

Northumbria Research Link

Citation: Little, Linda and Briggs, Pamela (2006) Using Ubicomp systems for exchanging health information : considering trust and privacy issues. In: e-Society, 18-19 September 2006, University of York, York.

URL:

This version was downloaded from Northumbria Research Link:
<https://nrl.northumbria.ac.uk/id/eprint/12597/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

This document may differ from the final, published version of the research and has been made available online in accordance with publisher policies. To read and/or cite from the published version of the research, please visit the publisher's website (a subscription may be required.)



**Northumbria
University**
NEWCASTLE



UniversityLibrary

Using AmI systems for exchanging health information:

Considering trust and privacy issues

Linda Little, Pam Briggs

PACT Lab

Northumbria University, UK

l.little@unn.ac.uk

Ambient Intelligence (AmI) and ubiquitous computing allow us to consider a future where computation is embedded into our daily social lives. This vision raises its own important questions and augments the need to understand how people will trust such systems and at the same time achieve and maintain privacy. As a result, we have recently conducted a wide reaching study of people's attitudes to potential AmI scenarios. This research project investigates the concepts of trust and privacy issues specifically related to the exchange of health, financial, shopping and e-voting information when using AmI system. The method used in the study and findings related to the health scenario will be discussed in this paper and discussed in terms of motivation and social implications.

1 The concept of Ambient Intelligence

Ambient intelligence (AmI) evokes a near future in which humans will be surrounded by 'always-on', unobtrusive, interconnected intelligent objects few of which will bear any resemblance to the computing devices of today. Devices embedded in the environment will communicate seamlessly about any number of different topics e.g. your present state of health, when you last ate. Interactions with devices and at the same time other people

will become anywhere, anytime. This seamless exchange of information implicates, motivation, trust, privacy and social values as core variables that need to be fully understood if we are to adopt and use AmI systems.

People have existing expectations about how technology works and social norms provide cues on how they should interact in any given situation (Jessup & Robey 2002).

Development in technology has never had the explicit goal of altering civilisation (Bohn et al 2005). The AmI vision is to fully computerise society, therefore we must question whether AmI technology will change the way humans interact socially. Friedewald et al (2005) question whether AmI systems will fulfil most of the promises made by researchers or whether the vision is just an illusion? Living in an AmI society suggests effortless communication, our needs, wants and desires met. The exchange of information has vast social implications and might not decrease but actually increase the complexity of life.

AmI systems hold the danger of increasing social pressure and the digital divide (Friedewald et al 2006). AmI has the potential to create an invisible and comprehensive network monitoring our private and public life (Bohn et al 2005). There is a chance people will become monitored and penalised by stakeholders for not adopting and using such systems. For example, insurance companies only insuring a person if they have a health monitoring system. What will motivate people to use such systems if there is a chance of exploitation?

Motivation and satisfaction are considered key factors associated with technology adoption and use (e.g. Malhotra & Galletta 2004). According to Herzberg et al's (1959)

Two Factor Theory of Motivation certain factors cause satisfaction and other factors dissatisfaction. The basic premise of the theory suggests satisfaction is related to two types of factors: hygiene (extrinsic) and motivating (intrinsic). The theory was originally developed to measure job satisfaction in the workplace and has now been used in other areas of research e.g. Human Factors (Zhang et al 1996), Tourist Attractions (Jensen 2004). To understand AmI adoption and use we must consider the concept of motivation, in particular when considering the benefit or cost associated with health information exchange.

1.1 Exchanging health information

The design and implementation of electronic health records began over thirty years ago (Goldschmidt 2005). The desire is for health services to improve healthcare by introducing systems where information can be accessed and exchanged in a timely manner. Healthcare professionals argue information and communication are crucial for their functioning (Hartog et al 2006). However, exchanging health information in an AmI society has vast legal and ethical implications and inappropriate disclosure of health data has huge liabilities (Stanford 2002).

AmI systems will not just store information but continuously monitor and access our health status. A typical AmI health scenario in a medical emergency envisages an ambulance will be on the way to the scene in seconds, updated reports and the medical background of the patient will automatically and continuously be exchanged between the ambulance, hospital and personnel involved (Hartog et al 2006). The vision is for

healthcare professionals to be able to evaluate and diagnose patients prior to arrival at hospital, thus delivering a more efficient service.

