A Stakeholder Centered Exploration of the Current Barriers to the Uptake of Home Care Technology in the UK

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ABSTRACT

An increase in the ageing UK population is leading to new ways of looking at how we deliver health and social care services in the UK. The use of assisted living technology (ALT) and telecare is already playing a part in these new models of care. Yet despite the current advances in the range of technology and networking capabilities in the home, ALT and telecare solutions have not been taken up as eagerly as might have been anticipated. The study reported here used scenario-based focus groups with a wide variety of stakeholders in home care to identify the existing barriers to the successful uptake of ALTs and telecare in Scotland. Six focus group sessions were conducted with individual stakeholder groups (social care workers, policy makers, telecare installation technicians, older users, informal carers) and five conducted with mixed stakeholder groups. The focus groups used the same home care scenario to identify and categorise the different perceptions, attitudes, and expectations of the various stakeholders when discussing telecare implementation for a fictitious elderly couple. The emerging themes from the focus groups were analysed and categorized according to the Framework Analysis approach. We present a synthesized list of the current barriers to the uptake of ALTs and telecare - and discuss how each of these barriers might be overcome. If these barriers are addressed, we believe telehealthcare technologies will be better designed, more usable, easier to prescribe effectively, more acceptable to more users in more contexts, and ultimately more common place in homes throughout the UK.

Categories and Subject Descriptors

H5.2. Information interfaces and presentation: User centered design.

General Terms

Design, Human Factors.

Keywords

Home care systems, telecare, care at home, stakeholder requirements, participatory design, focus groups, framework analysis, technology acceptance, ethical considerations.

1. INTRODUCTION

It is now well acknowledged that the UK has an ageing population and demographics have shifted such that families are not living as close to one another as in the past reducing the availability of informal carers (Grundy, 1999). It is costly and impractical to continue to provide sufficient specialized hospital and care home facilities to our ageing population in the UK (Miskelly, 2005) and therefore it is also increasingly accepted that it is both socially and economically beneficial to improve support for people managing their care within their own homes. Within the UK, there are now many policy documents (for example, DH, 2000; DH, 2005; DH, 2006; SE, 2005; SG, 2007; SG, 2008) which identify the future importance of information and communication technologies (ICTs) in offering support to those who have health conditions, or physical, sensory or cognitive difficulties and wish to continue living in their own home. Assisted living technologies (ALTs) are one of the main potential opportunities to be realized for addressing this problem. Telehealthcare has the potential to enable people to remain in a familiar environment, close to family and friends, and potentially increase wellbeing and reduce anxiety (Miskelly, 2005) while enabling people to manage their own care at home for longer. It is no surprise then that much attention is now on how to design, implement and evaluate health and social care technologies in the home in order to realize this opportunity.

In 2006 the Scottish Telecare Development Programme (TDP) fund was established by the Scottish Government, through its Joint Improvement Team (JIT), providing £8 million to promote the implementation of telecare within Scotland (from 2008 - 2010, a further £8 million was made available). This money was distributed across 32 health and social care partnerships across Scotland. Specifically, its objective is to enable the development of telecare services beyond the first generation alarm systems within each local partnership across Scotland. With this initial investment it was anticipated this could result in an additional 19,000 people living at home for longer (Mackenzie, 2007).

While some advances have been achieved (e.g. the mainstreaming of telecare within West Lothian), other local partnerships have had less success in normalising telecare into routine practice. In England, the Whole System Demonstrator programme is currently carrying out a 6,000 patient randomised control study of outcomes for the clinical cost/benefit case for ALTs in Cornwall, Kent and Newham. The results are due to be published in late 2010. Despite these advances, the renewed funding, and the increasing financial and societal motivators, the adoption by clinicians, health and social care professionals, informal carers and end users is far from extensive or sustained in Scotland

or the UK. Additional research is still needed on the social, environmental, and behavioural aspects of these technologies and their use if they are to be implemented and used on a large scale.

The aim of this work was to qualitatively explore (with the full range of stakeholders) some of the underlying sociotechnical issues regarding the uptake of home care technology in Scotland. The outcome is a synthesised list of barriers that should be considered by the telehealthcare communities, and some suggestions on how to overcome these barriers by improving the design, implementation, and evaluation processes in telecare and home care technology development in the UK.

1.1 Defining Home Care Technologies

In our work we intentionally use the terms 'home care technology' and 'home care system' rather than the term 'telecare'. The term telecare, although commonly accepted in the social care profession, was problematic in this work for several reasons. When discussing telecare initially with older people and their relatives, it was often a term that they had never heard of and we had to define for them. People who had heard of telecare considered it to be synonymous with pull cord and pendant alarms linked to a call centre, and nothing else. Our research project (MATCH) on the other hand was trying to design advanced technologies for care at home which could include (but not limited to) services and applications implemented on more mainstream devices (such as mobile phones and TVs), using novel interaction techniques (such as speech and gesture) to improve self care and health and well being management in the home. A more widely accepted term to that includes telecare is Assisted Living Technologies (ALTs) and this term is used synonymously with 'home care technology' in this paper. It should be noted however, that at the time this study was conducted, the term ALT was often misconstrued within the scientific academic communities to be specific to telecare point solutions and not to advanced mainstream hardware and communication technologies that can be exploited to enable or support care at home.

