



CogWatch – Cognitive Rehabilitation of Apraxia and Action Disorganisation Syndrome

D1.4.2 Report on Healthcare Professionals and Caregivers Requirements II

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EXECUTIVE SUMMARY

In June 2013 the first prototype of CogWatch was released for evaluation. In this second user requirements report the findings from focus groups and questionnaires carried out with health professional's stroke survivors and carers are discussed.

In total 45 health professionals and 32 stroke survivors along with 15 carers agreed to participate in focus groups. Out of these 18 stroke survivors and 10 carers completed demographic questionnaires.

The main findings from this evaluation are:-

- There appears to have been an increase since the first user requirements report in the use of technology in rehabilitation from both health professionals and stroke survivors perspectives – this is encouraging for the future of CogWatch
- Health professionals felt that having access to a clinical database would enhance their current practice and time spent currently on completing administration duties as long as the system was simple and flexible enough for them to adapt.
- Stroke survivors felt that with the necessary support and training they felt that CogWatch technology would definitely be a useful tool following discharge from hospital to increase independence and quality of life
- Overall at least 80% of health professionals and 60% of stroke survivors felt that Cogwatch is an excellent idea

For future developments of prototype two, stroke survivors suggested that it would be of benefit for a task within personal care to be addressed with 50% agreeing to brushing teeth.

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REVISION HISTORY

Revision no.	Date of Issue	Author(s)	Brief Description of Change
V1	15/08/13	HW	First draft
V2	22/08/13	HW	Work on introduction methods and results
V3	23/08/13	HW	Work on methods and results
V4	27/08/13	HW	Work on results and discussion
V5	29/08/13	HW	Work on results, discussion, contents page and appendix
V6	01/09/13	HW	Discussion, contents, figures, conclusion and executive summary
V7	1/10/13	UOB	Minor amendments
V8	10/10/13	HW	Final amendments

LIST OF ABBREVIATIONS AND DEFINITIONS

Abbreviation	Abbreviation
HW	Headwise
TSA	The Stroke Association
UOB	University of Birmingham
TUM	Technical University of Munich
P1	Prototype 1 of the CogWatch system
AADS	Apraxia and Action Disorganisation Syndrome

1. INTRODUCTION

In May 2012 the first part of this deliverable on user requirements D1.4.1 was successfully completed. That report had carried out an evaluation of the requirements of Health professionals, stroke survivors and carers, in order to ensure that CogWatch would 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 careers.

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 were:-

- 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 would have the potential to monitor patient progress in a time and cost effective manner.

As a result of the D1.4.1 report the development of CogWatch prototype 1 (P1) began with the selected task being “making a cup of tea”. This prototype was released for evaluation at the beginning of June 2013. Since then it has been tested with a number of stroke survivors as well as healthy individual’s within “set up kitchens” in both UOB and TUM.

As a result the aim for the present deliverable D1.4.2 is to evaluate P1 in terms of:-

- The current features of the prototype in relation to its usability and acceptability for stroke survivors and their carers
- The practicality and effectiveness in terms of use within rehabilitation settings
- An overview of current technology that stroke survivors have access to
- Features that should be included within the CogWatch prototype 2 including which task should be covered.

On completion of the previous deliverable there were some recommendations that were adhered to during the present evaluation. These included:-

- To find ways to increase in particular carer participation and to develop a questionnaire similar to the stroke survivors in order to gain views from those that were in able to attend focus groups.
- To try and target an audience from different ethnic groups.

2 METHODOLOGY

2.1 Questionnaires

Two questionnaires were developed for both stroke survivors and carers. For the stroke survivor (Appendix 1) this questionnaire followed a similar format to the one distributed in the first report D1.4.1 as it was felt that this had given a lot of information around different areas of daily life that stroke survivors may struggle with. The only additional question was around ethnic group. These were distributed during the focus group for completion

For carers, (Appendix 2) the questionnaire was developed in order to try and capture a wider audience thus for those who were unable to attend focus groups, to give opportunity for them to share their information. Again these were distributed during the focus groups and arrangements made for collection for those stroke survivors who were taking copies home.

In total 18 stroke survivors and 10 carers completed the questionnaires.

TSA also surveyed its stroke survivors (stroke survivors or carers answering on behalf of a stroke survivor) and its service staff about their views of the use of assistive technology to help stroke survivors adapt after a stroke. The surveys were circulated online and also in hard copy in some of our support groups. The purpose was to understand the attitudes towards and current usage of assistive technologies for stroke and also to explore how our services user would like to receive information about new products from us, with a view of relevance to CogWatch.

In total 23 stroke survivors' responded and 69 TSA staff

2.1.1 Data analysis of questionnaires

The data from the questionnaires was analysed using the statistical analysis program, SPSS 19 (Gray & Kinnear, 2012). It was used to analyse the quantitative data, i.e. responses to closed questions, and to generate tables and graphs of the results.

2.2 Focus groups

Focus groups are known to encourage a more thorough exploration of issues than is possible through questionnaires and to stimulate debate (Silverman 2004). These were run for stroke survivors, carers and health professionals. For both groups the open-ended question format developed in D1.4.1 was used in order to try and gain information on the above questions (Appendix 3 and 4). This was piloted with 13 health professionals and also 8 users and 7 carers. Minor amendments made compared to D1.4.1 were to the health professional format:-

- Instructions were added in case someone else had to lead the focus groups in the absence of the researcher
- Additional questions relevant to this report were added regarding technology that may be used and how Health professionals monitor clients with AADS (Appendix 5).

A further change affecting all three groups, was that all focus group members were individually asked to say which of Snack preparation, Main meal preparation, Teeth brushing, Hair brushing, Dressing, Washing they would consider to be the best option to develop as the next CogWatch task.