In the USA access to electronic patient records has already resulted in numerous cases of abuse in the healthcare field (Rohm & Milne 2004). The California Healthcare Foundation (2000) found 75% of US citizens were concerned about healthcare firms sharing information. The Foundation also found health information was considered more sensitive than other types of information collected, especially when access was by insurance companies and employers. Our health records contain vast amounts of information from mundane (e.g. the last time you had flu) to the very sensitive (e.g. treatment for a sexually transmitted disease). Unauthorised access or disclosure has vast social implications ranging from social embarrassment to prejudice (Rindfleisch 1997).

Two important factors that will influence ambient technology adoption and use are trust and privacy issues. Streitz & Nixon (2005) argue areas of security, privacy, and trust are critical components for the next stages of research and deployment of ubiquitous systems. This paper will focus on the social implications of health information exchange in an ambient society, and not the technical limitations or constraints of such systems. If we consider that the exchange of information is what makes AmI tick, we need to ask questions about information that will have a direct impact on both trust and privacy, including: Who is receiving it? Who has access? Is the receiver credible, predictable and sensitive? Where is the information being sent and received? In what context is the device used? Does the user have choice and control? How does the device know whom to communicate with e.g. through-personalised agents?

2 Method

To understand and investigate the concept of AmI technology and subsequent use key stakeholders provided specific scenarios illustrating the ways in which privacy, trust and identity information might be exchanged in the future. The stakeholders included relevant user groups, researchers, developers, businesses and government departments with an interest in AmI development. Four scenarios were developed, related to health, e-voting, shopping and finance that included facts about the device, context of use, type of service or information the system would be used for.

2.1 Development of Videotaped Scenarios

The elicited scenarios were scripted and the scenes were videotaped in context to develop Videotaped Activity Scenarios (VASc). The VASc method is an exciting new tool for generating richly detailed and tightly focussed group discussion and has been shown to be very effective in the elicitation of social rules (Little et., 2004). VASc are developed from either in-depth interviews or scenarios, these are then acted out in context and videotaped. The VASc method allows individuals to discuss their own experiences, express their beliefs and expectations. This generates descriptions that are rich in detail and focussed on the topic of interest. For this research a media production company based in the UK was employed to recruit actors and videotape all scenarios. The production was overseen by both the producer and the research team to ensure correct interpretation. British Sign Language (BSL) and subtitles were also added to a master copy of the VASc's for use in groups where participants had various visual or auditory impairments. The health scenario is described below.

Health Scenario: *Bob is in his office talking on his personal digital assistant (PDA) to a council planning officer with regard to an important application deadline. Built into his PDA are several personalised agents that pass information seamlessly to respective recipients. A calendar agent records and alerts Bob of deadlines, meetings, lunch appointments and important dates. As Bob is epileptic his health agent monitors his health and can alert people if he needs help. An emergency management agent takes control in situations when a host of different information is needed; this agent has the most permissions and can contact anyone in Bob's contact list.*

Bob is going to meet his friend Jim for lunch when he trips over a loose paving slab. He falls to the ground and loses consciousness. His health agent senses something is wrong and beeps, if Bob does not respond by pressing the appropriate key on the PDA the agent immediately informs the emergency services. Within seconds the emergency services are informed of Bob's current situation and his medical history. An ambulance is on its way. Paramedics arrive, examine Bob and then inform the hospital of Bob's condition on their emergency device. The hospital staff are now aware of Bob's medical history and his present state, therefore on arrival he is taken straight to the x-ray department. A doctor receives the x-rays on her PDA. After examining Bob she confirms that he has a broken ankle, slight concussion and needs to stay in hospital overnight. After receiving treatment Bob is taken to a ward. His emergency management agent contacts John (Bob's boss) of his circumstance. The emergency management agent transfers the planning application files to John's PDA so the company do not miss the deadline. The agent also informs his parents letting them know his current state of health, exactly where he is so they can visit and that his dog needs to be taken care of. As Bob is also head coach at a local running club the agent informs the secretary Bob will not be attending training the following week. The secretary only receives minimal information through the permissions Bob has set.

