D 2.2: Report on Scenarios & Users Needs

06/06/2016

AIDE

Adaptive Multimodal Interfaces to Assist Disabled People in Daily Activities

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LEIT Pilar KET ICT

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V2.0	6/6/16	Cedar Foundation	Revised version

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1. INTRODUCTION

AIDE is an ambitious project aiming to work directly with target end users, caregivers and healthcare professionals to deliver a multimodal technology platform to promote functional ability and social engagement. Direct engagement with stakeholders is essential to keep the development of the system grounded in the needs and requirements of people who would use and benefit from the development of this type of assisted device. This documents presents gathering user requirements through focus groups with occupational therapists, students and individuals living with neurological conditions. Additionally, caregivers input was gathered through a questionnaire designed specifically for the project. This work combined with the theoretical frameworks of Maslow's theory, the International Classification of Functioning, Disability and Health (ICF) and activities of daily living (ADL) domains has driven the development of four scenarios to be achieved by the AIDE prototype with varying degrees of complexity depending on the stage of prototype development and the ability of the user to control the system. This document, the users requirements and the scenarios will continue to evolve as the project progresses and as the user centred engagement continues. Finally, a user requirements road map was developed to create a synergy between the technical design, the work packages, and the user's preferences.

2. DEFINITION OF USERS

An end user in terms of the AIDE project is a person living with a neurological condition. It is estimated that one in six people in the world are diagnosed with a neurological disorder and this number is expected to rise considerable due to extensions of life expectancy (WHO, 2006). A neurological condition is damage to the brain, spinal column or nerves due to illness or injury such as spinal cord injury, acquired brain injury, stroke, motor neurons disease and locked in syndrome (See Appendix One for more details). Neurological disorders are considered the primary cause of disability in modern society (WHO, 2006). These conditions can occur at birth such as cerebral palsy and also during childhood e.g. muscular dystrophy. Other neurological disorders can have a sudden onset as a result of accident or illness such as a brain injury, spinal injury or stroke. Furthermore, multiple sclerosis, amyotrophic lateral sclerosis and motor neurons disease are degenerative neurological conditions occurring typically in adulthood. Such conditions are correlated with a significant cost burden due to hospitalisation, rehabilitation, assistive technology, and long-term dependency on healthcare services (Andlin-Sobocki et al., 2005). Some individuals with neurological conditions can regain full

motor and cognitive function after extensive rehabilitation (Ashman et al., 2006). On the other hand, degenerative conditions such as multiple sclerosis and amyotrophic lateral sclerosis can have greater reliance on health and social care due to the progressive nature of the disease (Trisolini et al., 2010). The debilitating consequences of neurological disorders include communication difficulties, impaired memory, inappropriate behaviour, physical disability, restricted independence, social isolation and poor quality of life. Assistive technologies aim to increase quality of life (Sellers, Vaughan and Wolpaw, 2010) reduce dependence on care giver (Brandt et al., 2011) and reduce dependence on the long term care system (Agree et al., 2005).

The purpose of the AIDE system is to maximise the abilities of people living with severe neurological conditions that have resulted in significantly limited mobility. In particular, the project will aim to focused on three groups of end users with different residual capabilities:

- Group 1 – Wheelchair users with some residual upper-limb movement allowing them to partly move arm/hand but who still need assistance to accomplish a reaching and grasping task, thus still need assistance to carry out activities of daily living in an effective way. For this group of users we envision a multi-modal human-machine interface where: (i) an EEG/EOG-based hybrid brain-machine interface (BMI) is used to support the user to grasp an object, (ii) proximal EMG signals to decode the intention of starting a reaching task and the direction the user wants to reach, (iii) gaze tracker and cameras are used to identify which object the user is interested in and its location in the workspace (EMG and gaze tracker will provide info with a certain degree of redundancy, thus will promote the possibility to enhance robustness), and –when appropriate, i.e., no speech disorders– (iv) voice semantic recognition system to identify the intended task of daily life to perform. This group of users will also benefit of: (i) a module which is able to recognize the environment/context thus helping the identification of the intended task, and (ii) a module which is able to monitor the psychophysiological stress level of the user.
- Group 2 – Wheelchair users without any functional control of the arm and/or hand, and who are unable to speak (due to a speech disorder or aphasia). In this group, the AIDE multimodal interface could be composed of: (i) an EEG/EOG-based hybrid BMI system for decoding the intention to reach and grasp an object, and (ii) a gaze tracker to decode the object/task the user is interested to; this module shall be combined with a set of cameras for context recognition. As in the case of Group 1, these users will also rely on a module which is able to monitor their psychophysiological stress level of the user.