All 3 groups were given information sheets prior to agreeing to take part (Appendix 6 and 7), as well as giving informal written consent (Appendix 8, 9 and 10). During the focus groups they were shown a video produced by UOB of P1 as well as pictures of the watch and sensors.

In total, four stroke survivor and carer groups and five health professional groups were conducted throughout July 2013.

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 were then transcribed for final analysis.

2.2.1 Data analysis of focus groups

ATLAS.ti (<http://www.atlasti.com/index.html>) was used to analyse the data using a grounded theory approach. 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 the health professionals' focus groups. For the purposes of this report the comments were categorised by group (health professionals, carers and stroke survivors) and analysed on a question by question basis.

3 RESULTS

3.1 Subjects: Stroke survivors

Thirty two stroke survivors were approached to attend a series of 4 focus groups. Inclusion criteria were minimal: ability to give informed written consent. 85% were British with a mean age of 65.64 years of age (range 43 to 93 years: standard deviation =12.45). There was an equal male to female ratio and all subjects had suffered a stroke in the last six years (mean =2.53 years: standard deviation =1.56).

A total of 15 carers also agreed and participated in the groups. For the questionnaires 18 stroke survivors and 10 carers completed them

3.1.1 Subjects: Health Professionals

45 health professionals gave written informed consent to take part in focus groups, their professionals are shown in the chart below:-

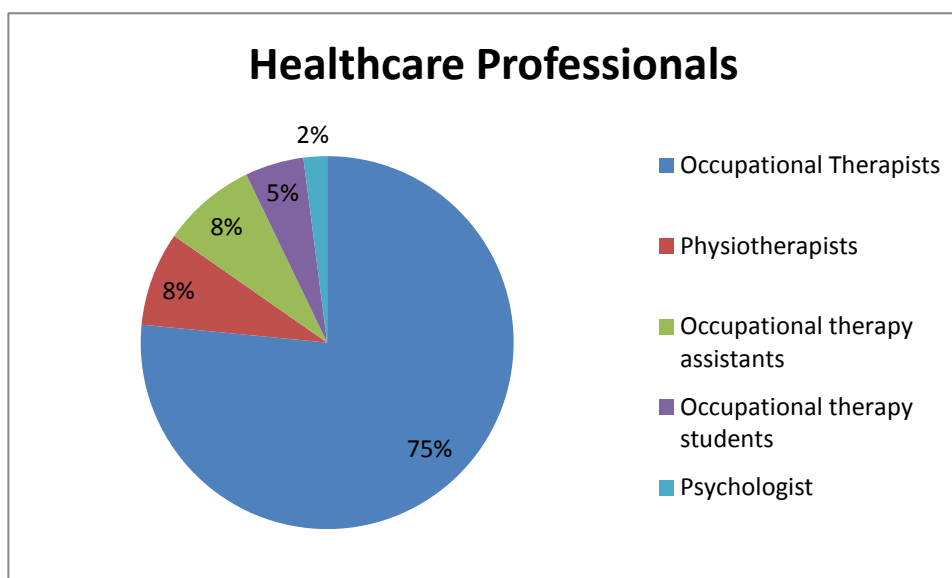


Figure 1: Occupation of health professionals

They had been qualified a mean number of 11.35 years (range 1 – 38; standard deviation = 8.83) and a mean number of 6.71 years of direct stroke experience.

3.2 Thoughts on P1: including current methods for prompting and monitoring clients with AADS.

3.2.1 Health professional views on system

Six themes emerged from these discussions: improvements; negatives; use in hospital settings; a good idea; flexibility and concerns about using a watch.

1. Improvements (7 statements) included: “Need to be able to rate your patient each day and adapt the system accordingly as patients vary from day to day”; “Consider fitting sensors to taps etc.” and “Concentrate on a talking rather than a visual watch”.
2. Negatives raised (6 statements): “it doesn’t cover all areas of stroke”; “Patients like human contact, not technology”; “Patients may become dependent on it” and “This client group does not like technology”; “having therapist present allows for observation skills, clinical reasoning and also most importantly immediate feedback and face to face discuss with user on progress”
3. Hospital setting: Health professionals liked the idea of using Cogwatch in the hospital setting (3 statements): “Very helpful immediately following stroke” and “Identifies whether activities can be problem solved with technology”.
4. The majority (3/5) of focus groups thought Cogwatch was a good idea: “A good idea that needs tweaking” and “The concept is brilliant. Useful objects like mobile phones are enjoyable to use, will Cogwatch have the same appeal?”
5. Flexibility of the system: “It needs to be adaptable so therapists can programme it as rehabilitation progresses”.
6. Watch: “Considering the hemiplegia and cognitive problems stroke patients face, the watch does not seem to be a good idea”.

3.2.2 Thoughts about the system as a whole – Stroke survivors and carers

Three themes emerged: it was a good idea: personalised and adaptable.

1. Personalised and adaptable to the individual (5 statements) “this would have helped following discharge from hospital as long as it could be personalised and adapted to the individual’s needs and environment”.
2. Overall they felt it was a good idea (3 statements) “this would be useful as I do forget to put the kettle on and often forget the tea bag in my cup”.

3.2.3 Thoughts on prompts – health professionals

Four themes emerged from the health professional focus groups regarding prompts: audio prompt improvements and visual prompt improvements; personalise the prompts; does not replace the human interaction and consider incorporating other technology.

1. Improvements for both the audio (8 statements) and visual (7 statements): “Need the ability to personalise it”; “The audio prompts may be too negative (stop doing that)”; “The audio prompts seem to give conflicting information (stop doing that, thank you)”; “Perhaps a voice recorder would be easier to listen to”; “Prompts such as ‘What do you do next?’ may help sequencing”; “The visual prompts need to be large and clear”; “Video clips may be helpful”.
2. Personalising the equipment was also a strong theme (6 statements): “Visual prompts were too fast for those with processing speed impairment” and “As the patient becomes familiar with the task, is there a way to reduce the number of prompts?”
3. Some health professionals had concerns about replacing carers with technology (2 statements): “What if the patient becomes anxious, the computer can’t respond to this?”
4. The last theme recommended other technology that may be worth incorporating with Cogwatch and captured only one statement “Look at Therapy box; it may give you some ideas”.

