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***Deliverable 1.1***  
***Privacy Report***

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## Executive Summary

The deliverable, D1.1, describes the privacy requirements of the ACANTO system and outlines a privacy profile for users.

In this study, we adopt on a provisional basis, the definition of Westin as ‘the claim of individuals, groups or institutions to determine when, how and to what extent information about them is communicated to others.’ This is provisional because in further studies we want to explore the meaning of privacy for older adults rather than imposing a definition on them. Nevertheless, the definition is helpful insofar as it identifies four aspects of privacy germane to the research: (1) when information is communicated, (2) how information is communicated, (3) what information is communicated and (4) who the information is communicated to.

Using these categories, we explore interviews conducted with several participants who prepared sociograms to illustrate their offline social networks. We asked questions about what information they would share with different groups in their networks and under what conditions. The results show that certain types of information (e.g. steps taken) are regarded as not sensitive whereas other information (e.g. emotional states) is regarded as highly sensitive. We explore the reasons for such sensitivity in terms of issues such as concern for others, self-presentation and concerns over what others will do with the information.

We conclude by presenting a privacy profile that can be used in the social network. In the profile, variables used in the system are identified and levels of privacy associated with each are specified in order to ensure the privacy for older adult users.

# Introduction

One of the biggest obstacles to social network use among older adults is privacy [1], [2]. In the ACANTO system, because we are designing for older adults and because it is a networked system, privacy will be a key design issue. Users of the system will be monitored by the FriTab and the FriWalk, they will input information into the system, and they will have that information shared with some other users. One of the key goals is to enable older adults to extend their social circle by encountering others with similar interests in order to share activities. But if a system designed to extend social contact [3] fails on the privacy front, then it will not accomplish the desired goal. In this deliverable, we set out some of the key requirements for privacy in the ACANTO social network system. To begin though, we outline a definition of privacy and then survey current research on what is already known about privacy and social networks, and in particular, the privacy concerns of older adults when using social networks.

## What is privacy?

The definition of 'privacy' is somewhat ambiguous and there are conflicting ideas of what privacy actually is. However, Westin (1967) defines privacy as 'the claim of individuals, groups or institutions to determine when, how and to what extent information about them is communicated to others.' In this definition we see four aspects of privacy that are germane to our work: (1) when information is communicated, (2) how information is communicated, (3) what information is communicated and (4) who the information is communicated to. To understand the privacy concerns of older adults in the system, these questions need to be answered.

These factors are further supported by (Giannetsos, 2011) who described components of privacy decisions within a community context. The factors that were outlined are identity (who is asking for the data?), granularity (how much does the data reveal?) and time (how long will they have the data for?). While *how* information is communicated may overlap slightly with granularity, there is a distinct emphasis on the mode and manner of communication which is not wholly apparent in the granularity category. Thus we suggest that all four categories are important.

## What attempts are currently made at promoting privacy?

Attempt has been made to allow users to set personalised privacy preferences on social media through the use of programmes that look at the individuals demographics and 'guess' what their privacy settings should be [4], [5]. Typically, however, social network sites allow users to choose from a range of options that allow more or less of their content to be visible to others. Sometimes this is rather crude (such as having a "private" or "public" profile as on Twitter or Instagram) and sometimes it is more sophisticated (such as Google+ circles or Facebook's settings). Taking Facebook as an example, users can create lists of friends so that their posts can only be visible to certain groups of people. Users can also limit who can send them friend requests to friends of friends. Also with group page settings, users can create closed groups, secret groups (not visible to non-members) or open groups. While such settings are more complex than some sites, they still do not provide controls for all the aspects of the aforementioned definition of privacy. The settings do not allow full control of *when* people can see information (e.g. expiry of posts) or *what* information can be seen by others (e.g. photos or text or videos, for example). One could feasibly imagine that one would want to restrict photos of one's family to the rest of the family and no one else. While this could be done, it would be done on a post-by-post basis rather than having a general rule that says, "All photos relating to family should only be seen by family". So while sites such as Facebook have complex privacy settings, they do not always cover all that is required to easily maintain privacy.

## What types of information will older people share?

One of the key aspects of privacy is the types of information that people are happy to share with others. Information can be categorized into various types: medical, health, financial, and so on. Through the use of disclosure grids (Little, Briggs & Coventry, 2011), researchers can explore the perceptions of sharing specific types of information with specific others. These information types are: personal identity, health, lifestyle, and financial. Research has shown that most users are very willing to disclose personal identity information (e.g. name and date of birth) – more so than other types. With all types of information, there tends to be a U-shaped curve relationship between age and information-disclosure. Younger and older people tend to disclose more

whereas middle-aged people disclose slightly less. The researchers relate this to a carefree attitude towards information-disclosure in both the young and old.

The utility of disclosure-grids is notable since it provides a way of seeing what information gets shared with what people. Nevertheless, there are other types of information that have not been explored in this way but are worth exploring. For example, location tracking information has the potential to be sensitive data. But how do older adults feel about having their location tracked? Qualitative analysis of one group of older adults (Thomas et al. 2013) revealed that users were concerned about who controls the data, who sees it, and who benefits from it. Germane to our interests are the comments about who sees the data: older participants, compared with younger, were more conservative about who could see tracking information. Nevertheless, partners, family, friends, police, carers, doctors and caretakers were often deemed acceptable. While this is helpful, the category of “friends” is somewhat elusive for our purposes where a “friend” on a social network could range from someone very close to someone who is only an acquaintance.