- Group 3 – Wheelchair users without functional motor control of the arm and/or hand, with speech disorders and limited ability to control the movement of their eyes. In this case, the multimodal interface could be composed of a BMI system (EEG recording) to send commands to the high-level control of the wearable robot and to interact with the user control software; a commercial wearable device for physiological signals monitoring; and RGB depth cameras to sense and understand environment and context to automatically recognize the necessary abilities for different ADL.

Participants within group one and group two will be the main profile of users for the AIDE system (Table 1). However, we will keep group three profile as a potential application of the system.

Group	**Pathologies**	**Affected Motor functions and abilities**	**Interfaces**	**HW**
3	Severe locked-in syndrome (LIS)	- No motor control of the arm and/or hand - No control of eyes movement - Unable to speak	BMI system	Communication Environmental control
2	Classical LIS/ ALS/ Tetraplegia	- No motor control of the arm and/or hand - Unable to speak - Control of eyes movement	EEG/ EOG-based hybrid BMI system Eye gaze tracker Context recognition Physiological signals Indoor location system	Communication Environmental control Exoskeleton Robotic arm Online services Entertainment
1	Severe paralysis	- Limited motor control of the arm and/or hand - May or may not be able to speak - Control of eyes movement	EEG/ EOG-based hybrid BMI system Eye gaze tracker Context recognition Voice control EMG signals from arm Physiological signals Indoor location system	Communication Environmental control Exoskeleton Robotic arm Online services Entertainment

Table 1. Overview of User Groups, Interfaces and Hardware

3. LIFE SKILLS AND ACTIVITIES OF DAILY LIVING

It is important when considering what a person would like to be able to do on the AIDE system to consider the different types of needs a person has. There are a number of ways and theories to explore and priorities these tasks and requirements. Maslow's hierarchy theory of needs sets out a pyramid beginning with a person's most basic needs at the bottom and as the persons needs are meet they move up the pyramid towards the need to develop into the person they desire to be (Figure 1). In AIDE we want create an environment where a person with limited mobility is able to meet their needs at each stage of the pyramid in order for them to ultimately engage in their community as active citizens through the use of the system.

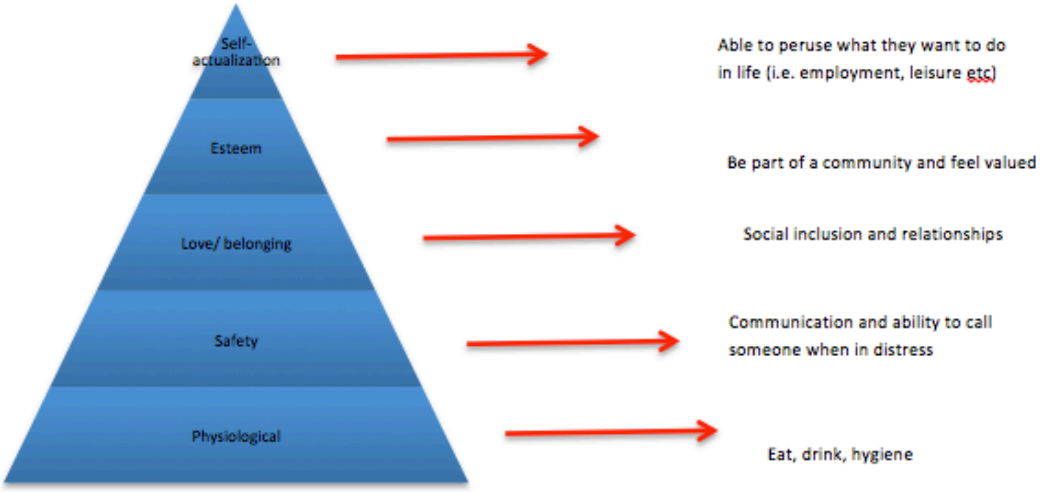


Figure 1: Maslow's Hierarchy Theory of Needs and Related Tasks

Activities of daily living are essential for existence and include fundamental tasks such as personal care, feeding, drinking, hygiene and mobility (Wade, 1992). However, a person requires more than their basic survival needs to get satisfaction from life. Legg et al's (2006) set out useful domains of activities of daily living within their Cochrane literature review to support a more holistic approach to daily life activities. The first domain are personal activities of daily living (pADL) and these are the essential tasks for each day to maintain ourselves such as feeding, dressing, toileting, grooming, transferring, and moving. The second domain is the extended or instrumental activities of daily living (IADL) which are the tasks so that a person can be self-reliant in their community (Hartigan, 2007). These tasks include preparing