3.2.4 Thoughts around the prompts – Carers

Three themes emerged regarding prompts: audio prompt improvements; visual prompt improvements; personalising prompts.

1. Improvements for the audio (2 statements) and visual (5 statements) generally mirrored those of the health professionals. However some new suggestions were made: “Choose colours compatible with colour blindness”; “Writing for the visual prompts should be highlighted one line at a time”.
2. Carers only made one statement about personalising the prompts: “Everyone has good days and bad days, so the speed of prompts should be flexible”.

3.2.5 Thoughts around the prompts – Stroke survivors

Four themes emerged: positive feedback for audio prompts; visual prompt improvements, personalising prompts and risks.

1. Improvements for visual prompts (5 statements) which focussed on the speed of prompts being too fast although one stroke survivor commented “I’d like to see pictures and words combined”.
2. Stroke survivors’ feedback for the audio prompts was all positive (3 statements): “Glad audio prompts have been used”; “Thank goodness someone realises audio prompts are equally as important as visual ones”.
3. Personalising prompts (2 statements) included the comments “Pictures and voices need to be familiar” and “Can a familiar voice be used?”
4. One group of stroke survivors identified a potential risk “Not sure a vibrating prompt would be safe especially if I’m holding a kettle.”

3.2.6 Health professionals views on prompts in current clinical practice

Health professionals were asked what they currently use in their current practice, all groups mentioned verbal and physical prompts. However four out of the five groups mentioned that as a technique they use errorless learning: they do not allow errors to be committed during everyday tasks. All then voiced that it would be worth considering for CogWatch, perhaps instead of waiting for errors before prompts, it has the ability to just talk through with pictures or videos of the sequence.

3.3 Current use of technology including TSA evaluation

3.3.1 Results compared to D1.4.1

55% of health professionals reported they currently use technology to support their clients compared to 14% in the last report D1.4.1. 70% of stroke survivors are currently using technology at home to assist them in everyday activities compared to 10% in the last report.

