may act as a warning signal to others that something is wrong, and this might then trigger some action. Social connectedness in this sense extended a safety net. Social contact was also mentioned as a means of improving self-esteem and getting stimulation.

...a number of other people in the building did get worried when they didn't see her out walking her dog, because they hadn't been warned like I had. It just goes to show that people care about others around them. People are good. I see it all the time. (MADoPA IF1 P2)

What you were saying earlier is very important. In the CLICs [Local center of Information and Coordination]^v for example, we rely a great deal on neighbours, a great deal indeed. It's really important for people to be integrated into their community. (MADoPA IF1 P1)

R1: *a person may really object to this or may be a little scared to get into this, it might be fear of something new*

M1: *This was not so much of interest to him but now you see because of the social contact there is physical improvement as well*

M5: *Is he physically better, mentally I still have my doubts*

M1: *yes he still needs to be activated more*

M2: *more stimulated I think* (ZUYD IF2)

he would feel really useful if on this virtual fishing forum he could actually help a newcomer to fish so he is giving his advise and his expertise. And he is actually not aware that he is making friends with someone new because he is the expert so again, it's like building up self confidence and self esteem. (UH IF P4)

but it is clear when people have limited social contact at first and this increases because of their contact in home care or informal care visiting them or helping with groceries this has a positive effect on people. I see this happen (ZUYD IF2 M1)

3.4.12 Privacy

Views about privacy in the informal carers groups were of roughly two kinds: views about privacy in general and views about how the robot could protect privacy.

^v This is a local service providing information for older people and their families. The Senior Citizens' Office depends on CLIC.

Taking general considerations about privacy first, it is worth noting that the focus groups in France were convened during the period when French data protection legislation was under review. This may have influenced views that were expressed in the MADoPA groups. In an extensive exchange on hacking, the participants did not seem unduly concerned about people gaining unauthorised access to some kind of personal information.

Privacy was generally regarded by the participants as an important value – sometimes as an extension of autonomy - though not necessarily of absolute value.

but it [information] has to stay [within the home] ...there mustn't be any invasion of the person's privacy.(MADoPA IF1 P5)

this may affect many things, how healthy you eat, how many cigarettes you smoke. So this can be many things. I can imagine when I have a robot in my home and this checks everything I do, whether I comply with all the rules, I will feel like being watched. Big brother (ZUYD IF M2)

Data sharing by the robot was generally regarded as both necessary and desirable when it involved healthcare professionals or other paid carers, since this was necessary to ensure effective care. The robot may have been regarded as an extension of the care team and therefore to be governed by the usual norms for sharing information between members of such teams. There was more ambivalence about sharing information with family members/informal carers. Views here, however, need to be taken together with views about negotiation, persuasion and the role of healthcare professionals (see above) in which it seems to be assumed that family members do have access to at least some information about the older householder. There was no explicit mention about how they came by this information (so participants could, for instance, be assuming that the older person themselves disclosed the information or that the family member was being involved in discussion with the consent of the older person).

If you say that the robot is going to replace a home-help, if the home help learns that the lady never raises her foot, she will take that back to the nurses or the doctor saying that there's a problem. If something is medically prescribed, which she hasn't complied with, that has to be reported –perhaps confidentially—to the doctor. But that has to be reported, otherwise it's not much use (MADoPA IF3 P1)

Yes, that the robot does something. That it notes things down, just like we do. For instance the number of times she got out of her chair. (ZUYD IF1 M6)

If the nurse was the point of contact initially and if the nurse has got concern she could take it to the doctor. (UH IF P3)

Whereas the situation with Louis and his daughters, yes he should be able to maintain the right of privacy. (UH IF P3)

3.4.13 Non-robotic alternatives and resources

Like the older people group participants, the informal carer group participants were aware of the range of telecare technology that already exists to support older people in their own homes.

But alarms and cameras are always suggested for old people, there are I don't know how many things with cameras. They also say that the problem of falling among old people is serious; after it's hospitalization—so prevention needs to be discussed with him (MADoPA IF3 P3)

somebody who can't cope with Skype and computers can do with some really simplified things through the Care-o-bot, that would be fantastic. A video screen in the same time would be even better (UH IF P1)

You could also give him an alarm. (ZUYD IF2 M5)

People who are wearing an alarm necklace and who never ever want to lay on the floor again in their own home (ZUYD IF1 M5)

I think the costs of homecare will get out of control and this is why... But it also should stay functional eh? (ZUYD IF2 M1)

On the other hand, participants in two groups pointed out that if Marie did not have the robot to get things for her, she would actually have to get up and get things for herself. In this respect, the robot might be regarded as hindering rather than improving her rehabilitation.

I would say the robot should not react when a drink needs to be fetched, then she must go herself... that's what I would say, I think the robot should not get the drink, she should get it herself but then she must also stand up. (ZUYD IF2 M5)

In her situation I wouldn't actually program the robot at all to get her the treats. Because there isn't actually a need in her normal state (UH IF P1)