We define ***telecare*** therefore to be the use of telecommunication systems where the users are separated in space and/or time. This can be used to exchange information between home users and their family or professionals and be used for diagnostic, advice, support, education or management purposes. It has been argued that telecare is technology that specifically supports social care, while telemedicine and telehealth support medical and health related issues. We consider the terms telehealth and telemedicine to refer to the delivery of health-related services and information via telecommunications technologies. It is now more commonly accepted that telecare and telehealth are converging and that the term '***telehealthcare***' should be used to include both health and social care technologies. With many ambiguities over the definitions at the time of starting this work, we used

the term '***home care technology'*** to be an umbrella term to encompass telecare and telehealth technologies within the home. This includes all technologies (specialized or mainstream) in the home used for the purposes of enabling or supporting health and/or social care provision or management. This term can however be used synonymously with ALTs.

We define a '***home care system'*** as a linked set of services of social care or health care, or both, that provide or support the provision of care in the home (McGee-Lennon, 2008). Our focus is on technologically supported home care systems. Such home care technology typically includes sensors, devices, displays, data and networks. Computing infrastructures can include simple stand-alone electro-mechanical alarms installed in a person's home, perhaps to indicate a bath overflowing or a door left ajar (as in first generation telecare). At the other extreme they can include systems integrated into the home's physical infrastructure that monitor patient state, perform sophisticated analyses, deliver customised information to patients and clinicians, and support communication among them (McGee-Lennon & Gray, 2007). The people that use these devices, and/or the data that they generate are wide and varied. This will be discussed briefly in the following section.

1.2 Stakeholders in Home Care Technology

Growing networking capabilities have increased the potential for users to send and receive important care information from their own home to friends and family or to health and social care professionals involved in their care (McGee-Lennon, 2008). When considering the design of new home care technologies we need to consider the wide variety of people that might be users of the technology. These users may be directly or indirectly interested in the data that technology collects or produces regarding a person's health or wellbeing. We refer to these people as the *stakeholders* in home care technology.

Home care involves a number of direct users and other stakeholders all of whom are interested in and potentially able to influence how such a system should perform and behave (SG, 2008). In addition to the person being cared for in the home, there are likely to be: partners living in the same space; friends and family living elsewhere who are involved in care or interested in its status; visiting medical personnel such as community nurses; and remotely located care staff, such as a consultant in a clinic or a social care worker. Six main stakeholder groups were previously identified by the MATCH project (McGee-Lennon & Gray, 2007; McGee-Lennon, 2008). Following consultation with these groups an additional key stakeholder group (TECH) was identified for inclusion in this study (See Table 1). While potential stakeholder groups may also exist, we believe that we these are the key stakeholder groups important for us to understand the current barriers to

uptake of assistive technology in the UK. The MATCH project has access to all of these stakeholders via and health and social care partners and a cohort of around 50 older users who volunteered to contribute to the research project. For this study, we included representatives from each of these groups.

Insert Table 1.

This work used both single stakeholder groups (people from the same category) and mixed stakeholder groups (a mixture of stakeholders in the same group) in order to extract issues and themes both within and between the different groups. Each person involved in the system and its development is likely to have very different needs, perspectives, and accountabilities, all possibly changing over time as the condition of the person and the possible behaviours of a system change (McGee-Lennon & Gray, 2007; Toivanen *et al*, 2004). Understanding the different attitudes and expectations of each of these stakeholder groups is important and helped shed some light on the underlying issues leading to the existing barriers to the uptake of home care technologies.

2. DESIGN AND METHODOLOGY

Within the MATCH project, we undertook a variety of stakeholder engagement activities with the aim of creating awareness, gathering requirements, and resolving conflicts around the needs and requirements of the home care systems we intended to design. Rather than generate clear requirements and guidelines for our technology developers, we were encountering many issues surrounding the general attitudes towards and expectations of telecare and telemedicine in Scotland. We believe that further understanding these barriers is necessary to move forward with telehealthcare development and implementation in the UK.

2.1 Participants

Eleven focus groups were conducted in total. Six focus group sessions were conducted with ‘individual stakeholder’ groups (see table 2 for details). In addition, 5 ‘mixed stakeholder’ focus groups were conducted involving a combination of people from social and health care professions, home users, technologists, carers and policy makers. See Table 2 for a breakdown and description of the 11 different focus groups. Each focus group contained between 2 and 7 people.

Insert Table 2

By comparing themes and issues emerging from both single and mixed stakeholder groups, we aimed to examine the quantity, quality, and nature of information obtained. It is hypothesized that in a domain with many social and professional complexities, single stakeholder focus groups would

elicit issues that mixed stakeholder groups will not and vice versa. Mixed stakeholder groups might be good for creating empathy and consideration for the other stakeholders involved. For example, a social care professional might want a device X to do Y but the technologist can explain why this is not feasible. On the other hand, individual stakeholder groups might be useful because in mixed groups certain people might lose confidence to convey their true opinion. For example, older users often perceive that the care professionals know more about appropriate care regimes.