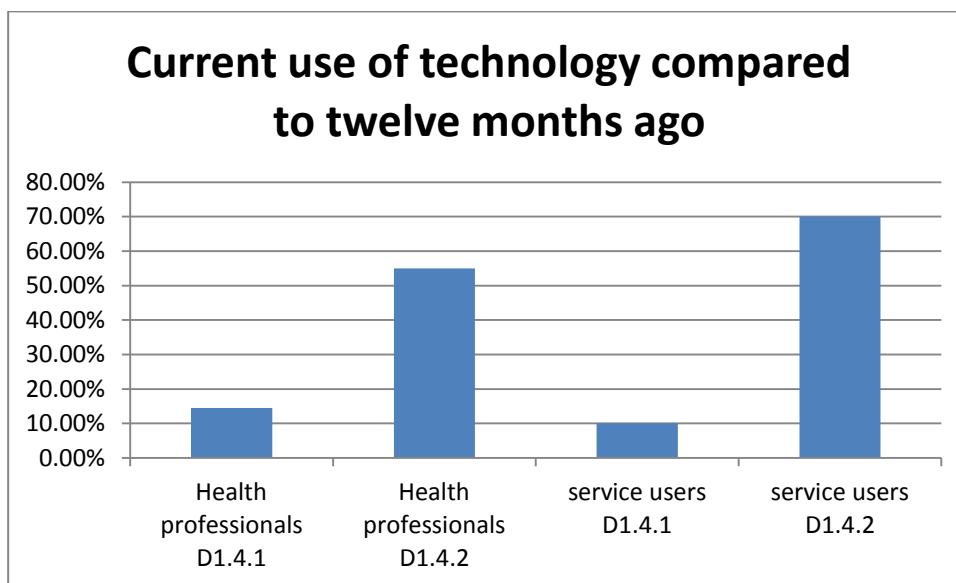


Figure 2: Current use of technology

3.3.2 Types of technology being used in rehabilitation

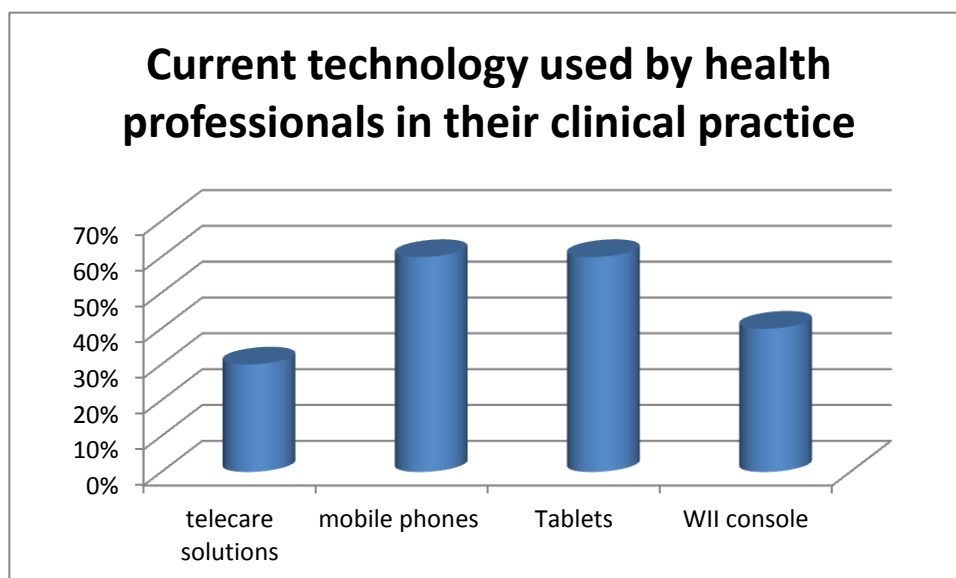


Figure 3: Current technology used by Health professionals

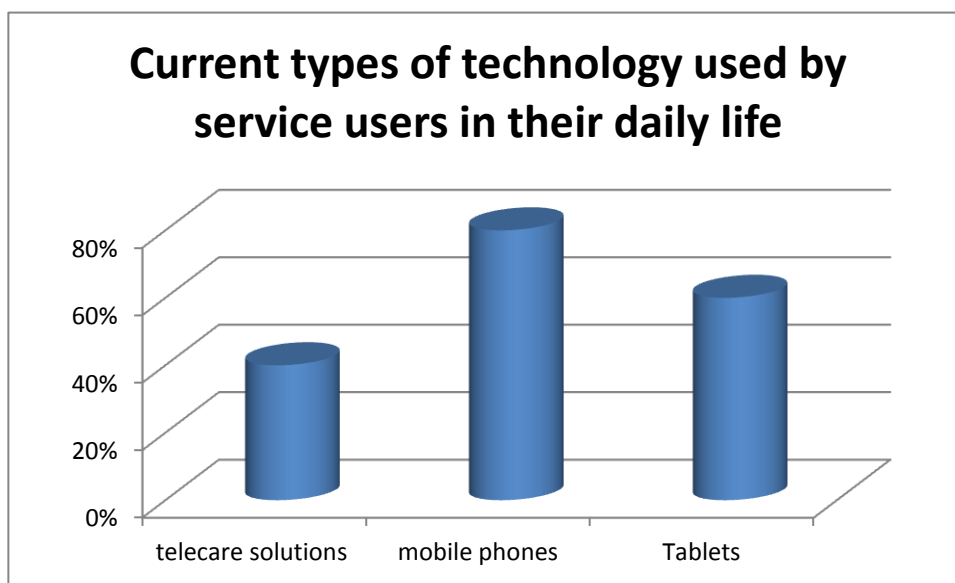


Figure 4: Current technology used by stroke survivors

Both graphs show that both health professionals and stroke survivors report to use mobile phones and tablet computers to support rehabilitation.

3.3.3 Results from TSA survey

Stroke survivors/stroke survivors (n=23)

Question 1: Have you every purchased or used a product to help you, or someone else, after a stroke?

Yes	91.3%	21
No	13.0%	3

Question 2: If yes, what type of products have you bought/used?

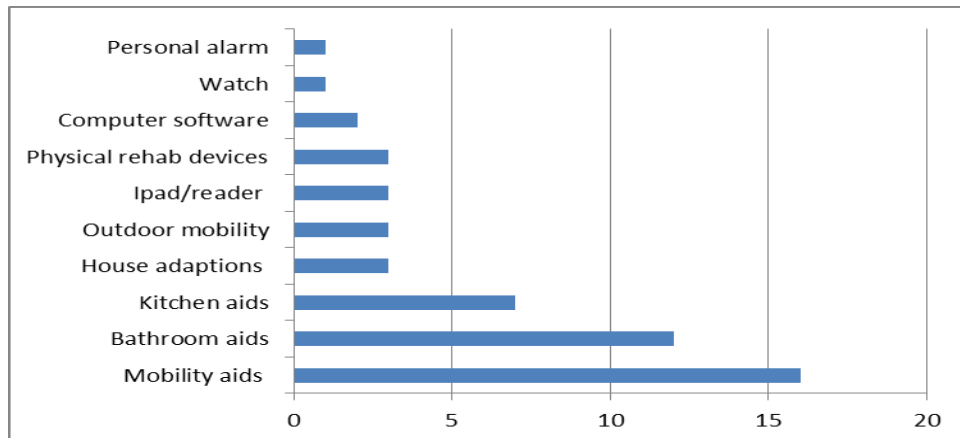


Figure 5: Breakdown of products used from TSA survey

Question3: Have you ever been unable to find a product you wanted to aid your recovery?

No	95.2%	20
Yes	4.76%	1

If yes, what?

Safe aids for cutting food with one hand

Question 4: How do you feel about technology (computers, smartphones, ipads)?

Positive; I would like to try	80.0%	16
Unsure; Would like to try but I have little experience	15.0%	3
Negative; I have never tried it and I don't want to	5.0%	1
Negative; I have had a bad experience and don't want to try again	0.0%	0
Other (please specify)		11

Other:

- Fingers too shaky for most tiny keys on phones or ipads
- I am a computer programmer
- I have an iPad

- I have and use all of the above. I don't have an alarm button because I have quick deal on my smart phone and my phone comes with me every where
- aphasia reduces the ability to use these in my case
- I have all, but find that too much time on them is not a good thing
- I use my computer every day for research, e-mailing, online shopping , downloading a daily paper on my Kindle , reading books for the Kindle, music for MP3 , downloading machine embroidery designs , using mobile phone.
- Computers good, other technology not so good
- I was the computer user in the house, but now cannot get upstairs to access it

Question 5: Where do you currently get information about products and technology that might be of help to you, or someone affected by stroke?

Websites	52.2%	12
Recommendations from others	34.8%	8
Recommendations from health professionals	65.2%	15
The Stroke Association	69.6%	16
Catalogs and Magazines	30.4%	7
Never looked for any	8.7%	2

Question 6: At what stage of your recovery would you want information about technology to be provided by The Stroke Association?