3.5 Formal carers groups

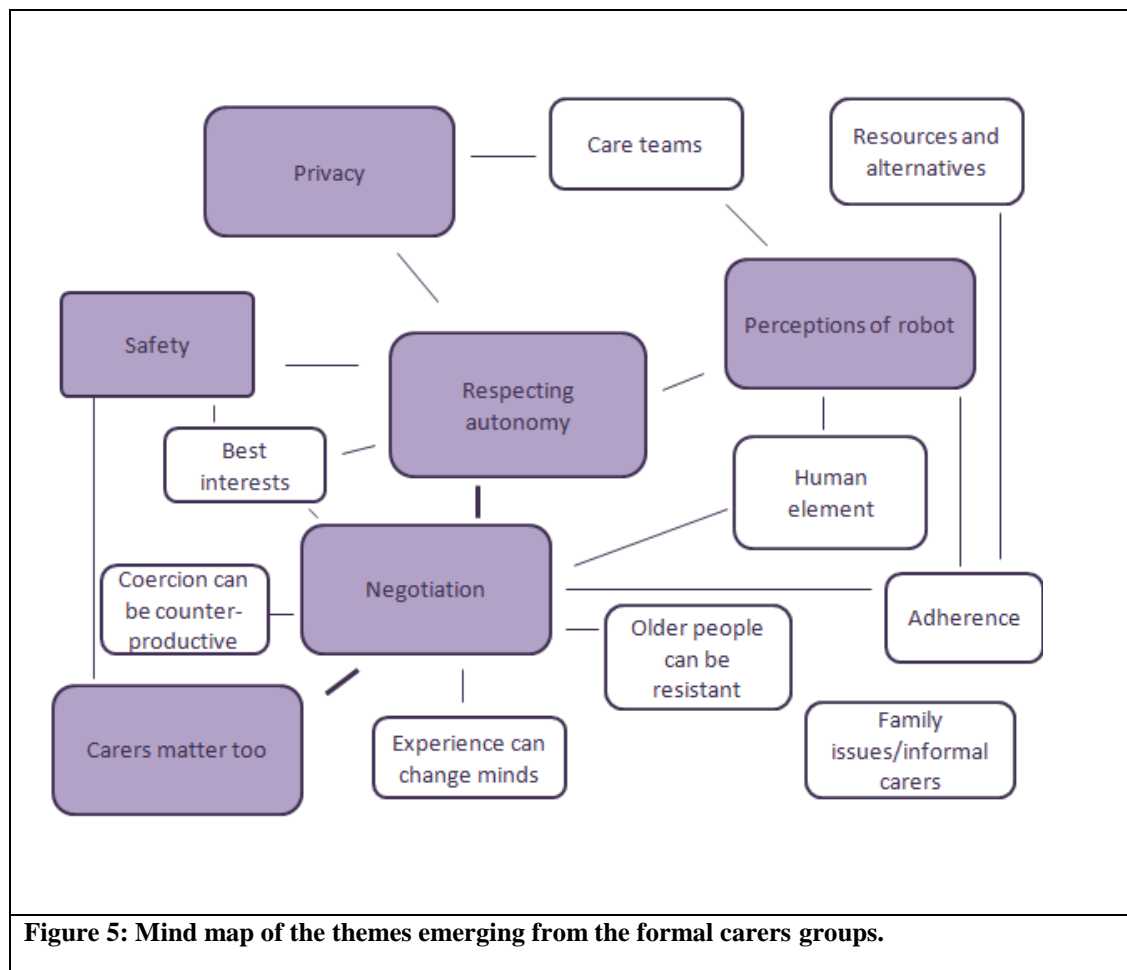


Figure 5: Mind map of the themes emerging from the formal carers groups.

The themes emerging from these groups, and the connections between them, are illustrated in Figure 5. Again, there was overlap and inter-relatedness between the themes. To avoid repetition in reporting the results we will refer to inter-relatedness without elaboration, save where this is necessary to explain nuances. Quotations have been assigned to the most relevant group in the reporting.

Participants who commented on them thought that the scenarios were realistic and could identify with them. As with the informal carers, the formal carers did not general try to problem-solve the scenarios.

3.5.1 Respecting the autonomy of older persons

The participants were in general agreement that the autonomy of older people should be respected, and that older clients should therefore be able to make their own choices. Older people should not lose control over their lives, they thought. This feeling was expressed in a variety contexts, including in relation to Louis being free to spend his money as he wished, though some participants thought that if an older person is getting into debt or losing a great deal of money (which itself may be a relative judgement) intervention may be justified.

It always comes back to the fact that what the professional care worker needs or wants is not necessarily what the user needs or wants. Our priority is the user's need or want and we have to take it into account. We aren't going to do anything without the user; if he or she doesn't want to do something, we can't force them to do so against their wishes. MADoPA PC1 P6)

When there would be financial problems, I would have a different opinion. But not when financially all is well. (ZUYD PC1 P2)

I suppose what you want with people is for them to take control as much as possible themselves (UH PC PB)

Formal carers commonly have several clients – unlike informal carers who are often family members with responsibility for one or perhaps two people. It is perhaps not surprising, therefore, that participants in the formal care groups talked about individualising care to meet the requirements of older clients and also the need to balance the interests of different clients (see negotiation below).

It all depends on the individual, the family, the family's situation with the individual, that's all I can say. Each beneficiary is different; each beneficiary's situation is very different. It really all depends. (MADoPA PC1 P4)

Participants in these groups also distinguished between respecting the wishes of an autonomous older client and going along with or respecting the judgements of people who lacked capacity to make decisions for themselves. Many expressed the view that it was more acceptable not to be guided by the wishes or actions of those who lack capacity.

We deal with people who are mentally fit and able, unless their health has deteriorated and they have cognitive problems, but for as long as a person is in full possession of their mental faculties, they are free to do whatever they want at home. (MADoPA PC1 P7)

P5: It does not anywhere say he is mentally limited.

P4: Exactly, that is why

P2: He is not addicted to the gambling (ZUYD PC1)

A: And some people like decisions to be laid for them whereas stronger people prefer to make their decisions themselves.

F: Rights of choices versus health and safety.

B: And the capacity the capacity of the individual isn't it? The capability and capacity, you know. (UH PC)

As with the other types of focus groups, opinion differed on the extent to which Nina should be regarded as autonomous, with some thinking that she wasn't responsible for her rudeness as this could be a result of her stroke, and others noting that she did appear to have a measure of control over her behaviour, as she was not equally rude to everyone.