Perhaps further information related to our concerns can be derived from ubiquitous technology research. Research into relatively invasive ubiquitous technology for healthcare purposes in older adults has found some interesting findings. When using cameras in the home it was noted that the need for anonymity was vital for the acceptance of such technology. The ability to have control over such technologies by being able to turn it on and off also proved to be an important factor (Demiris, Oliver, Giger, Skubic, & Rantz, 2009). Furthermore, findings show that participants are significantly less comfortable with audio rather than visual data being transmitted as it is deemed more invasive (Adams & Sasse, 1999).

For the purposes of the ACANTO project, further research needs to ascertain the privacy attitudes of older people towards sharing location information (with specific categories of friends), levels of exercise, mood/emotion information, health information (with specific categories of friends) and information about who the user is conducting activities with.

### **Who do older people share information with?**

The disclosure grid method has already been mentioned, which is an effective way of determining who older people share specific information with. More detailed information about who people share information with has been extracted from disclosure grids by performing cluster analysis on the groups of people with whom specific information is shared (Olson, Grudin and Horvitz, 2005). People tended to cluster into the categories of public, co-workers, managers and trusted co-workers, family, and spouses. Of course, these categories are closely related to work-life and may not be suitable for those older adults who have retired. It is likely that there are separate categories of others in their (offline) social networks. Furthermore, individuals vary on their information disclosure to these groups based on their personality. Some people are privacy unconcerned, others are privacy pragmatists and others are privacy fundamentalists (who share least).

Because the types of people older adults have in their circle of acquaintances is likely to be different from people who are still in full-time employment, it seems wise to explore what types of people older adults have in their offline social networks. Using sociograms to explore their social networks would reveal the different categories of people that they are acquainted with. With these categories, using disclosure grids would be an ideal way of exploring their privacy attitudes.

### **When do older people share information and for how long?**

Little work has explored the temporal aspects of information sharing with older adults. We know that with ubiquitous technology, users like to be able to switch monitoring on and off at specific times (Demiris et al. 2009). Beyond that, research has yet to explore whether there are temporal limits to information sharing. Do older adults want information to be permanently available? Do they want it to auto-delete after a certain period of time? Certainly the permanence of online conversations is a concern to some older adult users (Gibson et al., 2010) who are concerned about making accidental social blunders that are then on permanent record. This difference from normal face-to-face communication is something that needs to be dealt with in designing social networks for older adults.

Roick and Heusner (2013), while not dealing with older adults specifically, have suggested that due to the dilemmas of privacy in location-based social networks, such networks could maintain privacy by either generalizing location information or providing a time-delay on the information. If users were interested in such a possibility, it would provide a safety mechanism whereby their

location data was not instantly available. Such a possibility would need to be raised with older adults to explore their views.

### **How do older people share information (modes of communication)?**

Again, little research has been done in this area. Research using adolescents has found that MySpace users tended to be careful about the types of information they were willing to share publicly (Hinduja and Patchin, 2008). While 57% of profiles included a picture, only 8.8% included a full name. The difference in modality and the privacy implications are interesting since there seems to be an assumption on the part of users that it is safe to share a photo but not to associate it with a name.

Research with older adults shows a marked preference for communication via telephone rather than e-mail or text messaging (which was used pragmatically) but it is unclear whether this is linked to privacy concerns in any way (Hope et al. 2014). This is a possibility given the aforementioned concerns of older adults about the possibility of making a permanent social blunder (Gibson et al. 2010) but needs to be explored in research.

The deficit in research about privacy concerns relating to specific modes of communication calls for more to be done.

### **How do older people think about privacy?**

Given these four key questions that help understand the dimensions of privacy that need to be accounted for in the design of a social network for older adults, the next question is, "How do older adults think about privacy in terms of deciding whether or not to share specific information with specific people at specific times and in specific ways?" Most research has agreed that older adults weigh costs and benefits (Rogers and Fisk, 2010). They will allow reduced privacy for the right people (e.g. daughter) given that there are the right benefits.

In the use of ubiquitous computing (ubiquomp) there is a general consensus that information is provided based on the perceived costs and benefits. For example, Courtney & Demiris, (2008) and Little & Briggs, (2009) found that the transmission of sensitive health data was more freely given in a health context because the benefits explicitly outweigh the costs. This is also true for potentially invasive technologies, which are more likely to be accepted if the benefits outweigh the perceived costs (Demiris, Oliver, Giger, Skubic, & Rantz, 2009). However, the cost or benefit of the scenario is dependent upon the individual's beliefs. Demiris et al (2009) somewhat explain these individual beliefs. The needs of every individual are different and so if you have technology that monitors the health of someone then an elderly adult is more likely to see the benefits of this technology rather than a young teenager, and so the older adult is more likely to engage in the technology and exchange information. Adams & Sasse (1999) also add that those who show a level of 'private self-consciousness' carefully monitor their own behaviour, and would be less likely to give up personal and sensitive information.