2.2 Stimulus and Procedure

The same text-based scenario (a married couple living in their own home, Fred has hearing loss and some memory problems and Shirley has worsening arthritis) was used to drive each focus group. We had two main aims during these focus groups:

(1) To identify better-informed user requirements that could be directly fed into the development of home care technologies within the MATCH project.

(2) To collaborate with different stakeholder groups to identify and potentially resolve conflicting perspectives and issues surrounding the use and uptake of telehealthcare in Scotland.

Each focus group meeting lasted on average one hour. Participants were presented with a text-based scenario describing an older couple living at home with care needs. In a facilitated group discussion, participants were first asked to identify the limitations of the couple that might eventually lead to a care home admission. Participants were then asked to think about how technology could play a role, allowing them to remain at home for longer. The groups were not explicitly asked to identify barriers but to openly think of potential problems and solutions for the couple in the scenario. The same (trained) facilitator attended all the focus groups to balance any effects she might have across the groups. A second (trained) facilitator took extensive observation notes during each of the sessions.

The focus groups were recorded on a digital audio recorder and transcribed for analyses. Each focus group participant was allocated an identifier code to ensure anonymity. This code was based on their stakeholder group (see Table 2): social care (SC); policy (POL); Telecare Installation Technicians (TECH); older users (OU); informal carers (IC) and mixed stakeholder groups (MIXED). Each quote was also labeled with the chronological order of focus group within that stakeholder category and participant number within that group. Hence, SC1P3 refers to social care, group 1, participant 3 while TECH1P1, refers to the telecare installation Technicians, group 1, participant 1. In mixed groups the stakeholder category is also included within the code, e.g. SCMIXED3P5. Anonymised transcripts and observer notes were used for data analysis.

2.3 Data Analysis

There are a number of different approaches to the analysis of qualitative data. We used a Framework Analysis approach as described by Ritchie and Spencer (1994). A benefit of using Framework Analysis is that it provides systematic and visible stages in the analysis process. Although the general approach is inductive, this form of analysis allows for the inclusion of 'a priori' as well as emergent concepts and themes which is very useful in this type of research. This is important because there are 'a priori' issues that are rooted in the text-based scenario that should be explicitly addressed, as well as themes and issues that emerge due to the nature of the stakeholder group being exposed to the scenario. Framework Analysis involves the following five key stages:

1. familiarisation (with the data)
2. identifying a thematic framework
3. indexing the data
4. charting themes
5. mapping and interpretation

It is important to note that analysis does not take place in a linear form and that the five key stages overlapped one another. The process of data analysis began at the point of data collection. We read each transcript several times to familiarize ourselves with the data. Secondly, a thematic (coding) framework was identified based on both a priori themes (i.e. from the scenario) and emergent themes from the familiarization stage. Emerging themes were identified on post it notes independently by the two researchers and these were agreed by discussion. These were then organized into families of overarching themes. This was then applied to the data to categorise and structure the data according to the agreed themes. The final stage of analysis was data mapping and interpretation in relation to the predefined categories and emerging themes. This allowed us to examine what the main themes were, and which group or groups these themes were connected most and least with.

2.4 Limitation of the study

Our study used participants who had volunteered their time to participate. Therefore, it could be argued that our participants may have a more active interest in technology. This may be a confounding variable to some extent, especially within the older user group. A further group omitted from the study was technology users with dementia or with learning disabilities. Overall, more people would be needed in all of the groups to further validate and understand these results – particularly in representing the wide range of views of the direct end users (older users).

3. RESULTS: EMERGING THEMES

Five main overarching themes emerged from the focus group study that categorize the attitudes and perceptions of the various stakeholders consulted in the uptake of home care technologies (See Table 3). This means that all the issues and themes that were identified in the data can be categorized into one of these 5 main themes. Each of these main themes will now be discussed in turn using stakeholder comments as the evidence base to support and illustrate each.

Insert Table 3

3.1 Acceptance Issues

There was a strong perception across the focus groups (not including the older person group) that many older people have 'technophobia' towards advanced home care technologies. This perception may be linked in part to the current under prescription and/or mis prescription of more advanced homecare technologies in some local authorities where no telecare champion exists to educate staff about the pros, cons and how to appropriately match telehealthcare that is on offer to service users:

> **SC2P3:** *"Most folk round that age group (70) are technophobes and sometimes to go in and start putting in pieces of assistive technology can be a wee bit fearful for them".*

However, more basic pieces of technology were considered acceptable:

> **SC2P3:** *"I think the basic things that we would put in just now, like the community alarm and different pieces are ok but when we start talking about, you know, something a wee bit more major this is where we start having a problem"*

Many of the discussions surrounding more advanced telecare showed evidence of misconceptions and their resulting negative connotations. These often centered on monitoring, video surveillance, unusable devices, and possible invasions of privacy (discussed later in section 3.2). The older groups however did not cite as many acceptance concerns as the social care groups predicted on their behalf. However, there was consensus within the older user group that non video surveillance was more acceptable within the home:

> **OUP3:** *"It depends if it was sensors or cameras. I think people would be more wary if it was cameras because they would think…oh Big Brother's watching, I can't go to the toilet without cameras watching me."*