their own food or meal, shopping, light housework and managing finances. The third domain presented was the occupational activities such as the person's employment or job. Finally, discretionary activities was the final domain outlined which included leisure activities, hobbies, engaging in the community, spiritual activities, caring for people, shopping, gardening and so on. In line with the framework set out by Maslow, the domains of activities of daily living are particularly helpful in the development of tasks for the AIDE system to support prioritising requirements to enhance occupational performance in daily life in advance of approaching end users and stakeholders.

The final framework important during the scenario and task development is the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). The ICF focuses on the interaction between the health condition, and the contextual factors i.e. the environment and personal factors. The ICF created a checklist to support clinicians identify the functioning and impairment level of an individual while also considering activities, participation, environment and personal factors. This checklist is also an important tool to reflect on the activities important to people within the overall context of their living situation and environment.

A person completes 90% of their tasks each day within their home and these tasks range in complexity from pADL to IADL. It's where a person showers, sleeps, communicates, eats and engages in leisure activities. Additionally, managing a home is a process that requires numerous physical skills, and intellectual acumen. Within a persons home the IADL are instrumental to move beyond basic needs for existence and to incorporate more complex skills for autonomous independent living. At home, a person will need to masters skills to maintain their health and independence. These are outlined in Table 2.

Daily living skills	Physical skills	Intellectual and psychological skills
• Meal planning and preparation • Grocery shopping, choosing foods (online) • Eating and drinking • Adhering to a medication schedule • Mobility and movement within the	• Housekeeping, domestic skills • Using the internet and online services • Ability to keep up a home, and accessing services • Navigating within the home • Entering and exiting a home • Identify strange odours, sounds, situations • Organizing all	• Money management, budgeting, banking • Interviewing, interacting with attendants • Implementing an emergency plan • Emotional self-regulation coping alone or with guests • Managing time • Transport arrangements

home • Using the phone (possible to seek medical assistance if necessary) • Managing personal care assistants, if applicable • Practicing first aid, safety measures	needed tools and objects in a way that works	• Maintain privacy and control of affairs

Table 2: Tasks within the home environment

The focus of the tasks first and foremost is on the physiological aspects of Maslow's theory and the first pADL domain. This means that self-care tasks within the home are a fundamental priority. Some of the self-care skills that are required within the home include: Communication; Personal hygiene; Dressing and undressing; Toileting; Grooming; Eating and drinking. It is essentially to go to users of the system next and gather their requirements to build on the theoretical framework provided by Maslow, the ICF and the domains of activities of daily living.

4. PROTOCOL FOR EACH FOCUS GROUP

A protocol was established for each focus group to ensure consistency and to explain the technologies used within the project. The ethical framework to recruit participants is set out in Deliverable D2.1. Each participant had consented to taking part in the focus group in advance of their arrival. Additionally, the information sheets and consent forms for the target end users and healthy user groups can be found in Appendix 5 (Consent form, Information sheet, Project Leaflet for Participants, Presentation). A presentation was developed to describe the AIDE project and explain each component of technology included in the system. Each 'signal actuator' was explained using pictures and video so that each person had a basic understanding of how it worked and how to interact with it. The presentation can be found in the Appendix 5 illustrating the pictures used and the questions asked to target end users. The videos used to support the explanations were:

http://www.bbc.co.uk/news/uk-england-31007874
https://www.youtube.com/watch?v=04Rhnt4J2b4
https://www.youtube.com/watch?v=8LCKlwqnnEA

The presentation was the same for healthcare professionals with the exception of the questions at the end. Healthcare professionals were asked: *How does your client's neurological condition impact their daily life?; What type of assistive technologies would be useful for your client group use?; Are there any limitations to using this type of technology? Can you tell me what you would like technology to help your client do?.* Each presentation lasted up to 20 minutes depending on the questions asked by participants for clarity. The discussion would begin when all questions were answered adequately and would start with the first predefined question.

5. ENGAGEMENT WITH THERAPISTS

To date 3 focus groups with therapists have been completed so far and this work will be on going throughout the lifecycle of the project. Each focus group lasted between 1.5 to 2 hours. The session started with all participants within the group watching a presentation of technologies related to AIDE. Following this, participants broke out into groups of 3 to 4 people to engage in discussions. In total over the 3 focus groups 100 participants have informed working on scenarios and user needs for the AIDE project; the 1st group had 39 participants, the 2nd group was made up of 45 participants; and the 3rd group was made up of 16 participants.

