Privacy Considerations when Designing Social Network Systems to Support Successful Ageing

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ABSTRACT

A number of interventions exist to support older adults in ageing well and these typically involve support for an active and sociable ageing process. We set out to examine the privacy implications of an intervention that would monitor mobility and share lifestyle and health data with a community of trusted others. We took a privacy-by-design approach to the system in the early stages of its development, working with older adults to firstly understand their networks of trust and secondly understand their privacy concerns should information be exchanged across that network. We used a Johari Windows framework in the thematic analysis of our data, concluding that the social sharing of information in later life carried significant risk. Our participants worried about the social signaling associated with data sharing and were cautious about a system that had the potential to disrupt established networks.

Author Keywords

Older adults; privacy; health; trust; social networks

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous; J3 Computer Applications: Life and Medical Sciences: Health. K4.1 Computers in Society: Public Policy Issues: Computer-related health issues and Privacy.

INTRODUCTION

Ageing is a significant and growing area of interest for human-computer interaction (HCI) and, for many years, HCI research and design was based upon a 'deficit' model of ageing that placed strong emphasis on a gradual decline in functioning and quality of life after a certain age. However longitudinal research with older people has suggested that this type of year on year loss is not true for many individuals (see [5]) who can be described as having

aged 'successfully' [44]. In their critical analysis of literature spanning 30 years, Vines et al. [55] have argued that ageing is too often framed as a 'problem' or loss that can be managed by technology. They propose that a shift in focus to successful ageing is a fruitful space for HCI research and design. In this paper, we describe a project (ACANTO) that explores technological support for successful ageing. In particular, ACANTO recognizes that improvements to mobility and social engagement are likely to promote successful aging [12], but recognizes that privacy concerns are likely to be an important design consideration in this space. Ultimately, the success of ACANTO is dependent on whether potential users are receptive to long term monitoring and the consequences of the knowledge gathered via such monitoring. These users are identified as older adults as well as family members and others such as medical practitioners who will receive the information from the monitoring.

Our longer-term aim is to improve the wellbeing of older adults (classified here as people over 65 years) through the combination of an intelligent walker to improve physical mobility, a social network to develop social contacts, and a recommendation system to generate personalized ideas for activities (combining the physical with the social (e.g. recommendations to go out with a friend). Studies of such systems often assume that the goals of maintaining independence and wellbeing supersede concerns about privacy or security. However, since the system may collect substantial amounts of personal data (e.g. physical activity, health indicators, emotional state, activities, social contacts), privacy concerns are significant and should be understood. Potentially, such a system would feed information to the user, medical professionals or family members who may look for early warning signals of decline in an older adult who, for example, has not left the house for several days. However, the data could also be used to personalize recommendations to the current abilities and interests of the user to optimize uptake of those recommendations. Older adults may not want such data to be shared and therefore their privacy preferences related to the dissemination of such data will need to be made clear.

In this paper, we take a privacy-by-design perspective [29], involving older adults in a participatory design process that will help us understand the ways in which health and mobility data generated by the system might meaningfully be shared with others in their social network. We present

two studies. The first with a small (n=6) group of older adults was designed to understand more about what their trusted network might look like. The second, with a larger (n=20) sample, more explicitly addressed older adults' privacy and disclosure preferences towards the individuals in their network. Our contribution is twofold: firstly, we provide a new framework for understanding the social sharing of data in older adulthood, giving particular consideration to the sharing of health information and secondly, we include for the first time, the right for information not to be made known, i.e. not to be revealed even to the self – casting this as a privacy issue, rather than as a medical issue around the sharing of prognostic information [24].

BACKGROUND LITERATURE

In this section we briefly review the different forms of activity monitoring that have been associated with ageing, but with a particular focus on those technological interventions designed to minimize age-related decline. In particular, we discuss those interventions which promote increased mobility and social engagement - two of the more important correlates of successful ageing. We then describe the privacy implications of such interventions, before introducing our own studies.

Activity monitoring and the deficit model

A significant research effort has been directed towards designing technologies that can directly monitor the behaviour of older adults – particularly those who experience age-related health decline. Sensor based systems can lead to early detection of a range of diseases or problems associated with ageing. For example, accelerometry and GPS systems that can capture sedentary behaviour or variability in gait have been shown to predict a range of cognitive issues as well as risk of falling [21,22]. Bed restlessness (as measured by a load sensor or a smart watch) can predict a range of health problems in older adults [4,34] and is also seen as one of the most reliable forms of embedded health assessment [47]; and a range of further indicators including speech, mobility and sleep disturbance have been used to predict depression and other forms of mood disorder [11,13,20].