She didn't have this kind of attitude with either her friends or her daughter before her accident; it really is due to what has happened to her. So in this case, the educational role no, but on the other hand, there may be other situations in which it could help. (MADoPA PC1 P7)

But you also have to consider, and I find that very hard, she had a stroke, actually making her character change. And that makes it a little more difficult, because before she was not like that so this is caused by

her illness. So you experience a change to a bad character and it is not her fault. Probably. (ZUYD PC1 P4)

But it is a strange situation because the scenario reads she is nice to her friends. So it is because of her disease, I am friendly or I am not friendly. To the robot she is not nice but for her friends is nice, to them she can talk civilized like "please" and "thank you" So she is able to do it, so whether it is caused by.... (ZUYD PC1 P6)

being irritable and impatient is probably the result of the stroke (UH PC PD)

Yea, but she is usually polite with her friends that's what it is saying, you know she is usually polite with her friends. (UH PC PB)

The participants in these groups, in common with the other groups, tended to think that the reminder function of the robot was a useful, especially in those cases where clients' memories were impaired or deteriorating. One participant in MADoPA PC1 made the interesting observation that reminders are also useful for people who cannot see well: "*elderly people who don't know what time it is, often because they can't see*" (P7). As in the other groups, some participants were concerned that reminders issued by the robot should not be irritating. The use of reminders is being reported in this section on autonomy as the participants often seem to associate reminders with what people wanted (i.e. that being reminded is something people should agree to) or because reminders helped them to remember to do things that they wanted to do but that they might forget to do.

5: They may still have all their physical faculties, so perhaps it could. The robot would just have to tell them what they need to do, for example when the alarm rings, that it's time for breakfast, then for a shower, etc.

7: But it could be more than that because there are people who need reminding that they need to pick up the flannel, put soap on it, wash their hair, etc. In certain cases, you really have to remind them of every detail. (MADoPA PC1)

If you're the type that watches television in the evening that will become a pattern for the robot. So than you should be able to receive the signal half an hour or an hour before. ZUYD PC2 P4

reminders and helpful reminders and actually wanting to be signed up to this. (UH PC B)

Some of the participants also noted that having a robot to do things might undermine their independence in the longer term. A participant in the informal carers group (P1 UHIF) made the related point that having a robot to get things from the kitchen for Marie was working against the recommendation that she move around more. In one of the MADoPA groups, some of the participants felt some of their clients developed a "why should I?" attitude to doing things for themselves because the carers themselves were at hand to do it, and that this attitude could be transferred to the robot.

why make the effort if there's someone here to do it for me? It's an attitude we're all familiar with and expect to see on a fairly regular basis. It's part of our job as well, as is often said, not to do things instead of people but to help them when they can't manage. But people, especially when it comes to services where they have to pay a contribution, tend to say if I've paid, they should do it for me. (MADoPA PC1 P7)

4: What I tend to hear is, "I pay to have someone do things for me". My response is, "Yes, you pay, but you pay to have someone help you do things", which people don't like hearing because for them it's a case of, "I pay therefore you do it instead of me".

5: That's even the way it is for us and we're not even a service that's paid for, I mean the person doesn't pay us directly, which is the same thing. (MADoPA PC1)

Participants in the formal carers groups also referred to the use of persuasion and coercion. In the case of the former, an interesting distinction could be discerned between persuasion and negotiation, and then again between negotiation, persuasion and people changing their mind as a result of experience. We have interpreted as persuasion efforts being made to coax older people into doing something that they are initially reluctant to do. We have included under negotiation the view that people will agree to things if they are informed about the benefits of doing so or the impact on others of not doing so (see 'negotiation' below). There was, however, a further distinction between persuading people to try something and the way in which experience can alter one's views about something (see 'experience can change people's minds' below). On this interpretation experience includes not just things that people have been persuaded to try, but also things to which they have been exposed perhaps through necessity or changing circumstances. The effective use of persuasion might be regarded as a tool that carers (formal and informal) use when they meet with reluctance. As with the other groups, this kind of coaxing was not viewed by these participants as undermining autonomy, and as in other groups, concerns were expressed that the robot might not be sophisticated or human enough to employ this tool (see 'human element' below)

Not necessarily without him being aware of it, but it could be a good idea to suggest it to him. In that case, you could bring along the robot or the people managing the robot and show him that he could just listen to people talking about fishing or something else for an hour or and then switch it off when he's had enough. Whenever he doesn't want to listen to it for any number of days, he doesn't have to. (MADoPA PC P5)

I think it will become difficult when the father says no. What are you going to do? If you know the father a bit you could possible push him, like just try it. Just try it. Even without knowing. (ZUYD PC2 P7)

I would, I mean, I would even, if the robot wasn't there, I would attempt to do that anyway, that encouragement, maybe putting it on and saying, 'You know, let's just have a quick look, if you don't like it you never need to' you know, human encouragement (UH PC PA)

Although the participants widely acknowledged and approved of the need to respect autonomy, some were also able to envisage circumstances where they might be willing themselves, or want the robot to be programmed, to act in ways that are arguably coercive (and therefore undermine autonomy) for paternalistic reasons usually associated with safety (see 'safety' below) or protecting clients from the effects of debt.

I can imagine this. Because it's also a bit harsh to say. But here it sounds simple: loose the crutches and here you have a walking frame. Walk with that. (ZUYD PC2 P7)

You have to protect him from the consequences. (ZUYD PC2 P7)

PE: *Yes, we quite often take the sticks away from people [and give them] new walking frames.*
 PF: *take them yea...They have a good use in their sticks and that's what they are obviously familiar with and then they need their frames the only way to do is unfortunately to hide their sticks...Unless they know what they are doing and then they can get back their sticks. (UH PC)*

Paternalism seemed to be much less of a motivator for the participants in the formal carer groups than in other groups. Rather the formal carer participants were inclined to offer a limited justification for undermining autonomy on that grounds that what clients wanted or how they were behaving affected them (see ‘carers matter too’), or other clients (see ‘negotiation’) or because they were sceptical that coercion would achieve its desired effect (see ‘coercion can be counter-productive’).