In terms of outcomes feedback gathered was collated, reviewed and inputted manually into wordle (http://www.wordle.net) to identify the most frequent terms and issues/topics emerging from the discussions. The size of the word in the word cloud is proportional to the number of times it was mentioned within the groups. It was necessary to join words together using – so that they were included as one word.

In the following sections the questions are presented with the responses in a word cloud.

Question 1: How does your client's neurological condition impact their daily life?

Question 2: What type of assistive technologies would be useful for your client group use?

* Wheelchair-adaptions= ways to operate wheelchair suck & blow/ eye gaze/ sip and puff

Question 3: Are there any limitations to using this type of technology?

Question 4: Can you tell me what you would like technology to help your client do?

*Control- ECS= Environmental control systems; Basic need= positioning, scratching,

6. ENGAGEMENT WITH STUDENTS

Two large focus groups were undertaken with N= 72 students persuing careers as healthcare professionals. The students were selected as they are a population with technology intregated into their way of life and have a fresh understanding and interest in the health care system. Although students were a mix of first and second year students they were studying modules in health care and had a specific module

in assisted technology. Each focus group lasted 2 hours and had a total of 36 participants in each group. The session started with all participants within the group watching a presentation of technologies related to AIDE. Following this, participants broke out into groups of 5 to 6 people to engage in discussions around four questions posed to them.

The first focus within the smaller groups was to put the tasks detailed below in order, beginning with the most important. The responses from the groups were collated and the order of the list starting from the most important was:

1. Move around the kitchen to reach different areas (refrigerator, cupboard, microwave)
2. Grasp objects from the refrigerator or the cupboard and bring them to the table
3. Eat a sandwich with hands
4. Eat a meal with spoon or fork
5. Drink from the straw
6. Pour the water in a glass and drink from the glass
7. Heat a meal in the microwave

The second task within the small groups was to discuss the types of things they would like the AIDE system to be able to support a person with limited mobility to do. The outcome of this discussion is summarised in Table 3 below.

Bathroom	Living room	Bedroom	Kitchen
Turn on tap Wash hands, face, and body Have a shower Pick up a toothbrush and brush teeth Personal care tasks such as toileting	Turn on and control the TV Control the lights Operate heating To control all electronics To sit down without help To move around the room To read a book	To get in/ out of bed To choose clothes To open curtains/ blinds Ability to dress/ undress To move around the room	Boil the kettle Make tea/ coffee, Choose food To eat and drink for yourself To turn on/ off appliances Ability to grasp To cook To clean

Table 3: Proposed activities for the AIDE System

The third discussion focused on the preferred use of an exoskeleton or a robotic arm. The majority of participants reported they would have a preference for using

the exoskeleton. However, participants felt this was challenging to answer, as they did not have experience using either of the systems.

The final focus of the discussion looked at the type of assistive technology that would be easiest for a person with limited mobility to interact with. There were wide ranges of responses from participants including: Eye tracking, EoG, Wireless EMG, Physiological monitoring, BMI EEG, and Robotics. Once again participants lack of experience controlling the difference operating systems resulted in challenges selecting the easiest technology to interact with.

The outcome of the focus groups with students was really helpful to gather the views from people with a healthcare perspective that use technologies within their day to day lives. This work was also important as a precursor to working with end users to establish the clarity of the technology presented and to gather their opinion on the possible applications of the AIDE system.

7. ENGAGEMENT WITH TARGET END USERS

People living with a neurological condition were invited to attend a focus group through their non-governmental organisations (NGO) in keeping with the ethical framework set out in D 2.1. Participants were living independently in the community with a neurological problem such as acquired brain injury, multiple sclerosis, stroke, muscular dystrophy, and spinal cord injury. They were all be post rehabilitation and no longer receiving services from the acute sector. Key workers within the NGO were asked to make the initial contact with any potential participant and they were welcome to bring a family member or caregiver with them to participate.

