CogWatch – Cognitive Rehabilitation of Apraxia and Action Disorganisation Syndrome

D1.4 Healthcare Professionals, Stroke Survivors and Carers Requirements

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EXECUTIVE SUMMARY

The aim of this deliverable is to evaluate the requirements of Health professionals stroke survivors and carers, in order to ensure that CogWatch will provide effective rehabilitation and support for stroke patients with apraxia and action disorganisation syndrome (AADS).

Questionnaires were sent to various groups of healthcare professionals and four focus groups were conducted with stroke survivors and their carers.

In total 96 health professionals completed the questionnaire and 7 carers and 11 stroke survivors participated in the focus groups.

The main findings from this evaluation are:-

- The CogWatch system should be simple to use for users, carers and professionals.
- The system should be very flexible in terms of the ways it provides feedback, so that it can overcome the wide range of problems people with stroke have.
- Any wearable devices should look as normal as possible to avoid stigmatising the person.
- The system should be cost effective and utilise any technology that an individual may already have in their home.
- Users, carers, and professionals should receive adequate training and support to use the CogWatch system.

Professionals felt that this system would provide the following benefits:

- Increased independence and improved wellbeing for users
- Improved wellbeing for carers through relatives being less dependent on their support and through offering reassurance and peace of mind.
- For professionals, through time saved and improved therapy outcomes.

Overall 91.3% of health professionals that responded to the questionnaire felt that the CogWatch system has the potential to monitor patient progress in a time and cost effective manner.

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REVISION HISTORY

Revision no.	**Date of Issue**	**Author(s)**	**Brief Description of Change**
v1	28/03/12	HW	Table of contents
V2	02/04/12	HW	Introduction and methodology drafted
V3	03/04/12	HW	Amendments to introduction and methodology and inserted appendix
V4	19/04/12	HW	Amendments to methodology and back ground section
V5	23/04/12	HW	Results section added with quantitative data
V6	27/04/12	HW	Background, discussion and lessons learnt sections
V7	01/05/12	HW	Amendments to introduction and results
V8	03/05/12	HW	Amendments to results. Discussion, conclusion and lesson learnt drafted
V9	04/05/12	HW, TSA	Editing of whole document
V10	16/05/12	HW	Amendments following partners comments and contents page
Final	28/5/2012	UoB	Revisions based on Peer Review and Quality Manager's feedback

1. Introduction

The aim of this deliverable is to evaluate the viewpoint of health professionals, stroke survivors and carers, in order to ensure that CogWatch will provide effective rehabilitation and support for stroke patients with apraxia and action disorganisation syndrome (AADS).

To assess the views of professionals, a questionnaire was devised and circulated to clinicians, therapists, and researchers with an interest in cognitive difficulties after stroke. To understand the system requirements from a patient and carer perspective, four focus groups were conducted. These sessions aimed to:-

- Gain insight into the experiences of health professionals working with people with stroke and AADS
- Collect information on the current assistive technologies available for stroke patients, including the benefits and limitations of each one
- Understand how these groups feel a solution like CogWatch could enhance the rehabilitation of stroke survivors
- Discover what feature should be included in the proposed technology solution
- Understand the views of care givers and users regarding how they feel this type of technology could enhance their independence and, in particular, which features would make it user friendly within the home environment.

This evaluation will guide the development of the CogWatch system to ensure the design will meet the needs of individual patients as well as being practical and affordable for home installation. These design requirements will ensure rehabilitation takes place in familiar environments and using familiar tasks.

2. Background

2.1 Classification of Assistive Technology

Assistive technology (AT) is defined as:-

> *Any item, piece of equipment, product or system, whether acquired commercially, off the shelf, modified or customized, that is used to increase, maintain or improve functional capabilities of individuals with cognitive, physical or communication disabilities.*
>
> (Marshall 2001)

There is an increasing range of devices becoming available under the umbrella of AT and these can be categorized as follows:-

- supportive technologies for helping individuals perform tasks that they may find difficult (for example, video entry systems, and medication reminder units)
- detection and reaction (responsive) technologies to help individuals manage risks and raise alarms (for example, unburned gas detectors and panic buttons/pendants)
- Prediction and intervention (preventative) technologies to help prevent dangerous situations and, again, to raise alarms (for example, falls predictors, monitors for assessing physiological symptoms, room occupancy monitors).

(Beech et al. 2008)

This broad category terminology can be inconsistent and confusing. Therefore it was felt important to explain and clarify the common terms used:

Telecare – This has been defined by the UK Department of Health as a service that uses '*a combination of alarms, sensors and other equipment to help people live independently. This is done by monitoring activity changes over time and will raise a call for help in emergency situations, such as a fall, fire or a flood'* (Department of Health 2009).

The development of telecare dates back to the 1940's when older people where given a buzzer to summon help in an emergency. This area of technology has since developed and continues to do so. The development of telecare technology can be divided into three distinctive generations: the first period in the 1980s to 1990s where systems were linked through community alarms (Cash 2003); during the second period, systems were developed around lifestyle monitoring whereby the sensors 'learn' an individual's routine and use these to trigger a response in the case of an emergency (Hanson et al. 2005); and the third generation which aims at improving both health and quality of life by enabling the home to function as a focus of 'care in the community' and as a 'virtual neighbourhood whereby' housebound people can use ICT to participate in the wider community (Hanson et al. 2005). Key examples of the new generation of telecare include the use of internet and TV to communicate to the outside world (Lemoncello et al. 2011). Typically, telecare technology uses a lot of stand-alone sensors such as pill dispensers, flood detectors, and signals used as a memory prompt.

Telehealth: This kind of service is aimed at helping people manage their long term health conditions in their own home. Conditions include - diabetes, heart failure and/or chronic obstructive pulmonary disease.

Telehealth uses equipment to monitor people's health in their own home. So for example equipment can be used to monitor vital signs such as blood pressure, blood oxygen levels or weight. These measures are then automatically transmitted to a clinician who can observe health status without the patient leaving home. The clinician monitors daily readings to look for trends that could indicate deterioration in condition. Readings that are out of the expected range are flagged to the clinician using a traffic light system. (Department of Health 2009)

Telemedicine: This term refers to a computer application or technologies that support the exchange of information directly among healthcare professionals (Hanson et al. 2005). An example of current telemedicine is EEG monitoring where by GP surgeries have access to machines and the results are sent directly to a consultant for review and therefore medical treatment if required is immediate.

Smart Homes: This term refers to the use of electronic assistive technology (EAT), including electronic aids to daily living (EADL) and assistive technologies for cognition (ATC) and these have been broken down into five categories:

Class one: homes that incorporate intelligent objects, such as doors or window shades that open via a remote control switch or motion-activated lighting;

Class two: homes that utilise wired or wireless networks for information exchange, such as a computer controlled thermostat or lighting;

Class three: homes that include electronic networks that reach beyond the home for information exchange (these are often called “connected homes”);

Class four: homes linked to computers that analyse patterns of activity and manage appliances accordingly (these are often called “learning homes”);

Class Five: homes that build upon the connectivity and learning characteristics of class four homes to control technology in anticipation of human needs or in order to provide adaptive cues for human occupants (these have been called “attentive homes”).

(Gentry 2009)

Given the above, a system like CogWatch could be incorporated into a class five smart home.

2.2 Assistive technology and Stroke

Stroke is the third most common cause of death and the single most common cause of severe disability in the UK. Each year over 150,000 people have a stroke in the UK, and over three quarters of these are over the age of 65. (Wilson et al. 2010). As the UK and Europe faces a significant growth in the number of citizens aged over 65 years, with an anticipated 47% increase by 2026, increased access to assistive technology is seen as a cost effective means of maintaining the independence, health and wellbeing of this growing population (Beech and Roberts 2008).

Many people who have had a stroke are not capable of independent living or economic self-sufficiency. One year after stroke, 35% of surviving stroke patients remain significantly disabled and many need considerable help with activities of daily living (ADL) (Department of Health 2011a). Most people require on-going rehabilitation after they are discharged from hospital, which results in a high demand on limited therapy resources resulting in inadequate follow-up and treatment. Twelve months post stroke, 85% of patients do not receive any therapy input, which can cause stroke survivors to withdraw from their daily activities and lead to an increased dependency on carers (Wilson et al. 2010).

Not only is current stroke rehabilitation usually short-lived, it is mostly delivered in the hospital setting with a focus on physical rehabilitation to reduce hospital stays. Too often, cognitive and behavioural difficulties, which determine long term independence and adjustment after stroke, are left untreated.

Cognitive impairment is often labelled as a 'hidden disability' and includes ones capacity for mental tasks, including conceptualizing, planning and sequencing thoughts and actions, remembering interpreting subtle social cues and manipulating numbers and symbols' (Lopresti et al. 2008). Between 35% and 72% of stroke survivors still have cognitive limitations one year after their stroke (Patel et al. 2003).

CogWatch focuses on two common cognitive impairments: Apraxia and Action disorganisation syndrome (AADS). However, it is important to note that individuals may also have other substantial disabilities including motor, sensory and communication problems. It is important that all aspects of a person's cognitive, physical and sensory capabilities are taken into account when designing an assistive technology solution because features designed to address one impairment may negatively impact on other aspects of a person's rehabilitation (Scherer 2005).

Assistive technology is a growing area of research but for stroke survivors, the majority of studies have tended to concentrate on the physical side of rehabilitation. Most studies of assistive technology for cognitive impairments are aimed at people with dementia. Although not directly relevant for stroke, these studies are demonstrating that, as technology emerges, it can help individuals with cognitive disabilities. Several studies using computer based assistive technology have demonstrated positive outcomes in supporting individuals with cognitive limitations, which can help increase their performance of everyday activities (Demiris et al. 2008; Kirsh et al. 2004; Lopresti et al. 2008; Orpwood et al. 2009).

Researchers are beginning to consider how assistive technology can improve the lives of stroke survivors with cognitive problems. In particular a recent study illustrated how routines developed with support from technology increased social contact and perceptions of control in everyday living amongst people after a stroke. The therapy routine also demonstrated a positive reduction in dependency on their spouses (Lindqvist & Borell 2011).
A systematic review of the efficacy and usability of assistive technology for patients with cognitive deficits found that most studies have not included individuals with apraxia and aphasia (Joode et al. 2010). The authors suggest this is because these patient groups require specific technology aids and that further research is warranted.

Studies have also shown standard technologies have had little impact on therapy, and are often threatening to patients. Most rehabilitation is therefore still very 'low tech'. A more efficient system would put the patient and their family at the centre, utilise labour-saving technology, and provide sufficient data for healthcare professionals to monitor progress and intervene in proactive and timely fashion (Orpwood 2009; Worthington and Waller 2009; Worthington 2010): suggesting the existence of a gap in the market for a system like CogWatch.

2.3 Barriers to acceptance of technology

In support of the notion that technology would aid professionals as well as carers and users, a preventative technology grant of £80 was introduced by the UK government in 2006 (Department of Health 2005). The aim was for every individual with a disability to be offered technology as an integral part of their disability care by 2010 (Hanson et al. 2005). However, this aim is not achieved in many areas due to barriers remaining amongst professionals, carers and users regarding the use of technology.

For professionals the common barriers that are identified throughout literature (Mahoney 2010; Beech et al. 2008; Joode et al. 2010) tend to be:-

- Resistance to change and organizational constraints within the workplace as change is usually required for technology to become an integral part of services (Care services improvement partnership 2007)
- The feeling that technology will take away their job or cause an increase in their workload, instead of viewing technology as part of a rehabilitation programme or care package (Cash 2003; Tinker et al.2004)
- A lack of information and training in the use of technology and what is available; professionals often regard the use of technologies as a speciality skilled area (Svoboda et al. 2012; Housing association charitable trust 2007)

For carers and users, the literature shows the common barriers include both technology issues and social or psychological issues, as discussed below:

- Studies have found that often people with disabilities have previously not used any form of technology (e.g. a computer), and therefore have fear of an area which is innovative to them (Lopresti et al. 2008). Most technologies are not designed for use by individuals with cognitive deficits and procedures for operating technology can be very complex
- Lack of training on how to use technology
- Lack of assessment of technological need linking in with above findings from professionals
- Lack of information on the benefits of using technology
- Feeling that technology will replace human contact

(Beechs et al. 2008; Lopresti et al. 2008; Joode et al. 2010; Mahoney2010)

Interestingly age is not seen as a barrier to compliance. Many of the studies done with technology have included older people (Tinker et al. 2003; Cash 2003; Beech et al. 2005; Mcreadie et al. 2005; Mahoney 2010) and have shown that older patients are open to technological interventions, as long as the technology is presented in a way that it demonstrates that it will increase independence and enable the person to remain in their choice of dwelling for longer.

A common barrier from the professional, user and carer viewpoints is the cost effectiveness of technology. Many studies found that the provision of existing technologies differs between geographical location i.e. services such as telecare may be provided free of charge in one location but require a financial assessment in others (Mahoney 2010). Often assistive technology comes with a high price tag and a limited record of reimbursement (Jones et al. 2010). However, when the cost of technology is compared to the overall cost savings, then substantial savings can be made. The potential benefits can include reduced hospital admissions and reductions in the amount of manual therapist care required. To date, however, empirical research to support these claims is lacking.

Finally, most completed assistive technology studies demonstrate the need for user and carer involvement right from the beginning before any prototype is produced (Orpwood et al. 2004). In most studies, the user involvement is carried out when a product has already been completed, leaving little or no room for further modifications as a result of user feedback (e.g. Joode et al. 2010; Lopresti et al. 2010; Copolillo et al. 2011). A small number of studies have started to recognise the need to involve users and carers from the start) and have demonstrated that user contributions have been critical to the design and eventual acceptance of the technology (Wilson et al. 2010. At present, no studies developing technologies for stroke survivors with cognitive limitations have considered involving users during the design process (Joode et al. 2010). However, it is recognised that future research should focus more on matching the demands of stroke survivors with the design of technology to ensure the production of successful products (Copolillo et al. 2011). Thus, it appears that CogWatch is at the forefront in its approach to design and development.

3. Methodology

3.1 Questionnaire

To gain the views of Health Professionals information leaflet (Appendix 10.1) and questionnaire (Appendix 10.2) was designed.

Questionnaires have the benefit of reaching large numbers, maintaining anonymity in the responses, and the potential for a high return rate. They are also compatible with both closed and open-ended questions which can be standardised to ensure there is no interviewer interpretation or distortion (Oppenheim 2000).

Before the questionnaire was widely distributed, it was first piloted with a small number of healthcare professionals. Research shows that, although time consuming, pilot testing can make questionnaires more effective. Without such tests, questionnaires have often produced unquantifiable responses and un-interpretable results (Oppenheim 2000).

The CogWatch questionnaire for healthcare professionals was tested in two rounds of pilot testing, as follows:-

1) In January 2012 an initial pilot of the questionnaire was completed with three health professionals: an occupational therapist, a physiotherapist and a nurse as representatives of the professional sample to be recruited to the main study.
Also during this phase, the questionnaire was circulated to all CogWatch partners. From the feedback given amendments were made to the questionnaire in particular Q8 and Q15.

2) In February 2012 a second pilot study was undertaken using feedback from CogWatch partners and professionals in the initial pilot at a residential neurorehabilitation service. The sample consisted of 8 health professionals, again from various backgrounds: physiotherapy, psychology assistants, speech and language therapists, and occupational therapists. After this round of testing, Q8 was amended and a rating scale introduced.

The final version (Appendix 10.2) was then converted into an online questionnaire, as it was felt using a web-based link would increase the response rate over postal questionnaires.