Sacco et al. [45] developed a Daily Activity Scenario (DAS) score, based on the Instrumental Activities of Daily Living questionnaire (IADL) that included watering plants, using a kettle, preparing a shopping list, using a telephone, watching TV and reading a newspaper. They demonstrated that such a scoring system could be used effectively in a smart home setting equipped with video monitoring to detect early functional impairment (although in their study there was relatively limited automatic recognition of IADL). More recently, Lee and Dey [30] used a range of ubiquitous sensors ('dwellsense') to collect a set of observations of daily living (ODLs) – objective measures that could more reliably be used for patient care and decision-making but that could also be used to aid patient

self-reflection as a first step in a behaviour-change programme. Basically, these systems are designed from the assumption that the user is on a path of decline and the system must protect the user.

Activity monitoring and living well

In a successful ageing intervention, we might gather similar data, but this time with the intention of promoting those behaviours associated with successful ageing (see [7,12]). Two factors in particular – mobility and social engagement – are of particular interest here. As people age, they tend to make fewer and shorter journeys and are generally less mobile within the home. Yet older adults who retain good mobility do better across a wide range of health and wellbeing measures [14,57]. Similarly, those older adults who enjoy good quality social engagement show a number of associated benefits including living longer, enjoying better health, and experiencing less depression [1–3,8,53].

Technologies exist for both mobility tracking and social network analysis, but most of the deployments in this space are with younger adults. Nonetheless, we are beginning to see behaviour change interventions using activity trackers such as FitBit in the older adult population (e.g. [48]), with mixed results. For example, one study on the use of FitBits showed an improvement in health awareness in older adults, but no associated improvement in exercise. Another study used pedometer monitoring as part of a larger trial that also involved coaching, resulting in a decrease in sedentary time in older adults [9]. However, the privacy issues associated with the social sharing of such data were not explored in either study.

Privacy and the disclosure of personal data

To ensure acceptance of the ACANTO systems, we must ensure that any design has properly accommodated privacy needs, as these systems will collect and distribute different types of personal information. In deciding whether to disclose sensitive data, people make personal assessments of the extent to which they can feel good, but not vulnerable about that disclosure [25,26]. There are, however, some systematic effects around data disclosure that we should take into account in considering the privacy aspects of our own system.

Firstly, people are more willing to disclose information about themselves in a technology-mediated interaction than they are face-to-face. A classic example concerns form-filling, where people will disclose intimate details in a computer-based test while withholding such details face-to-face [58]. This finding is particularly strong when questions are of a sensitive nature (e.g. medical health problems). Of course one reason for this is the relative anonymity with which people can disclose information online, but people can also exercise more control over their online interactions and manage information more effectively [56]. Essentially, people are pragmatists and make decisions to disclose information with a view to what is on offer [50]. When benefits are high, privacy concerns

can often be relegated [10]. In the health context, for example, people are often prepared to use social media and other smart forms of data sharing to exchange health-related information across a trusted network that will include healthcare providers, important family members and friends. This is the kind of network that Li et al. [31] describe as part of the 'Social Internet of Things (SIoT)' – where health data can be sensed and intelligently networked with selected parties.

A trusted social network for health and wellbeing data

Consider, for example, the kinds of elective social sharing of health information that takes place on PatientsLikeMe [16] and imagine that the everyday health devices used to support this information sharing (thermometers, blood pressure monitors, scales) could upload information automatically. Certainly there could be some interesting gains in epidemiology and the large scale assessment of treatment efficacy, but we can see some interesting new challenges emerging around privacy and trust. Li et al. [31] discuss ways in which trust might be established in such a cyber-physical-social network. The data derived from health and activity monitoring can be used by patients and shared with doctors, family members, friends and other agents [15], bringing advantages to healthcare providers in terms of the availability of more accurate and up-to-date health information, but providing challenges in terms of individual consent and privacy protection, particularly in circumstances when the '*distinction between personal data and health care data has begun to blur*' [42]. This is a major concern: if the social and mobility data describing the everyday life of a citizen is no longer owned or even generated by that citizen then this raises critical questions about issues of trust – not only in the data collected but also around the network of 'trusted friends' that might be given privileged access to that data [36].