3.5.2 Negotiation

Negotiation was a significant theme. It is worth looking at this in detail, as it highlights (either explicitly or implicitly) ways in which the robot could fail adequately to cope as a carer in their view.

As suggested above in relation to persuasion, the participants in these groups often expressed views that highlighted the importance of discussions with their clients (and sometimes other parties). Participants believed that older people would behave differently if they understood what was being asked of them or the potential benefit to them of changing. This seems to have been perceived of as a matter of ensuring that older people were more fully informed or of generally discussing or negotiating issues with them.

And we're not there to make the person do anything by force. We tell them they need to eat and if we see something's really the matter, we try other ways of finding out why that situation has arisen. If the person sees us every day, sometimes even twice a day, and if a feeling of trust has settled in, then we do get there in the end. (MADoPA PC P5)

It might also be because nobody's explained to them what the advantages of a frame compared to a stick are (MADoPA PC P7)

It's about him getting into trouble. You should discuss that. (ZUYD PC2 P3)

And how one gets to that end result, maybe a mix of you know, input from the nurse, further explanation, encouragement from other people might pop in, or I don't know. That's what I would be hoping for is this, you know, some[one] being able to understand the importance of what is needed (UH PC PB)

But negotiation was also reported to be called for when what clients want, what they expect, or how they behave, affects others, including the carers themselves (see ‘carers matter too’). Here again, it is suggested that by discussing issues with clients, formal carers are able to negotiate change.

They'll understand, but they'll still make some kind of comment like, "Ah, did you sleep through your alarm clock?", and I'll say, "No, but sometimes the unexpected happens", and they'll say "True enough". And if it goes too far, as it has done sometimes already, I'll say things like, "What if something happened to you? Would you like it if after half an hour I said to you, listen I have to go now because someone else is waiting for me? What would you say? I'm sure you'd rather I stayed with you." After that, they tend to calm down, but you always have to talk to them and explain things! (MADoPA PC1 P5)

Actually it should be such that persons are able to modify the time schedule a little bit, it should not be a black and white option like six o'clock is six o'clock, or 8 is 8, with no room for adaptation (ZUYD PC1 P4)

Some of the participants strongly held the view that care is provided in the context of a relationship, that it takes time to build and negotiate, and it would therefore be necessary for the robot to have the

capability of behaving in such a way as to generate a similar kind of trust with the older person. Some were doubtful that such a capability was possible – see ‘human element’.

You have to understand, they're human beings, it takes them time. We help them with very intimate tasks which they would normally be doing by themselves. For example, one lady said to me that she couldn't show her chest to just anyone. (MADoPA PC1 P4)

That's why you have to try and make the person understand that we aren't there to do everything, we're there to do the things they can't really manage to do, and that they should carry on doing everything they still feel able to do. (MADoPA PC P7)

It should have some human traits like OK today it will be quarter past or half past (ZUYD PC1 P4)

Interviewer 1: *so instead of just force a choice the robot would actually be part of the negotiations 'You could gamble, but you could do this and this.'*

PA: *yes, be more inventive*

PB: *Yes, that sounds good. He doesn't know about any possibilities perhaps. (UH PC)*

3.5.3 Affecting change in the behaviours and attitudes of older people

There seem to be three significant elements to participants' views about changing the behaviours and/or attitudes of older people for their benefit. These are (1) that older people can be very stubborn or set in their ways, (2) that forcing change can be counter-productive and (3) that experience can itself engender change, as it can alter people's perceptions and incline them in a different direction. Each of these will now be addressed in turn.

3.5.3.1 Older people can be resistant

Views expressed by participants in the formal carers groups echoed those expressed in the informal carers groups, namely that it can be very difficult to get older people to change their minds. These views were sometimes expressed within the context of whether the robot would be successful in negotiating with older people, but they bear also on respecting the autonomy of older users.

But you know what it's like with people as well, when they are in their armchairs and you say to them, "Come on, let's go and do this", and they say "Oh no, I don't want to". (MADoPA PC1 P5)

P5 *Yes but they are non-compliant eh*

P4 *They do what they themselves seem right (ZUYD PC1)*

They don't like changes well, elderly people are resistant to change (UH PC PD)

There is a link between the perceived resistance of older people and the next subtheme - that coercion can be counter-productive.

3.5.3.2 Coercion may be counter-productive

The idea that coercion can be self-defeating is interesting because it suggests that the objection to coercion is practical rather than moral: leaving aside its disregard for autonomy, coercion simply doesn't work, if one's goal is to change behaviour. A good example here is in relation to the scenario of removing Louis' sticks and replacing them with a walking frame. Our participants suggested that

rather than compelling an older person to use the frame (and therefore to move around safely) the person would instead attempt to walk unaided and thereby be at even greater risk of falling.

It's something that we see regularly. Sometimes, people's children want to force things upon their parents and in the end, instead of having an aid that perhaps was inadequate, they don't use anything at all. He didn't decide he wanted a walking frame, he didn't understand why he needed it! I think it's only human; we all need to understand why when people try and make us have or do something, and we don't like it if they just say "it's for your own good"! If he doesn't try it, if he doesn't realise for himself that it's more stable and helps him keep his balance better, he won't take it! So if they decide to take his stick away to force him to use a frame, well, he's just going to try and walk without using any aid at all, isn't he? (MADoPA PC1 P7)

But the participants also talked about coercion leading to resentment, which would also increase hostility to the robot.