2.2 Participants

The VASc's were shown to thirty-eight focus groups, the number of participants in each group ranged from four to twelve people. The total number of participants was three-hundred and four. Participants were drawn from all sectors of society in the Newcastle upon Tyne area of the UK, including representative groups from the elderly, the disabled and from different ethnic sectors. Prior to attending one of the group sessions participants

were informed about the aims and objectives of the study. Demographic characteristics of all participants were recorded related to: age, gender, disability (if any), level of educational achievement, ethnicity, and technical stance. A decision was made to allocate participants to groups based on: age, gender, level of education and technical stance as this was seen as the best way possible for participants to feel at ease and increase discussions. As this study was related to future technology it was considered important to classify participants as either technical or non-technical. This was used to investigate any differences that might occur due to existing knowledge of technological systems. Therefore participants were allocated to groups initially by technical classification i.e. technical/non-technical, followed by gender, then level of educational achievement (high = university education or above versus low = college education or below), and finally age (young, middle, old). Overall this categorization process culminated in 24 main groups. Due to poor attendance at some group sessions these were run again at a later date. Although several participants with physical disabilities attended the main group sessions two group sessions for people with visual and auditory impairments were carried out at the Disability Forum in Newcastle. The forum was considered to have easier access and dedicated facilities for people with such disabilities.

2.3 Technical Classification

To classify participants into technical or non-technical six questions based on a categorization process by Maguire (1998) were used. Participants answer the questions using a yes/no response. Responding yes to questions 1, 3, 5 and 6, no to questions 2 and 4 would give a high technical score of 6. If the opposite occurred this would give a low technical score of 0. Participants in this study who scored 0-3 were classified as non-technical while participants who scored 4-5 as technical. The questions were:

If your personal devices e.g. mobile telephone or computer were taken away from you tomorrow, would it bother you?

Do you think that we rely too much on technology?

Do you enjoy exploring the possibilities of new technology?

Do you think technologies create more problems than they solve?

Is Internet access important to you?

Do you like to use innovative technology as opposed to tried and tested technology?

2.4 Procedure

On recruitment all participants received an information sheet that explained the study and the concept of AmI technologies. Participants were invited to attend Northumbria University, UK to take part in a group session. The groups were ran at various times and days over a three-month period. Participants were told they would be asked to watch four short videotaped scenarios showing people using AmI systems and contribute to informal discussions on privacy and trust permissions for this type of technology. They were told all of the other participants in their particular group would be of approximately the same age and gender and informed the discussion groups would be recorded for further analysis. Participants were not informed about the technical/non-technical or the level of educational achievement classification that was used. An informal interview guide was used to help the moderator if the discussion deviated from the proposed topic.

At the beginning of each group session the moderator gave an explanation and description of AmI technologies. After the initial introduction the first videotaped scenario was shown. Immediately after this each group was asked if they thought there

were any issues or problems they could envisage if they were using that system. The same procedure was used for the other three-videotaped scenarios. The scenarios were viewed by all groups in the same order: e-voting, shopping, health and finance. Once all the videos had been viewed an overall discussion took place related to any advantage/disadvantages, issues or problems participants considered relevant to information exchange in an ambient society. Participant's attitudes in general towards AmI systems were also noted. The duration of the sessions was approximately ninety minutes.

3 Analysis

All group discussions were transcribed then read; a sentence-by-sentence analysis was employed using the Atlas.ti™ qualitative software programme. The data was open coded using qualitative techniques and several categories were identified. The data was then grouped into categories using sentences and phrases from the transcripts. Categories were then grouped into the different concepts, themes and ideas that emerged during the analysis.

The various themes and concepts that emerged from the analysis provided greater insight into the issues regarding information exchange in an ambient society. Different issues related to the user, device and stakeholder emerged. Further in-depth analysis revealed several constructs related to disclosure, privacy, trust usability and social issues associated with the use of an AmI system. These constructs were found to be interrelated and multidimensional. For clarity and ease of interpretation the constructs were further analysed and grouped based on Herzberg's (1959) Two Factor Theory of Motivation. Table 1 depicts the main groupings of Motivators, Benefits, Costs and Social Implications.

Motivators	Benefits	Social Implications
Credible	Better healthcare	Over-reliance
Secure	Convenience	Dehumanisation
Reliable		Bystander apathy
Accurate	↕	Reduced social interaction
Transparent		Enforced participation
Context aware		Health risks
Personalised	Inflexibility	Environmental issues
Easy to use	Profile abuse	
Accessible	Surveillance	

Costs

Table 1: Grouping and constructs associated with use of an AmI system and based on Hertzberg's (1959) Two Factor Theory of Motivation.