Privacy in older adults

For many years we believed that young people were profligate in their disclosure of personal data, but that adults were more cautious, although some reports suggested lax privacy behaviours and preferences by both the youngest and the oldest members of society, when compared to middle-aged participants (e.g. [32]). In recent years, the privacy pendulum has swung so that recent reports tend to show more caution on the part of young people but a growing problem for older people who sometimes struggle to manage their personal data [38].

Successful privacy management requires that we have both the knowledge and the means to achieve a desired degree of access to information by others at a particular time and under particular circumstances [40]. At present, older adults are not heavy users of social networking systems (SNS) [41], in part because they may not have a clear understanding of why they would use them, the risks that are present or the privacy protections available [38,61]. Those who do use SNSs are not always aware of the

privacy settings available nor how to control them [17,35]. Research suggests that only a small number of users change their initial privacy settings, which often default to maximum visibility [19]. For these reasons, discussing the potential for privacy features in a new SNS for older adults can be difficult and so, as part of our project, we felt it important to draw upon some of the rich participatory 'privacy by design' methods available in the literature.

Aims

Our aims were to investigate what privacy functions and modes are desired within a number of specific scenarios developed for the ACANTO system. This system is currently under development as part of a European project and has an overall aim to support older adults in successful ageing by monitoring physical health and general mobility but also by providing them with a social networking system (SNS) that can promote social engagement and shared activities. The proposed system includes two core elements: Firstly, an assisted walker that monitors gait, balance and walking speed. If walking ability declines (i.e. if balance becomes decentralised, or walking speed reduces) then the system can notify a health care professional in order to suggest ways this decline can be arrested e.g. through the use of exercise or confidence-building activities. The SNS will link older adults with other people who share preferences including similar interests. The network will use sensor and other data to create a user profile that can be used to suggest personalised activities with other users who share interests, location, age, ability etc. The system will suggest things to do together and will suggest places to go. The aim is to design a system that is not only easy to interact with but that is able to persuade people to be more active and socially engaged. The system can also act as a means of safe introduction to new people, before meeting face to face.

The specific privacy challenges of such a system are many and involve considerations of the kinds of trusted network that would be appropriate for older adults and the kinds of data that might be shared with that network. These two considerations were the subject of our two studies, below. In the first, we used sociograms as probes to learn more about information sharing across the trusted network and in the second, we used a range of scenarios that explained to participants what specific information would be collected and for what purposes in order to understand how potential users would wish their data to be handled.

STUDY ONE

In this first study, we mapped the trusted social networks of a small group of our participants, using sociograms to get a sense of the size of their social networks and some of the key players within them. Our goal here was to understand the types of information that older adults will share with different groups of people in their offline social networks.

Participants

Six 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. Participants 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 of Hogan, Carrasco, & Wellman [23] 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. Very close people were defined as those with whom they are in regular contact, and with whom they might discuss important matters. Somewhat close people were defined as those who are more than casual acquaintances but who are not very close. Names were recorded on sticky page markers (using different colours for 'very close' and 'somewhat close').
2. After free recall, participants were shown a list of categories on a card (e.g. immediate family, neighbours, work colleagues, etc.) and asked if they had forgotten anyone. Each name tag was labelled according to category.
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 were closest to the participant were placed closer to the centre. People who knew each other were placed close together.
4. Participants drew circles around groups of people that belonged together (already clustered together).
5. Participants drew lines between people who were close to each other.
6. Participants then identified a label or description for each of the circles, with an example of a completed social network diagram is shown below in Figure 1.

The diagram was then used as a prompt in a semi-structured interview that addressed the different forms of information sharing that occurred within the social network.