On a social network for older adults, users would need to see the benefit of sharing information with others and be shown wherein the benefits lie. Costs would also need to be identified. This ensures that older adults can make careful decisions about whether they want to share certain information or not.

### **How do older adults currently use social networks' privacy controls?**

Research shows that 48% of social media users report some level of difficulty in managing their privacy controls, with only 31% of those aged 65 plus say that privacy controls are 'not difficult at all' compared to 57% of those aged 18-24 [6]. It has also been found that only a small number of users change the initial privacy settings, which are set to maximise visibility [7]. This could be attributed to lack of understanding of the privacy controls or the fact that they are difficult and time consuming to change. There is thus a need for social networks for older adults to enable clearer presentation of privacy controls.

### **What are the requirements for a network that would consider older adults?**

Given that privacy is one of the key barriers to adoption, Coelho and Duarte (2016) have made several recommendations regarding the design of social networks for older adults with respect to privacy: privacy settings should be clearly displayed, default settings should be more private and adjustments should be about expanding the reach of information, and privacy settings should be tailored to fit each mode of communication. This latter includes *types* of information and not just the modality of information. So for example, they recommend that the presence of a user at home

should be kept private despite other changes to privacy settings; changing this setting would be independent.

Research also finds that the exchange of sensitive information depends on certain hygiene factors such as credibility of the site, security of information, transparency, accessibility and convenience. The most important constructs when looking at privacy in ubiquitous computing are trust and usability. Usability is an important concept for developers as it may be 'overlooked as a crucial component of privacy management' (Little & Briggs, 2009). Consequently, the design of a social network system for older adults needs to pay attention of GUI design, accessibility and security in order to foster credibility and trust from users.

### **The current study**

Surveying this research has identified key areas where research into older adults' privacy concerns could be carried out. In this pilot study, we attempted to touch on each of the four questions relating to privacy: who will older adults share information with, when will they do it, what type of information will they share and what modes of communication will they use. While we do not exhaustively cover these topics, they provide introductory data to guide further research in the ACANTO project to refine and articulate our understanding of older adults' privacy concerns.

## **Method**

### **Design**

This was a qualitative study using participant aided sociograms and qualitative questions to explore privacy concerns. Sociograms were chosen because when examining the question of *who* older adults share information with, it helps to have these categories emerge from their own network structure rather than imposing a set of categories.

### **Participants**

6 participants (5 female, 1 male; mean age = 71.3 years) took part in interviews in which they completed a social network diagram (sociogram) for their offline very close and somewhat close relationships. These were recruited from the NorthEast Age Database at Northumbria University. Ethical permission was obtained for the study from the ethics board at Northumbria University.

### **Procedure**

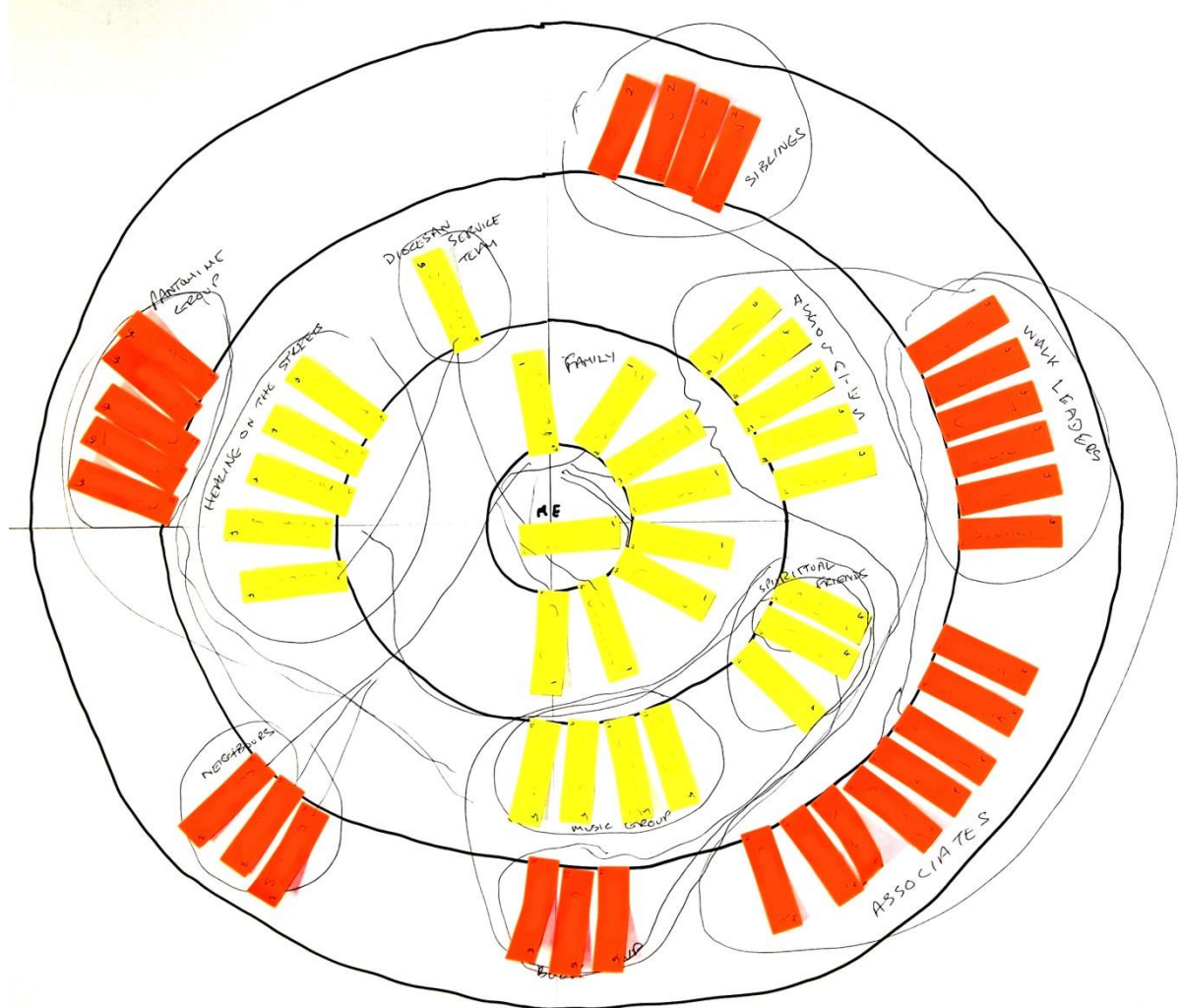
We followed the method found in [8] in creating social networks. This process had six steps:

1. Participants were asked to name people who are (a) very close to them and (b) somewhat close to them. Very close people were defined as those with whom they are in regular contact, and with whom they discuss important matters. Somewhat close people are those who are more than casual acquaintances but who are not very close. Names were recorded on sticky page markers (different colours for very close and somewhat close). Very close others and somewhat close others were written on separate pages of page markers.
2. After recall, participants were shown a list of categories on a card and asked if they had forgotten anyone from the categories: "(1) immediate family outside the house, (2) other relatives, (3) neighbours, (4) people you currently work/worked with, (5) people you only know online, (6) people from organizations (bowling, club, church, team), (7) friends not included above, (8) other." [8]. Participants were asked to label each name tag with the number associated with each of the categories named.
3. A large sheet of paper was provided with four concentric circles with "Me" at the centre. Participants were asked to place their name tags on the lines of the circles. People who are closest to the participant were placed closer to the centre. People who know each other were placed close together.
4. Participants drew circles around groups of people that belong together (already clustered together).



5. Participants drew lines between people who are close to each other.
6. Participants identified a label or description for each of the circles.

An example social network diagram is shown below in Figure 1.



**Figure 1: Anonymised example of a participant-created social network diagram**

After creating the diagram participants were asked a series of semi-structured questions. The list of questions can be found in Appendix 1. Participants were all recompensed for their time and travel costs. The subsequent semi-structured interview was analysed using thematic analysis.

## Results

Before exploring the interviews, it will be helpful to outline some of the key features of the network diagrams created by participants. A breakdown of the network features for each participant is given in Table 1 and a summary of the different groups identified is given in Table 2.

*Table 1:* Summary of network features for each participant-created social network diagram

Participant	Nodes	Very close/somewhat close	Number of circles
1	39	17 / 22	6
2	64	32 / 32	8
3	35	26 / 9	16
4	28	21 / 7	11
5	56	27 / 19	12
6	18	18 / 0	7
<b>Average</b>	<b>40</b>	<b>23.5 / 14.8</b>	<b>10</b>

In contrast with other studies which used similar methodologies, the average number of nodes is relatively high in our sample (cf. 23.8 in [8] for a general population and 14.0 for older adults aged 55-58 in [9]). This seems to indicate a relatively well-connected group of older adults. While Hogan et al. (2007) found that somewhat close others were slightly more frequent than very close others (12.2 and 11.6 respectively), we found that participants named more very close others than somewhat close others. While our sample is too small to make strong conclusions, this may suggest an increasing emphasis on closer relationships in older age. The finding that participants have ten circles on average indicates that participants have a fairly large number of discrete groups.

In Table 2 we report a summary of the different types of groups participants identified. Because these groups were of different levels of closeness, participants had different privacy views for the different groups. More importantly though, within specific groups there were people who were more or less trusted (e.g. one could have a close friend in a dancing group but only know the others on a more formal basis) and this meant that privacy concerns differed within the groups identified (a point we return to later).

*Table 2:* Summary of different groups identified in participant-aided sociograms

Group	Description
Family	Most participants reported close relationships with family and many reported close relationships with grandchildren.
Online contacts	These were people whom the participant had known in an offline context and because of distance, were now contacted online (usually through email).
Long-term friends	Participants often reported friendships that had been sustained for many years. These were seen as particularly valuable.
Interest groups	These were groups such as U3A (University of the Third Age), craft clubs, writers' groups, quiz groups, etc. Many in these groups were not particularly close but it often depended on the size and nature of the group.
Volunteering groups	Some reported that they were actively engaged in volunteering (e.g. in charity shops or in hospitals).
Physical activity groups	For example, dancing groups and walking groups.
Neighbours	Most participants had at least one neighbour they were close to. They

	were sometimes important sources of support.
(Ex-)work colleagues	Even though the participants were all retired, many sustained close relationships with previous colleagues. Sometimes there were organised groups of previous colleagues who would arrange activities together.