When still in hospital	15.0%	3
Soon after hospital discharge	45.0%	9
When occupational/speech therapy has finished	40.0%	8
In the first year after stroke	20.0%	4
Other (please specify)		6

Other:

- I think it's important right from the beginning and through the first year
- If you live alone it's nice to have someone to come and help you and answer questions that you may have i.e. Money and Transport
- All stages are important as needs change with time and response to therapy
- When requested
- On-going as my needs change with my recovery

- Also provide information to carers

TSA service staff (n=69)

Question 1a: How often are you asked by clients about assistive technology?

Never	8.7%	6
Rarely	40.6%	28
Intermittently	30.4%	21
Regularly	17.4%	12
Often	4.3%	3

Question 1b: If the answer was never, rarely or intermittently, why do you believe this is so?

Open text responses almost all related to age of clients, i.e:

- Not interested in technology
- Fear or anxiety about being able to use products
- Too difficult to use
- Cost issues
- Lack of awareness about what is available or how it could help them
- Lack of experience using such technologies

Question 2: In your experience, what are stroke survivor's attitudes towards technology (i.e. ipads, smart phones, computers)?

Keen to learn	26.6%	17
Cautiously interested	42.2%	27
Apprehensive	50.0%	32
Indifferent	10.9%	7
No interest at all	9.4%	6
Actively against it	4.7%	3

3.4 Preferences for next task to be developed in CogWatch prototype 2

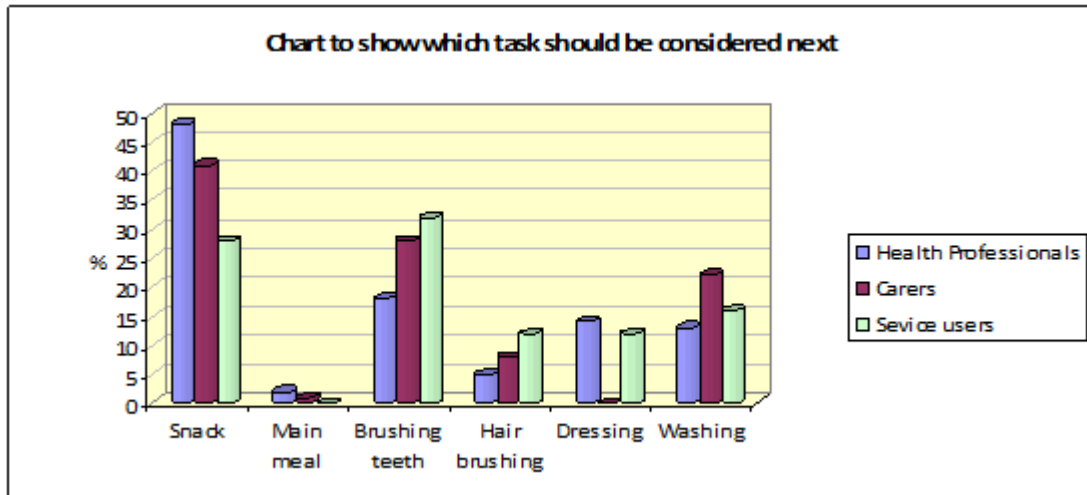


Figure 6: Considerations for next Prototype 2

All members of the focus groups were asked individually to say identify one task they would favour for CogWatch prototype 2. The figure shows health professionals and carers favoured snack preparation, whereas stroke survivors favoured brushing teeth. The stepwise decrease across health professionals, carers and stroke survivors in those favouring snack preparations reflected an increase across the groups for independence in some aspect of personal care, albeit distributed across different tasks in the latter category.

3.5 Feedback that health professionals feel would be of benefit in terms of a clinical interface/database including training and support

3.5.1 Health professional feedback on features for the database

Five main themes were generated: simplicity, assessment, errors, goal setting and outcome measures, prompts and time taken to complete task, sequence of activity and suggestions on feedback for stroke survivors and carers.

1. Simplicity (5 statements). "Need easy to use pages" "be able to produce simple graphs at the touch of a button – these would be good to feedback for commissioners as well as during clinical meetings".
2. Assessment, outcome measures and goal setting were all discussed in context (4 statements) "this will be useful if I can input findings and then generate a report which will also allow me to include smart goals and outcome measures that we currently use" "access to be able to input different outcome measures".
3. Feedback on errors (2 statements) included "type of error and frequency would be good for assessment purpose" Prompts (3 statements) "would be good to know what types of prompts had been required and the frequency"

4. Sequence of activity (2 statements) and time taken (3 statements) overlapped in the discussions: “feedback on time taken and order of steps and sequence including prompts would be very useful information.
5. Feedback Health professionals felt would be useful for stroke survivors (2 statements) “this would be good in picture format on the watch perhaps” “we always involve family and carers in rehabilitation therefore it would be good for them to have access to some simple information regarding how well the user completed the task”

3.5.2 Health Professional feedback on training and support

Four themes emerged from discussions: stroke survivors’ ability to be trained, cost time and updates and system set up.

1. Concerns that stroke survivors would not have the ability to be trained to use the system (5 statements). There were 2 in relation to age: “elderly people may find the technology too much bearing in mind they often don’t use technology and so their knowledge base would be low” other discussions were in relation to cognitive deficits and initiation: questioned if stroke survivors would have the cognitive ability to learn new IT process’s “would the system have the ability to prompt the person to use it as clients following stroke often struggle with initiation and motivation”.
2. The other three themes were linked together “ the time it would take to train I guess would be 3-4 hours, this would then be needed to be repeated and updated as the system developed, however if problems occur then further input etc would be needed and this I feel would add to the cost”. Regarding system set up (3 statements) discussions included “once the system is set up it does look simple to use, I don’t feel this would take much time if used regularly however for this reason I do feel it fits better into the hospital setting”

3.5.3 Stroke survivor and carer feedback on training and support

The themes mainly emerged from carers and just two themes emerged around simplicity and support.