Motivators

a) *Credible*

Participants discussed the different types of relationships they had with other people would impact upon what information should or could be exchanged. Findings revealed participants who visited their GP and/or hospital consultant on a regular basis discussed access and exchange of health information in terms of loyalty and satisfaction. However, participants raised concern over stakeholders using AmI systems to gather personal health information and then using this information to exploit people.

'I'm getting to this point, trust is the main thing I think that bothers me. It think it gives the information, private information and how accessible that information is to others and how they will be using it.'

'It's not trusting organisations to use that information for my best interest.'

'If you could do it through something like the BBC because it's typically British, you are going to trust the BBC, it's always been there, it's something tangible, but for a lot of older people, it's new and it's different, you know they don't trust it, whereas they trust their television because they have watched it all of their life.'

b) Secure

Security of AmI systems for exchanging and storing health information emerged as key factor that would limit adoption and use. Fraudulent use, hacking, access by third parties, leakage and storage of information were all areas discussed. Participants agreed that being able to verify and access information stored on systems was needed.

'There not as security conscious as I would like them to be. I don't like the security part of it It's time saving yes and helpful like and you not having to think for yourself.'

'Many people can hack into that system.'

'How secure would the information be? It could be that you have got a specific condition. You could have a drink problem or whatever and that could get back to your employer or it could get back, you know what I mean, I would have serious concerns, not that I've got a drink problem, not yet anyway!'

c)Reliable

Participants discussed the reliability of the system. For example, if the machine malfunctioned and the user was unaware of this what would the consequences be?

'The greater worry I think is that because you have then got a health system taking care of Bob on the basis of the information held in the system, is how correct is that, is the veracity of that information, because if there was a mistake in that information, then things could go awfully wrong. So it says, I see that you are allergic to aspirin, but say actually I was allergic to something else. If that was wrong then, although she verified that, you could verify that I suppose, but you would worry that there were going to be pieces of information that might be false, that people are acting upon.'

d) Accurate

Discussion highlighted human fallibility in keeping systems updated, entering the correct data and setting preferences for who has access to their health information. Data gathering and data mining by stakeholders would create profiles about a person that would contain false information.

'So it is all about the information, is all this information accurate or will they make mistakes? You know will it be useful? Some of it maybe is good, and some of it not. So I don't know for other people or for myself if RIFD would be accurate information. I don't think the information will be a hundred percent accurate.'

e) Transparent

Participants commented systems needed to be transparent and accessible so information could be verified and changed. Participants acknowledged stakeholders already hold information about you that you are unaware of and this should be made more transparent.

'I mean they don't really know where the information is going and what individuals are actually accessing it or is it just completely churned up by computers? I don't even know but the information is going somewhere and the customer, the consumer should actually have, be allowed to know where that information is going and it should be an open process, open to the consumer, if the consumer wants to know of course, some people might not want to know, but if the consumer wants to know how all that information is processed it should be open.'

'They can't demand it off you, but it does make you look very suspicious if you start saying no.'

f) Context aware

Participants commented that human behaviour is dynamic and context changes continuously, therefore having preset preferences for information exchange was very problematic. Comments related to appropriateness and AmI systems being truly context aware. For example, programming a system to alert parents to a minor accident when one of the parents could actually be very ill or on holiday. Participants agreed changing and resetting preferences would be tedious, time consuming and complex.

'Because if it makes a decision for you and you think to yourself, I've changed my mind, I'm not in the mood for that and therefore you have mucked your system up on your computer thing and you have to go in and tell it I've changed my mind, I don't want to do this, I want to change that.'

'It's just I don't want technology to structure my life, I don't want it telling me know what to do, I don't want it telling other people what I will probably do next, what I will probably buy next. I don't want it predicting what my wishes and desires are, because I don't know what my wishes and desires are from one day to the next sometimes and..... and it's like you say we are spontaneous, I want to be spontaneous and intelligent and articulate and respected and react with people not machines.'

g) Personalised

Participants agreed having a personalised electronic health record was beneficial. These benefits were discussed in terms of allergy alerts and reminding people to take medication. Discussion focused on the confidential nature of health information and that the system and stakeholder required sensitivity regarding sending and receiving health data.

'I do think the hospital should have access to your information so say, If I do have a weak heart, that should be able to convey to the hospital that plus your entire medical record.'