The belief that older people are technophobic may be partly a result of lack of information about the possibilities and potentials of current generations of telecare and the future enabling potential of assistive technologies:

> **SC2P5: "***… there needs to be more awareness raising or education, if you like, of professionals, you know, because I think there is a, kind of, mismatch of knowledge out there,…, people maybe have their own particular view, you know, about the rational about using technology, so I think there is scope there to develop some sort of training for us".*

Perceptions that there may be a lack of ability in the older population to learn how to use these technologies may be preventing more advanced assistive technologies being offered to this group:

> **POL1P2** *"…training a guy in his 70's to use this [referring to home care technology] might be difficult."*

The perception that technology is feared by older people is not necessarily supported either in the literature or in practice where it has been found that, if appropriately prescribed, assistive technology is welcomed by older users (Tinker & Lansley, 2005). This was supported by our older user focus group where barriers were less centered on fear of technology use:

> **OUP1:** *"You are going to get people who will resist but I think the vast majority of people could be shown and once they see how helpful it could be they would embrace that."*
>
> **OUP2: "***I think a lot would depend on the explanation that was given."*

It is important to identify the existing foundations to the belief by many professionals of 'technophobia' among older people. It may be that assistive technology is being underused simply because it is being under-prescribed as it is incorrectly perceived as unacceptable or unusable by older people. The older user's focus group believed that technophobia may have been a problem in previous older generations but that this was something that was less relevant now:

> **OUP1:** *"Older people are becoming more technology conscious…I use technology, I use a lot of technology and my friends are all the same. We're in our 70's and shortly are going to be among the very old population and people younger than us will be much more open to technology."*

Acceptance of services and technologies was more positively affected by changing conditions in health or wellbeing. A decline in health status was seen as a risk factor and therefore a direct motivator for telecare prescription and acceptance:

SC1P2: *"I've just recently persuaded her to have a mobile phone….she thinks that she got the flu off the phone in Marks and Spencer's the last time she was there. She's got a bad chest and she's quite protective of herself".*

This simple example illustrates that technologies are often perceived as acceptable only when they offer a noticeable benefit to the user. Often, assistive technologies are being prescribed without the benefits being explained or justified in conjunction with the user and their family. This generally may account for under-use and/or misuse of these technologies.

The focus groups suggest that the frame of reference in which the technology is presented may also have an influence on acceptance. Often telecare is seen as something that people get when they cannot manage or cope on their own, or that is directly associated with a disability:

SC2P5: *"…It is about the language we use in terms of technology…when there was a recent publicity about granny tagging and stuff, you know, about technology that was there to help people but because they use it to tag criminals, if you like, it was kind of seen as a very negative, you know if we were going to tag old people"*

In addition, the policy group feared that advanced home care technology may mean:

POL1P2: "*…turning their [older people's] wee family bungalow into something resembling 'Fort Knox'."*

De-stigmatising home based care technologies may be one way of increasing the general acceptance of home care technologies. This is an issue that the older users' focus group emphasised as a barrier to the uptake of certain home care technologies. Social care practitioners also confirmed this:

SC2P4: *"I think incorporating technology into mainstreaming things also, kind of, de-stigmatises it….you're not singled out as being a bit different."*

Some stigmatism and poor acceptability however may simply be a matter of poor aesthetic design of home care technologies in general or the fact that many of the solutions are 'one size fits all' and do not allow for personalisation of the devices (barriers 4.1 and 4.2) to fit with users individual needs, preferences and lifestyles more successfully.

The public and professional perceptions surrounding developments in technology to support care at home needs to be carefully considered. More work needs to be done on identifying misconceptions and fears and identifying strategies to ameliorate these (see 3.5).

3.2 Ethical and Legal Issues

A range of ethical and legal issues were identified. Several comments were made regarding misconceptions about what the current technology does and what future technology could do. Many attitudes and perceptions centered on the potential privacy issues that arise with the improved range and resolution of data (such as video streaming and still images) and the improved technology that enables a person's location and activity to be tracked:

> **TECH1P1:** "*It can get a bit like Big Brother with satellite positioning and video cameras…"*

Most of the issues regarding privacy were centered on the potential for home care technology to monitor 'everything the person does'. Monitoring was almost always referred to by these groups as a potential breach of privacy:

> **POL1P2:** "*if the system is watching what you are doing and monitoring your health…it has many uses….but there would be a strong societal opposition to it."*

> **TECH1P1***:* "*They [the service users] are frightened because [they think] hidden cameras behind them…they think they are being watched".*

Strategies for reducing these concerns were suggested by many of the people in the different focus groups (both single and mixed). They usually concerned awareness raising and providing clients with accurate knowledge so they understood what the system was doing with their data and why:

> **TECH1P2:** "*…so they know what is being monitored…who is seeing the information…and well, why they are monitoring it, I suppose".*

The mixed focus groups offered an opportunity for such knowledge sharing. The social care professional within one group was able to clarify the privacy position for one home care technology example:

> **SCMIXED3P5:** *"[The] community alarm means that privacy is still maintained. [The user] only presses it when they need help".*

Some of the concerns were not rooted in assistive technologies themselves but rather the storing of their health data electronically:

> **POL1P1:** "*people are prickly about keeping personal data and how it is stored etc."*

> **POL1P2:** "*the opposition would be in the security and safety of their health information."*

The issues of storing people's health information safely and securely is ongoing and not restricted to the study of home care technologies. Again, this is something that increased knowledge and

awareness might help to reduce the perceived risk of storing and sharing of health information within and beyond the home.