1. Regarding simplicity carers felt anything which they have to use/change on the system needs to be clear and quick to sort.
2. For support carers would want to know that if problems occurred there would be immediate help on hand.

4. DISCUSSION

4.1 Current use of technology in rehabilitation and everyday life.

The results highlighted that just in the last twelve months there has been an increase in the use of technology both from a professional perspective as well as stroke survivors. From the TSA questionnaire the main findings included:

- 91% of stroke survivors report purchasing an aid, suggesting that they are willing to spend money to enhance their recovery and/or life quality. However most of the devices they have bought are general mobility devices and may not reflect more high-tech computational devices.
- 80% of stroke survivors report being positive to technology and only 5% (1 person) would not want to try to use it.

It is interesting to note that from both the focus groups and the TSA questionnaires over half the professionals were concerned that stroke survivors tend to be part of the elderly population and therefore they would be very apprehensive to use technology. However the mean age of stroke survivors used within this research were over the age of 65/70 and as the results highlighted 70% currently use some form of technology, mobile phone or tablet in their everyday life, with reports that this is often used for memory, communication and the internet as well as 20% reporting different apps they use to aid sequencing. Both health professionals and stroke survivors voiced that it would be good if CogWatch could utilise any technology that an individual may already have thus addressing issues regarding cost effectiveness.

Only 20% of the health professionals voiced issues regarding barriers to the use of technology and these were often those who did not currently see its use in current practice.

4.2 The current features of the prototype in relation to its usability and acceptability for stroke survivors and their carers: including practicality and effectiveness

Approximately 80% of health professionals and 60% of stroke survivors and carers felt that the system was a good idea and could see the benefits of this concept. Health professionals felt that if used in the hospital setting prior to discharge this would enable the system to be customised and personalised for each client and would enhance rehabilitation in the home following discharge.

There were only around 20% of health professionals that raised concerns and potential barriers to the idea of CogWatch within stroke rehabilitation. This was often around social isolation and the need for human contact within this area rather than technology.

For both parties the most common theme that came out was around personalisation and the ability to customise the system in particular reference to the prompts; at least three quarters felt that the prompts should be individualised with the ability to adapt with either auditory (familiar voice and cues) and visual, and that there was negativity to using vibration as a prompt as over half felt this would increase potentials risk and harm, especially in the current task.

Health professionals recommended that the length of time between an error being committed and a prompt appearing on the screen needed to be reduced and in fact felt it would be better to train

the individual with constant cueing similar to the concept of error less learning rather than waiting for the stroke survivor to make a mistake/error.

Suggestions were made from both parties around improvements. Health professionals in particular felt that if the watch is to be used then this should be a talking watch rather than it having visual cues. They also felt it would be good if the sensors could be adapted to go onto cupboard doors in order to help locate items.

For stroke survivors the main theme was for it to be individualised to their needs and to be adaptable into their current home environment and technology that they may have.

4.3 Features of a clinical database including training and support

Health professional's felt that having a clinical interface would be an excellent idea with over 90% agreeing. However they would want this to be simple and clear to understand, with the ability to input assessments, outcome measures and goals, which could then be generated into reports for both clinical practice but also commissioners.

Information which they felt would be very useful is the ability to see at the click of a button how the stroke survivor performed in terms of errors, prompts required and sequence of the activity.

A common point was that it should not be something that increases their workload but something that would support and if possible reduce the amount of time spent on administration.

In terms of training health professionals felt this needed to be a continual process with regular updates as the system progressed. In terms of training for stroke survivors, health professional's felt this would be difficult, with issues regarding age and ability in reference to cognitive and physical impairment following stroke.

For both stroke survivors and carers they both felt it would need to be simple and clear and most importantly those they had access to support as and when problems occurred.

4.4 CogWatch prototype 2 and task to be considered.

Nearly half of the health professionals and carers and a quarter of stroke survivors favoured a kitchen task to be considered in the next CogWatch prototype 2, with these being around snack preparation – sandwich, toast. Snack preparation was the preferred option (ahead of teeth brushing) for health professionals and carers or was favoured slightly behind teeth brushing (stroke survivors). The third most popular choice was washing, ahead of hair brushing and dressing. A desire for more independence with personal care was often noted by stroke survivors; thus three quarters would like to see CogWatch be developed into personal care areas. This last point is particularly interesting when compared to the results in D4.2.1 where it was kitchen tasks that both carers and stroke survivors felt needed most support.

5 CONCLUSION

This report has looked at the current CogWatch prototype 1 (tea making) in relation to health professionals, stroke survivors and carers' needs. Over three quarters feel that CogWatch is a good idea and can see its benefits within rehabilitation both in the hospital setting and client's home.

Health professionals and carers recommendations for the next CogWatch prototype 2 were that it should continue with another kitchen task, snack preparation. Stroke survivors were roughly equally divided between snack preparation and brushing teeth, however taking the responses of the latter group as a whole, it is clear they would be eager for CogWatch to move into an area of personal care.

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APPENDICES

Appendix 1: stroke survivor questionnaire

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, *including your opinions on the development of the CogWatch prototype to date. Assistive technology 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. What is your ethnic group? – please circle from the list below

White

A British

B Irish

C Any other White background

Mixed

- D White and Black Caribbean
- E White and Black African
- F White and Asian
- G Any other mixed background

Asian or Asian British

- H Indian
- J Pakistani
- K Bangladeshi
- L Any other Asian background

Black or Black British

- M Caribbean
- N African
- P Any other Black background

Other Ethnic Groups

- R Chinese
- S Any other ethnic group
- Z Not stated

4. 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)

5. 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) _____ ☐

6. 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) ☐

7. 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) _____ ☐
8. 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) ☐

8. 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 impacts 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 ☐

9. 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 ☐

11. Are there any other day to day tasks within the home that you find difficult since having a stroke? Please list:

Please add any further comments you wish to make

Thank you very much for your participation

Appendix 2: Carer questionnaires

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, including your opinions on the development of the CogWatch prototype to date. Assistive technology 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 the needs of the person you care for. 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 relationship to the person you care for?