A total of five focus groups were run with N=28 participants (N=5; N=7; N=4; N=6; N=6). Individuals neurological conditions ranged within the groups with a considerable number of participants present living with spinal cord injury, acquired brain injury and stroke. End users were not asked directly about their current use of technology however within the groups no person used a device for communication. The majority of end users had no communication impairment and were aligned to user group 1. Participants with communication difficulties were able to express themselves without support once they were given time and repeated themselves on occasion. It is a significant challenge to include individuals from group 2 and 3 during a focus group session due to difficulties with communication but also travel, and the additional support needs. Therefore, participants who had experience of locked in syndrome following an acquired brain and stroke were recruited to give an insight into the needs of these profiles. Additionally, a person who fits the profile of group two but currently has no functional access technology was able to contribute to one

of the groups through specific questioning techniques (closed questions yes= noise/ No= silence). Each focus group last approximately an hour and started with the protocol outlined in section 4. The discussion focused on four key questions and these are outlined below within the structure of the results.

1) Top three priorities for the system

Important tasks for people to be able to complete independently at home ranged from communication to washing to cleaning to home automation to driving to walking. Some of the ideas that emerged for the conversation would be beyond the scope of the AIDE system in development however in general the ambition of the users could be facilitated within the project (see Table 4). Communication emerged from each group as the most important. To be able to express a person's basis needs, have choice, enable relationships and start to be seen as an equal was fundamental. Hygiene was described as any personal care task such as washing, showering, brushing teeth, brushing hair, wiping face, and washing hands. To achieve these personal and private tasks ones self was considered to be a huge boast for a persons self esteem. Being able to take control of ones live by completing simple tasks independently within the home environment such as turning on lights, setting alarms, controlling entertainments systems were also important. Essentially any tasks that could be completed on the prototype so that individuals were less reliant on another person would be positive.

	FG 1	FG 2	FG 3	FG 4	FG 5
1st	Communication	Communication	Communication	Communication	Communication
2nd	Hygiene	Hygiene	Environmental control	Eating & drinking	Hygiene
3rd	Eating & drinking	Eating & drinking	Hygiene	Entertainment	Eating & drinking

Table 4: The top priorities to be enabled by the AIDE prototype

2) What would be your favourite way to control the system?

Voice recognition emerged as the preference to interact with the system however their were concerned about its reliability as it can struggle to recognise accents. Additionally, a number of the participants had speech impairments meaning they were unable to speak or their speech was unclear making voice control difficult. It was also highlighted that voice recognition would mean the user would not have to wear the additional technologies- therefore aesthetic appearance was an important

factor. The opinions around controlling the system were very person to the abilities, strengths and weakness of those in the group. Preferences included the use of BMI because of involuntary eye movement, EMG because Stephen Hawkins makes it look easy to operate and eye tracking because of its perceived efficiency. Additionally, a consensus emerged that the preferred way to control the system would be reliable, require little effort and not be bulky.

FG 1	FG 2	FG 3	FG 4	FG 5
Voice control priority but if no ability to talk	Voice control or EMG	Voice control or EMG	EMG	Voice recognition feels more mainstream

Table 5: Each Focus groups preference to control AIDE system

3) Exoskeleton or robotic arm?

Each group was asked to consider their preference of operating the exoskeleton or the robotic arm. The exoskeleton was the preference in general as it was felt the person would exercise their muscles; get the feeling they are doing something; once the size is reduced down it would look like a prosthetic. However, fear of wearing this exoskeleton, the pain from movement of own arm and the ability to stop the exoskeleton if something went wrong were discussed. Views around the robotic arm were that it would be bulky, you are still not moving it is external to you; aesthetic appearance; however, it looked simpler to operate. Once again it was acknowledged that it would really be around personal preference and the neurological condition as one participant who could benefit from using the system would not be able to wear the exoskeleton due to the tone and spasticity in his muscles.

4) **Kitchen tasks in order of importance**

The task to support a user to prepare a meal in the kitchen, eat the meal and take a drink will be very challenging for the developers to enable this capacity through the prototype and users of the AIDE system the achieve this. To focus the development of the technical team for this very complex task users were asked to order the 5 tasks listed below in order of importance (See Table 6).