Discussion revealed participants concerns over systems being truly sensitive to circumstances under which health information could legitimately be exchanged. Leakage of sensitive information in inappropriate circumstances was seen as very problematic. Concerns were also raised at the predictability of the system and stakeholder. Would the system only reveal what information was appropriate at that moment in time. For example, if a person was admitted to hospital with a broken foot should health professional have full access to the patients health record that reveals he or she had previously suffered from depression or a sexually transmitted disease?

'I mean there are various aspects of medical information which are protected and it would not be necessary for everybody or for even for emergency services to be aware or anybody in emergency services to be aware of say for example if someone was HIV Positive and okay on treatment it's not necessary for the x-ray department for example to know that, if he is going along for an x-ray of his ankle, but that sort of thing so the next question is yes is there any data protection

information that's going, that's floating round in that way so yes, I must say I would be a little bit anxious if information is flowing in a free and uncontrolled way, if it was a really good system, I think safeguards could possibly be built in.'

h) Easy to use

Participants discussed concern over the complexity of AmI systems. Comments related to the fact existing technologies are difficult to use. Participants commented setting preferences for who has access to information time consuming and complicated. Comments related to the dynamic, complex nature of human behaviour and that we are not always predictable. Participants questioned whether in reality we could actually set preferences for all types of information. Discussion also focused on age differences in technology use, experience and familiarity.

'I think that is good but new technology for older people is always difficult to comprehend.'

'I think that is brilliant. To the younger generation they have been brought up with that technology. What about the minority groups, disabled, etc?'

I) Accessibility

Participants commented widespread exclusion would occur if people had to adopt AmI systems. Exclusion would occur due to age, anxiety, ability, disability and socio-economic status.

'The thought of my Dad using that would cause more cognitive problems rather than solve them. It all depends on your technical ability to start off with.'

'Well I think at this age, the young folk would accept that. They'll accept anything.'

'I think it is only aimed at executive types, rather than ordinary people like us.'

Benefits

a) Better healthcare

The majority of participants discussed the concept of AmI systems for exchanging health information as advantageous, and in particular for people with existing medical conditions. Advantages for personal use related to convenience, allergy alerts and health professionals having immediate access to patient records when needed. Stakeholder benefits were discussed in terms of monitoring, immediate access and updating patient records and marketing.

Participants agreed the type of information shared normally depends on who, what, where and why, but crucially is informed by the type of relationship they have with the other person. If their relationship is close e.g. a hospital consultant then the majority of information is shared quite freely. Participants agreed that electronic exchange of health information was beneficial and would create a more efficient service.

'I'm just thinking about the benefits of it you know like, you know the way things work now, I mean the only benefit I would say now is electronic exchange of information that the doctor or hospital sees.'

'I would be quite happy about generalised medical services knowing my medical history but you've always got the risk with the lone trader haven't you or the lone individual basically going through health records.'

b) Convenience

All participants agreed the mobility of AmI systems was advantageous and that through diffusion, adoption would probably occur. Participants discussed AmI systems in terms of convenience related to their own use and the stakeholder.

'Yes, it was useful for him because he has epilepsy but if you don't have anything specific I don't know that it is that much use, that particular bit. For an elderly person who really wanted one, again you have somebody you trust, like a member of the family, to discuss what you want put in and if you don't want something put in, then you don't have it put in.'

Costs

a) Inflexibility

Participants commented the pressure to adopt AmI systems would increase and have a negative impact on behaviour. Participants were concerned about access to health information by third parties. These concerns were discussed in terms of screening people for jobs and insurance. Participants were concerned AmI systems would become tools for marketing by various stakeholders e.g. advertising diets to people who are overweight.

'I think people who join are going to be pressurised into it. You know when there are facilities there and it gets a little bit pushed and all their friends are doing it and all of their family is doing it. Look at the time here, I've got to do this, I've got to do that and package it all into one. Let's just get it all out the way in one go.'

'Are we being subtly manoeuvred into doing things that actually, given our own freedom without technology, we wouldn't do, so therefore are we being manipulated in some way into being people that we actually want to become without it?'

b) Profile abuse

Concerns were raised over the probability that stakeholders would collect personal information in an ad hoc manner without informing the person. The concept of profile abuse was a major concern for all participants. Participants believed profiling would lead to untold consequence. For example, a person might be refused insurance as his or her profile states he has high blood pressure.