The Sociograms

A breakdown of the network features for each participant is given in Table 1. In contrast with other studies which used similar methodologies, the average number of nodes is relatively high in our sample (cf. 23.8 in [23] for a general population and 14.0 for older adults aged 55-58 in [52]). This seems to indicate a relatively well-connected group of older adults. While Hogan et al. [23] 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. This may suggest a strong emphasis on closer relationships in older age, although we should also note the
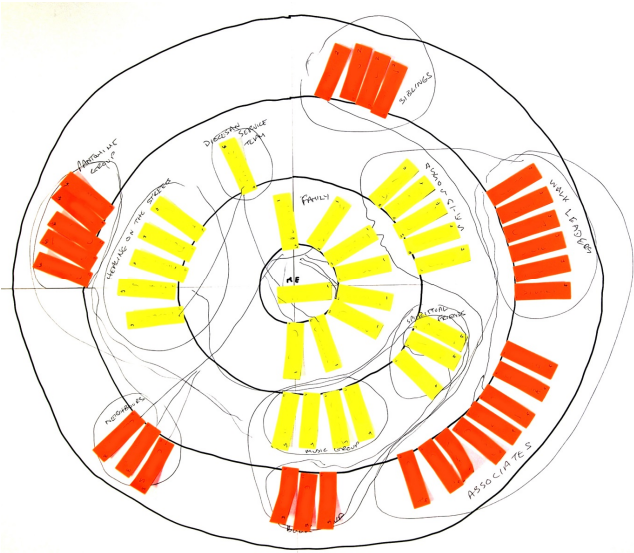

Figure 1: Anonymised example of a participant-created sociogram

relatively large numbers of discrete groups as indicated by number of circles.

The different groups identified included (i) family - including close relationships with grandchildren; (ii) long-term friendships that had been sustained for many years and were seen as particularly valuable; (iii) neighbours that were sometimes important sources of support (most participants had at least one neighbor they felt close to); (iv) interest 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 this might depend on the size and nature of the group; (v) volunteering groups including co-workers in charity shops or hospitals; (vi) physical activity groups including dance groups and walking groups; (vii) ex-work colleagues that were sometimes seen individually or sometimes in organized outings and (viii) online contacts: typically people formerly known face-to-face, but who, because of distance, were now contacted online (usually through email).

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
Average	**40**	**23.5 / 14.8**	**10**

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

Patterns of Information sharing

At one end of the spectrum we found "strangers" who should not have access to our participant's data. At the other end were doctors who were generally offered complete access to the social network data in our potential system. Even when some forms of data were seen as particularly problematic (e.g. mood data), sharing this with doctors was seen as acceptable. Generally, however, disclosure preferences were highly individualistic and it would seem a risky assumption to believe that trust could be generalized across groups of friends:

"*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 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.*"

This is consistent with other findings [46] that show how, even for one's own children, information sharing may occur with some and not others (e.g. the "worrier" might not be given access to certain information).

Location sharing

Location data, while potentially sensitive, did not seem to cause undue concern, providing that the data was limited to others in the social network. In part this was because "*we're all friends*" but some said they didn't mind others seeing their location data because, "*I got nothing to hide.*"

One participant was more restrictive in her sharing of location data and named only a select few who could receive that information (from different groups), giving very specific reasons for her choices:

"*Because he's a very sensible, not over the top character [...] there's people go like, you know over the top and hysterical and you think, "For goodness sake!". John's dead down to earth and whatever would happen, he would deal with it calmly and sensibly [...] I wouldn't want Sam cuz he wants to know where I am anyway. Cuz he's a nosy bugger.*"

Her thought seems to be that location data could reveal situations that cause alarm or that would support prying. From such accounts we can see that social sharing is often based on individual personality characteristics rather than their membership of a specific group.

Exercise sharing

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)*"

Only one participant expressed some concern sharing regular physical activity information arguing that it would make her seem '*pretentious*' to her pub friends.

Mood sharing

Most participants were very cautious about sharing mood data. They worried that others may feel obliged to respond, but not always with the most helpful suggestions:

"*There are some people I know who would look at it and say, 'Oh Bob's feeling good, feeling bad.' There are other people who would say, '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 would restrict that to the inner circle*"

Participants were sensitive to the idea that doctors might find mood information symptomatic of a deeper problem and this was seen as a reason to allow them access to this information:

"*If he put it in a way like, '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".*

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

"*[Feeling a bit] down ... Yes you just want a bit of time to yourself you know, keep that time to yourself. But happy, yea, spread the joy! (laugh)*"

Consistent with previous research that talks about the action tendencies of emotions (Frijda, 1987) and the social functions of emotions (Fischer & Manstead, 2008), it was clear that participants were more prepared to share positive than negative mood information, in part because of the threat of negative emotions to a positive self-presentation:

"*I think it's very private. Because [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, for goodness sake, I mean I've lost my temper with poor little John because he rattles on 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 my moods to be [visible]*"

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.