In mid-February 2012, the survey link was sent out to target professionals from a range of disciplines with experience in the area of stroke and/or AADS and/or technology. These groups included:

- All CogWatch partners
- All relevant contacts within local PCT's
- The College of Occupational Therapists – Specialist section neurological practice (SSNP)
- BABICM (British Association of Brain Injury Case Managers)
- Specialist rehabilitation units for stroke and brain Injury
- Participants in a Royal Society of Medicine telecare conference
- Speech and Language specialist groups
- Psychology specialist groups
- A selection of stroke clinicians, allied health professionals and academic researchers with a declared interest in cognition or assistive technologies from the Stroke Association database of contacts.
- Regional Telehealthcare network group
- School of Occupational Therapy – University of Derby

The deadline for completion of the questionnaire was initially given as four weeks from the date of distribution. However, to maximise sample size, the deadline was extended to 6 weeks

3.1.1 Data analysis of Questionnaires

The data from the questionnaires was analysed using two computer programmes, SPSS 19 (Gray & Kinnear, 2012) and ATLAS.ti. (http://www.atlasti.com/index.html)

SPSS 19 is a statistical analysis programme. It was used to analyse the quantitative data, i.e. responses to closed questions, and to generate tables and graphs of the results.

ATLAS.ti allows large quantities of qualitative data from different sources to be analysed. The programme was used to determine themes within opened ended and opinion based responses.

3.2 Focus Group

Focus groups are known to encourage a more thorough exploration of issues than is possible through questionnaires and to stimulate debate (Silverman 2004).

3.2.1Professionals

In addition to the questionnaire, the views of professionals were assessed in a focus group with the West Midlands Regional Telehealthcare group. This group’s membership comprises of various representatives from health and social care who all take a lead role in the area of technology.
A presentation on the project was given and then questions were put to the group regarding the proposed CogWatch system and what features should be considered in its design.

3.2.2 Carers and stroke survivors

To survey the views of patients and carers, focus groups were chosen in preference to one-on-one interviews. It was considered that the group discussions of a focus group may help participants understand the complex issues surrounding AADS and the proposed CogWatch rehabilitation system.

During the first two weeks of February, two researchers attended four groups run by The Stroke Association (TSA) in the West Midlands to discuss the project and invite potential participants to attend the focus groups. All of these groups were for stroke patients with communication problems thereby ensuring this important group of users were included from the outset.
For those identified as willing to take part in the evaluation, an information leaflet (Appendix 10.3), a demographic questionnaire (Appendix 10.4) and

consent form (Appendix 10.5) were all handed out and participants were asked to complete these prior to the date of the focus group.

In addition, a group was conducted at the University of Birmingham (UOB) following identification of stroke patients and carers that attend the UOB on a regular basis. The majority of the groups tended to have more users than carers, reportedly due to carers' work or other commitments.

The format of open questions was produced (Appendix 10.6). The questions aimed to:-

- Discuss any technology that is currently used and what features of this technology they found useful.
- Gain views on what features the CogWatch system should have in order to make it user friendly.
- Share experiences of daily tasks that stroke survivors found difficult following stroke.

A communication prompt (Appendix 10.7) was also developed to assist stroke survivors with varying degrees of communication difficulties.

In total, four patient and carer focus groups were conducted throughout the course of March. Each group was led by two researchers to increase the validity of the collected responses. Each focus group lasted for approximately 1hr 30 minutes. Both researchers took notes which these were then transcribed for final analysis.

3.2.3 Data analysis of focus groups

ATLAS.ti was used to analyse the data, using a grounded theory approach whereby the data was coded and grouped into common themes.

The themes that emerged from the user and carer focus groups were compared to those that emerged from health professionals' focus groups and the open ended questions on the health professionals' questionnaire. There were some themes specific to a particular group but also themes that were present across all three groups.

4. Results

4.1 Professionals Questionnaire

Results in this section are based on responses to a questionnaire designed to explore the experiences and opinions of healthcare professionals working in the field of either stroke, cognitive deficits and/or assistive technology.

Table 1

Profession	**Frequency**
Occupational therapist	**47**
Physiotherapist	**12**
Case Manager	**11**
Speech & Language Therapist	**10**
Psychologist	**8**
Other…….	
Nurse	**2**
Social Worker	**2**
Neurologist	**1**
Counsellor/patient journey coordinator	**1**
Academic in Rehabilitation Engineering	**1**
Assistant Psychologist	**1**
Total	**96**

Table 1: Professional backgrounds of the participants

Professionals - Time since Qualification

Ninety-one professionals who completed the questionnaire responded to the question ‘How long have you been qualified in years?’
The mean number of years since qualification was fifteen, with a range of one to forty years.

Figure 1

Figure1: Amount of experience each participant had of working with stroke patients

Of those who responded 79.8% had at least two years experiences of working with stroke patients, and 39.3% had more than ten years' experience.

Figure 2

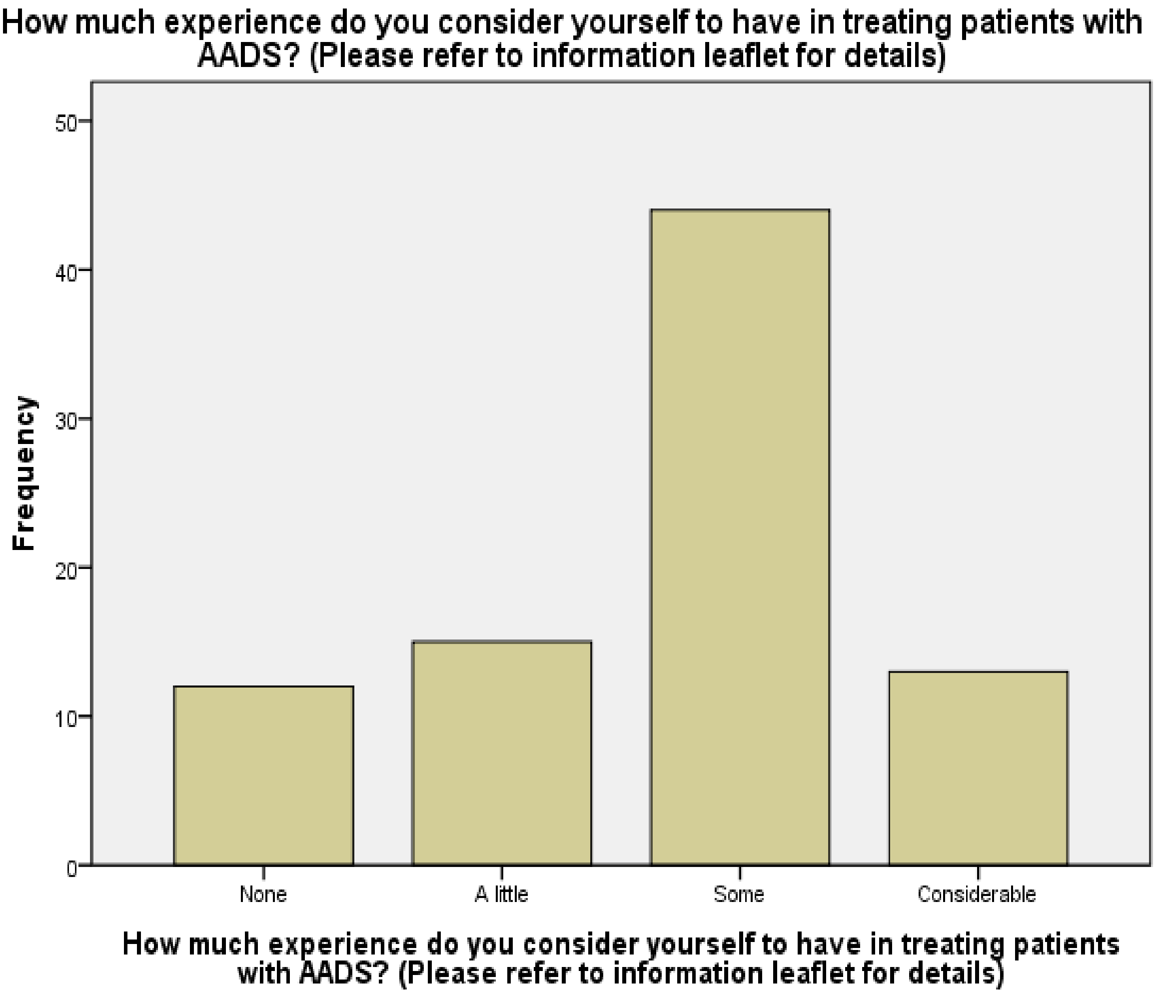

Figure 2: Amount of experience in treating apraxia and action disorganisation syndrome

67.9% of those who responded considered themselves to have either some or considerable experience in this area.

Figure 3

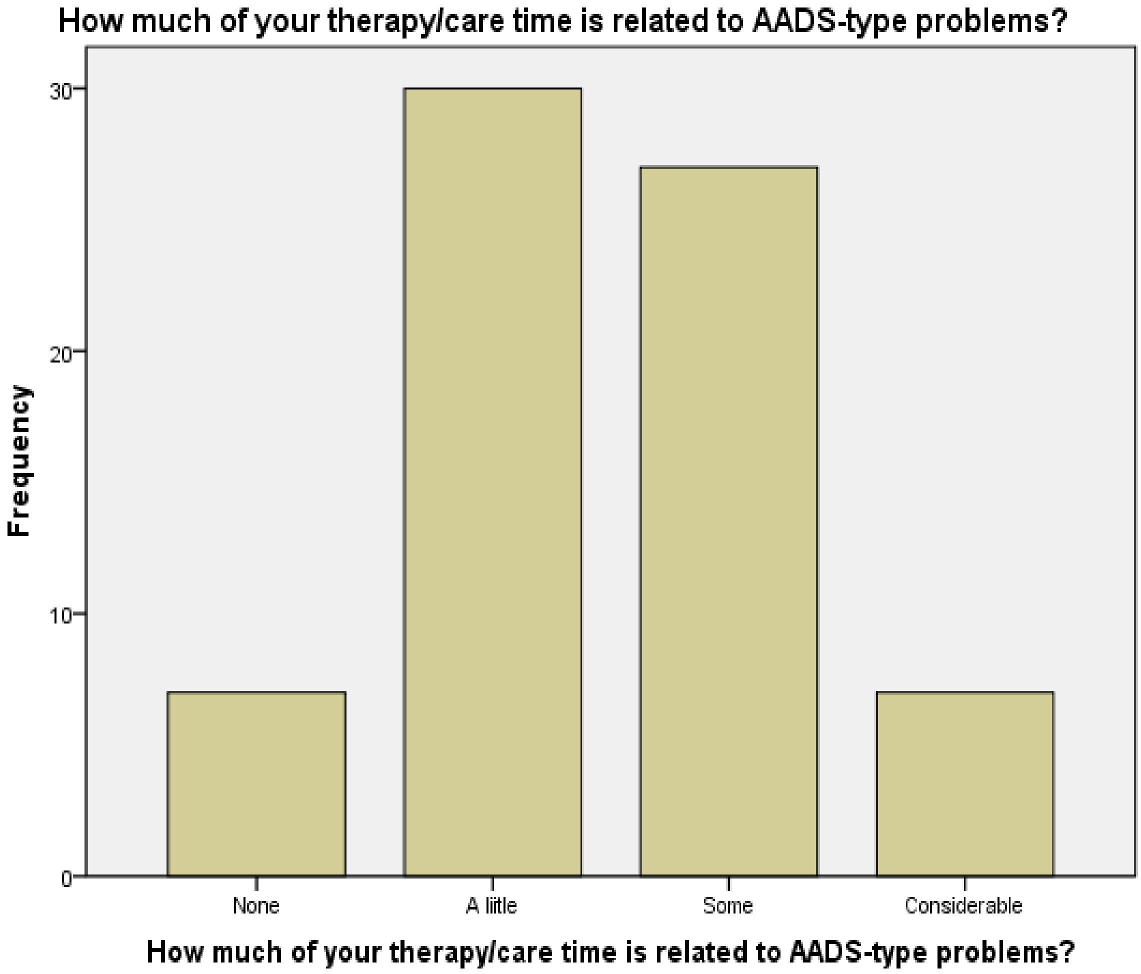

Figure 3: Amount of therapy/care time spent treating difficulties related to AADS

80.3% of participants spend a little or some of their therapy/care time in this way, while 9.9% spend a considerable amount of time.

Table 2
Do you have a service available to see stroke patients in the community following discharge from hospital?

		Frequency	Percent
Valid	Yes	34	35.4
	No	24	25.0
	Total	58	60.4
Missing	System	38	39.6
Total		96	100.0

Table 2: Availability of community stroke services

Of the 60% of respondents who answered this question 58% had access to a stroke service in the community

Figure 4

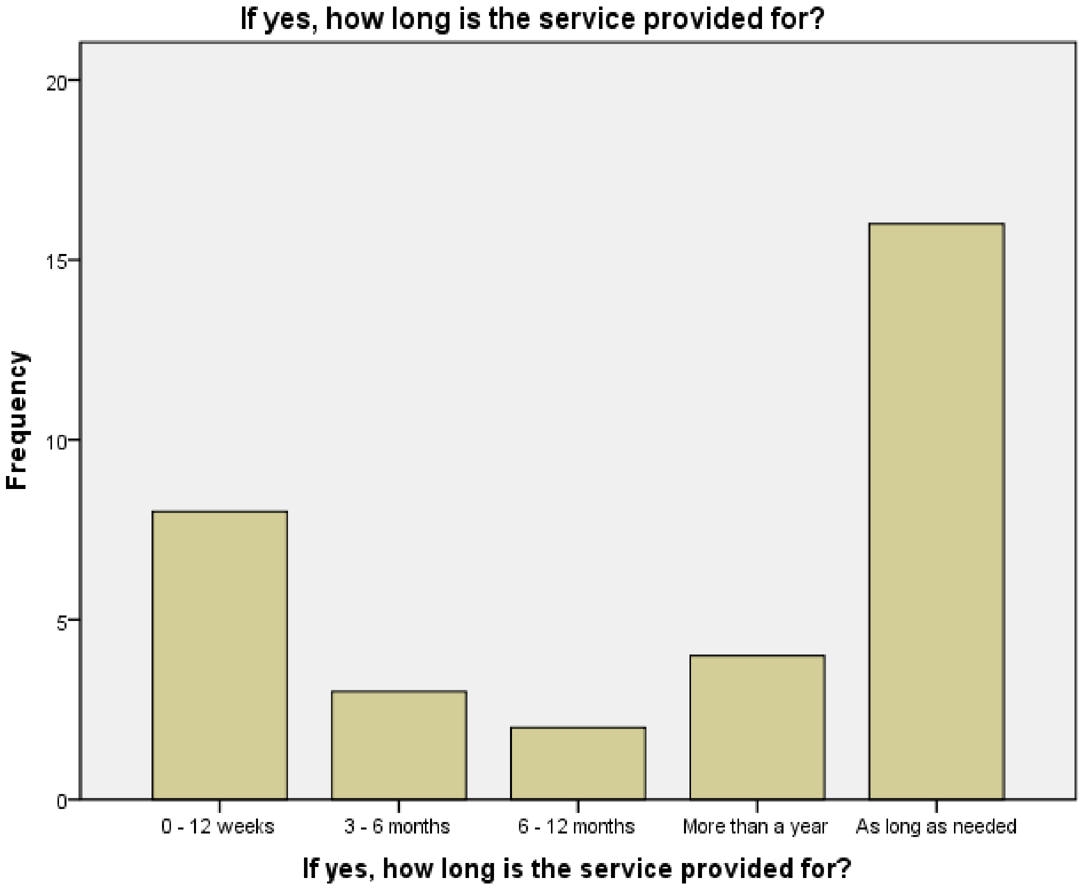

Figure 4: Duration of post discharge follow-up

Where a stroke service of some kind exists in the community 60.6% provided follow-up for at least a year if needed