She is very interested in something and then it gets turned off in the middle of something that she is very interested in, that would really annoy her. (UH PC PD)

Frank hates that intrusive and interference-hassle of others so I would never do this, as a daughter, behind his back. I think it's totally counterproductive (ZUYD PC1 P6)

P6: *But rather like "we agreed to watch television till 6 o'clock and then we will walk for 5 minutes, but not like "bang, 6 o'clock television is switched off".*

P4: *I think this would have an adverse effect, that the resentment against exercise would only grow* (ZUYD PC1)

3.5.3.3 Experience can change minds

The participants in the MADoPA PC1 group seemed to agree that building up a relationship, particularly a relationship of trust, was important, and that this required discussion with the older person (see section on negotiation). But they also spoke of the way in which the experience of being cared for may help to build up trust between themselves and their clients.

We know that on average it takes two months to get someone to really come to terms with being cared for by another person. That's two months bearing in mind that this is what really makes it the job difficult; you have to make people feel safe and that they can trust you before you can get a certain number of things done. So that's about the amount of time we allow. For example, if we're told, you have a care plan and you're going to start by giving the person a full bath, it never happens the first time, you can only work up to it gradually. It is precisely the relationship that the care worker builds up with that individual that will help that person little by little to accept help firstly with washing their hair, or feet, and then gradually work up to a full bath (MADoPA PC1 P7)

A similar view was expressed by other participants who felt that it would take time for older people to get used to and accept the robot, because they would need to experience the advantages in order to be won over (just as occurs with other forms of technology or change).

P5: *Not only the elderly I think, also us, Everybody has that, right? Something new that you at first think oh no and later you start to notice the advantages. I think this is with all new things.*

P4: *Imagine yourself at home and you have this robot walking by*

P5: *Depends on what it does*

P4: *Yes but I think I would need to get used to that, big time.* (ZUYD PC1)

We had somebody whose granddaughter was on a gap year and I said to her, 'do you wanna Skype with her?' she said 'I don't even know what you're talking about.' But I did set it up with the granddaughter through email and she was, she said 'Is that Sarah there, now talking?' She just thought it was amazing. (UH PC PE)

3.5.4 Carers matter too

Many of the formal carers expressed views which suggested or implied that they thought that the impact of the older person on those around him or her had to weigh in the balance alongside the wishes of the older person. This was also a driver to negotiation (see 'negotiation' above), one purpose of which was to get the older person to see things from the point of view of others.

I also see it when people want to stay living at home then this has consequences. They do not want that, most often, but it does have those consequences. People sometimes do not want such a system with sensors and I say, but you want to remain living here, so we will have to ensure that it is safe, so there will be some changes to come. So in some ways I think you should expect this. You cannot force them, but that really has consequences. If he really does not want, what you can do as children is tell him. Then we also cannot take care of you. Because I think these children do a lot for him. Then it is allowed to expect a number of consequences of him. (ZUYD PC1 P3)

That's what makes it complicated between the professional care worker and users, and the patient, when it affects us. (MADoPA PC1 P6)

The participants' view that they matter too was used to justified being quite firm about what they would be willing to tolerate (i.e. if a more negotiated agreement could not be reached).

P5: This is also the issue, should you accept that?

P6: But if so they get more aware of their behaviour like I am not friendly, I am not nice.

P4: What you give is what you get in return

P3: Yes, yes (ZUYD PC1)

P7: But you don't know the consequences. Because if he falls you have to be there for him. I think you will start to think differently about this.

P4: That it would be up to me to say: "dad we talked about this. If you fall another time you will have to replace those crutches or I won't be here to help you." (ZUYD PC2)

Personally, I think it's really good that the robot doesn't react if she speaks to it too demandingly. I wouldn't like it if someone spoke to me like that. (MADoPA PC1 P5)

These views are in contrast to those expressed by some of participants in the older people's groups that the autonomy of older people should be respected even where this had consequences for others that they found undesirable. And they are in contrast to some of the views of the informal carer participants, who sometimes seemed resigned to having to cope with unreasonable behaviour.

3.5.5 Adherence

Some participants in the formal carers groups expressed the view (also found in the other two groups) that if householder agreed to have a robot, it was reasonable to expect the householder to co-operate with and use it.

You of course need to judge certain things in an objective way, and when you say at every occasion oh well, people should do it themselves hoping people will be honest in their reporting, then I say, then there is no point in bringing in the robot. You must of course have certain registrations, information, you need to be able to access that otherwise there is no point in all this. (ZUYD PC1 P4)

Well, I had a bit of an issue when you were first reading it, to me if you are gonna have any kind of [robot] the very minimum you want it to do is to alert you, the family and the carer services when someone falls so they are not lying there all night. But why would you want the Care-O-bot there if it is not going to tell somebody every time there is a fall? (UH PC PE)

3.5.6 Safety

Safety was clearly a consideration, and concern for the safety of the older person, especially after a fall, was used to justify overriding the wishes of an older person.

Because suppose he can get up with help of the robot, there would be a need for an alarm but when he lies there for say an hour and he cannot get up with just the help of the robot , then yes someone should be warned. (ZUYD PC1 P3)

But if that care robot and sensors in the home notice that someone is on the floor an hour or half an hour or whatever you make of it, on the same spot. Only then and not every time. He indeed falls multiple times a day and you don't have to be alarmed every time, but you can set the sensors that they send an alarm if he's on the same spot for 10 minutes. (ZUYD PC2 P4)

P2: *It should call the emergency services.*

P1and 7: *It should raise the alarm.*

P7: *It should at least raise the alarm. According to this example, we're dealing with a gentleman who falls a lot but generally manages to get up again by himself, but the day he didn't manage, the robot didn't do anything.*

P1: *Precisely!*

P7: *The robot should have raised the alarm. (MADoPA PC1)*

PD: *somebody has to be alerted, whether it's the family or [someone]*

PC: *Maybe only after 10 minutes or something.*

PD: *yes (UH PC)*

At the same time, however, some participants recognised that safety is only one consideration and that sometimes taking risks is part of living or having a reasonable quality of life.

