# Pervasive Computing and Disability: designing for independence?

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## ABSTRACT
In order to introduce disabled users to the ideas underpinning pervasive technologies, three filmed scenarios were created to illustrate near-future interactions in health, commerce and e-voting domains. These filmed scenarios were used in a focus group session with fourteen participants who had either a visual or auditory impairment. Participants were asked to comment on the scenarios and reflect on the costs and benefits of such technologies. The resultant data was coded in terms of general and disability-specific concerns. Particular issues were raised about the need for disabled individuals to delegate certain tasks to trusted others.

## Author Keywords
Disability, pervasive technology, ubiquitous computing, privacy, identity, trust.

## ACM Classification Keywords
K4.1 Public policy issues; K4.2 Social issues

## INTRODUCTION
The vision of pervasive technologies is often one of effortless communication in order to satisfy our needs, wants and desires. Yet increasingly we realize that the seamless exchange of information might increase life's complexities and challenges, especially for those people with disabilities. Ubiquitous systems hold the danger of increasing the digital divide [3].

According to the World Health Organisation there are over 750 million people worldwide with some form of disability. We need to acknowledge that the likelihood of having a disability increases with age and the world aging population is growing [12]. While pervasive technologies offer some opportunities to alleviate the problems associated with disability [9] disabled people often have to rely on intermediate technologies (screen readers, voice synthesizers) or simply on other people before they can begin to benefit from technological innovation. This is a particular problem with ubiquitous systems, as the vision of an embedded, seamless interaction does not sit well with an additional layer of assistive technology.

Most current research into disability and technology focuses on Internet accessibility, where accessible options are fairly well rehearsed [11]. Many designers ignore the context in which disabled people operate, tending instead to focus upon the chronic or health aspects of disability [1]. Increasingly, however, researchers recognize that the social and environmental context for interaction is vitally important [10]. Stephen Beesley a Senior Web Developer for the Disability Right Commission who stated 'People tend to concentrate on the technical guidelines for accessibility, but real life is much messier than that. You have to take the human element into account.' [5].

As innovative technologies such as the touch-screen mobile or the MP3 player become commonplace, the everyday exclusions for people with disabilities mount up such that physical disabilities gradually become social disabilities. Thus a focus on accessibility alone is not sufficient when trying to understand the opportunities and barriers pervasive technologies create for the disabled.

We commonly carry devices (mobile phones, personal digital assistants) that exchange personal information with other devices – often without our explicit knowledge, and so we need to ask questions about control and advocacy for disabled users. Of course every user has concerns over personal data storage, exchange, mining and unauthorized access by third parties [8] but it is the disabled user who might be presented with particular challenges in terms of, for example, identifying proxy users to negotiate information exchange on their behalf. Are there specific issues that we need to recognise in terms of how persons with disabilities manage and control information exchange, trust stakeholders with personal data and set and maintain privacy preferences related to who has access to their personal information? This was the focus of the current study.

## METHOD
This investigation was part of a wider investigation in which we asked various user groups about their attitudes to pervasive technology. The first requirement for the project was to find a means to communicate the concept of pervasive computing to the



PETRA'09, June 09-13, 2009, Corfu, Greece.

ordinary citizen. There are many potential visions of the future and so we engaged with a number of key stakeholders (industrial R&D teams, government scientists, ubicomp researchers) in order to generate specific scenarios capable of communicating something about near future information exchanges in different ubicomp contexts. Research staff met with the stakeholders and discussed content and structure of scenarios that would contain information relevant to everyday activities people undertake. Three novel scenarios were developed, related to health, e-voting, and shopping and these included descriptions of devices, contexts of use, type of service and category of information transmitted.

## Development of Videotaped Scenarios

The elicited scenarios were then used to create four 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 [6]. 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. 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 with participants who had various visual or auditory impairments. All scenarios were approximately three minutes in length. Illustrations of the health and shopping scenarios are 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 to deadlines, meetings, lunch appointments and important dates. As Bob is epileptic, his health agent monitors his wellbeing and can alert people if he needs help. Finally, an emergency management agent takes control in situations in difficult situations when information needs become complex; this agent has the most freedom, with permission to access 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 looses 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) about his circumstance. The emergency management agent transfers the planning application files to John's PDA so the company does not miss the deadline. The agent also informs Bob's 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.*