Figure 5

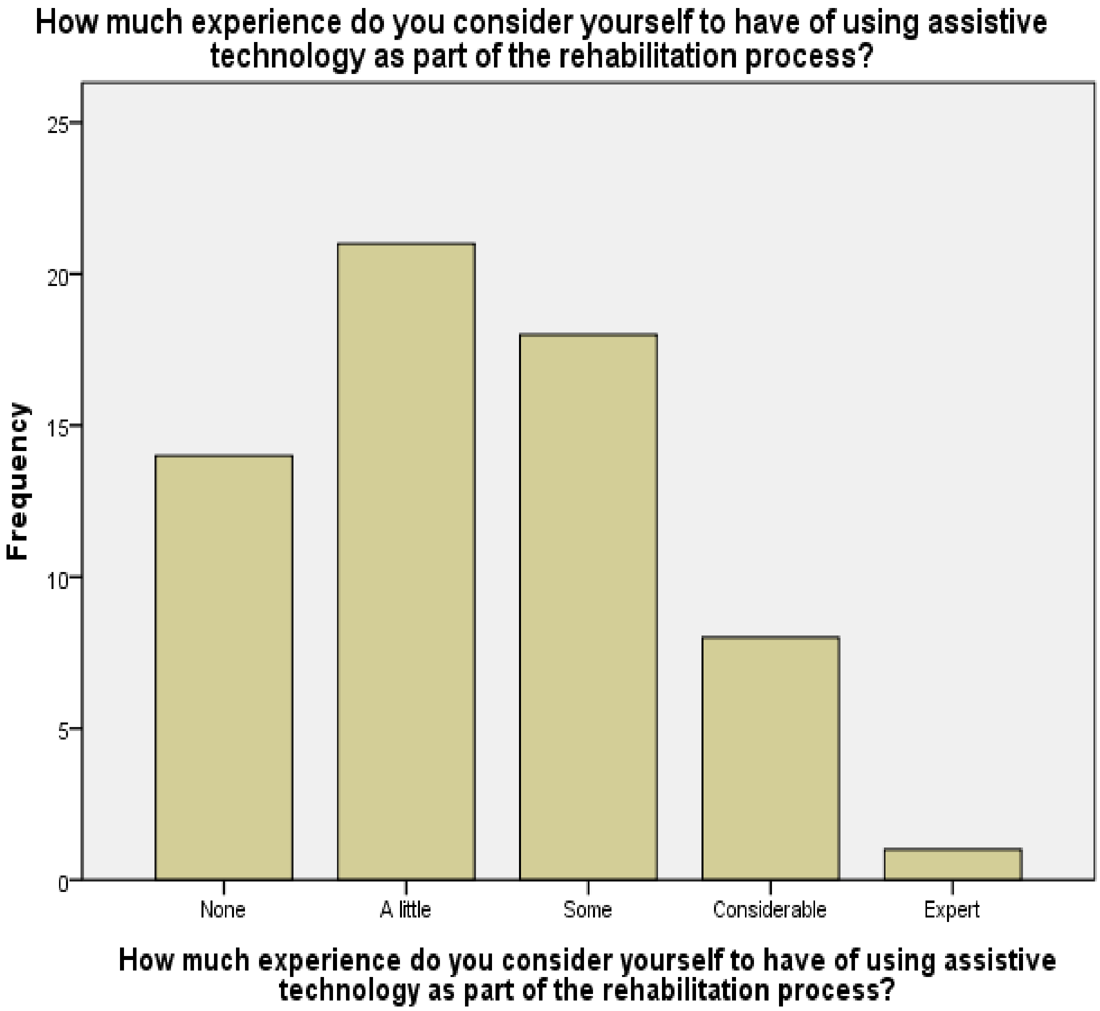

Figure 5: Amount of experience of use of assistive technology in rehabilitation

Almost a quarter (22.6%) of those who responded had no experience of using assistive technology as part of the rehabilitation process. 62.9% considered themselves to have a little or some experience, while 14.5% rated their experience as ‘considerable’ or ‘expert’.

Table 3

Type of assistive technology	Number of professionals	Specific examples given
Epilepsy alarm	1	
Pill dispenser	7	
Memory aids	13	Neuropage, Memex
Pendant alarm	8	
Mobile phone	12	
Watch/clock	3	
Fall detector	3	
Communication aids	7	Lite writer
Environmental controls	12	Possum
Interactive metronome	1	
Computer	5	
Sensors	3	
Talking microwave	2	
Detectors, e.g. carbon monoxide, flood	3	

Table 3: Technology that professionals have used in Rehabilitation

Of the ninety-six professionals who completed the questionnaire, forty-one responded to the question ‘what types of assistive technology have you used within rehab?

Table 4: Descriptive Statistics

	N	Range	Min	Max	Mean	SD	Variance
Omission: Failing to initiate essential action or sequence of actions to complete a task	46	7	3	10	7.4	1.8	3.2
Initiating an incorrect or inappropriate action	45	8	2	10	6.6	2.2	4.7
Sequence: performing component actions in the wrong sequential order	46	8	2	10	7.2	2.0	4.1
Additions: inserting an extra component action incorrectly	45	9	1	10	5.5	2.4	5.8
Semantic: using an object as another semantically related item	46	9	1	10	6.2	2.2	4.9
Perseverations: repeating an action or action sequence once its goal has been achieved	46	7	3	10	7.6	1.8	3.3
Quality: using excessive quantities of ingredients	45	9	1	10	5.8	2.2	4.8
Tool omission: failing to use tools	45	9	1	10	5.9	2.1	4.2
Spatial: failing to grip the object correctly or unable to produce correct movements with objects, or unable to recognise correct spatial relationships between task objects.	44	8	2	10	7.1	1.8	3.2
Toying: reaching/holding an object without purpose	45	8	1	9	5.1	2.0	4.1
Action reversal: undo an action	45	8	1	9	4.5	1.9	3.7
Valid N (listwise)	42						

Table 4: Descriptive statistics related to the frequency professionals felt that AADS patients made different types of errors

Ratings were made on a ten point scale where 1=rarely happens and 10=happens all the time.

From the data it can be seen that professionals’ opinions varied in terms of their ratings, which is indicated by the large range of responses, and by the relatively large standard deviation (for those responses that were normally distributed). The smallest ranges can be observed for errors relating to additions and perseverations, where the range of ratings was between 3 and 7 out of 10 for both types of errors, which indicates the greatest degree of agreement in the frequency of these types of errors between professionals.

Despite there being a wide range of responses, the lowest mean rating for any type of error was 4.5 (action reversal), which indicates that on the whole professionals acknowledged that all types of error may occur in people with AADS to some degree. The highest mean scores were observed for omissions, sequencing errors, perseverations and spatial errors, all of which had a mean score over 7, which indicates that professionals felt that these types of errors occurred most frequently. This is further highlighted by the graph in figure 6.

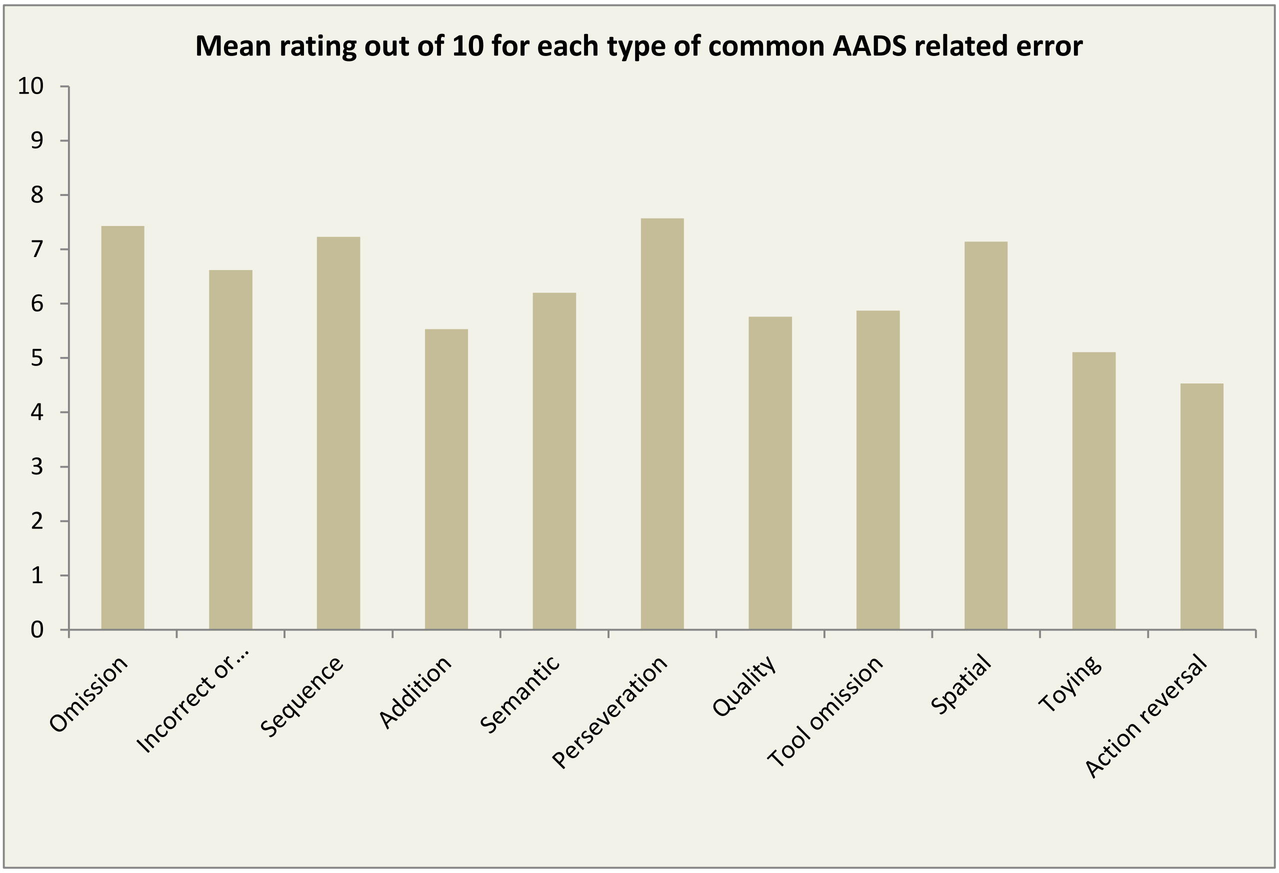

Figure 6: Mean rating for each type of AADS related error

Figure 7

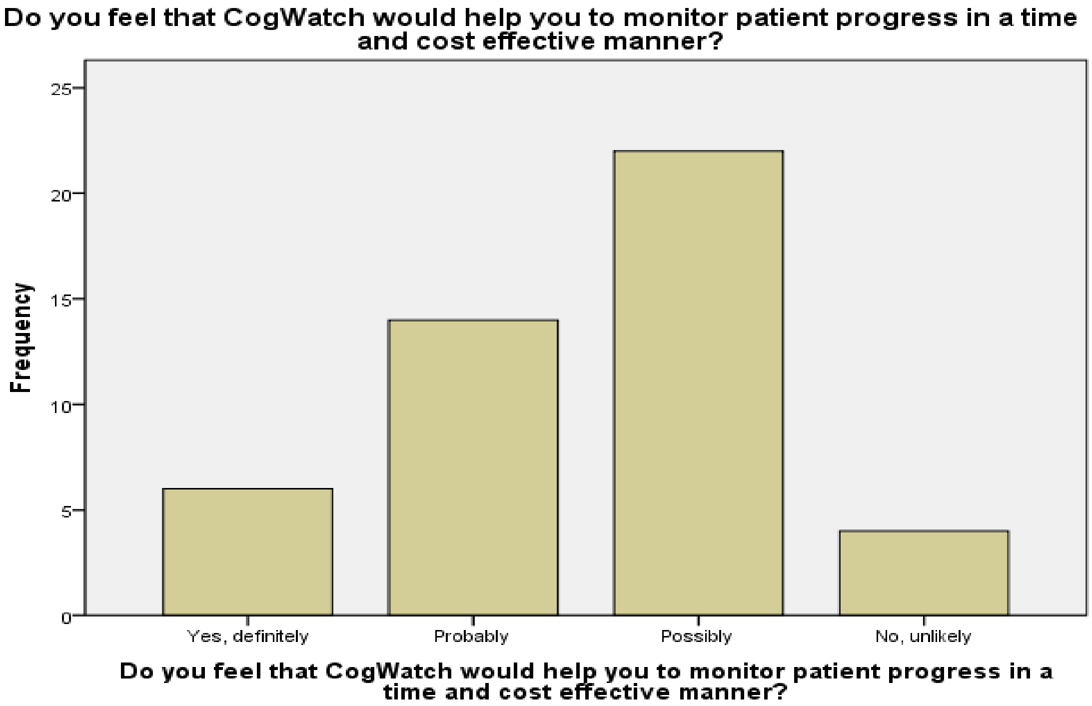

Figure 7: Opinion on the potential for CogWatch to assist healthcare professionals to monitor progress in a time and cost effective way

91.3% felt that there was potential for the CogWatch system to achieve this, with 56.5% of those believing these benefits were probable or definite. 8.7% felt that the system would be unlikely to deliver such benefits; the reasons for this were not specified within the majority of questionnaires; however, one participant commented that ‘the system may be trying to deal with too many variables, which is laden with logistical difficulties’.

4.2 Stroke Survivors and Carers questionnaire

Results for stroke survivors and carers are based on four focus groups that took place at groups run by the Stroke Association and one arranged by the psychology department at the UOB.

Stroke survivors who attended the focus groups were also asked to complete a questionnaire looking at demographic information, as well as their support needs pre and post stroke.

In total 7 carers and 11 stroke survivors participated in the focus groups, of which 9 stroke survivors returned completed questionnaires.

4.2.1 Questionnaire to determine patient and carer demographics

Figure A

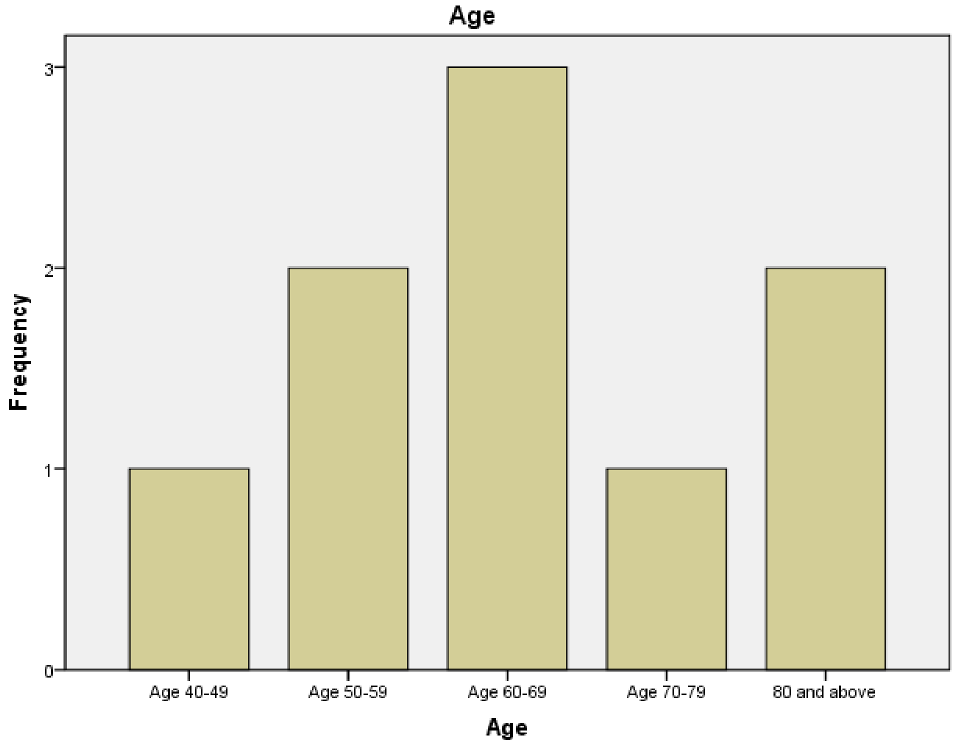

Figure A: Age of Stroke Survivors

Figure B

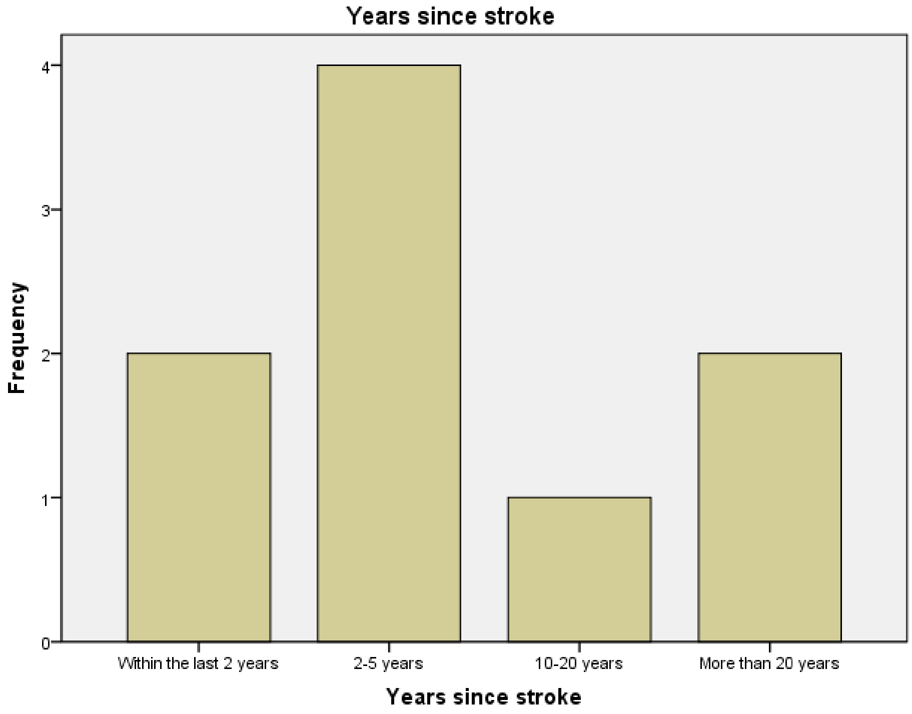

Figure B: Time since stroke

Of the 9 people who completed the stroke survivors' questionnaire 7 were males and 2 were females. Figure A and B show their ages ranged from 40 to 80 years old, and the time since stroke varied from 1 to 22 years.
The questionnaire showed that there were no changes in living arrangements as a result of the stroke with 8/9 (90%) living with family prior to and after the stroke and one still living independently.