Health information sharing

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:

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

"*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 and that was how I coped with it.*"

"*Oh I tell everybody ...Everybody who wants to know. Like you, I'd never hide the fact that I've had breast cancer*"

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

"*Well it helps people make allowances for me I hope. You know. I mean, 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 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?*"

Only one participant was not happy with sharing health information widely believing that it may create some kind of mutual obligation:

"*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 I wouldn't feel it appropriate to share it. Cuz you've got the obverse of it 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.*"

An important point to note here is that information has action implications; when someone shares information, it may place an obligation on those who see the information to respond in some way. This, in turn, has privacy implications as an individual may not wish to take on the responsibilities associated with particular forms of information sharing across the network. Other research has highlighted similar problems: monitoring older adults can turn ordinary care into care *work* and the availability of information may disrupt ordinary routines of caring for others [54]. In short, data carry implications for action that can disrupt ordinary life.

Sharing at the right time

Our participants understood that there was an important temporal dimension to the sharing of information - that there was a time and a place for information to be shared. One 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:

"*I had angina, about four, five years ago. [We were] coming from a match, going to get a taxi and I had a huge angina attack and 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 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.*"

Again, we see that the sharing of information brings certain responsibilities – and the themes of 'not worrying' another person or 'not creating an obligation' for them to take action were strong.

Discussion

In this first study, our focus was on the question, "Who are older adults happy to share specific types of information with?" Our participants were thoughtful in their sharing of personal data and 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 obligations or actions will be triggered by the act of sharing?

We did not find it easy to map disclosure preferences onto group boundaries. Within specific groups there were close, trusted friends and there were more distant acquaintances and the nature of these relationships were critical. The most severe privacy violations were not linked to strangers being given access to information, but were tied to close friends being told things they were never meant to learn. This theme is explored further in study two.

STUDY TWO

In this study, we conducted a series of interviews with older adults by presenting them with short scenarios of information-disclosure within the proposed system. Asking them to think about the consequences of this disclosure and their attitudes to it, enabled us to explore the relationship that older adults feel towards their personal information. In study one we examined the user's information in relation to other groups but in this study, we examined the user's information in relation to the self as well as others.

Method

Semi-structured interviews were conducted with older adults from who were recruited by email through the North-East Age Database. We recruited 20 participants in total (M=10, F=10; Mean age =72.58, SD=7.33).

Participants were presented with a sequence of specific use-case scenarios and asked about likely privacy concerns. For example, participants were told that the system would collect their location information and that it needed this information to make recommendations about local events. Having been supplied with this information, participants were asked to think about the potential positive and negative consequences of other people within the system knowing this. This made participants explicitly weigh the advantages and disadvantages of privacy vs. disclosure. They were then asked how much of this information they would disclose, to whom would they disclose it, and under what circumstances would they disclose it. For each of these questions, the interviewer asked for the reasons behind these decisions in order to understand the functions for which privacy was being sought. Each of the interviews lasted about one hour.

Materials

The scenarios for the interviews were devised from the ACANTO system requirements so that the questions were highly specific to the system thus improving the validity of the findings. The scenarios are too numerous to reproduce here but involved four types of information: general information, health information, location information and information required to recommend activities. An example of each is given below:

1. *General information*. The system stores your education level. This will be used to recommend activities that are appropriate to your education level.
2. *Health information*. The system records walking information (number of steps, distance walked) in order to record progress to achieving targets. You will be able to review your activity level. If physical activity declines it will inform your doctor.
3. *Location information*. The system will store your home location to provide useful and accurate navigations.
4. *Recommendation information*. The system will store how far you are willing to travel to activities in order to make appropriate recommendations.

In total, there were 36 distinct pieces of information that the system would need. This was divided into three lists of twelve so that each participant was shown 12 pieces of information from each of the four categories. Lists were selected randomly for each participant. Lists 1 and 2 were used for 7 participants, list 3 used for 6 participants. This reduced the time required for the interview to around one hour and avoided duplication of answers to the questions.