There were concerns across all focus groups about the robustness of home care technology systems and who had the legal responsibility for ensuring the equipment was working correctly and safely:

> **SC1P2:** "*…there is a lot of fear still…..like for example the fear of what happens if the equipment breaks or fails?"*
>
> **SC2P1:** *"…the sort of blame culture that there is now, you know, if something goes wrong it's someone's fault when it's not necessarily the case but there is always looking for someone to blame…".*

Maintenance and accountability is an ongoing issue that presents a possible barrier to the uptake of advanced home care technologies. It is crucial that these technologies are seen as support for the management of care rather than a replacement for either professional care or self management of health and well being. It is important to educate people on the positive and empowering role that technology can play in future care models (see 3.5).

The technicians group also highlighted two additional considerations. There can be a conflict between providing care to support one situation and potentially reducing safety in another:

> **TECH1P3:** "*Dementia is a problem…you can't automatically lock doors to stop wandering…what if there was a fire…"*

It is also important to ensure that each stakeholder is fully informed about what technology has been placed in the home and the implications that this may have on supporting care:

> **TECH1P3:** "*When we went to change the battery in the door contacts…the carer was just leaving…they hadn't seen it…they didn't know what it was…"*

Not placing technology within the home of some potential users was also seen to be necessary if a home visit to a patient was not simply about taking clinical measurements:

> **HCMIXED3P7: "***The blood pressure monitoring may be an excuse for the district nurse to visit and check up that the couple are coping."*

The use of technology to support the care of vulnerable people living at home has many legal and ethical implications, some of which have to be acknowledged or overcome before the technology can be successfully implemented. In addition, these issues may also be subject to change as the

technology advances. Indeed this is such a complex issue that there is no room here to discuss them all in full detail. A good discussion of some of the issues surrounding ethics and telecare can be found in (Perry *et.al*, 2010)

3.3 Availability of Resources

Participants across all focus groups were concerned with how much a home based care service with technology would cost to provide and how care provision would be resourced and organised. Response times and how call centres currently operate definitely have to be taken into consideration when implementing new technologies. Any technologies that assume a connection with emergency services or current call centres would have to ensure that they conform to current practices and do not increase the maximum allowed response times. If resource restrictions have an impact on call centre target response times then this may conflict with the expectations of carers who have a relative with technology installed in the home:

> **SC1P5:** "*My experience of assisted living technology is, my clients are predominately over 75 and it tends to be their families that have heard about it and they want every piece of equipment in the house but their expectations if you put in a piece of equipment is that if that buzzer goes off a member of the council will respond to it immediately*."

Furthermore, the practicality of implementing home care technology packages within Scotland was considered and lessons learned from previous national Scottish initiatives:

> **POL1P2: "***Free personal care…has been a big issue in Scotland and..…certain local authorities can't afford it and are digging themselves into holes because of what was expected of them…so it comes down to the dynamics…..the area of Glasgow that I work has the highest population of pensioners compared with anywhere in Western Europe so, you know, there are big demands in sort of areas like that."*

Maintenance of the technology has additional cost implications:

> **SC1P1:** "*I think one of the implications of technology as well is that it's all powered… if a piece of technology breaks down you are relying on an engineer to come out and fix it."*

Another theme that emerged across all groups was the need to continue to invest money in both the human and technological aspects of care. There is a lack of time available to qualified social care professionals and this may act as a barrier to them being able to increase their knowledge on technologies:

> **TECH1P1:** "*the staff need to be trained….there isn't enough money invested in this*…"

SC2P3: "*our case loads are extremely high and we don't have time to learn about it*".

3.4 Personalisation and evolution of provision

The potential for conflicting needs when there is more than one person living in the home was raised:

SC1P1: "*The fact that as a couple, they are still two individuals and they have got different needs and they may have different expectations to what's available and what they'll agree to accept or be able to accept…best to have two care workers….the needs of one person might conflict with the other person's needs."*

SC2P4: "*…need for a full assessment. Not assumed needs but real needs….of both the individuals and of their joint needs together…...they are two individuals but they share the same space…"*

The solutions being designed within our project acknowledge the home as a shared interaction space and as such provide options for personalization, negotiated configuration and alternative modalities of interaction tailored to user capabilities, preferences, and location. Several comments across all the focus groups supported this design aim:

SC1P2: "*…offering new ways to do things if they have a stroke for example or start to lose their hearing…*"

POL1P1: "*different people have different needs…how can it work for everyone?"*

POL1P2: "*things like autism might be too individualized. Care packages need to be tailored*."

Adapting and tailoring technology to people's varying needs was also discussed explicitly in the focus groups:

POL1P1: "*it could be adaptable…but this could be tricky…"*

POL1P2: "*Mind you…this is also true of existing [non AT] care packages as well*."