'I mean I do think that having all the information in one place and an exchange of information and the doctor and the hospital and maybe even the ambulance service being able to forward the information is good but I don't know whether I like it to that degree.'

c) Surveillance

Participants commented when using AmI systems surveillance was a major issue. They discussed issues related to leakage of personal information in public settings and surveillance by others. Participants agreed surveillance would be beneficial for some people with certain medical conditions.

'They (systems and people) can be very invasive, even among friends. I go to one group where there is one person who has to be careful with her diet or something and one of the other people were saying quite, they weren't being catty or anything, I can't understand how she can eat so and so, she can't eat that and things like that you know and you think for goodness sake, it's her first day and she wanted some chocolates or something. And I think it would be far too

regimented. If you say you've got diabetes, you must never do this, this, this, well yes for your health right but sometimes.'

'It could work against you like at work for checking what you are doing and everything. Will your boss know what you are doing outside of work?'

'In fact I wouldn't mind being tracked if I had epilepsy, you know if I was in certain circumstances or had a heart condition. In that situation I wouldn't mind in fact but generally, no.'

Social implications

a) Over-reliance

Participants discussed relying too much on the system and/or themselves to exchange information and the responsibility associated with this as very problematic.

Concern arose over trust in the information exchanged. For example, how would the user be assured that his or her health information was actually secure and free from interference from others? Participants agreed stakeholders would have to be very responsible when dealing with any electronic system that contained health data. Stakeholders should only be made aware of the relevant health information, therefore access and exchange limited to pertinent others.

'I mean whose life is that busy they have to have a machine to do everything for them?'

'The other thing is if you actually hand over all responsibility to automated systems you know if they make a mistake in your calculation and you are not actually paying any attention, you are just trusting this, you know it is essentially dis-empowering you.'

b) Dehumanisation

Participants found the concept of AmI and the use of agent systems as dehumanising (in the scenario used in this study agent systems were portrayed with human-like features). Participants commented they would not trust such systems and found the concept very impersonal.

'They are pretending to be human. Why not be up front, this is the computer speaking, not this rather twee, dark haired person, who is able to blink.'

'With the hospital one; it makes you feel as though you are processed.'

'It's all this de-humanisation is how I see it. Do his parents really want to know that he has had an accident, by? Why can they not wait until he can tell them himself? And alright he can't do his running club, but it's not the end of the world, they will realise something has happened, the message will get there somehow. Do we have to have everything working like clockwork?'

c) Bystander apathy

Participants discussed how existing technology has changed the way we behave and were concerned that AmI systems would have a greater impact. Reference was made to AmI systems making people lazy, decreasing human cognitive ability and reducing the workforce.

'On the other hand, if you expected that everybody was like that and someone collapsed in the street, would it stop you going to help them, because you thought oh well the paramedics will be here in a minute, I'm not going to bother!'

'Are we going to exist without this type of technology. I mean are you going to be able to have a day to day life without this technology?'

Participants discussed the possibility that AmI systems would foster social isolation as less human-human interaction would take place, this was considered very problematic. For example, after being admitted to hospital talking to a health professional about your symptoms and being reassured were considered beneficial. This type of interaction would be lost as there would be no need for personal contact or conversation. Participants also commented in our social world we already leak information to others in the form of visual cues e.g. a plaster on your foot, without any serious implications. In the physical world strangers knowing certain information about you is not problematic, however people do not want to share the same information with friends or even family e.g. your medical history.

'Yeah, well it's all about, I think you've picked it up it's all about, talking about it before, it's all going too far, this with people's business. I mean I'm not a totally private person, don't get me wrong, I'm quite open a lot of things but some things you just want in your own head and you don't want in the head of a microchip of a machine or whatever you want to call it.'

'Yes you are losing contact with people if you are going to be somebody sat in a room by themselves with a machine like that, talking to people on this internet kind of thing, but there's no substitute for human contact. Its wonderful discourse with human beings face to face rather than through a machine I think.'

d) Reduced social interaction

Discussion highlighted how use of AmI systems would result in less human-human interaction and this was considered very problematic.