Figure C

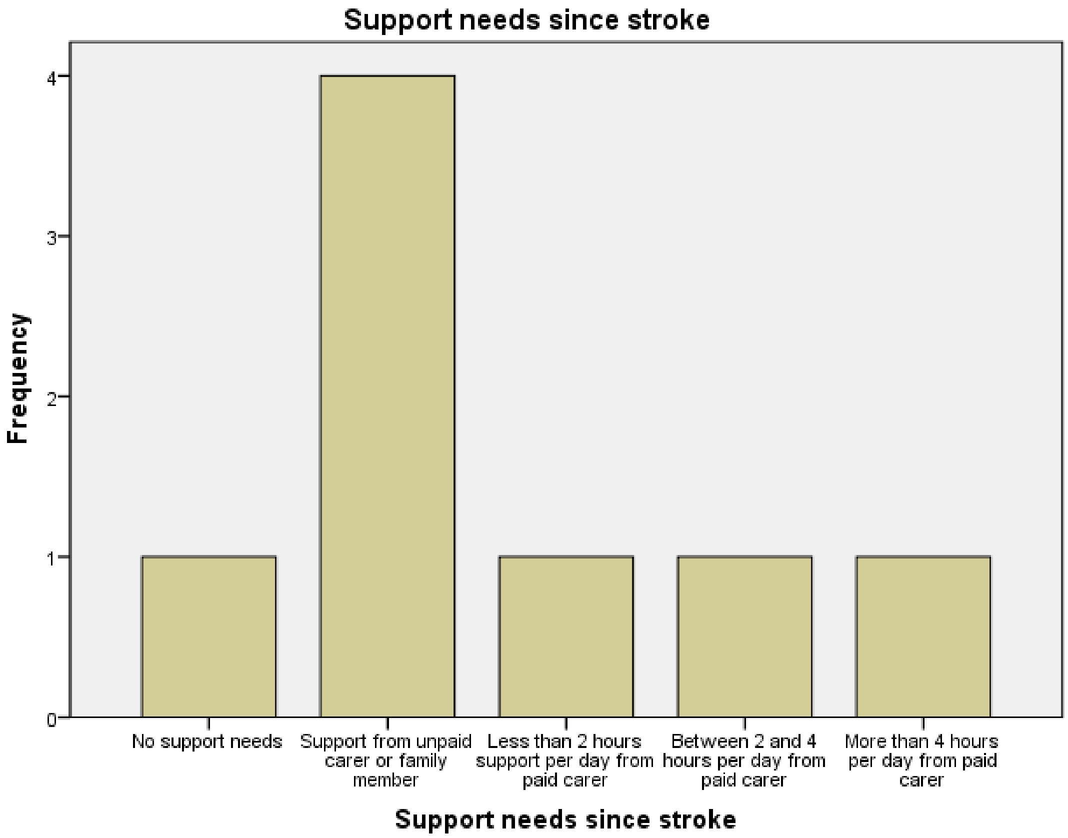

Figure C Support needs since stroke

Prior to their stroke, all participants were fully independent describing themselves as having ‘no support needs’. After their stroke, only one of the 8 people who completed the question continued to consider themselves as having no support needs. Fifty percent (n=4) reported that they receive support from a family member or unpaid carer, and the remaining 3 participants required support from a paid carer.

Figure D

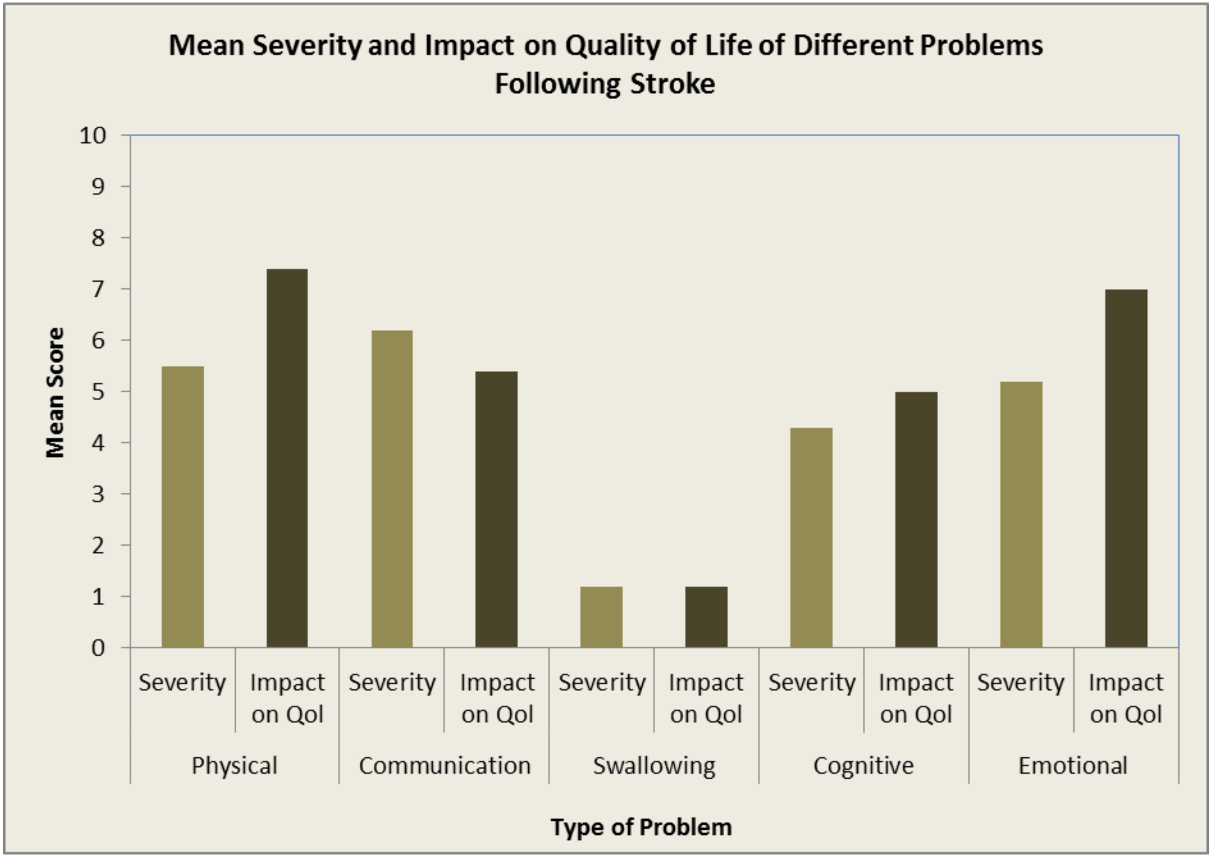

Figure D: Mean severity and impact on quality of life of different problems following stroke

Figure D demonstrates how stroke survivors rated their current impairments in terms of severity and the impact on their quality of life, where 1= no difficulty and 10=extreme difficulty. While the sample size is small (n=5 or n=6), it can be seen that despite having the same diagnosis (stroke) people consider themselves to be affected differently. In terms of cognitive deficits (the target of the CogWatch device), severity was rated as an average of 4.3 out of 10, and impact on quality of life an average of 5 out of 10. Physical problems, communication problems and emotional problems were considered as more severe and as having a greater impact on quality of life than cognitive problems; however, the small sample size limits the generalizability of the findings.

Figures E to H below represent the amount of support that stroke survivors judged themselves to require in completing the four activities of daily living focused on in the CogWatch project

Figure E

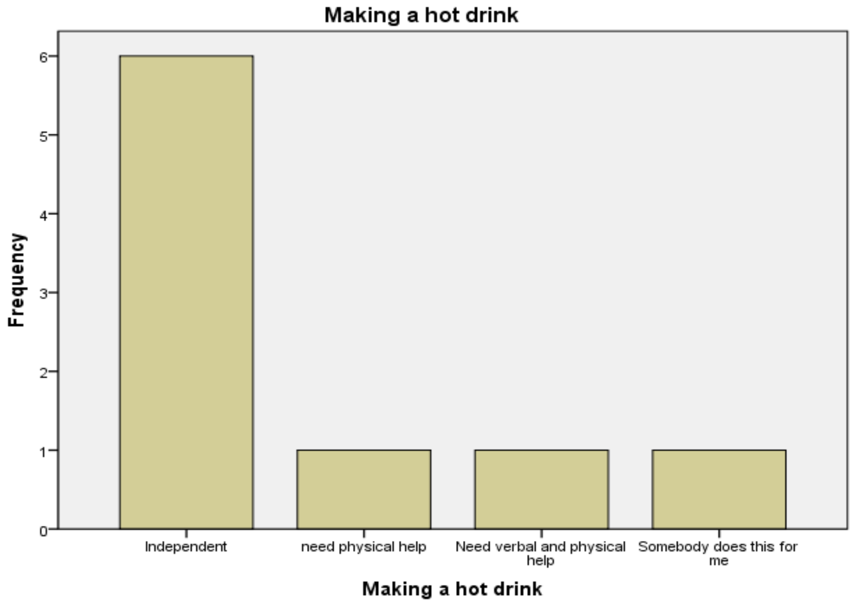

Figure E: Making a hot drink

Figure F

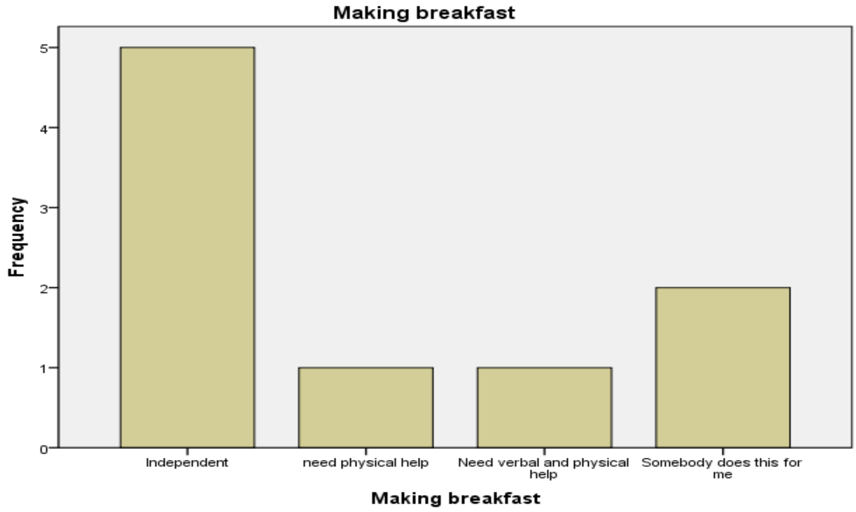

Figure F: Making Breakfast

Figure G

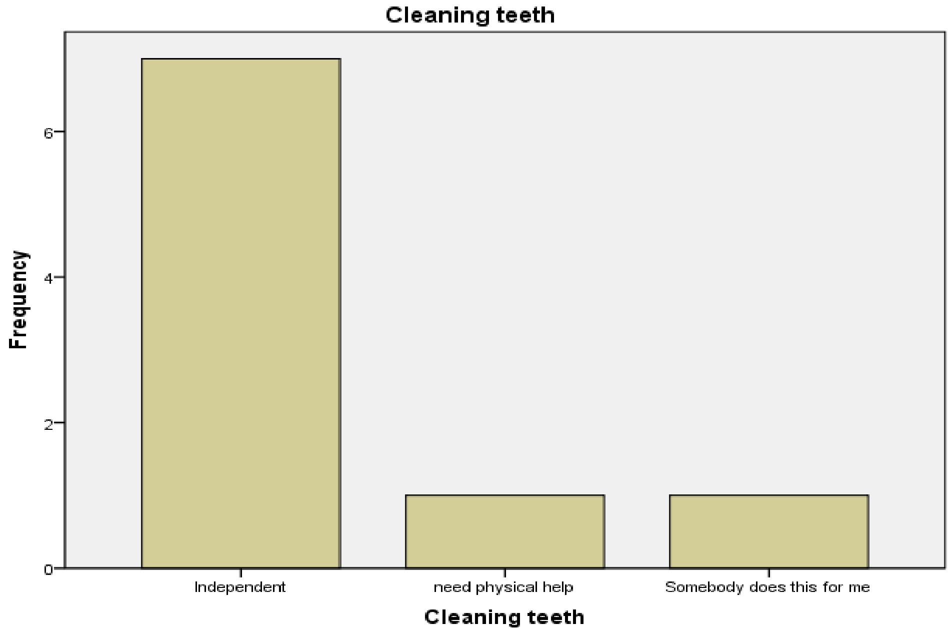

Figure G: Cleaning teeth

Figure H

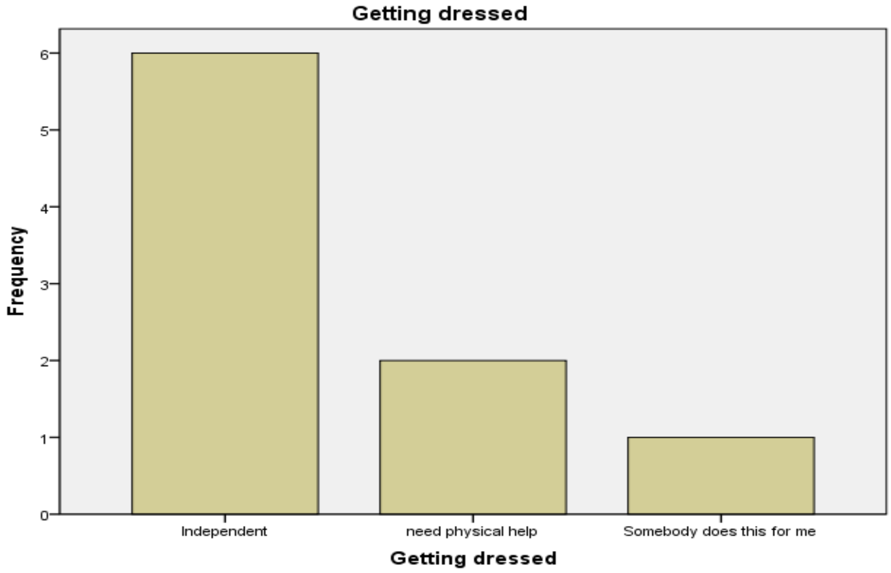

Figure H: Getting Dressed

Figures E to H:
Most participants rated themselves as independent in all tasks (77.8% for cleaning teeth, 66.6% for making a hot drink and getting dressed, and 55.6% for breakfast). 11.1% had somebody make them a hot drink, get them dressed and clean their teeth, while 22.2% had somebody make their breakfast for them. The remaining participants required either physical help or both verbal and physical help. None of the participants rated themselves as requiring only verbal help.