- a. I am their spouse ☐
- b. I am their parent ☐
- c. I am their child ☐
- d. I am their sibling ☐
- e. I am their friend ☐
- f. Other (please specify) _____

2. Are you their main carer? Yes ☐ No ☐

3. When did the person you care for have a stroke (month/year)?

(If they have had more than one stroke please tell us the month and year of the most recent stroke)

4. When did you begin providing them with care/support (month/year?)

 /

5. Do you live with the person you care for? Yes ☐ No ☐

6. What were their living arrangements before the stroke?

- f. Living alone ☐
- g. Living with family ☐
- h. Living in sheltered accommodation, e.g. warden controlled premises ☐
- i. Living in a residential service ☐
- j. Other (please specify) _____ ☐

7. What were their support needs before the stroke?

For the purpose of question 6 and 8 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*'

- h. No support needs, they were independent in all everyday living tasks ☐
- i. They received support from an unpaid carer or family member ☐
- j. They received less than 2 hours support per day from a paid carer ☐
- k. They received between 2 and 4 hours support per day from a paid carer ☐
- l. They received more than 4 hours support per day from a paid carer ☐
- m. Staff were available to help them 24 hours per day ☐
- n. They used some sort of assistive technology to help with everyday living tasks (please refer back to definition above if needed) ☐

8. What are their living arrangements since the stroke?

- k. Living alone ☐
- l. Living with family ☐
- m. Living in sheltered accommodation, e.g. warden controlled premises ☐
- n. Living in a residential service ☐
- o. Other (please specify) _____ ☐

9. What are their support needs since the stroke?

- h. No support needs, they are independent in all everyday living tasks ☐
- i. They receive support from an unpaid carer or family member ☐
- j. They receive less than 2 hours support per day from a paid carer ☐
- k. They receive between 2 and 4 hours support per day from a paid carer ☐
- l. They receive more than 4 hours support per day from a paid carer ☐
- m. Staff are available to help them 24 hours per day ☐
- n. They use some sort of assistive technology to help with everyday living tasks (please refer back to definition above if needed) ☐

10. In an average week, how much time do you spend supporting the person you care for with the following tasks?

Task	Hours spent per week
Hot drink preparation	
Breakfast preparation	
Snack preparation	
Main meal preparation	
Personal grooming, washing	
Dressing	

11. Are there any other day to day tasks within the home environment that you support the person you care for with? Please list:

12. Using the scale below please rate how much your carer responsibilities impact upon your quality of life:

-10	-9	-8	-7	-6	-5	-4	-3	-2	-1	0	1	2	3	4	5	6	7	8	9	10									
Very negative										Does not impact										Very positive									
Impact upon my life										upon my life										impact upon my									
life																													

Please add any further comments you wish to make

Thank you very much for your participation

Appendix 3: Initial health professional format for focus group

1. Initial thoughts on prototype one **will aim to show video**
 - Would you use it with your clients? If yes, what would you hope to gain? If no, what are the barriers?
 - What problems do you for see using the system? How could we address these problems?
2. Thoughts around prompts – visual and auditory **will aim to show video**
 - What cues do you currently use to guide patients through ADL tasks?
3. Thoughts around tools used – sensors/ watch/ screen etc. **if possible to have some examples of the tools used with the sensors**
4. What tasks do you think should be covered in the next prototype
Use following as prompts or may get to rank
 - Teeth brushing
 - Grooming – brushing hair shaving
 - Snack prep – sandwich or soup in microwave
 - Any others
5. Thoughts on the system as a whole and any changes/ additions for prototype 2 to include around the prompts as well

Appendix 4: Format for use in focus groups for stroke survivors and carers

1. Initial thoughts on prototype one **video will have been shown**
2. Thoughts around prompts – visual and auditory **examples of these will have been shown**
 - Are they easy to follow and understand?
 - Can you see any potential difficulties with them? How could these be overcome?
3. Thoughts around tools used – sensors/ watch/ screen etc. **if I can't get mock examples will ask for pictures**
 - Would they wear the watch? If not, why not?
 - Can they see any potential problems with the tools? How could these be overcome?
4. What tasks of everyday activities do you think should be covered in the next prototype EG
 - Tooth brushing
 - Grooming
 - Snack preparation - toast
5. Thoughts on the system as a whole and any changes/ additions for prototype 2 to include around the prompts as well
 - Would they use this – reasons etc.
 - What might the benefits be? What would put them off using it?
6. What support do you feel you would need to use a piece of equipment like this?

-
7. Do you currently use technology to support you in your everyday life? if so details
 8. Do you think a system like this could reduce care needs? If not, why not?

Appendix 5: amended health professional focus group format following pilot

1. Initial thoughts on prototype one **will aim to show video before hand**
 - Would you use it with your clients? If yes, what would you hope to gain? If no, what are the barriers?
 - What problems do you foresee in using the system? How could we address these problems?
2. Thoughts around prompts – visual and auditory **will aim to show each of these**
 - What cues do you currently use to guide patients through ADL tasks?
 - What factors do you consider when choosing what cues to use?
3. Thoughts around tools used – sensors/ watch/ screen etc. **if possible to have some examples of the tools used with the sensors this is picture format**
4. What tasks do you think should be covered in the next prototype **Use following as prompts or may get to rank**
 - Teeth brushing
 - Grooming – brushing hair shaving
 - Snack prep – sandwich or soup in microwave
 - Any others
5. Do you currently use any technology? If so what and what for
6. Thoughts on the system as a whole and any changes/ additions for prototype 2 to include around the prompts as well

7. How do you currently monitor progress with your patients? Including what types of prompts do you currently use in tasks of everyday living
8. What feedback would you want the system to provide for you to monitor progress? – perhaps show interface
9. What training/support do you feel you and your patients would need to use a piece of equipment like this?
10. Do you think this system could result in a reduction in care needs in a cost effective way? If not, why not?