This confirms our belief that home care technologies need to offer configuration choices to tailor devices and interaction methods to the user(s). Furthermore, solutions should also aim to examine methods for supporting longer-term configuration of home care systems over time as the available devices or services change, or as a person's living circumstances or care needs change.

Several comments were made regarding the quality of the assessment protocols currently in use for prescribing technology. It emerged that much of the technology and technicians' time could be better

utilized if the service users and those prescribing the technology knew exactly what was available and to what extent these can address identified risks and unmet needs. Furthermore, it was believed that low-tech solutions should always be considered first and then, if appropriate, the matching of the right technology to the right person for the right purpose needs to take place:

> **TECH1P1:** *"OTs [Occupational therapists] need to assess what they [the users] actually need first."*

> **TECH1P2: "***Matching the right equipment to the users [is important]."*

A lack of knowledge was suggested by the telecare technicians to lead to mis-prescription or over-prescription for many of the users which results in equipment being switched off or put in a drawer.

> **TECH1P1:** "*If they [social care professionals] are not well trained they tend to go over the top and fit things that are not required to cover every possible scenario.*"

> **TECH1P1:** "*Sometimes we fit things and I think 'why am I fitting this here?...when you go back you can't find it…it's often in a drawer…."*

One way to monitor if technology is being both prescribed appropriately and used successfully is to include some form of audit or evaluation of the technology in use.

> **POL1P2**: "*put in some technology and then revisit to assess how it is working.*"

With the increasing numbers and types of sensors available, data can be collected easily by the system that sheds light on when and how the system is being used and responded to. This may help to identify and further understand the factors that lead to the use, non-use or misuse of technology for supporting social and health care at home.

There was some evidence of general reluctance to prescribe technology routinely:

> **SC2P3: "***I would see in the community before I'd look at technology."*

Some of this might be attributable to a continuing desire to retain the human element of care:

> **POL1P1:** "*…any system would [still] need help from social care workers coming in…for example with cleaning and cooking."*

An existing barrier is the perception that technology will replace human care and a lack of willingness to view technology as an enabling supplement to existing care packages.

> **POLMIXED3P4** "*The attitude to technology by social and health workers is that it is a cost cutting exercise and technology is there to replace the workers."*

If there is to be a successful implementation of government documents such as the White Paper, 'Our health, our care, our say' (DH, 2006), care professionals need to acquire knowledge and confidence in technology and understand how it can be used to support current care packages and not replace them. This relates directly to the final theme discussed in section 3.5.

3.5 Awareness, Education, and Training

There is strong evidence from across the focus groups that there is an urgent need for training, awareness raising, and independent, supplier-neutral information on currently available telecare and what the state of the art in ALTs will be in the near future. Addressing this barrier alone will play large role in ameliorating the other barriers discussed.

> **SC2P2: "***I think there is variance in understanding of it [referring to home care technologies] and I think that is something that needs to be addressed."*

> **SC2P2:** "*…when I'd spoke to the workers [referring to prescribing technology for a client] they were like, they panicked slightly, they don't know who to speak to about it…the reaction was oh I don't know how to do this, is that not for old people and there was that kind of reaction."*

At present the main source of training opportunities in assistive technology are limited to:

> **SC2P5:** "*We have with the Tunstall case here now, you know, that has all the different bits and pieces and we have a DVD from Sensorium*".

It is important that every practicing care professional should have access to detailed, accurate, objective and consistent information on assistive technologies. There was a general feeling from all focus group participants that they wished to increase their knowledge in assistive technologies. However, there was a belief that:

> **SC2P4:** *"because technology changes so fast and because there's, kind of, multiplicity of need out there,….., it would be really hard to,….., if it wasn't your mainstream job to keep abreast of technology and to be able to attend, whether it's national or local conferences, look at developments and how they would apply in a local context so I think, you know, probably it does need to be somebody's job"*.

In addition, there is a lack of time available to qualified social care professionals that may act as a barrier to them being able to increase their knowledge:

> **SC2P3:** *"our case loads are extremely high and we don't have time."*

However, if there is to be a successful integration of advanced technologies into the care packages prescribed by social care professionals' up to date knowledge is needed:

> **SC1P2:** *"we need to know what is available and actually see it working for ourselves"*

There is also a desire for hands on demonstration showing the possibilities of new available technologies and allowing time for interaction with these technologies:

> **SC2P3:** *"I've got to see it physically working, you know, and I hate reading from books or whatever…"*

Previous misconceptions about or negative attitudes towards technology may partly be resolved by improving education, training and awareness of home care technologies:

> **SC2P5:** *"a small presentation with some equipment there for demonstration purposes….. that's an opportunity for people to be able to raise things that they're concerned about and, you know, maybe where they've thought about technology in the past and, you know, had some issues maybe with some of the alarm stuff or that so I think it's a good opportunity or forum to be able to feed that back"*

The telecare installation technician's focus group highlights that a possible lack of knowledge may also account for the frequent non-use of installed technologies in the homes of older people.