Figure I

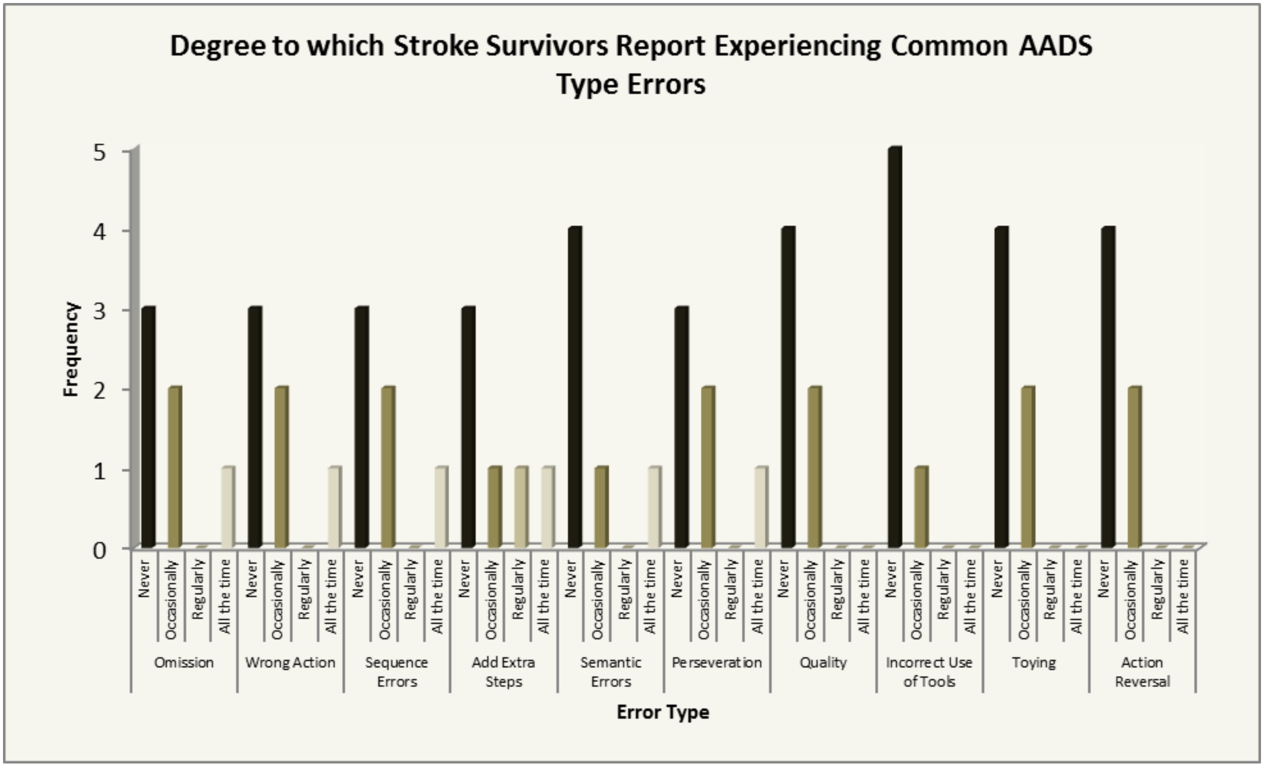

Figure I: Specific types of cognitive errors experienced by stroke survivors
As can be seen from the graph, for each error type, at least half of stroke survivors (n=3 to n=5) rated themselves as 'never' experiencing that type of error. For each type of error one or two stroke survivors rated themselves as experiencing that error type 'occasionally'. One stroke survivor rated themself as experiencing omissions, wrong actions, sequencing errors, adding extra steps, semantic errors, and perseverations 'all the time'.

4.3 Healthcare professionals’ perceptions of the Benefits of Assistive Technology for therapy, carers and service users from the questionnaire

4.3.1Benefits for Service Users – Professionals Opinions (96 respondents)

The most commonly cited benefit was an increase in independence. The term ‘independence’ was used by twenty-five healthcare professionals to describe the potential benefits for service users. Seven professionals described similar benefits without specifically using the term ‘independence’, comments included ‘more autonomous’, ‘greater sense of autonomy’, ‘less dependent on others’, ‘increased participation’, ‘more able to do activities of daily living’, ‘greater ability and control’, and ‘relearning tasks’.

Ten professionals commented on the potential for technology to have a positive impact upon service users’ wellbeing. Their comments included ‘improves mood’, ‘more confident’, ‘better lifestyle’, ‘increased self-esteem’, ‘greater sense worth’, ‘increased participation’, ‘more motivated’, ‘happier’, ‘sense of achievement’, ‘feel more control’.

Three professionals commented on the potential to make the person safer within their own home: ‘enable the person to remain at home’, ‘safer at home’, ‘can provide safety’.

Two professionals commented on the potential benefits for younger service users: ‘many patients like technology, especially younger patients’ and ‘engaging, particularly for younger people’.

One professional commented that technology can be ‘more cost effective’ for patients.

One professional commented that technology ‘can provide continuing therapy between meetings with the therapist’ and another said it provides ‘consistent rehabilitation’.

4.3.2 Benefits for Carers – Professionals Opinions

Fifteen professionals surveyed considered that technology has the potential to have a positive impact on carer wellbeing. Eight commented that technology can provide ‘peace of mind’ or ‘reassurance’, while other phrases included ‘reduced anxiety’, ‘reduced feeling of burden and stress’, ‘less tired’, ‘less pressure on carer’, ‘feeling less anxious’, ‘less frustration’, and ‘more free time’.

Fourteen professionals commented on the ability for technology to reduce the amount of support that carers are required to give, for example: ‘less care work’, ‘less dependent relative’, ‘reduced supervision needs’, ‘less support needed’, ‘less reliant patient’, ‘not having to provide prompts’.

One professional commented that technology can help carers ‘gain insight into relatives deficits’, while another commented it gives carers ‘a sense that something is being done’, and another said ‘something the carer can do with the patient between visits’.

One professional suggested it can lead to a ‘better relationship’ between the service user and carer.

4.3.3 Benefits for Therapy – Professionals Opinions

Twelve professionals commented on the potential for technology to improve therapy outcomes for service users, with six remarking that it could lead to increased ‘independence’. Other comments included ‘increase in function’, ‘better outcomes’, ‘better functional ability’, ‘more skills’, ‘better engagement’, and ‘better medication compliance’.

Nine professionals commented on the potential for therapy to continue outside of sessions with the therapist. Comments included: ‘24/7 opportunity to generalise skills’, ‘less dependent on professionals and appointments’, ‘complements therapy’, ‘therapy can continue in the absence of the therapist’, ‘continued therapy in non-clinical setting’, ‘rehabilitation when the therapist isn’t present’, ‘increased time spent on rehab tasks’, ‘consistent prompts in the absence of the therapist’, ‘supports therapy input’.

Three Professionals commented on the potential for technology to save therapists time, ‘reduced time load on staff’, ‘frees up therapist time’ and one commented that it can also save money, ‘saves time and cost’.

Two professionals commented on the potential for technology to help with the assessment of patients, two suggested it allows the therapist to focus on other aspects of patient care, one commented that it can ‘help with risk management’ while another said it can ‘enable safer discharge’, and one commented it can provide ‘standardised measurable results’.

One professional commented on the potential for technology to provide professional development for the therapist, saying it ‘expands role and provides a learning opportunity’.

4.4 Limitations of Technology

4.4.1 Limitations for Patients – Professionals Opinions

Sixteen of the ninety six professionals surveyed considered technology that is difficult use to have limitations for patients, e.g. ‘struggling to understand how to use equipment’, ‘new equipment causing confusion’, ‘learning something new’, ‘may struggle to learn how to use technology’, ‘sometimes too complex for people with cognitive problems’, and ‘may be technically too difficult to use’.

Seven professionals commented that cost can be a limiting factor, e.g. ‘initial cost’, ‘cost’, ‘lack of funding’, and ‘cost of device’.

Three commented on potential faults with the technology; ‘technology can fail’, ‘frustration with poorly functioning equipment’, and ‘frustrating if system breaks down’.

Three professionals commented that a lack of on-going support may be a limiting factor in patients using technology. Comments included ‘lack of support on a continued basis’, ‘lack of training’ and ‘not enough specialist support’.

Two commented that patients may feel stigmatised by technology, ‘embarrassment for client’, and ‘perception, it may not be seen as normal’.

One commented that ‘technophobes may prefer a person’, one said ‘patients do not use’ technology, and another said the ‘patient may lose interest’.

4.4.2 Limitations for Carers – Professionals Opinions

Six professionals commented that issues with understanding how to use technology, or understand its potential benefits, may be a limiting factor for carers. Comments included: ‘may not be familiar with equipment’, ‘carers lack of understanding of technology’, ‘ignorant about technology’, ‘lack of understanding’, ‘not understanding the benefits or purpose’, and ‘hard to use’.

Four commented that carers may have issues with trusting technology; ‘carers have to put faith in technology’, ‘it could break down, carers need to be able to trust it’, ‘anxiety about equipment’, and ‘may not have confidence in technology’.

Three professionals commented that the cost of technology may be a limiting factor for carers; two said ‘cost’, and the other said ‘cost implications’.

Three commented that training can be too time consuming, while a further three commented that there was a lack of training available.

Two professionals said carers may have concerns that technology is taking their place, ‘loss of role’ and ‘fear of being replaced by technology’.

One commented that technology may not ‘fulfil expectations’ and another said carers ‘don’t get a true break, they still need to be on call’.

4.4.3 Limitations for Therapy – Professionals Opinions

Eight professionals commented that the cost of technology was a limitation for use in therapy; six used the term ‘cost’, while other comments included ‘cost to implement’, and ‘access to funding for equipment’. Five commented on access and availability issues: ‘limited availability of devices’, ‘waiting times’, ‘waiting lists’ and ‘access to services’ and ‘problems with availability’. Four commented on limitations in terms of professionals time: ‘time consuming’, ‘therapists have limited time’, ‘length of time to set up and monitor the programme’ and ‘can be time consuming for therapist’.

Seven commented on issues with professionals knowledge and understanding, e.g. ‘don’t know how to use equipment’, ‘lack of knowledge of what’s available’, ‘therapists understanding of technology’, ‘therapist not always knowing how to use equipment’ and ‘lack of knowledge and experience’.

Seven commented on potential difficulties with the device, with three of the comments stating that the technology may not be flexible enough to meet the needs of different patients, ‘inflexible, ‘difficulties adapting software to individual needs’ and ‘not flexible enough for different needs’. Two felt that the device may not provide adequate feedback to inform therapy, ‘does not provide sufficient feedback’ and ‘might not provide necessary feedback’. One felt technology may have ‘faults’ and another said it might be ‘hard to use’.

Four commented on the need for training and support: ‘lack of engineering support’, ‘training’, ‘requires training’, need training and engineering support’.

Two commented on patient factors: ‘the person has to remember to wear a watch’ and ‘patients might forget to wear a watch or take as phone with them’.

One commented ‘computers are never as good as humans’.

4.5 Daily tasks AADS patients struggle with – Professionals Opinions

Four professionals commented that AADS patients struggle with ‘all’ activities of daily living. Twenty-nine commented on difficulties with personal activities of daily living, of these 14 used the term ‘personal care’, while the remaining fifteen mentioned specific activities such as ‘washing’, ‘dressing’, ‘brushing teeth’, ‘showering’ and ‘grooming’.

Three used the term ‘domestic’ tasks, 25 spoke about kitchen based activities, four of which mentioned making a ‘hot drink’, while the remaining 21 mentioned food preparation, for example, ‘making food’, ‘cooking’ and ‘making meals’.

Eighteen commented on cognitive abilities, specifically five said ‘planning’, three said ‘organising’, three said ‘sequencing’, three said ‘initiation’, two spoke about ‘memory’, one about ‘problem solving’, and one about difficulties with ‘learning’.

Two commented on difficulties in accessing the community safely, including ‘community safety’ and ‘safety in the street’.

One professional mentioned difficulties with ‘speech and communication’, another with ‘feeding self’ and another with ‘driving and work’. One mentioned problems ‘cleaning’ and another with ‘using the phone’.

4.6 Daily Tasks Stroke Survivors Find Difficult – Results from focus groups

During the focus groups stroke survivors and their carers mentioned a number of daily tasks that can be difficult following stroke. Their comments reflected their personal experiences. It should be noted that it was not determined whether stroke survivors who participated in the groups met criteria for a diagnosis of AADS.

Specific tasks participants struggled with included: setting the table, changing the bed sheets, gardening, going into the community and ‘kitchen activities’. One stroke survivor’s comment demonstrated the breadth of activities that were affected following his stroke: ‘when I was discharged my family had to teach me how to do everything, like washing and dressing, shaving, brushing my teeth, tying my laces, and fastening buttons. A system that could do that would have been useful and meant my family would have had more time'.

Some stroke survivors spoke about how the cognitive and physical effects of stroke impacted upon their ability to perform certain tasks. Comments included 'I have problems with my memory and speech. I can't take in lots of information'; 'I can't read for long now. If there is too much information I get tired and can't retain what I have read'; and 'I had to relearn everything as my dominant hand was taken so I've got no movement'.

4.7 Service users experience of rehabilitation after discharge from hospital

All service users and carers who participated said they felt there had been a lack of follow-up after they were discharged from hospital. One said that they had 'seen a physiotherapist a few times, but it didn't last long enough'; the others denied receiving any community based rehabilitation post discharge.

4.8 Service Users Experience of Technology

During the focus groups, one stroke survivor said they had been offered a pill dispenser and a pendant alarm. All remaining stroke survivors and carers said they had never been offered any technology as part of their recovery.

4.9 Features that the Cogwatch system should include – professional opinions (results from the questionnaires)

4.9.1 For professionals – Professionals Opinions

Five commented on the data generated by the system, comments included: 'easy and quick interpretation of data', 'provide therapeutically useful information', 'remote monitoring', 'data that is easy to collect', and 'feedback that can be accessed'.

Eight raised the need for the system to simple to use, for example, ‘easy to access and use’, ‘easy to use’, and ‘fast and simple to set up and use’.

Six commented that it needs to be able to be tailored to meet the needs of individuals, for example, ‘tailored for the individual person’, ‘meets the patients needs’, and ‘adaptable to individual needs’.

Five commented that it must be cost effective, for example ‘low cost’, ‘affordable pricing structure’, and ‘cost effective and efficient’.

Five commented on the importance of the professional receiving support to understand and use the system. Suggestions included: ‘help lines’, ‘easy to contact help if system breaks down’, ‘training days as appropriate’, ‘education so we know what is available and how it can be used so we can identify appropriate patients’ and ‘clear instructions and training’.

4.9.2 For Carers – Professionals Opinions

Fourteen professionals commented that carers would benefit from the system being simple to use, for example: ‘ease of use’, ‘be very simple to problem solve’, ‘very clear with few instructions’, and ‘easy to use features, such as touch screen’.