Following this overview, we report the results of the interviews to answer the questions proposed in the introduction: who are older adults happy to share specific information with, when will they share it, and what modes of communication are they happy to use? The first question collapses two questions (who and what) because they are inextricably linked; it is meaningless to talk about what information will be shared unless a specific audience is in view.

## Who will older adults share specific information with?

### Generally

In general, there were some clear findings about whom information can be shared with. At one end of the spectrum are “strangers” who should not have access to the user’s data. On the other end are doctors who are generally conceded complete access to the social network data in a potential ACANTO system. Even with types of data (mood data) that raised privacy concerns, sharing this with doctors was seen as acceptable.

One participant opposed doctors receiving information because,

*“it's far too big brother. And even taking a scenario where you're saying that the doctor would be given more information, I think they have trouble coping with their workloads to start with. Being realistic, prevention's one thing but they're not exactly going looking for trouble. And what you were talking about say sharing medical data, there's a whole minefield and you're getting into money and commercialism there” (P6)*

This particular person held very conservative views on privacy and was unwilling to share very much information with the network. Much of this was because of concerns about security breaches. While the user might be reassured of privacy, this is only provisional:

*“Especially when we find out more and more, it doesn't matter what man invents, what passwords barcodes, protection he puts on, somebody else, in probably yes than a year, is going to break into it. I mean just start with you know, the FBI hacking, you work it down from there. You know.” (P6)*

Generally, however, users were more willing to share information. Nevertheless, the assumption that users can be divided into neat categories based on their social network structure that could then be used as discrete categories for privacy settings was not always sustainable. It was argued that privacy is more individual and less about groups:

*“I mean I know a group who are close. But they say things to me that they wouldn't say to their friends. So it's like a trust thing isn't it? You know you build up trust. So everybody is different and even in a group may not be telling all of them em what's happening. They may just think no, I'll keep that to myself, I'll tell so and so, you know. So that's what human beings do.” (P4)*

Potentially there is a need for a social network to divide people into groups based on the level of trust conferred to them rather than assuming that trust can be generalized across groups of friends.

### Location

Location data, while potentially sensitive, did not seem to cause any concern to participants.

While strangers were generally seen as unacceptable viewers of this information, most others in their social networks were considered as acceptable. The reason for this was because “we’re all friends” (P1) and thus preventing access to location data was seen as unnecessary. Other participants elaborated more and said they didn’t mind others seeing their location data because, “I got nothing to hide.” (P2).

One participant was more restrictive in her sharing of location data and named only a few people (from different groups). When asked why, she responded,

*“Because he's em, he's a very sensible eh, not over the top character. Personality. You know if somebody was, there's people go like, you know over the top and hysterical and*

*you think "For goodness sake!". John's [pseudonym] dead down to earth and whatever would happen, he would deal with it calmly and sensibly." (P4)*

Her thought seems to be that location data could reveal situations that cause alarm. Some users of the system might react badly to this but others (such as John) are calm and would respond appropriately to this information. An example of someone who would be excluded from seeing this data is Sam (pseudonym):

*"Oh aye, I wouldn't want Sam.*

*I: And why's that?*

*Cuz he wants to know where I am anyway. Cuz he's a nosy bugger." (P4)*

Nosiness is thus seen as a reason to exclude someone from seeing information. And from these explanations of privacy concerns it can be seen that the rationale for sharing some information with specific others is based on the personality characteristics of the other rather than their membership of a specific group.

One participant suggested that a good privacy feature in this system would be the option to "go incognito":

*"I suppose you would want to build in a safeguard that says, "I want to go incognito now".*

*Em. It could be for various reasons but em, yea.*

*I: Yea. Potentially would you not think that might raise suspicions if somebody just disappears off the radar?*

*No coverage! I could be out in a field in Northumberland" (P5)*

So while participants generally are happy to share location information with a wide variety of people, some users would want to restrict it to specific individuals and for all users, having the ability to go "incognito" would provide them the possibility of privacy in specific settings where they do not want their location to be known.

### **Level of exercise (e.g. steps)**

This was seen as unproblematic by all participants. Reasons for this included the fact that people already knew the general activity levels of the participant:

*"I think they've all got a good idea of what I'm like (laugh)" (P1)*

*"I: What about level of exercise. Would you be happy with everyone here knowing your level of exercise?*

*They would probably know anyway" (P4)*

While one participant said that they would be happy to share this information with anyone, they noted that they probably wouldn't share this information with her pub friends:

*"Is there any groups you don't want to let know if you're active or not active?*

*Em. (.) Possibly the pub. You don't like to bandy stuff about sort of at the pub." (P2)*

The explanation behind this suggests that this is less a concern about privacy than about being pretentious and sharing information to show that one is an active individual. Consequently, this taps into another issue where the concern is not so much about privacy per se (if someone found out the information it would not be important) but about self-presentation, where to present the information in a certain context would be perceived as inappropriate.

### **Mood on a certain day**

Sharing mood was a more provocative issue and most participants felt quite negatively about sharing moods. Some participants said that they would not want it to be shared with anyone while others were happy to share it with a few individuals. So why do older adults choose to share or not share mood information? There are several reasons: (1) the sense that others will respond to negative moods by making unhelpful advances, (2) the sense that only some people will respond appropriately, and (3) the social effects of emotions/moods.