***Shopping scenario:*** *Anita arrives at the local supermarket grabs a trolley and slips her PDA into the holding device. A message appears on screen and asks her to place her finger in the biometric verification device attached to the supermarket trolley. Anita places her finger in the scanner and a personalised message appears welcoming her to the shop. She has used the system before and knows her personalised shopping list will appear next on the PDA screen. Anita's home is networked and radio frequency identification tags are installed everywhere. Her fridge, waste bin and cupboards can monitor the movement of goods in and out in order to create a shopping list of items needed that is then communicated seamlessly to the PDA. The supermarket network alerts Anita of special offers and works alongside her calendar agent to remind her of any important dates. As she wanders around the supermarket the screen shows items she needs in any particular aisle and also helps her find their exact location. The device automatically records the price and ingredients of every item she puts into trolley and deletes the information if any item is removed. When Anita is finished she presses a button on the PDA and the total cost of her shopping is calculated. Anita pays for the goods by placing her finger on the biometric device and her account is automatically debited, no need to unpack the trolley or wait in a queue. The trolley is then cleared to leave the supermarket. Anita leaves the supermarket, walks to her car and places her shopping in the boot.*

## Participants

Fourteen participants were recruited by staff at the Disability Forum in Newcastle upon Tyne, UK. The forum was considered to have easier access and dedicated facilities for people with such disabilities. Participants had either a visual or auditory impairment. There were 3 men and 11 women ranging in age from 18 to 70+ years. British Sign Language interpreters accompanied participants with hearing impairments thus enabling them to take part in the group discussion.

## Procedure

On recruitment participants received an information sheet that explained the study and the concept of ubiquitous technologies. Participants were invited to attend the Disability Forum in Newcastle upon Tyne to take part in a group session. Participants were told they would be asked to watch short videotaped scenarios showing people using ubiquitous systems and contribute to informal discussions. They were informed the discussion would be recorded for further analysis. An informal interview guide was used to help the moderator if the discussion deviated from the proposed topic.

At the beginning of the group session the moderator gave an explanation and description of pervasive technologies. After the initial introduction the first videotaped scenario was shown. Immediately after this the participants were asked for their comments. The same procedure was used for the other two videotaped scenarios. The scenarios were viewed in this order: e-voting, shopping and health. 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 ubicomp society. Participants' attitudes in general towards ubiquitous

systems were noted. The duration of the session was approximately ninety minutes.

## RESULTS AND ANALYSIS

The group discussion from the forum was transcribed then read; a sentence-by-sentence analysis was employed using the Atlas.ti™ qualitative software programme. Two members of the research team coded and compared the data for consistency and good inter-rater reliability was found.

### General issues

The first point to make is that these disabled participants raised a number of general issues that were consistent with those discussed in the non-disabled groups and reported elsewhere. For example, the following table, adapted from earlier work [7], illustrates some of the major privacy concerns shared by disabled and non-disabled citizens. The first column describes those 'essential' factors that must be right before individuals would feel secure in using a pervasive system; the second column describes some of the perceived costs and benefits in using the system and the third column details some of the longer term or more global concerns.

| **Essential factors** | **Benefits** | **Longer-term Implications** |
|---|---|---|
| | Better healthcare | |
| Credible | Convenience | Over-reliance |
| Secure | ↑ | Dehumanisation |
| Reliable | | Bystander apathy |
| Accurate | ↓ | Reduced social interaction |
| Transparent | | Enforced participation |
| Context aware | Inflexibility | Health risks |
| | Profile Abuse | |
| Personalised | Surveillance | Environmental issues |
| Easy to use | | |
| Accessible | **Costs** | |

Table 1: Privacy constructs associated with use of a ubiquitous system.

Generally, our participants were more comfortable when considering the role of pervasive systems in the working environment where they were likely to have a more restricted social impact. Outside of work there was a general concern that pervasive systems might somehow lead to more isolation:

*'It would stop you from communicating, even in the basic form, just writing or signing and various other things. We barely speak to each other now.'*

*'That would be really cold and really artificial wouldn't it?'*

### Exclusion, autonomy and choice

The specific issue of exclusion was important to our disabled group. Participants believed people would be excluded by factors relating to age, ability, disability and cost. Participants discussed exclusion in terms of their own disability and noted particular problems for people with physical disabilities.

*'They (ubicomp system) are going to have extra and extra and extra things on it, you say inform parents to feed the dog, but people have physical disabilities you know, so maybe it is suitable for a carer, but not for the person with the disabilities.'*

Our disabled participants were keen to emphasise the importance of independence. They recognised that they often had to ask others for help in social settings such as the supermarket. They liked the fact that ubiquitous technologies had the potential to offer them a choice of systems which could lead to greater independence.