1. Grasp objects from the refrigerator or the cupboard and bring them to the table
2. Heat a meal in the microwave
3. Eat a meal with spoon or fork
4. Eat a sandwich with hands
5. Pour the water in a glass
6. Drink from the straw

7. Move around the kitchen to reach different areas (refrigerator, cupboard, microwave)

FG 1	FG 2	FG 3	FG 4	FG 5
Eat spoon	Move	Eat spoon	Drink	Drink
Drink	Grasp	Drink	Grasp	Eat spoon
Grasp	Drink	Move	Move	Move
Move	Eat spoon	Grasp	Eat sandwich	Grasp
Pour water	Heat	Eat sandwich	Eat spoon	Pour water
Eat sandwich	Pour water	Pour water	Pour water	Eat sandwich
Heat	Eat sandwich	Heat	Heat	Heat

Table 6: Kitchen tasks in order of importance

8. ENGAGEMENT WITH FAMILY AND CAREGIVERS

Families and caregivers often have very little time to contribute to research. This is because paid caregivers are often under significant pressure to meet the needs of multiple service users and tenants. Additionally, family members caring in an unpaid capacity are often juggling their caring role with the up keep of the household and any others roles they fulfil within the home. To make participation as easy as possible for this key stakeholder group a survey was developed and make available online and hardcopy (Appendix 4). The survey was distributed to paid caregivers in two supported living housing schemes for people with complex physical disability and to personal assistances that support the attendance of trainees. Additionally, a number of family members linked to the Cedar Foundation were emailed the questionnaire to complete.

A total of eleven questionnaires were returned and completed in full by caregivers. It was indicated that respondents had an average of over eight years caregiving experience, ranging from 22 years to 2 years. The age ranges are illustrated in figure 2, highlighted the majority of carers were under 45 years of age.

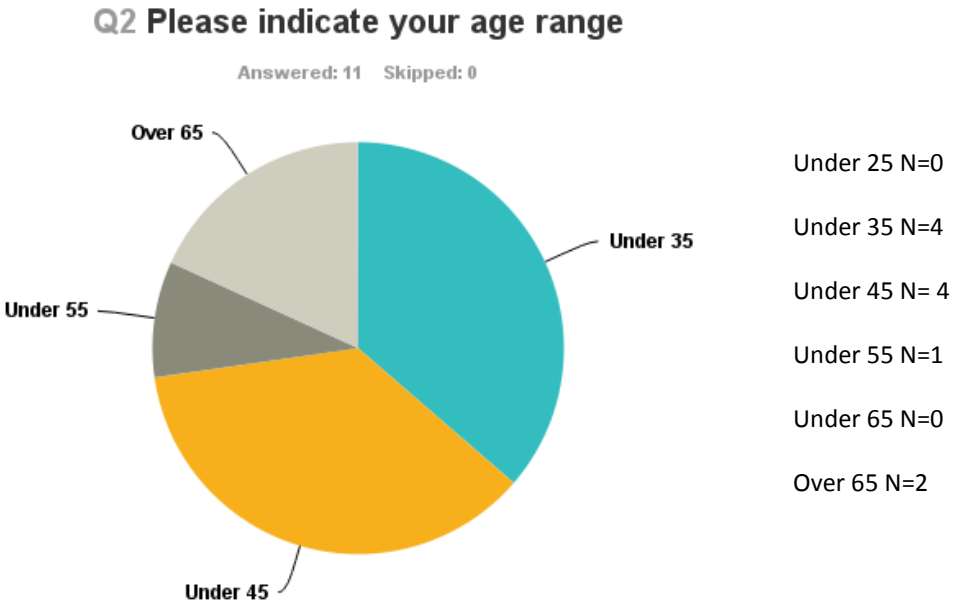


Figure 2: The age range of the caregivers

The majority of responses focused on the ability for this type of technology to give the user independence and give carers time to do other things. Advantages included choice, control and independence. One caregiver suggested that the system could bring about a change of mood for the user as they would be *'able to do more increasing confidence, promoting independence and they wouldn't have to wait for your assistance'*. Disadvantages for such a system ranged from system failures, to additional workload, and need for training. An observation from one caregiver shared this concern '*This depends on how physically restrictive in terms of size the equipment is and how efficiently the assistive technology works- potentially this could be very frustrating and not live up to expectations.*' A range of characteristics to support technology fitting into the caregiver's role were suggested. Primarily, simplicity of the device and ease of use were most commonly indicated. One caregiver said that you should '*not require a degree'* to set the user up on the system. All but one caregiver reported a technology that currently supported their caregiving. Six of the caregivers stated that smart technology supported their caring role. One caregiver stated that although smart home technology could support the person they are caring for to independently undertake tasks, often the caregiver is called to undertaken the task instead.