'We are so anti-social anyway, unless Andrew has his friends to the house and I must admit I mean I communicate with a lot of my friends now by text messages whereas before you would have called to them or you know send an email but I see less of people that I care about because it's more convenient to send them a text or an email and I hate it, I really do hate it and I think that's going to encourage more because then you're not even going to have to make the effort to send the text message, your machine is going to be sending them a text message because you're overdue writing to them, it's just.'

e) Enforced participation

Participants commented little or even no choice would exist in an AmI society. Comments suggested 'forced choice' would become the 'norm', making people use such systems for all forms of information exchange even if they did not want to. Participants expressed concern over the right not to reveal information having vast implications leading to exclusion in some circumstances.

Participants were concerned about reliance on AmI systems for exchanging health information reducing personal control. Discussions revealed AmI systems would create 'Big Brother' societies that lacked control and choice. Concern was raised over how information would be controlled by stakeholders, i.e. storage and transmission.

'You see all that information where is it going? And even if you say no I don't want you to pass my details on you never really know do you?'

'Yes, the technology side is perfect, it is who controls it.'

f) Health risks and environmental issues

Participants discussed concerns over health risks and environmental issues related to living in an AmI society. Participants referred to problems with radiation from the systems and the global impact of such use. Comments related to development and cost of AmI systems and the realisation that in parts of the world people were starving, therefore should we not focus resources on global problems.

'Also we are in a time when we are starting to think more and more about the materials we use and the amount of energy we are using and whether we shouldn't be thinking as humans how we should use our energy to think better, write lists rather than use the technology there.'

'We have a problem in the world; half the people in the world don't have enough to eat. We see them wandering across our television screens in our newscasts and so forth, but its random images of starving people. Suppose if every single one of those persons on earth became a number and you can't ignore it because so and so, this named person in Ethiopia is starving to death right now and needs help, now we've got all of these supermarkets with all of this blip, blip, blip and all the food in the world piled up and you've got all these people who really need it and it's just a matter of finding a way to actually sort out the payments and get it sort of flowing there, you know.'

4 Discussion

The framework used in this study to evaluate trust and privacy has revealed motivation, cost/benefit and social implications as major constructs that will influence AmI adoption and use. Furthermore trust, privacy, usability and social issues need to be understood. Also different contexts, stakeholders, device type and the actual user all need to be considered. This is important if we are to fully understand user interaction with AmI

systems.

We need to understand user motivation and how AmI systems can be made secure and at the same time transparent. Consideration must also be given to the costs, benefits and social implications incurred when using an AmI system. Within the framework used in this study has revealed the concepts of trust and privacy are interrelated and multidimensional. These constructs have underlying factors that dynamically change according to context. The findings support the view of Sillence et al. (2004) in that trust is multidimensional.

To establish trust and privacy we must also ask the following questions related to information exchange: Who is receiving it? Who has access? Is the receiver credible, and predictable? Where is the information being sent and received? Does the user have choice and control?

Interestingly, although participants were grouped by technical stance, age, gender and educational achievement the recurrence of themes across groups were similar. This suggests AmI systems raise similar issues for all relevant users. The majority of participants agreed AmI systems for monitoring health were advantageous, especially for people with medical conditions. Participants reported higher levels of trust in exchanging health information with healthcare professionals. Discussion focused on the benefits of such exchange e.g. healthcare professionals being alerted to any allergies, automatic access to health records. However, concerns were raised over unauthorised access and (mis)use. Participants discussed exploitation through insurance companies and employers having access to their health record. These findings support the view of California

Healthcare Foundation in that people are worried about third party access. These findings have major implications for AmI systems.

Findings support the view of Friedewald et al (2005, 2006) and question whether AmI systems will actually increase social pressure and the complexity of life. Participants discussed the negative impact AmI systems would have on our social world. Concerns were raised over how such systems would result in exclusion, increase social pressure, change and reduce social interaction with others. Participants also commented that entrusting and relying on agent systems to exchange information was dehumanising. Stakeholders and designers of AmI systems need to consider the fact humans are inherently social beings and their actions are always directly or indirectly linked to other people.