I mean, you aren't denied the right to have a car just because you have a car accident, are you?! So why should you have to have a walking frame just because you've had a couple of falls? (MADoPA PC P7)

People do fall. One of our things we are looking at the safety, sometimes the family would say 'Is it safe to still be at home on his own?' Sometimes very fine line isn't it? But you know that if you would move him or go into a care home, he would be completely miserable, might live for ages, but very unhappy. There is a risk management thing in this isn't it? (UH PC PE)

3.5.7 Privacy

Generally speaking, privacy was regarded as important. This may be unsurprising: formal carers should have received training in data protection and their duty of confidentiality. Their views about how data should be shared between different groups were also revealing. Some participants clearly felt that data collected by the robot should be accessible to carers such as themselves because clients couldn't be trusted to tell the truth. In other words, one of the advantages of the robot as a carer or extension of the care team was its potential capacity to monitor the clients for carers.

Because you always find out what's going on in the end. Whatever they say, after a few minutes we know what's really going on, no need to worry about that. (MADoPA PC1 P5)

I think that she should check it all the time, it should be automatic. You should get into the habit of checking every day. (MADoPA PC1 P1)

P4: With the blood pressure meter, this happens already, there are these blood pressure meters people use of which the results are automatically transferred. The children are not informed on these data.

P2: They cannot cheat, right? ... That is the difference. The measures are taken and the robot sends them on to the physician. So there is no possibility to add a few degrees, or make it some degrees less. (ZUYD PC1)

Monitoring was disapproved of by some of the participants in the older people groups and the difference between the two sets of groups on this point was striking.

Some participants thought that information should pass freely between members of the care team and that the robot could potentially be a useful part of this team. Interestingly, some were resistant to passing on information to family members, even where family members were also involved in care for the same person.

P3: I think, as long as he can deal with [the blood pressure] this himself, not.

P4: When he would go the GP, they [daughters-in-law] also would not be informed. (ZUYD PC1)

Well, I agree with (pointing at F) [information] about the blood pressure is between the patient and the doctor, not necessarily common knowledge for everyone. (UH PC PA)

Again, for the involvement of the individual I mean I would have hoped to see the nurse speaking to the patient first in person and then saying something. I don't know, you know, I can't remember what she might say, 'Well, I can check this out, we can, I can talk to the robot as well', you know, almost, you got it as a three-way situation. I don't know whether that would be possible but it sounds a bit more friendly and participative than 'I'm just gonna secretly check out with the robot what has been going on.' (UH PC PB)

I think she should, after all she is a professional and so if there is an assistant, even a robotic assistant, a professional, whether doctor, nurse or otherwise, has the right to look and see what's been going on - not

necessarily all week, if it's data recorded for a full week, but the robot will have recorded that the person walked around with it twice a week and they'll be able to see if that's enough or not. And in any case, someone will have to ask this robot questions! If its job is to record data, someone somewhere will have to look at that data and see what's been going on. (MADoPA PC1 P5)

The effect of the robot on the privacy of the carers themselves was a concern, and also whether robotic monitoring would interfere with or enhance the care they provided.

We were involved some months ago with a client, she and her family wanted her to stay at home as long as possible but we had got worries about her safety so they installed cameras into the house. And that was quite strange, it did initially certainly change how we felt we were behaving and interacting, the lady herself I think was totally oblivious to it all. But there was a sense of kind of big brother watching us there and that was nowhere near as intrusive as what you were describing. (UH PC PE)

P4: I think is all very big brother is watching you if you have such a thing in your home and it can be programmed at all times to turn against me.

P1: Yes. You could look at it like that. (ZUYD PC2)

They could look at the print out together, that wouldn't be quite as invasive as the robot saying: 'Actually she didn't do that when I told her three times and she didn't get up!' Because she is afraid of falling and walking is uncomfortable so no wonder that she doesn't wanna get up. (UH PC PF)

3.5.8 Perceptions of the robot

There is a strong link between views about the robot and the human element (see next section) largely based on the view that the robot would not genuinely replace human carers (see to the link here with 'negotiation').

Like the older people and the informal carers, these participants often expressed the view that the robot is "*just a machine*" (ZUYD PC2P5). This view was important in relation to whether or not the robot should respond to Nina when she was behaving apparently rudely. The fact that a machine could provide care continuously and consistently and be impervious to things like Nina's rudeness – were noted as advantages.

P7: It seems to me that attitudes towards machines should not be the same as attitudes towards human beings, they're two different things. The professional is going to be able to explain why, say "No, because...", "That's not a polite way to speak to me", etc. This in turn will enable dialogue with the person and help her to understand her attitude and reaction to people. The robot on the other hand stays immobile. But it's still a machine, and you don't say please and thank you to a machine!

P5: I can think of some people – one lady in particular – who if you put a robot in their home are going to greet it every morning with a "Hello my little robot" (laughter). (MADoPA PC1)

Well, why not because this robot has no feelings so it would be ideal for getting rid of all your aggression ... Because this would be safe, because you do not hurt anyone because it does not feel anything. (ZUYD PC1 P1)

Though there was some ambivalence expressed, as in other groups, about giving older people a complete discretion as to how they treated the robot:

When you take the robot in, and this is the case here, to replace a set of hands, then I have the idea that it also should be treated like it is someone. You should not use it as a doormat you can use to ventilate all frustration and anger. (ZUYD PC1 P4)

Like some of the participants in the older people groups, some of the formal carers were concerned that a robot that was provided specifically to fulfil a care role could be used to facilitate something harmful, like Louis' gambling (this notwithstanding the stipulation that it was Louis' autonomous choice to gamble).