One person said that, *"nobody wants to really hear about other people's problems you know. I'm off today and what not you know. I mean, someone may say, pick yourself up and let's go do this and that and you'll soon get out of it." (P1)* There is a sense then that by sharing information, the user is obliging others to respond to it. In the case of temporary emotional upsets, the user does

not want others to respond to that emotion; they will recover by themselves. P5 expresses a similar concern when asked if he would be happy to share mood information:

*"I would have to think that through. As to what I would expect people to do if they knew my mood and there are some people I know who would look at it and say oh Bob's feeling good, feeling bad. Eh. There are other people who would, "Oh he's feeling bad I better go and cheer him up" and you'd think "Oh no, I don't want to." So I'd - I would restrict that to the inner circle" (P5)*

The idea that people would use this information to then try to cheer the user up is something which causes discomfort because the user may not want to be "cheered up".

The second reason why some people choose to restrict the sharing of mood information is their concern that not all people will respond appropriately:

*"And why would you share it with them?*

*Because I know what they're gonna do with it.*

*Right ok. Yea. I know they're not gonna use it in any bad way or they're not gonna judge me or judge whoever's being nasty to me or. I think they're just gonna listen and let me get rid of it. And em" (P3)*

The participant says that specific individuals could see her mood information because they are not going to "judge" her or "use it in any bad way". Doctors were also perceived as part of a category of people who would use this information appropriately:

*"I Ok. Em, what else. Mood. What about if you were feeling down on a particular day, would you be happy with your doctor seeing that? Is he in a different category from everybody else?*

*P If he put it in a way like, Why? Why are you like that? You know or – not like "Oh you're grumpy" (laugh) you know what I mean. Yes. Cuz there could be a symptom for something, you just don't know.*

*I Yea he could notice that you're feeling down an awful lot and that could be a sign that*

*P There's something else going on yes. Aha." (P1)*

The idea that doctors might find the information useful and might see it as a symptom of a deeper problem was seen as a reason to allow them access to this information. Of course, the participant acknowledges that it could be used on a personal level to note that the person was "grumpy" – and that this would be unacceptable. But in a professional capacity, this information could be useful. So how the recipient uses the information is a key determinant of whether the user chooses to share this information with him/her.

The third determinant of sharing mood information is the awareness that moods have a social function. Consequently, positive moods can be shared because they "spread joy":

*"I: So you wouldn't have a problem with people, or would you have a problem with people knowing that you were happy?*

*P: I don't think so, no no.*

*I: So it's just if you're feeling a bit down*

*P: Down, you wouldn't want to, you know, I don't know, socialise if you were*

*I: It's a bit more private when*

*P: Yes you just want a bit of time to yourself em you know, keep that time to yourself. But happy yea, spread the joy! (laugh)" (P1)*

Consistent with previous research that talks about the action tendencies of emotions [10] and the social functions of emotions [11], it is clear that negative emotions make people want to withdraw and share less information whereas positive emotions make people more outgoing and willing to share the emotion. There may also be stigma associated with negative emotions that are not associated with positive emotions and this too, the self-presentational aspects of emotion, must be considered. One participant highlighted the self-presentational concerns about such a system by saying:

*"I think it's very private. Because that and that [face and thoughts] don't go together... Well we're all human and everybody gets on your wick at times. And it just, if you just had a bad night's sleep, and you got people ringing you or calling or whatever, eh, for goodness sake, I mean I've lost me temper with poor little John because he rattles on about. And I say, "Has it got something to do with you? Is it really interesting?" "Well I was just telling you",*

*he says. "I know but don't make it a big thing." So that would be a mood so I would be putting the phone down, then I'd get the guilt. So I wouldn't want me moods to be eh" (P4)*

The participant makes two references to self-presentation issues. Firstly, there is sometimes a mismatch between the outward expression of emotion and the inner feeling of emotion. Consequently, a system that indicated your emotion might betray more than you want to convey. Secondly, there is sometimes guilt associated with negative moods and the participant does not want those negative moods to be displayed. The negative mood should finish and be forgotten about.

Because moods are such a sensitive issue, it is interesting to see the reasons why people choose to share or not share them. As discussed, there are three issues: (1) how will people respond to seeing the emotion? If it is an unwanted response, then the emotion should not be displayed to others. (2) How will people use the information? Will they judge you or will they use it in a helpful way. And (3), how will the emotion present you to others? Will it maintain your positive image or will it reflect badly on you? These are the questions that participants ask before deciding to share information with specific others.

### Health information

Surprisingly, perhaps, health information was seen as less sensitive than mood information.