Discussion also highlighted the complex nature of human behaviour. Participants commented behaviour is not always predictable and humans have complex relationships with others. Setting preferences for who has access to their personal information at any one point in time as difficult and socially unacceptable. Participants agreed AmI systems would have to be fully transparent and accessible at all times so people could verify what information was stored about them. For AmI systems to truly work total honesty between stakeholders and users was seen as a major concept. Participants questioned whether people could actually be honest all of the time and discussed the use of 'white lies' was appropriate in certain circumstances so people did not get upset/

Ambient intelligence is now an area intensely researched and undergoing rapid development already visible in advanced mobile, PDA and notebook services. The vision

of a future filled with smart and interacting everyday objects offers a whole range of possibilities. If Weiser's (1991) vision is to be realised then we must acknowledge the advantages and disadvantages this transformation will have on society. For example, sensor and communication mechanisms in the environment will help people with disabilities lead a more independent life. We will be able to track everything from children, family, and friends to missing keys. However we must question whether the transformation that will take place is ethical or even socially acceptable. Do we want or need to rely on embedded devices seamlessly exchanging information on our behalf?

The next stage of this research is to develop a survey from the project findings. The survey will be a useful tool in measuring concepts related to trust, privacy and social issues when considering ambient devices and information exchange. The findings will give further insight into how ambient devices can be designed to deliver specific services and information and therefore acceptance.

5 References

Bohn, J., Coroama, V., Langheinrich, M., Mattern, F., Rohs, M. (2005). Social, Economic, and Ethical Implications of Ambient Intelligence and Ubiquitous Computing. *Ambient Intelligence*, Springer-Verlag, 5-29.

California Healthcare Foundation (2000). Ethics survey of consumer attitudes about health web sites. Downloaded August 2006

<http://www.chcf.org/press/viewpress.cfm?itemID=1015>)

- Friedewald, M., Costa, O., Punie, Y., Alahuhta, P., Heinonen, S. (2005). Perspective of ambient intelligence in the home environment. *Telematics Information*, 22 (3), 221-238
- Friedewald, M., Vildjiounaite, E., Punie, Y. & Wright, D. (2006). Privacy, identity and security in ambient intelligence: a scenario analysis. *Telematics and Information*, *In Press*
- Goldschmidt, P.G. (2005). HIT and MIS: implications of health information technology and medical information systems. *Communications of the ACM*, 40 (10), 69 -74
- Hartog, F., Schmidt, J.R. & Vries, A. (2006). On the potential of personal networks for hospitals. *International Journal of Medical Informatics*, 75, (9), 658-663
- Herzberg, F., Mausner, B., & Snyderman, B. B. (1959). *The Motivation to Work* (2nd ed.). New York: John Wiley & Sons.
- Jensen, J. (2004) The application of Herzberg's two-factor theory to the realm of tourist attractions. in Smith, K.A. and Schott, C. (Eds.) *Proceedings of the New Zealand Tourism and Hospitality Research Conference 2004*. Wellington, 8-10 December. pp. 180-190
- Jessup L., & Robey D. (2002) The Relevance of Social Issues in Ubiquitous Computing Environments. *Communications of the ACM* 45(12). 88-91.
- Little, L., Briggs, P., & Coventry, L. (2004). Videotaped Activity Scenarios and the Elicitation of Social Rules for Public Interactions. BHCIG Conference, Leeds, September 2004
- Maguire, M.C. (1998). A Review of User-Interface Guidelines for Public information kiosk Systems. *International journal of Human-Computer Studies*, 50. 263-286

- Malhotra, Y & Galletta, D. F. (2004). Building systems that users want. *Communications of the ACM*, 47, (12), 89 – 94
- Rindfleisch, T.C. (1997). Privacy, information technology, and health care. *Communications of the ACM*, 40 (8), 93-100
- Rohm, A.J. & Milne, G.R. (2004). Just what the doctor ordered: The role of information sensitivity and trust in reducing medical information privacy concern. *Journal of Business Research* 57 (9), 1000-1011
- Sillence, E., Briggs, P., Fishwick, L. & Harris, P. (2004). Trust and Mistrust of Online Health Sites. Proceedings of CHI'2004, April 24-29 2004, Vienna Austria, p663-670. ACM press
- Stanford, V. (2002). Pervasive health care applications face tough security challenges. *Pervasive Computing*, 8-12
- Streitz, N., & Nixon, P. (2005). The disappearing computer. *Communication of the ACM*, 48, 3, 32-35
- Weiser, M. (1991). The Computer for the 21st Century. *Scientific American* 265(3):66-75. September.
- Zhang, L, Helander, M.G., & Drury, C.G. (1996). Identifying factors of comfort and discomfort in sitting. *Human Factors*, 38, 377-389