Other the other side I think it is just a danger for someone. Because he can get into financial troubles. Look, I think he should be able to do what he wants on his own computer. But if a robots, from a care agencies, leads to this. Then you are responsible. So if that would be the case. Than there should be made some limitations. Then it won't reach its purpose...But if the robot is not received from a care agency it will be different. (ZUYD PC2 P5)

A: It's almost like saying, has the robot then introduced him to gambling?

Interviewer 1: Yes, maybe not to gambling but to this particular form.

A: Or anything else that could be considered detrimental to him? (UH PC)

3.5.9 The human element

As with other groups, the formal carers expressed two types of concern regarding the loss of the human element: first that the robot *should* not replace human contact and second that the robot *could* not replace human contact. It is possible in relation to the former that there was some appeal to the importance of social connectedness, but this is not completely obvious and social connectedness did not emerge strongly as a theme in any of these groups.

the person might like to see you as well, so you will be losing that, the human contact. (UH PC PE)

But besides this I think it is important that someone will keep on visiting her as wellStill that someone visits every week , or every day and will confirm like listen when you want to achieve things, you will have to, in a normal way... yes. (ZUYD PC1 P3)

There was much greater concern in these groups that the robot could not replace human carers because it lacked the human skills associated with persuasion and negotiation (see 'persuasion' and 'negotiation' above). The following is typical of the kind of concerns expressed in this regard:

That's the thing that's going to make the difference between a carer and a machine. A professional care worker is going to be able to stimulate, encourage and repeat all these requests, and so on, and also explain again and again why we're there, why that person has to get up and go for a walk, etc. I think that's what's likely to make the difference. (MADoPA PC1 P7)

3.5.10 Resources and alternatives

Some of the participants in these groups noted that many of the robot's attributes were available on a laptop computer (which would be much cheaper than the robot)

If you should use it as an assistive device for care that could also use for fun. But if you don't use it for the right purpose than he could get himself a laptop. (ZUYD PC2 P3)

This carer could just switch on the computer (UH PC PF)

And online alternatives were also mentioned included on line cognitive behavioural therapy by one participant:

PB: There is quite a success with the therapy online.

PE: Is there?

PB: Uh-hum

PE: What do you think about that?

PB: Not something I have been involved with but I know some people who I respect who do this and there are some benefits to it. With someone with disability or can't get to a therapist or you know (UH PC)

Another UH participant noted that sensors that detect falls are “*surprisingly cheap*” (PE) and provide peace of mind also, but one participant did not think that robots were that expensive:

4: As we're mainly talking about people who aren't necessarily very well off, isn't it going to cost them too much? Isn't that a problem with the robot?

2: It doesn't cost that much anymore. (MADoPA PC1)

As previously noted, some participants felt that in agreeing to have a robot there was an expectation of adherence (see ‘adherence’ above) but this kind of feeling was also prompted by how the robot was financed:

I wanted to say that is also matters who finances it. If you receive the robot from the municipal then I would say you should follow it, but if you paid for it yourself you should be able to use it in any way you want. (ZUYD PC2 P4)

3.5.11 Family issues and informal carers

The participants in these groups were not always very flattering in their portrayals of the relationships between family and client. These portrayals had a bearing on the Louis scenario: Louis's family's worries over his gambling were assumed to be more about the protection of their inheritance than his well-being.

Our role is then to help them become aware that they have to accept there's no such thing as zero risk and that they have to allow their parents that freedom and their own individual lifestyle. We have to try and reduce their feelings of guilt, especially as they feel responsible for their parents, and thus in a way help them to realise that they have no responsibility when it comes to their parent's life choices. (MADoPA PC1)

And you also have to take into account that there are children who will try and curb their parents' spending because it's part of their inheritance going out of the window! So, given the facts we have here, it's a difficult question. (MADoPA PC1 P7)

The daughters also could think of their own benefits. If he spends all of his money his inheritance will not be as much. (ZUYD PC2 P7)

I mean I can just imagine it if I was the daughter-in-law, cooking food, doing the cleaning, doing the laundry and I think that my reward at the end just ain't coming, I could be pretty hacked off with that. You know so my motives for wanting to take care of my father-in-law might be very suspicious I think. So the robot has not got that sort of issues, so you know again, you throw it up, where is the boundary there, I don't know, that's an interesting one. (UH PC PB)

I think this kind of attitude stems from the great affection children feel towards their parents. They want what's best for their parents, are worried about them, and consequently behave a bit like parents towards their children, trying to make them do certain things. They see their parents as dependent and elderly, and forget that above all else they are individuals who are free to make their own choices. They also forget that there's no such thing as zero risk... Of course they love them, of course they don't want them to die in the immediate future, of course they don't want them to have any accidents, and yet at the same time, they don't realise that they are behaving – and please forgive the harshness of the word – like tyrants. (MADoPA P7)

Yes because I can imagine when you are together with two, and one has indeed the tendency to boss the other around, then at a certain point it could be better to have a robot do this – like “we will do this”, than by the partner. Yes then you have a moment that it is not the partner who needs to do this, while it is better for the person to do a certain thing. Then there is someone else who can do this, but in some cases I agree with that, yes. (ZUYD PC1 P3)

The issue of whether Louis' sons, rather than daughters-in-law, should be making decisions about his care was less prominent and more ambivalent than in other groups.

By all means, the daughters. I do not think you should have daughters-in-law decide this. I think the sons should talk to the father. ... here it [the boundary] has become rather faded because his daughters-in-law take care of the care as well. That boundary has faded here. But I believe the sons should talk to the father I can imagine he could think they are only worried about the inheritance which I do not know of course but it is just difficult. (ZUYD PC1 P4)

R1: *Is there a difference between daughters or daughters-in-law?*

P3: *No, not for me. (ZUYD PC2)*

R1: *So saying negotiations, so really it's an issue between the daughters-in-law and Louis.*

PC: *and possibly the sons (UH PC)*

4 Limitations

The study was undertaken by various researchers in three European countries. The team met regularly to discuss progress and to attempt to standardise the conduct of the research, but in spite of this there were differences in the way that the focus groups were facilitated that may have affected the data that emerged. For example, different focus group mediators asked different questions or used different prompts, possibly based on their own individual research interests or leanings. Similarly, the research was coded by more than one member of the research team, so that the analysis was subject to the same potential variation, even though attempts were made to standardise the coding and to get an agreement on the themes. Research personnel within partner organisations also changed.