> **TECH1P1:** *"A big proportion of the equipment isn't used…it's hard to tell if they don't know it's there or if they know about it and don't want to use it."*

The older user's focus group suggested this may be due to a lack of knowledge about the technological solutions available:

> **OUP1** *"A lot of people don't know it is available [referring to assistive technologies] because you don't see it advertised."*

In addition, a lack of knowledge about home care technology was suggested by the telecare technicians group to have a negative affect on the quality of life of the older person.

> **TECH1P1: "***They [the service users] are frightened because [they think] hidden cameras are behind them…they think they are being watched."*

> **TECH1P2:** *"…when he saw [a man with an epilepsy monitor] the light…he called the centre to say he was okay every time….he thought the flashing light indicated he was having a fit and he wasn't".*

It was also highlighted that the expectations of technology can sometimes be unrealistic due to a lack of knowledge regarding the technology itself:

> **SC1P3:** *"[the technology] is not going to stop particular problems occurring and I think that's where some people think it's the miracle – we'll put something in and their elderly parent will stop falling or stop trying to get out and wander down the street."*

This demonstrates the importance of a protocol to assess if the person prescribed technology and the other stakeholders involved have clearly understood the purpose of any technology in their home and know where they can get any additional information.

Furthermore, the mixed stakeholder focus groups highlighted there to be a lack of shared knowledge between the different stakeholders in home care technology. Home users and care professionals possess a limited awareness of what is technologically possible and have a lack of communication with research institutions and technology developers. Active user involvement is required throughout any technology development project from design, development, implementation and evaluation. However, this methodology has shown to be lacking in one of our mixed stakeholder focus groups:

> **ENGMIXED4P1:** *"you [referring to the others in the group which included a mixture of social and health care professionals or home users] should be coming to me with ideas for function specifications, then leave it to technologist to do it"*.

User requirements capture is not simply asking the users to describe a problem or need. It is an opportunity to have a dialogue with the end users and raise awareness at the same time. It is clear from our stakeholder engagement work that awareness, education and training need to be addressed to increase the successful uptake of home care technologies. We believe that, if this is addressed, many of the existing barriers discussed here can also be addressed.

4. CONCLUSIONS AND FUTURE WORK

Home care is a complex domain with many characteristics making it difficult to apply any one standard existing design methodology for the technology that is required (McGee-Lennon & Gray, 2007). The home is a unique and personalized interaction space. Health and wellbeing are personal and precious enough that many people are reluctant to change their current daily activities or care plan. They also hesitate to accept new technology in their homes if not aware of the benefits or equipped with the correct knowledge and skills to exploit the technology. If technologies are introduced that are desirable, usable, cost effective, improve health and/or wellbeing, and fit into

care plans and peoples' lives then the true potential of home care systems might thus be more likely to be realized.

The 'users' of home care technology can cross many stakeholder groups, from the persons receiving the care themselves, to friends and family interested in their care, to health and social care professionals prescribing the equipment, configuring it for their clients, or sending or retrieving data from the system within the home or remotely in their office or on the move. Each of these stakeholders has an individual set of goals and needs all prioritized in a manner that can be unique to each stakeholder group. Many pilot projects have highlighted the need for significant organizational changes before these benefits can be fully realized. However, professionals can often seek to preserve their own professional identities when working in multi-disciplinary teams (Brown *et al*, 2006). While ICT has the ability to enable information to be transferred between organizations this may not match current ways of working and threaten embedded cultures and ways of working across each discipline. This has been previously presented as a factor in the delayed evidence base to support the clinical and economic cost effectiveness of new technologies (Dickinson, 2006). Planned and systematic stakeholder engagement can be the basis for creating awareness, gathering requirements, building consensus, generating participation in processes of change and development, making informed decisions, and resolving conflicts around the needs and requirements of home care systems and telecare.

The focus group discussions and the emerging themes have been useful in indicating a number of current barriers to the uptake of home care technologies (see Table 4). By further exploring these barriers, and the perceptions and attitudes that cause them, we can derive a useful set of recommendations for the design and implementation of future home care technologies:

- The technology design and function should be able to cope with multiple users (of both the device and the data it generates).
- Acceptance levels may vary depending on the social context and the amount of knowledge a stakeholder has regarding what the technology can and cannot do.
- The technology should allow for personalization, customization, and adaptation where appropriate.
- The technology should achieve a balance between being unobtrusive yet not hidden entirely from the users.
- Different users will want different levels of visibility and control of the systems behaviour and capabilities.
- Continued stakeholder engagement can increase knowledge and likelihood of usability and acceptance of the technology

Ethical and privacy issues also continue to drive what is possible and acceptable in the field of home care technology. Monitoring of up-to-date ethical and legislative issues will be an ongoing task. The commonly identified ethical concerns include:

- fear over the *technology failing*
- *accountability* when technology negatively impacts on a person's health or wellbeing
- worry about infringing on the *privacy* of the individual being monitored
- concern over who has *access* to confidential information collected by sensors in the home
- uncertainty over the *security* of health data being sent to and from the home
- varying capacity of the individual to provide *informed consent.*