Question	Summarised Responses
How do you think this type of technology could help you in your caring role?	• Enabling independence and autonomy • Give caregivers more time for other duties • Offer opportunity for more choices • Make user self sufficient
Can you think of any advantages to the using AIDE system?	• Control over environment • Give caregivers more time for more duties • Empowerment • Increased Independence which leads to confidence, more choice and control
Can you think of any disadvantages to the using AIDE system?	• If the user was unable to use it correctly it could lead to frustration and stress • Training • Maintenance required • System failures • Size • Extra workload and time for caregiver • Need for carer education • Carer might be required to sort out problems more often.
What characteristics would this system need to have so that it could fit into your daily support routine?	• Simple to use • Simple to explain use • Robust • Mobile • Quick set up • Reliable • User friendly interface.
Do you have any type of technology that supports your caring role currently?	• SMART technology- environmental controls i.e. lights, blinds, windows, doors • Touchscreen communication aid • Hoists • Light writer • Eye gaze • Switches • A buzzer system

Table 7: Outcome for Caregivers Questionnaire

It is acknowledged that caregivers are a key stakeholder to contribute to the design and development of the AIDE system. Although the sample size was modest there contribute is key to develop a perspective from an additional user of the system and because of their knowledge of the target user group. Future work will aim to increase the engagement of this caregiver population through: email blasts to recruit caregivers through non-governmental organisations (NGO) that provide services for people living with neurological conditions such as Spinal Cord Injury Northern Ireland, Motor Neurone Disease Association of Northern Ireland, Muscular

Dystrophy Northern Ireland, Multiple Sclerosis Northern Ireland, Northern Ireland Stroke, Northern Ireland Stroke and Chest Heart and Stroke Association; caregivers will be recruited in collaboration with the recruitment of target end user for WP8 effort commencing, and we will aim host a workshop for caregivers in the Autumn.

9. USER REQUIREMENTS ACCORDING TO PACT

The purpose of this deliverable is to identify target end users, outline user requirements through stakeholder engagement and as a result develop scenarios of use. The challenge is converting user requirements into usable specifications to inform the design. The PACT framework stands for People, Activity, Context, and Technology and it offers a constructive approach to analysis user requirements in terms of their real world application to inform design (Benyon and Macaulay, 2002; Widya et al, 2010). The themes and content of the user requirement gathering were synthesized and are illustrated in Table 8 according to the four pillars of the framework. This framework is a useful starting point as we move to develop the technical specifications of the system according to users' needs (D2.3) and describe the emerging scenarios of use.

PACT	Person	Activity	Context	Technology
General User Requirements according to PACT	Unique presentation Secondary conditions Personal preferences Energy/Fatigue Type of wheelchair Ability to get out of bed Time frame for sitting Residual movement Range of movement Pain/ sensation from pressure (even in paralysis) Degree of muscle spasticity/ tremors/ contractures Comfort Normality and ease to interact with device Appearance Claustrophobia Additional technology- ventilator Percutaneous endoscopic gastrostomy Handedness (right or left)	The type of activity, the complexity of achieving it and the number of step to complete a task will be impacted by each component of PACT. Activities of Daily Living Communication Control home Personal care Eating Drinking Leisure activities Operate wheelchair Access computers Basic tasks to regain control and maximise independence	Appropriate environment i.e. space, flat surfaces, within a home The size of the system and exoskeleton when all components are mounted on wheelchair Level of counter tops, table, and sink so that electric chair can easily manoeuvre underneath Dimensions of fork, glass, tooth brush handle for exoskeleton hand to grasp The need to perform simultaneous actions i.e. controlling wheelchair and carrying a plate Who will set user up? Non expert or expert Set up time, training and simple set up	**Hardware** Wear ability Weight Robust Manoeuvrability Portable Balance on wheelchair (centre of gravity) Space (clutter) and technology surrounding user Aesthetic design of system and appearance of user Safe Adaptability **Software** Reliable Easy to use Low error rate Customisable Functionality Personalisation for each user Speed of use Effort required for control Automation of steps

Table 8: User requirements presented according to the PACT Framework

10. SCENARIOS TO BE ADDRESSED

Gathering user requirements lead to tasks of varying difficulty according to what people really want and need to do through the AIDE system. Table 8 highlights the key activities that emerged as important during this phase. The scenarios have been developed according to these preferences and have be outlined below according the the system specification for each end user group as set out in Deliverable D2.3. The outlined scenarios will undergo feasibility tests with a population without a disability in advance of working with people living with a neurological condition.