Seven commented on the need for carers to receive support to use the system, for example ‘instructions what to do if system breaks down or assistance is required’, ‘help lines’, ‘point of access for on-going questions’, and ‘ensure they know all the uses’.

One commented that carers would benefit from the system ‘meeting patient’s needs’. Another said it should be ‘unobtrusive for others sharing the same accommodation’, one said it should include a facility for carers to ‘check back how the patient is progressing’, and one commented that ‘pictures, a large screen and audio’ would be good features to include for carers.

4.9.3 For users – Professionals Opinions

Sixteen professionals commented that users would benefit from the system being easy to use, for example ‘clear instructions and simple to use’, ‘needs to be very simple’, ‘easy to use’, and ‘very easy to use’. Two of the sixteen mentioned this in the context of specific communication difficulties commonly faced by people following stroke and/or with AADS, saying ‘dysphasia friendly, as dysphasia often presents alongside apraxia’ and ‘clear instructions considering patients level of communication and communication difficulties’.

Six professionals commented that users need the system to be individualised to their specific needs, suggesting there is an ‘option to modify modality of feedback for individuals needs’, ‘tailor types of prompts to patient’, ‘everyone with a stroke is different and will need different types of information’, ‘personalised’, ‘adaptable for patients needs’, and ‘can be tailored to individual’.

Five commented on the need for the system to avoid stigmatising the user, commenting ‘should look nice and normal’, ‘normal looking’, look like a real watch so it doesn’t make them feel different or attract unwanted attention’, make it look like a consumer product’, ‘look normal’.

Three commented that touchscreen would be beneficial, while other features that were suggested for users included a ‘panic button to contact a carer’, ‘a big clear screen’, ‘bright and relatively small’, ‘sensors in the watch’, audio and visual alerts’, a ‘familiar voice’, ‘small and portable’, ‘light and attractive’, and ‘lightweight’.

Two commented that the system should be ‘unobtrusive’; one said it should be ‘low cost’, and ‘help lines’ and ‘on-going support’ were also identified as useful for users.

4.10 Features to include – Stroke survivors opinions (results from focus groups)

This exercise with stroke survivors was very useful in highlighting the wide range of needs that they have and the different ways in which people have been affected by stroke. It was summed up by one stroke survivor, who said 'no two people are the same after stroke'. This highlights the importance of the proposed CogWatch device being flexible enough to meet the needs of people with a range of difficulties.

Three stroke survivors said they would like a touchscreen, while one said they would 'prefer a keyboard as I am used to it. I've never used a touchscreen'.

One stroke survivor explained that his stroke had left him 'not able to follow written instructions, but I also have hearing problems', while another had 'physical problems and my eyesight is bad'.

One said he would like the system to be 'voice activated' while others made it clear they would not be able to use this kind of function due to speech problems. Three reported regularly wearing a wrist watch, while four said they would be unable to use a wrist watch due to varying degrees of weakness in one arm.

Other interesting comments were raised about the suitability of different people's homes; 'it would need to be assessed and then set up in the home environment' and 'not everybody's house has space for a lot of equipment'.

One stroke survivor raised his anxieties about technology saying 'I'd be frightened to death of technology, but I'd try to use it if I was taught how and had a lot of support'.

4.11 Features to include – carers opinions

Carers spoke about their experience of supporting somebody following stroke and the types of features that they felt would be beneficial.

One carer commented ‘after stroke people have good days and bad days and are variable in terms of memory and speech abilities. This can make it harder for them to use technology on some days’.

Two carers commented about the importance of the system being simple to use, one of which put this in the context of older stroke survivors ‘older people may be intimidated by technology, therefore it needs to be very simple to use’.

Two commented on the importance of the system being affordable in order to maximise access to it, commenting: ‘cost needs to be kept down. A lot of communication aids like Lightwriters are available but not used as each one costs £3000’; and ‘it shouldn’t be too expensive or people won’t be able to access it’. Three carers suggested one way of keeping cost down would be to use the equipment that people already have available within their homes: ‘equipment needs to be able to be used flexibly. It should be able to be installed on different pieces of equipment that the person already has in their home, such as a TV, a laptop, a tablet, or a mobile phone, in order to accommodate personal preference and keep cost down.’; ‘sensors should be able to be fitted into the persons existing home appliances, rather than them having to buy separate equipment’; and ‘everyday objects need to be lightweight and the persons own kitchen objects should be able to be adapted’.

Four commented on the importance of personalising the system to meet different people’s needs: ‘it needs to be able to be programmed for the individual’s needs, as everyone with stroke has different needs and progresses at different speeds’; ‘the way information and prompts are provided should be flexible. It should include options for touch screen, voice recognition, vibration, visual and verbal prompts, and then an assessment should decide which ones are used for each person’; ‘to be able to personalise it for different people, for example they might need thickener in their drinks’; and ‘needs to be able to be individualised as everyone is different’.

Four carers felt it was important for the system to allow the person to contact help if needed: ‘a panic button should be included and provide a way of having a two way phone call with the person where you can see them and hear them’; ‘it should link into a call centre, or carer support, or health professional following discharge'; 'having a button for an emergency would be good, so if the person was on their own they could call help' 'contact details for relevant people should be included, for example their GP or social worker'; and 'it should definitely link the person to the outside world, for example to a care agency or someone who can help them'.

Two carers commented on the need for the system to have a positive impact on the person's wellbeing: 'it needs to ensure it increases positivity, confidence and independence in the person', and the 'system needs to be manufactured to that person's age as it should not make them feel like a child'.

Specific suggestions for the device included: 'being able to see the image of a person so that they have gestures to follow'; 'if using words or text these need to be simple and at a speed that the person can follow across the bottom of the screen, like on a karaoke, but you need to be able to change the speed'; 'it needs to account for what people did before the stroke; my husband never used the kitchen'; 'it needs to be programmed for everything the person finds hard, not just a few tasks'; 'there should be options other than a wrist watch, such as a pocket watch like nurses wear'; 'language needs to be simple and easy to understand and should be provided in a range of different languages'; 'a lot of people with stroke have problems distinguishing their left from right, so instructions should also include arrows telling them the direction they should move in'; and 'my husband gets frustrated if things are not easy to use and would need training and support to use technology'.

4.12 Features the CogWatch System should avoid – Professionals Opinions

4.12.1 For Professionals

Eleven professionals suggested the system should avoid being too complicated or difficult to use, e.g. 'complex instructions', 'complicated equipment', 'complicated to use' and 'complexity'.

Four professionals commented that the system should avoid being too expensive, 'high cost', 'expensive', 'too expensive' and 'costly'.

Two commented on the need to avoid ‘techno speak’ and ‘jargon’.

One professional suggested avoiding ‘raw data collection only’, one said it ‘needs to be readily available’ and another said it should avoid being ‘inflexible’.

4.12.2 For Carers

Thirteen professionals commented that the system should avoid being difficult to use for carers, e.g. ‘complex’, ‘over-complicated or highly technical’, ‘over complication’ and ‘needs to be easy to use’. Three more commented on the need to avoid ‘jargon’.

Two suggested avoiding additional upkeep, ‘lots of upkeep’ and ‘additional burden such as charging up equipment’.

One suggested avoiding making the system ‘unreliable’, another said ‘cost’ could be an issue, and another suggested avoiding making the system ‘time consuming’.

4.12.3 For Patients

Sixteen professionals commented that for patients the CogWatch system should avoid being complex to use, e.g. ‘complex instructions’, ‘complicated to learn and use’, ‘complexity’, ‘complicated equipment’ and ‘over complication’.

Six commented on the appearance of the device suggesting the following features should be avoided; ‘uncomfortable’, ‘unattractive’, ‘fiddly’, ‘bulky’, ‘heavy’ and a ‘cluttered screen’.

Two said the device should not stigmatise the person, ‘stigmatising’ and ‘identify the person as having a disability’.

One said the device should avoid having ‘alerts that can be easily ignored’ while another said it should avoid ‘over repetition of prompts’.

5 Discussions

5.1 Provision of Stroke service follow-up

Due to the range of methods used to recruit participants (refer to methodology section), and the online nature of the questionnaire, we were unable to monitor response rates, to determine how many people from each profession received the link, or track how responders heard about the questionnaire. Almost half (49%) of those who responded to the health professional questionnaire were occupational therapists (OT's) which was a surprising large percentage given that many different professions were targeted. There are many possible reasons for this, for example a greater number of OT's may have been asked to complete the questionnaire, or perhaps this could be a reflection of the occupational therapists growing role in using technology within the rehabilitation process as one of the core skills for OT is the assessment and provision of aids and adaptations.

It is reassuring that the majority of participants reported working for a service that provides community follow-up after stroke patients are discharge from hospital, with a reported 60.6% providing follow-up care for at least a year if needed. This is in contrast to literature reports which state that stroke survivors often receive no follow-up care and often call for after stroke services to be improved (Smith et al. 2003; Lindqvist et al. 2011). Perhaps the considerable involvement in the follow-up care reported in this research reflects changes due to the implementation of the National Clinical Guidelines for stroke (2004) which called for a redesign in the services that were offered to Stroke survivors both in the hospital and community.

The reports from healthcare professions contrast with the reports of stroke survivors and their carers given during focus groups, where all participants reported to have received little or no follow-up after discharge from hospital. There are many possible reasons for this, e.g: service provision varies between geographic locations; services have improved since some of those who participated in our groups had their stroke (range 1 year – 22 years); stroke survivors and carers' expectations may be different to the actual services on offer;, or perhaps current services are not meeting the needs of stroke survivors.

Further study would be required to determine the exact reasons for this difference in reports.

The demographic questions in the professional's questionnaire show that the respondents were clearly experienced in working with stroke patients, with 79.8% of professionals having at least two years' experience. This high level may have been because the targeted groups were mostly specialists in the area of stroke/brain injury. When asked about their experience of working with AADS clients, 80.3% reported spending little or some therapy time in this kind of patient, which complements current literature stating that health professionals are often more focused on physical issues than the cognitive in order to reduce length of hospital stay.

5.2 Error frequency and daily tasks related to CogWatch

When asked about the common types of errors made by stroke survivors, healthcare professionals reported observing errors with a normal distribution, highlighting that professionals feel all types of errors may occur within this client group.

Healthcare professionals acknowledged the presence of all of the identified error types to some degree in AADS patients thus complementing what was found in the earlier deliverable within this project 'Literature Review' D1.2. It maybe error frequency can be given further consideration during the laboratory testing.

Stroke survivors and healthcare professionals reported different common errors for patients with AADS. At least half of those who completed the stroke survivors questionnaire rated themselves as 'never' experiencing the types of errors that were reported as common by the healthcare professionals. This may indicate that many of the stroke survivors who made up our sample did not have experience with AADS.

One stroke survivor rated themself as experiencing omissions, wrong actions, sequencing errors, adding extra steps, semantic errors, and perseverations 'all the time'. Interestingly health care professionals also rated omissions, sequencing errors and perseverations amongst the most common errors. When looking at which tasks should be addressed by the CogWatch system the health professionals and stroke survivors were in agreement. Both groups reported that tasks to do with personal care and kitchen activities such as ‘making a hot drink’ and ‘preparing meals’ are the areas which they feel patients with cognitive limitations find difficult. These results complement the current plans for the design of the CogWatch system.

When considering the dependence level of stroke survivors in the four activities of daily living, the results should be interpreted carefully. Stroke survivors were asked about making a hot drink, making breakfast, cleaning teeth and getting dressed, and given the option ‘somebody does this for me’. However, the questions did not ask the person to specify the reason for requiring assistance. It could be due to them being unable to complete the task themselves or it could be due to choice or habit. The specific reasons would have been useful to know, because it is unclear from the data whether dependence in these daily tasks is often due to cognitive factors that may potentially be ameliorated by the CogWatch device. This can be further considered during the next phase of evaluation, as it should provide user opinions to supplement the results gained through laboratory testing of the device prototype

It is important to note that other task were mentioned by healthcare professionals as problem areas for AADS patients, tasks which are currently not included in the CogWatch plans. These tasks were often to do with community support, work, driving and cleaning. Stroke survivors echoed these views: they mentioned tasks such as ‘changing beds’ and ‘setting the table’. Some of the carers mentioned that the tasks covered by the CogWatch plan, such as making a hot drink or preparing breakfast, were not completed by the stroke survivors prior to their stroke and so a device restricted to these daily activities would not be useful to all patients. This point reiterates the need for CogWatch individualised for the tasks it can assist. This is another topic for consideration during the next phase of evaluation.

5.3 Use of Technology within Rehabilitation

From the findings of this evaluation it is clear that the use of assistive technology is not common within the field of rehabilitation. The survey found that 62.9% of health professionals considered themselves to have ‘little’ or ‘some’ experience with only 8 respondents having ‘considerable’ and one classed as ‘expert’. When asked about types of technology professionals currently use or have used in the past, the high majority reported using equipment for memory and then stand-alone pieces that come under the umbrella of Telecare.

Interestingly stroke survivors and carers commonly reported in the focus groups that they had not been offered any form of assistive technology after hospital discharge, with only one stroke survivor reporting they were given a pendant alarm and pill dispenser. These findings may be due to the length of time since stroke (1-22yrs) but from a professional viewpoint, they demonstrate that technology still is not seen as a mainstreamed tool and is not embedded into care pathways. These findings dispel the literature where it was envisaged by the UK government that technology would be an integral part of all care pathways by 2010 (Hanson et al. 2005). Perhaps the press release from the UK Government in January 2012 which highlights the results from a large pilot study being completed around Telehealth and Telecare within three areas of the UK; www.3millionlives.co.uk increased the professional’s interest within this area and project thus enhancing the CogWatch project.

The results also suggest that there may be a conflict of opinion between professionals and users when it comes to technology use by stroke survivors. The results show that professionals felt that clients ‘*don’t use technology’* and ’*technophobes may prefer a person’* where as the user focus groups demonstrates that some stroke survivors are already using forms of technology – computers, tablets, mobile phones. One patient commented that despite anxiety surrounding technology, with training and support they would try it.

A big issue raised by both healthcare professionals, stoke survivors and their carers was lack of training and awareness around technology, which is known to be a common barrier for end users and healthcare professionals (HACT 2007; Gentry 2009; Svoboda et al. 2012). A high majority of participants reported the need for training and on-going support, especially from a technical view point if CogWatch is to be of benefit. Thus, training should be made available for all health professionals in order to embrace CogWatch within their day to day rehabilitation. Training and support must also be available to help stroke survivors and their carers use the device effectively and overcome potential concerns regarding technology.

Suggestions made around developing clinical champions within clinical settings (HACT 2007) or the development of a clear training package (SvoBoda et al. 2012) can enhance professionals, users and carers engagement in the use of technology, as well as having access to technical support; an area which will need clear consideration within the dissemination of this project.

5.4 Design of CogWatch

From the information gathered, a clear shared theme between stroke survivors, their carers and professionals is that people are affected very differently and diversely following stroke. Cognitive difficulties were reported to very rarely appear in isolation: '*no two people are the same after stroke'* reported one stroke survivor and *'CogWatch needs to be able to be programmed for the individual's needs, as everyone with stroke has different needs and progresses at different speeds'* reported carers.

These statements highlight the importance of the device being flexible enough to meet the needs of people with a range of difficulties, a point that is clearly stated in the literature (Scherer 2005; Nubia et al. 2008; Jones et al. 2010). The different way of overcoming physical, communication and sensory problems must be carefully considered and incorporated in the design to maximise usability, by patients with a range of daily challenges. The device would not be useful if it helped patients with their AADS impairments but hindered their recovery in other areas, such as motor movements or communication.

There is also a need for health professionals to have the ability to holistically assess the user for provision of technology. This was a clear concern of stroke survivors as they raised comments about the suitability of different people's homes.