Analysis

Interviews were recorded to allow for transcription and analysis of the data. The Johari Windows technique was then used in a framework analysis to make sense of participants' disclosure preferences. The Johari Window

[33] is a four paned "window" that describes personal information in terms of the extent to which it is open to the self or to others. The window is split into four quadrants as follows: open (shared freely), hidden (information known to self but kept from others), blind (information known by others but kept from self), and unknown (information unknown to self or others). The relative size of the four quadrants can be used to indicate different self-disclosure types or preferences.
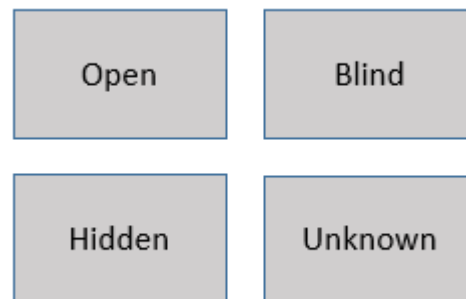

Figure 1: The Johari Window (Luft, 1961)

This approach was felt to be particularly useful insofar as it avoids a simple dichotomy of privacy *vs.* disclosure (open *vs.* hidden) and introduces the idea of potentially important information which is unknown to the self. It is thus a particularly useful way of conceptualizing privacy in a social network for older adults where privacy can be about what the system knows and shares about you without your knowledge.

Open

The "open" quadrant represents things that are open to the self and to others. These include certain demographic and biographical details and other subjective attributes – attitudes and emotional propensities for example. Here we used the 'open' quadrant to reflect the kinds of data that might be distributed across the wider SNS network and note that our participants were generally inclined to disclose a good deal of current information about themselves. Particularly when it came to factual or demographic information in relation to things like their age and interests but were also happy with the idea that location information could be shared if it meant facilitating a social interaction or simply making things more convenient. However, people were keen to avoid general disclosure of information that was not relevant – either because it had happened in the past or because it was simply 'none of their business'

I don't think any of those backgrounds- I mean, I wouldn't be interested in what folk had- I wouldn't want to see it put down in black and white, you know, "I was a salesman," or, "I worked in a factory," or, "I worked in a bar." I mean, I've done all these things. It's all in the past. It's just from today on I'm interested in, not what was in the past… I don't think it's anyone's business apart from mine of what I've done. I really don't.

In addition, there was a strong sense that such information could only be 'open' if there were no adverse social implications. People didn't want to 'rock the boat' by disclosing information to some individuals that had previously been hidden:

You've got to be careful, a general thing you could put on, but no specifics. It's too much personal information…. If you put too much personal information on it can alter your relationship with friends and acquaintances, never mind the bad guys or anything like that.

And it's, when you get to my age you don't want to upset anybody, you want to keep your friends, you want to have them, you want to have them the way they've always been

If you've got different groups of friends and different interests that you, then if you had like a clash of things going on, then they would also know that you've got choices to make, and you didn't choose them… I wouldn't want one friend to know that I was friends with somebody else…

Privacy and self-disclosure are thus seen in the context of identity and impression management, accepting the need to selectively portray different aspects of the self to different people. In other words, some information may be open to some but not to others, i.e. the information it is not disclosed to all without reserve.

Hidden
The "hidden" quadrant represents things known to the self but not to others. Here we use the hidden quadrant to reflect both information hidden to all in the social network, perhaps because it might cause embarrassment, or information shared unevenly across the network and made available only to highly trusted individuals.

A major motivation for keeping things hidden in the social network was a respect for confidentiality and an associated fear of causing unnecessary distress in others.

Well, if you call them friends, you wouldn't like to discuss personal things behind their back sort of thing, so you wouldn't want to discuss things that they might not be, want you to discuss. So it's like keeping confidentiality

Y'know you would just say 'ah talking to Bob there and everything, and he wants this, that and the other.' That would be confidential as far as they're concerned so I would want them to be the same, with my conversation with them. It would be a private thing, rather than going to tell everybody, Tom, Dick and Harry

However, there was also the risk of sharing something that would prove embarrassing or, for some, the fear that a medical condition or deterioration in health would lead to pity:

Yes, it's about how much you're happy to disclose of your failings or what you think are failings. When, I suppose in my heart, in my heart I know it doesn't matter; it's just

numbers of… It's a measurement of achievement, I suppose. In my head I know that, but in my heart I don't want people to know that I've only got low numbers. So yes it is, it's, I think to maintain the perception of others.

You wouldn't want to be felt pity and I suppose there is the possibility – some would just feel pity for you. Not all would feel pity for you but at the same time I think a lot of people, when you find with someone with illness, or serious illness the first inclination is 'aw I feel sorry for them' so I wouldn't like anybody to erh, at this particular time because I haven't got any serious illness, to feel pity for me.