One of the most prevalent findings from our focus groups is that there is a clear demand for awareness raising and knowledge building on the range, scope and capabilities of current assistive and home care technologies. This may be simply general awareness raising strategies, for example up to date leaflets and/or training courses, to a more in depth approach which covers the assessment protocols and procedures that exist within the care organizations. Examples include:

- Knowing what technology is available
- Knowing the advantages and disadvantages of particular choices of equipment
- Prescribing technology that is needed and desired rather than a one-size fits all package
- Being aware where is the technology available from and how to request it
- Awareness of your own local authorities organisational funding procedure
- Knowing what permissions are required (e.g. informed consent and other ethical aspects)
- Being aware of the privacy and security issues that increased connectivity of home care systems introduces
- Understanding how client preferences, attitudes and situation affect acceptability
- Revisiting clients and /or using data to evaluate if and how the technology is being used

The evidence to support the use of advanced assistive technologies for the provision of social and health care at home remains relatively sparse. This is partly because these services are still in their early days, but it also appears to be because of attitudinal issues, resource constraints, ethical concerns, a lack of training and information and a lack of evaluation of these kinds of services. It is important that appropriate evaluations are conducted to investigate all of these issues, and dissemination of the lessons learned is made more widely available.

The results from this work are being used to inform the design of future home care technologies that are acceptable, usable, and fit into current and emerging care models. This work can also form the basis for informing future guidelines around technology development, and the development of an implementation guide for home care technologies directed towards social and health care professionals. Our findings further suggest that technology-related policies and services for home care need to emphasize stakeholder involvement and the long-term needs of service users to reduce device abandonment and enhance user satisfaction. Further work should certainly include a larger sample of direct and indirect users of ALT and telecare services, particularly in the older users group. Other stakeholder groups to include in future work might be telecare providers such as Tunstall, and NHS service commissioners responsible for budgets affecting telecare provision.

Crucially, we are still at the stage in the UK that awareness raising, training and education are all still required in this area to reduce mis-prescription (or lack of prescription), reduce the negative impact of existing misconceptions and to resolve some of the complex underlying ethical issues that are currently barriers to the uptake of home care technology in the UK. Finally, an important extension to the work would be to revisit stakeholder groups with the emerging themes and barriers and allow them to rank, prioritise, and discuss the themes to shed further light on how these barriers can be overcome in the future.

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Older Users OU	People living at home with care needs – referred to as users, clients, patients, or service users
Informal carers IC	Includes friends, neighbours and family, and voluntary groups such as charities and church groups.
Social Care professionals SC	Includes care workers, home help.
Policy makers POL	Local authorities and councils, governmental agencies allocating money and resources and dictating legislation
Health Care professionals HC	Includes GPs, community nurses, occupational therapists, physiotherapists, consultants etc.
Technologists ENG	Designers, researchers, engineers and companies producing or supplying the devices, methods or infrastructure required
Telecare installation technicians TECH	Technicians who install and maintain telecare equipment currently provided.

Table 1: Stakeholders in Home Care Technology

Single/ Mixed	Code	Stakeholder
Single 1	SC1	Social Care Professionals
Single 2	SC2	Social Care professionals
Single 3	POL	Policy makers
Single 4	TECH	Telecare installation technicians
Single 5	OU	Older users
Single 6	IC	Informal carers
Mixed 1	MIXED1	Mixed stakeholder group
Mixed 2	MIXED2	Mixed stakeholder group
Mixed 3	MIXED3	Mixed stakeholder group
Mixed 4	MIXED4	Mixed stakeholder group
Mixed 5	MIXED5	Mixed stakeholder group

Table 2: Description and Coding of Focus Groups

1	Acceptance Issues
2	Ethical/Legal/Privacy Issues
3	Availability of Resources
4	Personalisation and Evolution of Provision
5	Awareness, education, and training

Table 3: Emerging Themes across focus groups

1.1	Lack of acceptance of telecare and assistive technology at the individual level. End users fail to accept that they need, or can benefit from the technology.
1.2	Lack of acceptance of telecare and assistive technology societal level. Friends and family do not buy in to technology as part of a solution for supporting the care of a loved one.
1.3	Lack of acceptance of telecare and assistive technology at the organisational levels. Failure of health and social care practices to integrate technology into existing care models.
2.1	Fears that health and well being data is private and it should not be shared or communicated digitally
2.2	Issues over the digital security of data being communicated and shared over a network.
2.3	Ethical concerns over who owns the data, who controls the system and the data it produces, and whether informed consent can be reasonably gained regarding technology use.
3.1	Increasing financial strain for personal care provision budgets leading to technology being perceived as an additional overhead.
3.2	The addition of new technologies being perceived as leading to additional time for social care professionals that prescribe, install and maintain the equipment.
4.1	Individual user needs. Many current technologies are one size fits all and do not cater for varying abilities and capabilities in individual users.
4.2	Dynamic user needs. Technology is not yet fully configurable to allow for complete personalisation of the technology to the users needs, preferences and contexts.
4.3	Lack of support for social care practitioners in prescribing an appropriate package of technologies suited to the individual users' needs and circumstances.
5	Lack of public and professional awareness, education, and training in the areas of state of the art in telecare and assistive technology leading to all of the above.

Table 4: Existing Barriers to the uptake of assistive technology in the UK