Numerous people said they would be happy to share their health information with a wide circle of friends:

*"I: So thinking about health information would it just, or how would you feel if some people in your circle knew that?*

*Actually, all these people in this circle know what I've been through." (P1)*

*"Well I got cancer, I've had cancer three times, I had ovarian cancer and I've had a double mastectomy so I brought that straight out into the open because I didn't see any point in hiding it so I wasn't bothered who knew. You know I didn't keep any secrets em, and that was how I coped with it. That was how I coped with it." (P2)*

*"What about your health information? How private is that?*

*Oh I tell everybody*

*You tell everybody?*

*Everybody who wants to know. Like you, I'd never hide the fact that I've had breast cancer" (P3)*

When asked why they were so willing to share this information, most participants felt that sharing this information helped them to cope better and it helped others to make allowances for them:

*"Does that help to share it or?*

*Well it helps people make allowances for me I hope. You know. I mean em, I've just got a deaf aid, well they gave me two but I've lost one, which I'm not used to yet. But eh, I don't hide that fact that I've got that. I don't see the point in hiding stuff. Because if you don't tell people how can they make allowances, you know?" (P3)*

On a social network where people are asked to perform activities together, sharing health information has the potential to enable contacts to make allowances for the person they are meeting. Perhaps they cannot walk as fast as they can – knowing health information helps to explain this and make allowances.

Only one participant was not happy with sharing health information widely and saw it in the same category as "mood":

*"Hmm. I think it's the same as the mood I think. I'm not sure - I mean I wouldn't have no problem with a professional knowing that information but em, I wouldn't feel it appropriate ... to share it. Cuz you've got the, the obverse of if you're sharing it with them, they're sharing it with you and therefore is there a requirement on you to do something about somebody - so if it becomes a mutual health, mutual help group I'm not sure that I've, I'm wanting to get involved with that number of people on an individual basis." (P5)*

The reason given for not sharing it widely is interesting: if he shared health information, other people would, and this would give him the obligation of doing something about it. Perhaps if he found out that someone had just been diagnosed with an illness, he would feel obliged to do or say something about this. Information has action implications; when someone shares information, it may place an obligation on those who see the information to respond in some way. If they do



not want to respond, they may not want to see or share such information. The reason for privacy in this case, is a desire to maintain a lower level of responsibility for others on the network.

### **Who the user is with**

Most participants had no objection to all the others in their social network seeing who they were with. Participants explained that they had no reason to hide that information from others. Even when there were private aspects to meeting someone, being with that person was not inherently private:

*I: Ok. So there'd never be any times when you would think to yourself, I'll have a private meeting or a private chat with so and so but I don't want anybody to know?*

*P: No because I think if I wanted a private chat, I would go where there was just the two of us or how many you know. Em. And they wouldn't overhear the conversation but if someone saw me with these people I wouldn't*

*I: It would bother you if they saw you together*

*P: No it wouldn't bother me, no no." (P1)*

### **What the user is doing**

Participants were divided over whether others should know about what the user is doing. Some foresaw potential problems:

*I: This device, say it was able to tell what you were doing, like say it knew you were at your line dancing club or that you were at the theatre, or that, I don't know I'm not entirely sure, maybe you're having lunch with a friend. Would you be happy with other people knowing that information?*

*Eh not really.*

*I: Not really. Is that a bit private?*

*Especially the going out for the meal with somebody – could cause problems.*

*I: Yea yea. And is there anyone there that you would be happy with them knowing it?*

*Em. Quite a few of them, yea. But not all of them. Certainly not this group." (P4)*

Interestingly, while the participant can identify whole groups who should not know this information, she is more nuanced about who can see the information; only specific individuals within group can see it.

### **When will older adults share specific information?**

While our interview questions did not specifically ask about when certain information would be shared, the subject came up naturally at several points. One participant explained that she rarely posted anything on Facebook. However, on one occasion when she couldn't use her phone to contact family, she left them a message on Facebook to let them know she was OK. In this case, the social network site functioned as an emergency or backup contact facility.

One quote has already been mentioned from P4 who explained that, with regard to mood, she wouldn't want that information shared if she was in a bad mood after some incident:

*"I wouldn't be very happy. You know yourself, somebody's phoned you and thought, what a load of rubbish they just spoken to me. So that's in your mind and you're putting the phone down, or you're sitting on it going, "Oh yea yea that's good!" No I wouldn't like that. I wouldn't like that." (P4)*

There is thus a temporal dimension to the sharing of information. Some situations render it inappropriate for information to be shared.

Another participant explained that when he had a heart problem, he delayed telling his family for as long as possible so that he did not cause them any unnecessary alarm. Often with health information, there can be ongoing concerns that are not diagnosed, and these are concerns that he would prefer to not share until he had a diagnosis:

*"I had angina, about four, five years ago. Em, [we were] coming from a match, going to get a taxi and I had a huge angina attack em and I, I actually got in the taxi and I, fortunately recovered, I didn't even tell them, didn't even tell my wife. I went to the walk in centre the next week, the next day and my blood pressure was off the scale and he wouldn't even let*

*me drive to hospital, I had to, that's when I had to tell them. I ended up with a heart bypass because they couldn't put a stent in so yea - your health is a*

*I: Why did you not tell them?*

*I didn't want to worry them. And I suppose that, the prostate, the potential thing, is the same thing that you know that if somebody tells you "I'm going for an investigation" the immediate thought is, you only investigate things that's there. So if you're going for an investigation for angina or prostate, then you've got a problem in your heart or problem with your prostate. So it's shielding them from going down tracks - but when it's confirmed, I, when it's confirmed I have no problem with sharing it."*

Because information has action implications for other people, this participant argues that some health information should be delayed in disclosure because it can cause unnecessary concern.