Unsurprisingly, then, people were keen that health information be shared with only a small subset of the network and with those in the medical profession:

it's becoming a little bit more personal, it's going back to the medication type of things. You would just want to tell people who you want to know instead of everyone.

Perhaps more interesting was the idea that our participants recognized that they had, in the past, kept information hidden from their doctor, recognizing that this was not always the most sensible approach if an accurate diagnosis was to be made, but recognizing this option might be lost to them in the new system:

I mean, it makes sense if you're part of a programme and you've agreed that and fully understand it and want to do it, then if something drops off then it can tell your doctor. Actually, then the downside is you can't lie to your doctor then about, "I've done it"

Deception or lying as a way of managing privacy was mentioned numerous times by participants. It was seen by many as a functional way of keeping things hidden, but an option that is removed if the system automatically acquires the relevant data. Nevertheless, while this might have been a concern of participants, users can become remarkably adept at finding how to deceive monitoring systems (as cleverly pointed out in "Uninvited Guests" [49].

Blind
The "blind" quadrant represents things unknown to the self but known by others. It includes 'blindspots' indicating a lack of self-knowledge in a particular domain. For example, an individual may be unaware that they have upset a friend, they may not have been invited to an event or they might not realise that a relative is ill. When people are 'blind' to their own state or behavior, then this can be a concern:

Well if y'know if things began to go badly I think I would need them to know in order to understand what was going on with me, Y'know that I hadn't suddenly changed my personality and didn't like them anymore, or couldn't be bothered to remember when their birthday was or whatever. I'd need them to know the reasons that the changes were happening to me… I wouldn't want people saying ooh "have you seen how that Dorothy has

changed", "ooh I don't know what I've done to her" and "oo I don't know why she's like this". I wouldn't want that.

Being blind to certain types of information can be a problem and is indicative of a lack of self-knowledge. However, some forms of self-knowledge can actually be threatening to the self, and this is dealt with in the next quadrant.

Unknown

The "unknown" quadrant represents things closed to both self and others in the trusted network. In the literature on Johari Windows this is often described in terms of situations where people learned new things, previously unknown to either themselves or others. In a health monitoring context, this becomes a very interesting quadrant, not least because people may wish to exercise a right 'not to know'. For example, our participants were aware that sensors in the system might pick up the first signs of an unidentified health problem, but some said they would wish to be protected from 'knowing too much' about their own possible health decline.

well I like games that challenge my memory, like quizzes, but I wouldn't like a game that said ooh you're falling here dear, watch it, you're going downhill.

I wouldn't want to know in case it had the effect it had on my friend when he thought it was going to happen, and it began to happen, mind over matter, y'know.

This 'protecting the self' from knowledge is a new consideration in privacy research and relates to the literature on patient preferences around health information and decisional conflict [28], particularly in the face of difficult prognoses, when patients may choose to leave certain information ambiguous [24]. This kind of knowledge has a direct impact on one's self-concept which in turn, is linked to health and well-being outcomes [51]. Information which negatively impacts the user's self-concept may have negative effects on the wellbeing of the user independently of the negative effects of the condition being reported to the user.

Another striking example of a preference for data to remain 'unknown' was tied to the idea that the system might be able to infer intelligence from the activities being recorded. Again, we see a sense that people don't want this information to be known – either to themselves or to others:

Because it's nobody's business but mine. I don't see- I mean, I play Candy Crush. I play Bingo Bash. I play these things maybe five, ten minutes a day. If I'm sitting in the evening and I've got nothing, television, I'll play Candy Crush. But I don't see why- I really don't see any necessity for the system to record my memory and attention scores.

I don't know, I suppose it doesn't matter, really. It's just everyone… Usually I'm thought of as, "Oh, Connie is clever." But then I'm maybe not.

Discussion

Using the Johari Windows technique to classify the different quadrants into which information-disclosure fell enabled us to show that an individual's relation to their information is not simply about the choice between "Open" or "Hidden", but also involves the individual's willingness to know information about themselves and to know what other people know about them. Privacy is typically considered in the manner of study one – the self in relation to others, which as we have seen involves intricate social judgments. But as this second study shows, there is another dimension of privacy involving the disclosure, *to* the self, of information *about* the self. This is a dimension that has not often been considered in HCI research, but one which may benefit from an understanding of the medical work on decisional conflict and the way information about the self may be received or rejected [28].