Common themes around the design of CogWatch:-

- The need for the device to be simple to use for users, carers and professionals.
- The need for it to be very flexible in terms of the ways it provides feedback, so that it can overcome the wide range of problems people with stroke have; suggestions being use of voice, auditory, text and vibration
- The need for it to look normal to avoid stigmatising the person.
- To need for access to a helpline for technical support for carers and professionals
- For users to have a panic button to summon help
- The need for the system to be linked to nominated health professionals i.e. therapist, nurse specialist, GP
- To be small adaptable and any tools used to be light weight

Through the discussions with Regional Innovations Group, regarding technology previously used by healthcare professionals, pieces of technology already on the market were identified that could potential contain elements to meet the objectives of CogWatch (Appendix 10.8).

The literature has shown that with the development of new technologies including smart phones and PDA’s, individuals may already have systems in place at home that could be incorporated within the design of CogWatch (Joode et al 2010; Lindqvist et al. 2011; Svoboda et al. 2012). This suggestion was also raised during the focus groups with stroke survivors and carers. Exploring the incorporation of existing technologies into CogWatch system in greater detail may help to keep the cost of the device down and prevent reinventing something that is already available.

5.5 Benefits **of CogWatch**

Common themes from professionals are:-

- User may experience increased independence and improved wellbeing.

- Carers may achieve improved wellbeing, particularly through technology providing peace of mind and reassurance and having a less dependent relative.
- Professionals may achieve improved therapy outcomes, save time and deliver safer discharge from hospital because of the continued assessment of patients in their homes.

91.3% of Healthcare professionals who responded felt that the CogWatch system has the potential to monitor patient progress in a time and cost effective manner.

6. Limitations of this evaluation

- With hindsight it may have been beneficial to also target General Practioners (GP's) as this may have provided a greater range of opinions and experiences. This could be included at the next stage of evaluation. As the project moves closer to the dissemination and exploitation phases it may be particularly useful to speak to GP's given their proposed role in commissioning within the UK as outlined by the Health and Social Care Bill (DOH 2011).
- Despite initial pilot testing of the healthcare professionals' questionnaire there were low response rates to some questions. No response may indicate the questionnaire was not user friendly enough, that respondents didn't feel able to answer certain questions or perhaps that responders did not consider certain questions relevant to them. These issues may require further consideration during the next stage of evaluation in order to maximise responses.
- Focus groups with stroke survivors and their carers were more time consuming than originally expected. Unanticipated delays included scheduling logistics and difficulty conveying necessary information to potential participants in advance. These delays resulted in a relatively small sample size of Patients (n=11) and carers (n=7) included in the evaluation and will be considered and during the next stage of evaluation.
- The small sample size of patients and carers was further compounded by two stroke survivors not completing the demographic questionnaire, and a further four failing to complete the entire questionnaire. This meant that there were only five stroke survivor questionnaires that were completed in their entirety. Because of time limitations, it was not possible to pilot the stroke survivor questionnaire on this occasion. Due to the restricted length of the focus group sessions, many participants being reliant on transport services and varying levels of fatigue and concentration, participants had to complete the questionnaire in their own time. For this reason, it was difficult to evaluate why some participants had difficulty completing the documents. For future evaluations, more time should be given during the sessions so that all necessary paperwork can be completed in the time allocated.

- In an attempt to make the Patient demographic questionnaire more user friendly and to encourage completion, written and diagrammatical information about the project was given alongside the questionnaire, and participants were encouraged to complete the questionnaire with a carer present. However, it is acknowledged that this may have not been feasible for all participants. If similar data collection methods are used in the next phase of evaluation it is suggested that a pilot study would be beneficial in ensuring the user friendliness of the questionnaire. It may also be beneficial to specifically target carers with a similar questionnaire.
- While many participants had experience of using assistive technology, almost a quarter had no experience in this area. It is possible that this may have influenced their perception of the proposed CogWatch system, particularly given the abstract nature of the proposal at this stage of development. It is probable that those without any experience in this area would find it more difficult to answer some of the questions on the questionnaire relating to the benefits and limitations of assistive technology, and the proposed features of CogWatch. It is suggested that having a means of demonstrating the prototype at the next stage of evaluation, e.g. through a video recording or workshop, may help overcome these issues and increase response rates to questions asking for opinions on technology.

7. Conclusion

This evaluation has gained an important insight into health professionals, stroke survivors and carers experiences of the current health provision for technology in stroke rehabilitation. It provides critical opinions from a range of relevant groups about the potential limitations, benefits and desirable features of the proposed CogWatch system, which should be referred to throughout the design process. The implementation of these results during the next stages of this product will ensure that the CogWatch system is designed to be personalised and of maximum benefit to stroke survivors and their carers by offering long-term cognitive rehabilitation within a familiar environment. Attitudes to the proposed CogWatch system were overwhelmingly positive from all groups involved in the evaluation, which is encouraging for the future use and exploitation of the developing technologies.

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10. APPENDICES

10.1 Professional Information leaflet

COG WATCH
Cognitive
Rehabilitation of
Apraxia & Action
Disorganisation
Syndrome

CogWatch

Information sheet for Healthcare Professionals

Technische Universität München
UNIVERSITY OF BIRMINGHAM
UNIVERSIDAD POLITECNICA MADRID
headwise

BMT Group
The STROKE Association
RGB

Introduction

Stroke is recognized as the leading cause of disability. According to the World health organisation 15 million people worldwide suffer from a stroke each year (WHO 2004).

Following a stroke, people can experience a range of cognitive problems in addition to any difficulties in motor function. Cognitive problems strongly influence how well people functionally recover following stroke.

A recent study in the UK found that 68% of stroke patients showed characteristics of Apraxia and Action Disorganisation Syndrome (AADS) (BUCS 2007). AADS can result in an impairment of cognitive abilities to carry out activities of daily living (ADL) such as washing and dressing, preparing a meal or hot drink. Apraxia and Action Disorganisation Syndrome is defined as:-

- **Apraxia** A neurological disorder of learned purposive movement skill that is not explained by deficits of elementary motor or sensory systems (Rothi & Heilman 1997)
- ***Action Disorganisation Syndrome(ADS)***: Cognitive errors when performing multiple-steps tasks (Morady & Humphreys, 2009)

AADS patients whilst maintaining their motor skills, commit cognitive errors during every day goal orientated tasks which they used to perform automatically. Patients most typically **omit** steps of a task (e.g. make cereal without milk) or **sequence** the steps of the task incorrectly (add sugar before the cereal).

AADS has great impact on patients' individual independence, their families, and the national healthcare systems which have to provide continuous support and care. Thus, technological advances that address these personal and economic costs by enabling independent living of AADS patients would be of great value and must be developed.

Healthcare professionals recognise that **stroke care is typically short-term**; hospital based and often focuses on physical rather than cognitive rehabilitation. Regardless of their functional state, patients are often discharged on physical grounds with the assumption that cognitive rehabilitation, if needed, will continue at home. Yet current methods of treating AADS are hampered by a lack of recognition of the prevalence and impact of the condition amongst many practitioners, inadequate training for therapists, and limited evidence base for effective therapy.

Many people with AADS after stroke are left with life-long disability and suffer unnecessary social exclusion and mental health problems because of inadequate rehabilitation. Cost-effective care for stroke requires the promotion of maximal independence in the stroke patient with minimal hospital admissions, through provision of home-based (community) services.

To date this has involved relatively expensive care arrangements, with bolt-on therapy, that is often reactive in nature. Standard technologies have had little impact on therapy, and are often threatening to patients. Most rehabilitation is therefore still very 'low tech'. A more efficient system would put the patient and their family at the centre, utilise labour-saving technology, and provide sufficient data for healthcare professionals to monitor progress and intervene in proactive and timely fashion (Orpwood, 2009; Worthington and Waller 2009; Worthington, 2010).

The purpose of the project

The CogWatch project will focus on neurological patients with symptoms of Apraxia and Action Disorganisation Syndrome. It is proposed as a Personal Healthcare System (PHS) that aims to:-

- Be personalised to suit the needs of individual patients
- Offer long-term, continuous and persistent cognitive rehabilitation to maximise treatment impact
- Be affordable and customisable to reduce unnecessary costs
- Be portable**,** wearable and ubiquitous to allow patients to continue rehabilitation and increase independence within familiar environments when carrying out activities of daily living.
- Be practical and adaptable for home installation

To develop a high- tech, personalised healthcare system for AADS patients, CogWatch has adopted a multi-disciplinary and multi-sector approach that includes Physicians, neuropsychologists, healthcare professionals, a stroke charity, engineers and industrial partners with expertise in commercial exploitation and medical devices markets.

The Proposed Solution

CogWatch will use sensors embedded in everyday tools and objects (e.g., cutlery, plates, boxes, toaster, kettle), a wearable wrist device ‘***the CogWatch’*** that provides feedback about a task, using images sounds and vibrations, and a *Virtual Task* Execution (VTE) module – which is a large screen (see figure 1 below) that can guide patient’s actions by providing words or images of the task being undertaken. The VTE module will synchronise virtual hand movements with the position of the users’ hands using feedback from the sensors in each intelligent tool. Using movement prediction programs developed by the CogWatch partners, the system will identify the task being carried out and provide appropriate feedback. This feedback will:-

- Guide patients’ actions
- Make patients aware of cognitive errors when they occur
- Make patients aware of the actions that they need to take in order to correct the errors

- Alert patients if their safety is at risk when handling tools and objects inappropriately

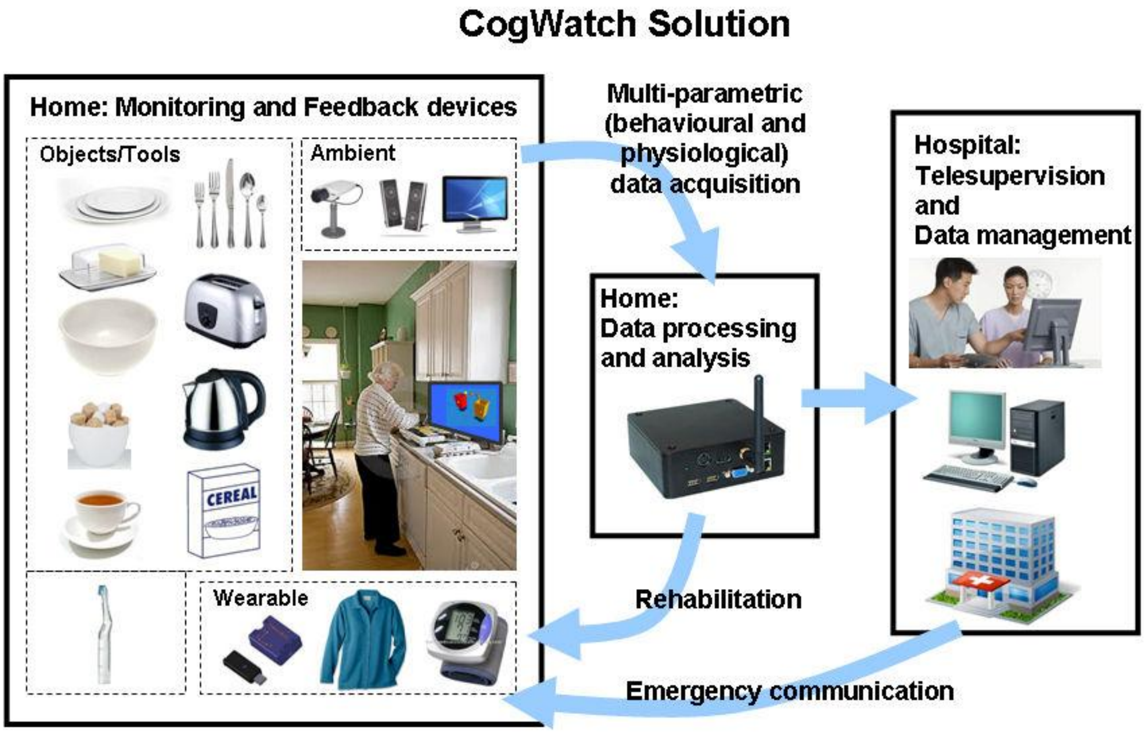


Figure 1 schematic representation of the Cog Watch system

Data collected by the CogWatch system can also be transmitted to a database at a healthcare centre or hospital where it will be available for relevant health professionals to access and use to monitor patients progress (Telesupervision).

Due to the nature of this project, the data will also be available to scientists and engineers who will use the information collated by the system to increase their understanding of AADS and improve the effectiveness of CogWatch

The CogWatch project will explore a scenario in which the three basic tasks of *meal preparation* and *eating*, *dressing* and *grooming* will be addressed. These tasks are used as a measure to assess patient's independence before they are discharged from hospital.

If CogWatch is successful it will enable stroke patients with AADS to enhance their cognitive deficits thus increasing their independence and quality of life.

Study Design

CogWatch has been funded by the European Commission; it is co-ordinated by the University of Birmingham includes several partners across various disciplines and industries. CogWatch will take approximately 3 years to develop:-

Months 1 – 18 – Pilot Phase

Development of prototype CogWatch system based on information gained from professionals, carer givers and users including studies of 100 patients, using psychological and statistical action modelling, and then tested with patients in a laboratory setting.

Months 17 – 36 – Randomised control trial

Development of 2nd prototype tested in lab and the home, for acceptability and efficacy.

Participation in the study

CogWatch was launched in November 2011 and during the first 6 months the project aims to gain the views of healthcare professionals and carer givers. This will be done through various methods including questionnaires and focus groups. These surveys aim to:-

- Gain insight into how health professionals regard the current procedure of healthcare provision and rehabilitation of patients with AADS
- Understand how professionals feel a solution like Cog Watch could enhance therapy/treatment
- Determine what features professionals feel this type of technology should include

We would also be looking into the views of care givers and users regarding how they feel this type of technology could enhance their independence and in particular features that would make it user friendly within the home environment.

We are hoping to gather a large number of opinions from healthcare professionals, care givers and users, in order to ensure that the CogWatch device best meets the needs of people with AADS once they return to live in the community; therefore, we would be most grateful if you would complete the enclosed questionnaire.

10.2 Health professional’s questionnaire

Questionnaire Exploring Health Care Professionals opinions and experiences of cognitive deficits and assistive technology'

This Questionnaire is designed to gather views from professionals in order to ensure that the CogWatch solution best meets the needs of people with Apraxia and Action Disorganisation Syndrome (AADS) once they return to live in the community (please refer back to attached information leaflet for clarity). Even if you feel you do not have much experience in dealing with Stroke and AADS your views will be invaluable regarding the use of Assistive technology which is

Technology used by individuals with disabilities in order to perform functions that might otherwise be difficult or impossible

(For the purpose of this project we are referring to technology systems such as electronic pill dispensers, environmental controls, electronic memory prompts not aids and adaptations such as shower chairs, wheelchairs etc.)

Please try to complete all the questions in full, there are no right or wrong answers we are interested in your opinions and experience. Thank you.

1. What is your profession?

Occupational Therapist ☐ Physiotherapist ☐ SALT ☐ Psychologist ☐
Case Manager ☐ Other ☐ please state

…………………………………………

2. How long have you been qualified in years?

3. In what setting(s) do you work?

Hospital	☐
Specialist Stroke service	☐
Residential setting	☐
Community	☐
Other Please specify …………………………………………………..	☐

4. How many years' experience do you have in working with Stroke patients?

None ☐ 0-2 years ☐ 2-5 yrs ☐ 5-10 yrs ☐ 10yrs and ove ☐

5. How much experience do you consider you have in treating patients with AADS? Please refer back to information sheet for details

None ☐ A little ☐ Some ☐ Considerable ☐ Expert ☐

If answered none please go to question 9 otherwise continue

6. How much of your therapy/care time is related to AADS-type problems?

None ☐ a little ☐ Some ☐ Considerable ☐ All ☐

7. In your experience what daily tasks do AADS patients struggle with? Please list in the box provided

8. Using the scales below please circle the number that represents how frequently you feel the following errors/mistakes are made by patients with AADS. 10 = happens all the time, 1 = rarely happens.