Finally, another temporal concern relates to the need for privacy settings to be clear to users. One person explained that because she never knew what her privacy settings were on Facebook, she never posted:

*"Oh yes, Well I don't know about that cuz that's why I don't make any comments. Cuz I never know if it's private or people can see it. Em. So I don't know enough about it." (P4)*

To enable users to regularly share information, the privacy settings should be regularly clear so that participants know when they are private and when they are public.

### **What modes of communication are older adults happy to share?**

Again, specific questions were not asked about this, but responses show that there are distinct communication preferences. One participant noted that she couldn't be "hassled" with the video-call software "FaceTime". Another said that she used social networks to share holiday photos and recipes. Still another was more negative about sharing information on social media:

*"If we want to communicate we talk to somebody, you see them face to face or you pick up the phone Now I know, you know, Facebook's wonderful you can share all your photos with all your friends, family and on and on. But I did read a really sad thing where they said that you know, there's the obligation to keep it fed with information and then it becomes competitive - oh look we went to Whitley Bay at the weekend - ooh look we went to Paris, so there's that, which becomes, I think for a lot of young ones, quite stressful. Probably because it's more in your face than you might bump into somebody later on who may or may not tell you that but because it's there and it's always there 24 hours a day. But I remember em, just reading in the paper when they'd been talking to young people about it and one girl said, "oh I haven't got time to see my friends and when I do, we haven't got much to talk about because we've seen it all already on the screen." And I thought, Oh, how sad is that! Dear me, all little people in their rooms doing this. And they learn, lack the ability to communicate as human beings." (P6)*

This reflects a reluctance to share too much information on social media because of the desire to communicate face-to-face or via the telephone. When too much information is shared, there is less to talk about in person or on the telephone.

## **Discussion**

In this study we conducted several interviews to explore the privacy concerns of older adults in a potential ACANTO social network system. Our focus was on the question, "Who are older adults happy to share specific types of information with?" We then asked questions regarding specific types of information that the system might have. While some types of information evoked strong reactions (e.g. mood information), more often than not, participants were happy to share information with people in their social networks. Furthermore, they were usually happy to share extensive information with their doctors on the assumption that this information would be useful and would be used appropriately.

The guiding thoughts behind much of this information sharing seemed to be: (1) Will the information be used appropriately by the recipients? (2) Will the information shared reflect badly on the sharer? And (3), what actions will be elicited from the recipients?

Finally, while we identified the different groups of friends that people had in their offline social networks, we did not find that privacy settings matched neatly onto the boundaries of these groups. Within specific groups there were close, trusted friends and there were less close acquaintances. For a social network for older adults then, it seems ideal to have lists or sets of



friends who have varying degrees of trust from the user. Different types of information can then be shared with different trust-categories depending on the sensitivity of the information.

Specific design suggestions were made in reference to location data (which should have an incognito mode), mood (which should not immediately display negative moods, if at all) and health information (which should not be immediately displayed, if at all, to avoid causing concern to other users).

Using this information, we have prepared a privacy profile based on the variables that will constitute the data collected from users. This privacy profile outlines how the social network system should manage the privacy concerns of users.

## Privacy Profile

Variable	Parameters	Options
<b>Location</b>	Who	Carers High-trust friends Medium-trust friends Low-trust friends
	When	Incognito Delayed Real-time
	Detail	City-level District-level Building level
<b>Physical fitness (incl. gait, steps, calories burned, balance)</b>	Who	Medical professionals High-trust friends Medium-trust friends Low-trust friends
	When	Month-summary Day-summary Real-time
	What	General fitness Step count
<b>Emotional state</b>	Who	Medical professionals High-trust friends Medium-trust friends Low-trust friends
	When	Month summary Daily summary Real-time
	Specificity	Positive only Positive + negative Detailed
<b>Health information</b>	Who	Medical professionals High-trust friends Medium-trust friends Low-trust friends
	When	Delayed Real-time
	Specificity	General health Diagnosed conditions Symptoms
<b>Companions (who the user is with)</b>	Who	Carers High-trust friends Medium-trust friends Low-trust friends
	When	Weekly summary Daily summary Real-time

	What	General (e.g. “work colleagues”) Specific
<b>User-activity</b>	Who	Carers High-trust friends Medium-trust friends Low-trust friends
	When	Weekly summary Daily summary Real-time
	What	General (e.g. “high/low intensity”) Specific



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## Appendix: Interview questions

1. Who (in your social network diagram) would you be happy sharing the following information with and for what purpose?
  - a. Your location
  - b. Your level of exercise (e.g. steps)
  - c. Your mood on a certain day
  - d. Your health information
  - e. Who you are with
2. Is there any other information you would share with these people, or information you would want to ensure was not shared
3. Sometimes some people who are not in your usual circle of contacts may want to see your information. What information would you be happy with...
  - a. A doctor seeing?
  - b. A health worker seeing?
4. What groups (both inside and outside the social network diagram) would you not want to share the following information with?
  - a. Your location
  - b. Your level of exercise (e.g. steps)
  - c. Your mood on a certain day
  - d. Your health information
  - e. Who you are with
  - f. What you are doing