The focus groups were conducted in three different languages (English, Dutch, and French). The non-English data was, after transcription, translated into English. In the process, the meaning of some of the quotations may have been subtly altered or distorted, and the English groups may have generated quotations that are truer to the original phrases uttered than those groups that were conducted in French and Dutch.

The study also reflects the limitations of qualitative research in general. Sampling involved elements of both convenience and self-selection, meaning that there is the possibility that the data is skewed because a certain group or type of people was attracted to participating. Furthermore, some of the focus groups suffered the problem of the dominant speaker, in which certain speakers do so much talking that they drown out the potentially interesting and relevant views of other participants.

Some of the participants had experience of the care-o-bot and it was clear that others did not. This may also have affected their views.

There was some overlap between the types of groups: many of the people in the older people groups were themselves caring for (or had previous experience – both formal and informal of giving care to) older people. The informal carers spoke also about the care that they would themselves hope to receive and some of the formal carers referred to experiences they had when providing care to their own family members. It is not clear this limited the variety of views expressed.

We cannot be sure that data saturation was reached, because the number of groups convened at each site was pre-specified. We did not have the resources to triangulate or otherwise follow up the data collected with individual interviews or surveys. On the other hand, this was a large study by qualitative standards, containing 21 focus groups in total. In terms of ethnicity only white French, white British and white Dutch participants were recruited. This may also have limited the range of views that we were able to collect and it would be useful for further work to be done in this area using participants from other ethnic groups at all of the sites.

The use of scenarios meant that the data collected was not completely free, and the scenarios may have overemphasized particular concerns that the researchers had. On the other hand, the scenarios were well received and considered credible and realistic by all groups.

The fact that there were so many more females than males is also a limitation of the study, as the participant groups did not necessarily reflect the real populations of each group. The age balance was

better, though one Dutch participant in the older people focus group was significantly younger than other participants, at age 42. She was deemed to face similar problems to older people receiving home care, however.

5 Conclusion

We have provided a detailed report on the rich data that were collected from 21 focus groups, convened in three different European countries exploring the views of potential users (older people and formal and informal carers of older people) of the ACCOMPANY Care-O-bot. These views focus on some of the tensions between ethical values relevant to the design and use of care-robots. To our knowledge, this is the first study of its kind. Our next task is to discuss the implications of our results for the use of social care robots in the future. Specifically, these results will also be used to refine the ethical framework that was suggested in our previous deliverable.

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7 Appendices

7.1 Appendix 1: Focus Group Topic Guide

Scenario 1

Potential prompts following general discussion

1. Should the Care-O-bot® be programmed to put more pressure on Marie to come to the window, or perhaps to turn off her television until she complies?
2. Should the Care-O-bot® be programmed to intervene when Marie puts her leg down for the comfort of the cat?
3. Should the Care-O-bot® be programmed to refuse to get drinks for Marie unless she has already come to the kitchen with it?
4. Should the nurse be able to ask for data from the robot about how often Marie is actually moving?

Scenario 2

Potential prompts following general discussion

1. Should the daughter be able to change the programming of the Care-O-bot® without Frank's permission so that the Care-O-bot® tries to get Frank to engage with the on-line fishing forum?
2. If so, how persistent should the Care-O-bot® in getting Frank to engage with the fishing forum?
3. If not, if I told you Frank really enjoyed the fishing forum and got his friend involved too, would this make it right that his daughter interfered?

Scenario 2

Potential prompts following general discussion

1. Does it matter if Nina is rude to the robot? Why?
2. Is it OK to use the robot, which Nina needs to live alone, to try to alter her behaviour? Isn't it up to her if she alienates her family and carers?
3. Should Nina be allowed to change to programming so that she doesn't have to be polite to the robot?

Scenario 4

Potential prompts following general discussion

1. Do you agree with Louis that it is up to him whether or not he plays poker? Would it make a difference if his savings are dwindling? Or if he is getting into debt?
2. Do you think that the robot should be programmed not to let Louis play on the poker site at the request of his daughters-in-law?
3. Do you think it was right that his daughters-in-law took his sticks off him so that he had to use the walking frame that makes walking safer?

4. Do you agree that the robot should be programmed to call his daughters-in-law if he falls? Why? (Press on whether the fact that if he is injured they have to care for him makes a difference)
5. Do you think that there is a difference between the daughters-in-law wanting to know about falls and them wanting to have access to the blood pressure results? Should they also be told if he doesn't send his results in regularly, for instance?
6. In general, what things should be private to Louis, and what things are his daughters-in-law entitled to know?

General notes

1. We have tried to use names for the elderly users that will cut across the four countries collecting data from users. The names can be changed if this is thought appropriate so long as the data is clearly assigned to the same scenario numbers.
2. It is desirable to get the participants to give reason for their responses where they can. Wherever possible try to get them to suggest what underlying values they are appealing to. This will require some active facilitation but we have used this very successfully on several other projects as UB.
3. Participants may draw on values that are not on our list and it would be valuable for them to explain what these are – it's not important that they put names to these values – it's fine for them to be described.
4. It is desirable for participants to address any apparent differences in their responses to the different scenarios. Draw out where possible what this says about how different values are prioritised in different scenarios and why, and draw attention to any inconsistencies asking the participants to discuss these.