- Omission: Failing to initiate essential action or sequence of actions to complete a task

  1 2 3 4 5 6 7 8 9 10

- Initiating an incorrect or inappropriate action

  1 2 3 4 5 6 7 8 9 10

- Sequence: performing component actions in the wrong sequential order 1 2 3 4 5 6 7 8 9 10

- Additions: inserting an extra component action incorrectly

  1 2 3 4 5 6 7 8 9 10

- Semantic: using an object as another semantically related item

  1 2 3 4 5 6 7 8 9 10

- Perseverations: repeating an action or action sequence once its goal has been achieved

  1 2 3 4 5 6 7 8 9 10

- Quality: using excessive quantities of ingredients

  1 2 3 4 5 6 7 8 9 10

- Tool omission: failing to use tools

  1 2 3 4 5 6 7 8 9 10

- Spatial: Failing to grip the object correctly, or unable to produce correct movements with objects, or unable to recognise correct spatial relationship between task objects

  1 2 3 4 5 6 7 8 9 10

- Toying: reaching/holding an object without purpose

  1 2 3 4 5 6 7 8 9 10

- Action reversal: undo an action

  1 2 3 4 5 6 7 8 9 10

9. Do you have a service available to see stroke patients in the community following discharge from hospital?

   Yes ☐ No ☐

10. If yes how long is this service provided for?

    0-12weeks ☐ 3 -6 months ☐ 6-12 months ☐ more than a year ☐

    As long as needed ☐

11. How much experience do you consider yourself to have of using assistive technology as part of the rehabilitation process?

    None ☐ A little ☐ Some ☐ Considerable ☐ Expert ☐

If none please continue to Question 14

12. What types of Assistive technology have you used within Rehabilitation? Please list in the box provided

13. What have been the benefits and or limitations of using assistive technology? Please list in the box below

	Benefits	**limitations**
Therapy		
Patients		

Carers		

14. What features should the CogWatch solution have to make it user friendly? Please refer back to leaflet for description

	Features that should be included	**Features that should be avoided**
For patients		
For carers		
For health professionals		

15. Do you feel that CogWatch would help you to monitor patient progress in a time and cost effective manner?

Yes, definitely ☐ Probably ☐ Possibly ☐ No, unlikely ☐

Any further comments please feel free to use the box provided

Thank you for taking the time to complete this questionnaire

10.3 Information leaflet for carers/users

How can you help?

CogWatch is currently in the development stage. To ensure the final rehabilitation system best meets the needs of people with AADS, the CogWatch group will run a series of focus groups for stroke patients, family members and carers.

The focus groups will be informal sessions with small groups of 6-8 where we collect the views of patients and caregivers on how they feel this type of technology could enhance their independence. We will discuss the kinds of mental difficulties experienced after a stroke, how technology could be used to assist patients with their everyday activities and what features of the proposed system would make it user friendly within the home environment. We would also like to gather opinions on the ability of stroke patients and their carers to work with high-tech devices.

If you would be interested in participating in a focus group, please contact Alexa Hazell – Senior Occupational Therapist at:

A.hazell@headwise.org.uk

Prepared by The Stroke Association on behalf of The CogWatch partners

CogWatch

Developing rehabilitation tools for stroke survivors with mental difficulties

This information booklet is aimed at:

- Stroke patients
- Family members
- Community carers

The Problem:

After a stroke, patients can suffer from a wide range of problems depending on which area of their brain was affected. ***Physical*** impairments, such as problems with motor movements, vision or balance, are addressed with physical therapy but ***mental*** impairments, such as problems with language, memory or problem solving, can be harder to identify and can get overlooked during a patient's rehabilitation.

Stroke patients can have trouble performing ***ordered sequences of movements***, such as those required to make a cup of tea or to brush their teeth. Patients with normal movement of their hands and arms find themselves unable to complete everyday activities because they cannot execute the correct sequence of movements necessary to complete a task.

This type of impairment is termed 'Apraxia and Action Disorganisation Syndrome' (AADS) by doctors and, although it is hard to diagnose, it is actually quite common. Recently, scientists in the UK found that perhaps as many as 68% of stroke patients have problems typical of AADS.

AADS can have a significant effect on a patient's recovery after stroke and on their ability to live independent lives in their own homes.

The Proposed Solution: CogWatch

Mental impairments are called ‘***cognitive problems***’ by doctors as they are problems with ***cognition***, which means mental processes.

The **CogWatch** project aims to develop a personalized home rehabilitation system for people with the symptoms of AADS. Installed in patients’ homes, the system will silently monitor the patient as they go about their everyday activities. When an error is detected, the **CogWatch** with provide helpful and relevant guidance cues to assist the patient in completing the particular task.

The **CogWatch** researchers are developing intelligent everyday objects such as cutlery, a kettle, a toothbrush and a vest which will sense the way the objects are being used and wirelessly transmit the information back to a central device. The objects contain sensors to monitor orientation, motion and grip strength that, when used in combination, will provide a detailed description of how the objects are being used by the patient.

During a task, such as making a cup of tea, a screen will display relevant images to the patients that will:

- Guide their actions to complete the task.
- Make them more aware of the mental errors they commit.
- Instruct patients on how to overcome the error.
- Alert patients if their safety is at risk when handling tools and objects inappropriately.

10.4 Demographical Questionnaire

Service User Demographic Information

As you will see from the information leaflet provided, the CogWatch project is aiming to develop technology that will support people with certain difficulties to carry out everyday tasks in their own home with greater independence following stroke. Everyday living tasks can be defined as *'activities that people carry out on a day to day basis, e.g. getting washed and dressed, and preparing food'*

The purpose of this information gathering session is to better understand the difficulties that people face following stroke and to ask your opinions and experiences on assistive technology, which can be defined as *'Technology used by individuals with disabilities in order to perform functions that might otherwise be difficult or impossible'.*

We would like to gather some basic background information about you. Any information you choose to share will remain anonymous. If you require any assistance to complete this form please let us know.

1. What is your date of birth (day/month/year)? ☐

2. What is your gender? Male ☐ Female ☐

3. When did you have a stroke (month/year)? ☐
   (If you have had more than one stroke please tell us the month and year of the most recent stroke)

4. What were your living arrangements before you had a stroke?

   a. Living alone ☐
   b. Living with family ☐
   c. Living in sheltered accommodation, e.g. warden controlled premises ☐

d. Living in a residential service ☐

e. Other (please specify) ______________________________ ☐

5. What were your support needs before you had a stroke.

For the purpose of question 5 and 7 support is defined as *'needing and receiving some level of help with everyday living tasks within the home, e.g. getting washed and dressed, preparing food'*

a. No support needs, I was independent in all everyday living tasks ☐

b. I received support from an unpaid carer or family member ☐

c. I received less than 2 hours support per day from a paid carer ☐

d. I received between 2 and 4 hours support per day from a paid carer ☐

e. I received more than 4 hours support per day from a paid carer ☐

f. Staff were available to help me 24 hours per day ☐

g. I used some sort of assistive technology to help with everyday living tasks (please refer back to definition above if needed) ☐

6. What are your living arrangements since you had a stroke?

a. Living alone ☐

b. Living with family ☐

c. Living in sheltered accommodation, e.g. warden controlled premises ☐

☐

d. Living in a residential service

e. Other (please specify) ______________________________ ☐

7. What are your support needs since you had a stroke.

a. No support needs, I am independent in all everyday living tasks ☐

b. I receive support from an unpaid carer or family member ☐

c. I receive less than 2 hours support per day from a paid carer ☐

d. I receive between 2 and 4 hours support per day from a paid carer ☐

e. I receive more than 4 hours support per day from a paid carer ☐

f. Staff are available to help me 24 hours per day ☐

g. I use some sort of assistive technology to help with everyday living tasks (please refer back to definition above if needed) ☐

h. For each of the items below please rate from 1 – 10 how severe you feel this difficulty is (where 1 = no difficulty, and 10 = extreme difficulty) and how much the difficulty impact upon your quality of life (where 1 = it does not affect my quality of life, and 10 = it has a very serious negative impact on my life).

Physical problems, e.g. walking, moving around the home, feeling weak

Severity ☐ Impact on quality of life ☐

Communication problems, e.g. finding the words I want to use, understanding what people are saying to me

Severity ☐ Impact on quality of life ☐

Swallowing, e.g. choking when eating and/or drinking

Severity ☐ Impact on quality of life ☐

Thinking problems, e.g. forgetting things, problems concentrating, making decisions

Severity ☐ Impact on quality of life ☐

Emotional Problems, e.g. feeling depressed, feeling angry

Severity ☐ Impact on quality of life ☐

i. For the following tasks please rate your current level of independence.

Making a hot drink

I do this without help ☐

I need someone to give me verbal instructions,
E.g. tell me the order to do things ☐

I need physical help to do this task, e.g. lifting kettle ☐

I need verbal and physical help with this task ☐

Somebody does this for me ☐

Making breakfast

I do this without help ☐

I need someone to give me verbal instructions,
E.g. tell me the order to do things ☐

I need physical help to do this task, e.g. pouring cereal ☐

I need verbal and physical help with this task ☐

Somebody does this for me ☐

Cleaning my teeth

I do this without help ☐

I need someone to give me verbal instructions,
E.g. tell me the order to do things ☐

I need physical help to do this task, e.g. toothpaste on brush ☐

I need verbal and physical help with this task ☐

Somebody does this for me ☐

Getting dressed

I do this without help ☐

I need someone to give me verbal instructions,
E.g. tell me the order to do things ☐

I need physical help to do this task, e.g. putting socks on ☐

I need verbal and physical help with this task ☐

Somebody does this for me ☐

10. For the tasks listed in question 9 please indicate the extent to which you have experienced the difficulties below:

I miss steps out e.g. pouring water from kettle without turning it on

Never ☐ Occasionally ☐ Regularly ☐ All the time ☐

I do the wrong action e.g. stabbing tea with teaspoon rather than stirring it

Never ☐ Occasionally ☐ Regularly ☐ All the time ☐

I get the order mixed up e.g. putting milk in bowl before cereal

Never ☐ Occasionally ☐ Regularly ☐ All the time ☐

I add extra steps that are wrong or not needed

Never ☐ Occasionally ☐ Regularly ☐ All the time ☐

I use an object whose use is similar but not correct for this task, e.g. eating cereal with a fork

Never ☐ Occasionally ☐ Regularly ☐ All the time ☐

I get stuck on an action e.g. I keep stirring tea even though the sugar is dissolved

Never ☐ Occasionally ☐ Regularly ☐ All the time ☐

The way I carry out the task affects the quality e.g. I use too few or too many ingredients

Never ☐ Occasionally ☐ Regularly ☐ All the time ☐

I use the tools incorrectly, e.g. holding the spoon upside down to eat cereal

Never ☐ Occasionally ☐ Regularly ☐ All the time ☐

I toy with objects e.g. holding an object that I don't need to use

Never ☐ Occasionally ☐ Regularly ☐ All the time ☐

I undo actions e.g. turn the kettle off before it has boiled

Never ☐ Occasionally ☐ Regularly ☐ All the time ☐

Please add any further comments you wish to make

Thank you very much for your participation

10.5 Consent form

COGWATCH CONSENT FORM

I ____ understand the information contained in the CogWatch information sheet.

I give my consent to participate in the focus group at ____ on ____________________ and understand that all information I share will be kept anonymous. No identifying information will be taken, and all data will be stored securely.

SIGNED ___________________________________

DATE _________________________

10.6 Focus group format

- Introductions given and diagram of Proposed CogWatch Solution
- One researcher asks each member the following open questions
- Have they/the person they support ever used assistive technology this would be defined for example: - pill dispensers, pendant alarms, aids to prompt memory – phone, watch or other etc.? What have they tried?
- What do they think would be the benefits and difficulties of a device like CogWatch – this would be easier if they had seen the prototypes as suggested by Clare. How could potential difficulties be overcome? Can also include a list similar to information we gathered from the innovation group

At each stage if required the communication prompt sheets are given

10.7 Communication prompts for focus groups

Technology Used Before

Touch screen mobile phone

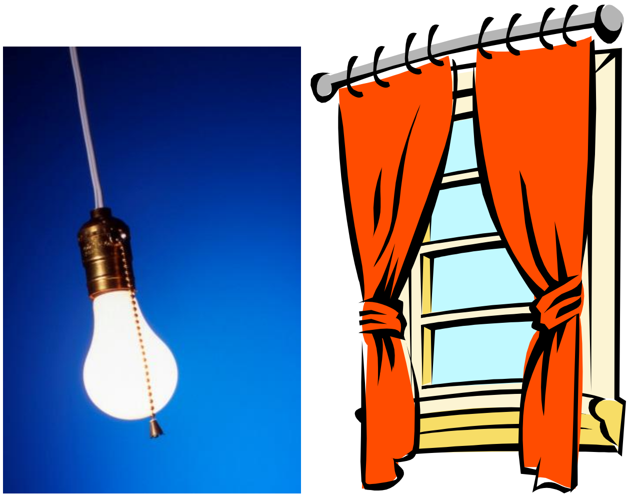
Mobile phone with buttons

Computer

Pendant Alarm

Pill dispenser

Environmental controls



<u>How will it be controlled?</u>

Touch Screen TV

Touch Screen watch

Buttons on TV

Remote Control

Buttons on Watch

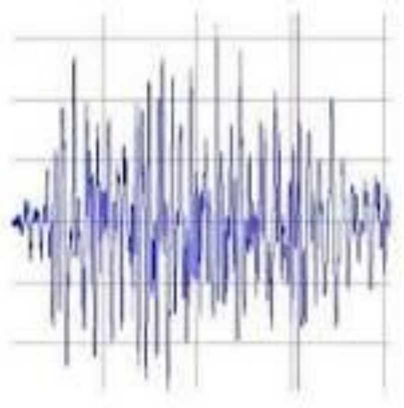
Voice Recognition

How should it give you feedback?

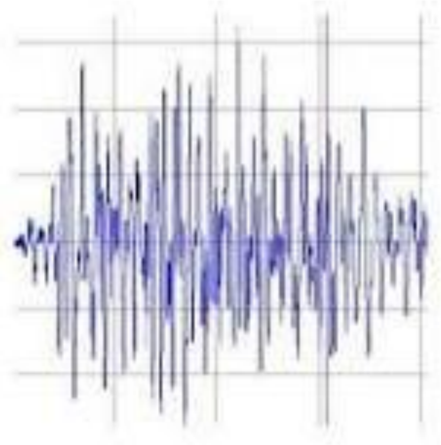
Computer screen/TV speaks to you

Watch speaks to you

Watch Vibrates



Tools Vibrate



Seeing info on screen

Pictures or Words

<u>OR</u> **GET YOUR MUG**

Or Both

GET YOUR MUG

How should the screen look?

Big

Small

Fixed to wall

Portable

How should the watch look?

Bright and colourful

Plain and neutral


STARCK

10.8 Table of technology

Table is a list gained from the regional innovations group in Telehealthcare of features that maybe suitable to link with CogWatch

Suggested Device/Organisation	Description
Virtual Visiting	**From their home the person is able to speak to somebody outside of their home using video conferencing.**
Wrist Care	**http://www.seniorwatch.de/cases/12.pdf** **A watch that continuously measures physiological signals: movement, body temperature, pulses and skin conductivity. If the Wrist Care system notices a significant change in the user's activity level or wellbeing, it automatically sends an alarm to a relevant party. During the first four days of use, it studies the user's normal activity level and wellbeing and adapts its function accordingly.**
AD Life	**Monitors activities of daily living including how the person is moving around their home, for example, door usage, electrical appliance usage, and bed/chair occupancy.**
Tunstall Laundry tags	**Tags implanted in clothes can be used to identify who the clothing belongs to.**
Thumb print recognition	**Thumb print recognition device that monitors the use of different areas within the home and can give/limit access to certain areas/appliances, e.g. the cooker.**
Southampton University	**Southampton University is studying wearable devices. http://eprints.ecs.soton.ac.uk/21802/**
CUHTec (Centre for Usable Home Technology), University of York	**http://www.cuhtec.org.uk/projects.php** **CUHTec has done work on 'architecture and design for ubiquitous systems'.**