*'For me or for a deaf person who can't talk to approach somebody can be quite daunting as well, you know so having this way of actually asking someone where something is seems a lot easier you know for a lot of people as well, but for me as an independent person you love to be able to find it yourself.'*

*'I remember when my local supermarket kept moving things into different aisles and closing aisles down and stuff like that and that was very confusing, especially for me and familiar things were moved all over the place and then I had human intervention and I asked where are the baked beans and as they answered they turned away from me and that is no good if you are a lip reader so I ended up in washing detergents or something, you know it was that basic human error, because to understand that I lip read or need extra support. So cutting out that base level of human error is fine and I also love the idea that electronically I am going to be told to buy milk.*

'*If voting, you had that choice, do it via either email or you prefer to walk to the polling station, but you should have a choice instead of sorry you can't walk we are going to close the polling stations, so that the choice is open so people do have those, so someone in a wheel chair may not want to go to a polling station, because it is too far'.*

### Usability

Participants were keen to discuss some of the usability problems associated with pervasive computing. They described difficulties in their interactions with existing technologies and wondered how much more difficult ubiquitous systems might be.

*''The only problem I have with this type of technology is how we are going to interact with it; I have such a hard time interacting with the new technology at the moment.'*

*'These systems would be difficult for deaf people to use. I am saying it may be better if they had some sort of video phone on it as well for deaf people, so they can manage text communication.'*

*'Some people use mobile phones for somebody to ring them. They cannot make a phone call back to them.'*

### Delegation and trust

Trust was an important construct for this group. On the one hand, they well understood the need for seamless communication with health professionals or services, recognising the value in systems that were able to automatically notify health authorities in the event of an accident and recognising the advantages in systems that could trigger effective communications without their explicit need to intervene. On the other hand, disabled participants were concerned about their need to delegate authority to trusted others

and were unsure about the way in which such delegated authority might work – noting problems particularly with identity management and personal advocates or proxies. They recognised a number of particular difficulties involved in setting boundaries around information exchange for a disabled population.

*'I would be quite happy about generalised medical services knowing my medical history but you always have the risk with others basically going through or having access to your health records.'*

*'If you go shopping with and have to use a biometric finger scanner for identification and you are called up in an emergency and you want somebody else to do the shopping for you, what are you going to do chop your finger off and say get on with the shopping, I have to go off you know!'*

*'Most service providers have a problem exchanging information with each other anyway, under the Data Protection Act. My GP for instance wouldn't request a hospital appointment for me because I am hard of hearing. And then all my consultants at the hospital wouldn't pass my information onto my GP then saying when she has an appointment she needs a lip speaker. You know it doesn't happen under normal circumstances, so I cannot see it happening any more whenever we get the new technology, because there is just certain information that will never be passed.'*

## DISCUSSION

The findings from the visually and auditory impaired group raise some interesting issues that go beyond mere accessibility. Clearly, social issues in respect of advocacy, trust and privacy are important for this group, recognising that they often have to ask family, friends or even strangers for help to be able to complete basic day-to-day activities.

Hong, et al., [4] suggest designers of ubicomp systems need to deploy a privacy risk analysis considering social and organisational content. This type of analysis considers: Who are the users? What kind of personal information is being shared? How is personal information collected? Hong, et al., suggest after the initial privacy risk analysis designers need to prioritise the findings and develop a privacy risk management record. The privacy risk management considers: What are the default settings? How does unwanted disclosure take place? [4]. Although our findings generally support this work, we need to further understand how disabled people will manage information exchange and be able to use systems effectively and more importantly independently.

The majority of our participants agreed that ubiquitous systems for monitoring health were advantageous, especially for people with medical conditions. Participants reported high levels of trust with the stakeholders involved in the healthcare scenario and were keen to discuss the benefits of pervasive technologies in this context e.g. healthcare professionals being alerted to any allergies and automatic access to health records. However, concerns were raised over unauthorised access and misuse of key information (e.g. insurance companies having uncontrolled access to confidential health information; employers accessing health records). Misuse of personal information was a concern with all participants in this project and not just those with a disability. These findings support the view of the California Healthcare Foundation [2] in that people are worried about third party access.

Our scenarios portray visions that might never be fully realised, but they have proved effective in promoting a discussion of the kinds of human and social values that are key requisites for design. For people with a visual or auditory impairment, or in fact any form of disability, we need to design for independence but we need to design not just for the individual, but for a community of individuals who provide implicit and often unacknowledged support.

## ACKNOWLEDGEMENTS

This work was supported by the Economic and Social Research Council's E-Society Programme.

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