GENERAL DISCUSSION

As with previous work our studies highlight that privacy decisions are dynamic, vary with context [39] and over time [37]. This is due to the changing nature of the information and is particularly pronounced with health information, which is subject to change, especially for older adults. The two studies reported in this paper highlight that active older adults have a broad social network which they seek to protect. They acknowledge the right to privacy of the other group members and seek to act to protect others, a view that is not always shared by younger adults [27]. Different members of that network are attributed different levels of responsibility and trust with information. However, those levels are not determined solely by the subgroup that they belong to.

Our participants sought to protect their family and friends through the hiding of negative moods and health problems, which supports the work of Prasad et al., [43]. While they may hide health information from some individuals, they are open to others who might help them manage better. They also seek to protect themselves from a negative future identity by requesting that information about their decline should remain unknown to them. They are willing to share open information with potential activity partners to facilitate active aging and social encounters.

Design implications

The careful management of relationships via the disclosure of information defines a need for more sensitive privacy controls for devices that track and collect data. These controls should be flexible and sufficiently expressive and granular to deal with the subtleties and changing nature of relationships. Yet the defaults should be sensible and the number of privacy decisions to be made should not overwhelm the user. In addition, it is important to provide visual feedback about the flow of information to ensure that the user is not blind to potential tensions arising from disclosure or to ensure opportunities are not being missed.

This research is particularly significant because recent developments in sensor-based socio-technical systems mean that data can be generated and shared seamlessly, without necessarily requiring the explicit consent or understanding of the participants. We want our system to be able to detect changes in the state of the user relating to health, physical activity and social involvement. However, these changes may not be obvious to the user and the decision about whether to keep them fully informed is a sensitive and difficult one. Other research has suggested that while older adults can imagine the benefits of a system knowing about the decline of others, they rarely like the idea for themselves [60]. This may be because of the threat to a user's self-concept or future identity. An older adult who is told that their memory is failing or that they are not walking as much may feel older, experience reduced subjective wellbeing [59], and subsequently entire a spiral of decline. Information which threatens a positive self-concept can have damaging effects on a person's wellbeing [51]. Clearly this would be counterproductive in a system which seeks to improve the wellbeing of its users. A system that aims to promote active aging may have to protect the user from his or her own decline-related information, similar to the way in which a clinician might encourage a patient by telling them that they are doing well while they are actually in a period of decline. The encouraging information, while not entirely accurate, may serve to slow further decline or even prompt improvement, but it open up an important ethical challenge.

Understanding when an individual is best served by positive, encouraging feedback and when they should be given the full facts about a prognosis, can depend upon whether there is the possibility of improvement and whether the information would be deeply threatening to the self-concept. If there is a possibility of improvement, then the information should be presented in a context that enhances feelings of self-efficacy so as to encourage remedial action. If, however, change cannot occur, or if the information relates to an aspect of the user's life that is central to their self-understanding, then the information is likely to be threatening and may cause psychological harm. An alternative solution may be to allow for active information-seeking (a kind of proxy for a sense of self-efficacy) in which the user is able to seek out information relating to themselves, but avoids the problems associated with passively collecting and presenting information relating to the user [18]. Designing privacy for active aging systems therefore, needs to consider the relationship of the user to their own information as much as the relationship of the user's information to others.

Limitations
The research reported here is based on scenarios describing the ACANTO system and not on actual use. We should take care that the final implementation meets the privacy needs outline in this paper, but also recognize that, while our participants expressed a readiness to share, they may change their views following actual use. We are mindful of the work of Boise et al. [6] who report that older adults concerns were increased after a year of using a monitoring technology. Successful implementation will be dependent on monitoring user concerns and adjusting the design to alleviate these concerns as they arise.

Conclusion
Our work recognizes a future where technology can support successful ageing, generating data that can be shared across a trusted social network. We recommend caution in this space as systems of the type we have described come with the ability to infer information that the user might prefer to keep hidden. We would expect any human in the social network to be respectful of the needs of their friends and family and we should expect no less from the health and social machines that come to operate within this space. We must be mindful that these systems could create new emotional and/or physical burdens for different members of the social network and that they are capable of causing unintentional hurt.

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