Appendix 6: health professional information sheet

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 46% of stroke patients showed characteristics of Apraxia and Action Disorganisation Syndrome (AADS) (Bickerton et al, 2012). 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 rehabilitation system 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

CogWatch Solution

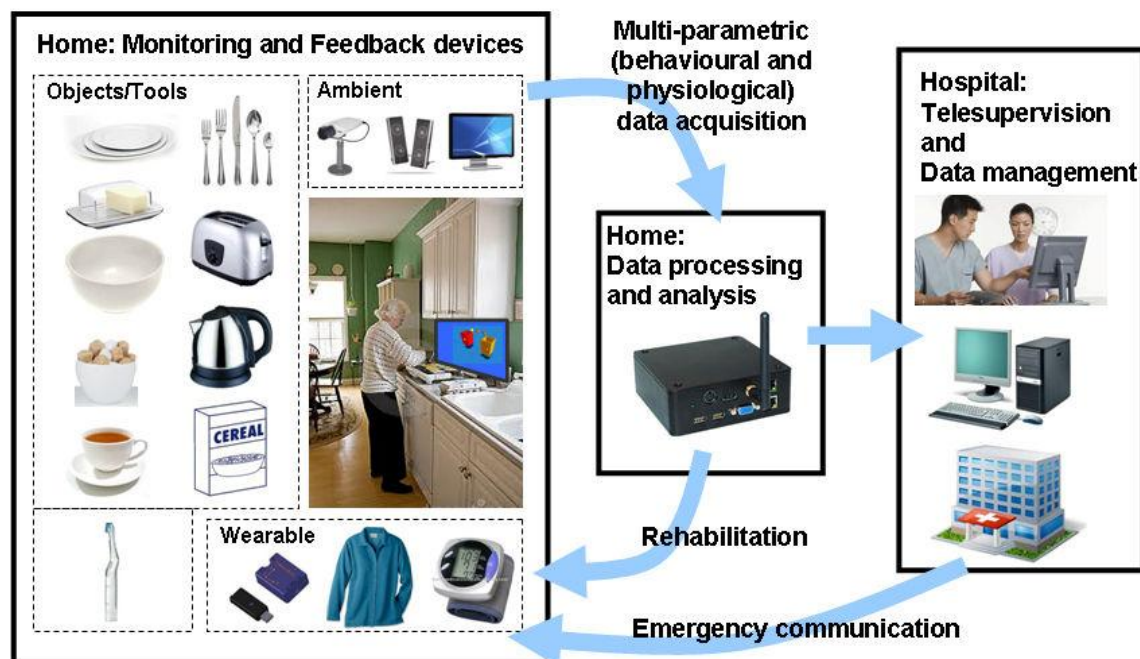


Figure 1 Schematic representation of the CogWatch system

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.

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 often 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 a first prototype 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 – Development of a second prototype based on information gained from Health Professional's, carers and stroke survivors. This will then be tested in the 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 gained views of healthcare professionals, carers and stroke survivors. This information contributed to the development of the first prototype.

Over the next 3 months we aim to test the usability, effectiveness and practicality of the CogWatch system – Prototype one. Therefore we aim to do this through a series of focus groups and surveys with patients, healthcare professionals, community workers and family members in order to assess the following:

- a) How well the technology is received by patients, their families and carers.
- b) Whether CogWatch provides any reductions in care needs c) How well health care professionals can use the system and the information it collects
- d) Whether a system like CogWatch can be cost-effective

We are hoping to gather a number of opinions and information 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. If you require further information or have any questions regarding this project please do not hesitate to contact:-

Alexa Hazell – Senior Occupational Therapist
Ahazell@headwise.org.uk

Appendix 7: Information sheet for carers and stroke survivors

How can you help?

CogWatch is currently in the development stage, however the first prototype has now been released and we would value your opinion's to ensure the final rehabilitation system best meets the needs of people with AADS, therefore 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.

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

The Proposed Solution: CogWatch

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** will 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.



Appendix 8: health professional consent form

COGWATCH

HEALTH PROFESSIONALS CONSENT FORM

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

I give my consent to:

a) **Participate in a focus group** at _____ on _____

and/or (delete as appropriate)

b) **Provide/collect information via a questionnaire**

I understand that all information I share will be kept anonymous. No identifying information will be taken, and all data will be stored securely. ☐

I understand that I will not be able to withdraw my participation later as all my data is being recorded anonymously. ☐

SIGNED: _____ DATE: _____

ROLE/PROFESSION: _____

Appendix 9: stroke survivor consent form

COGWATCH

STROKE SURVIVOR CONSENT FORM

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

I give my consent to:

a) **Participate in a focus group** at _____ on _____

and/or (delete as appropriate)

b) **Provide information via a questionnaire**

I understand that all information I share will be kept anonymous. No identifying information will be taken, and all data will be stored securely.

☐

I understand that I will not be able to withdraw my participation later as all my data is being recorded anonymously.

☐

SIGNED: _____

DATE: _____

Appendix 10: carer consent form

COGWATCH

CARER/FAMILY MEMBER CONSENT FORM

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

I give my consent to:

a) **Participate in a focus group** at _____ on _____

and/or (delete as appropriate)

b) **Provide information via a questionnaire**

I understand that all information I share will be kept anonymous. No identifying information will be taken, and all data will be stored securely.

☐

I understand that I will not be able to withdraw my participation later as all my data is being recorded anonymously.

☐

SIGNED: _____ DATE: _____

RELATIONSHIP TO STROKE SURVIVOR: _____