SCENARIO 1 - **COMMUNICATION**

Each focus group with end users had communication as their top priority for the AIDE system. Therefore, it is essential that enabling communication is the first scenario to be achieved. Through communication a person would be able to voice their opinion, communication their needs, make choices, alert their caregiver to an issue and have relationships. This scenario will have the lowest level of complexity and remain very open as the communication will be defined by the user. Additionally, the type of interface the user will adopt such as BMI; EMG, EOG etc. will be adapted according to preference and usability. Partners B&J Adaptaciones will provide the hardware for users to interact with according to their preferences (See Figure 3).

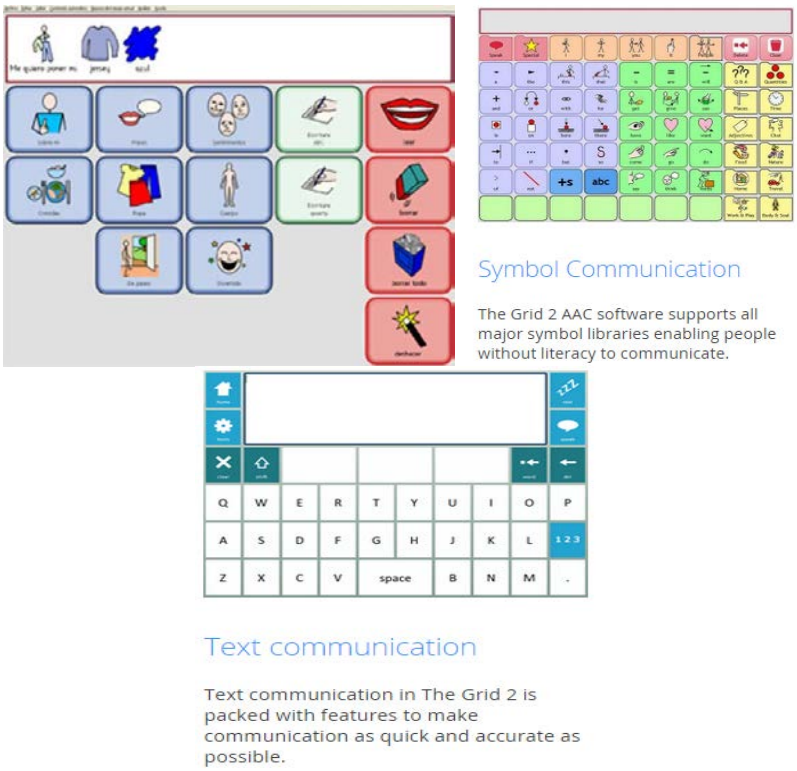


Figure 3: Interfaces to enable communication using the Grid 2 software provided by B&J Adaptaciones

Ideally, the user should be able to operate this aspect of the system from anywhere e.g. their bed, their wheelchair. Initially communication will be enabled through symbols to maximise the potential of the user to express their message and reduce the amount of effort required. The user would have potential to move towards text communication within the Grid 2 matrix as their skill level increases. It is envisaged that the user would only need to make a small number of selections using the symbol communication to express themselves and thus creating a scenario that could be accomplished with the least amount of effort from the user.

SCENARIO 2 – **ENVIRONMENTAL CONTROL**

The second scenario presented would increase the complexity from the very first scenario. End-user and therapist groups expressed their interest in controlling their surroundings. Scenario 2 will first focus on supporting the user to control their environment in one room. So for example, the first stage in this scenario the user will focus on the living room where they will be able to turn on and off a light, turn on and off the TV, control the TV volume and change the TV channel, or read an electronic book. As the development in the system progresses and the competences of the user improves control of devices in other rooms will be enabled on the user hardware (see Figure 4 for example). The continued progression within this scenario would aimed to enable the user to be in control of all the devices within their home. The indoor locator system would make the interface adaptable so that when a person is in a certain room the electronic devices within that room are easy to access on the tablet.

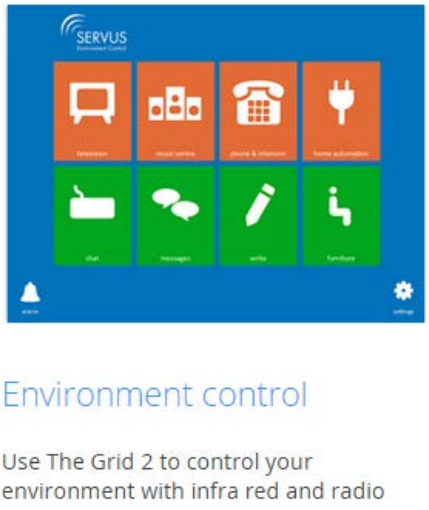


Figure 4: The Grid 2 Environment control interface provided by

SCENARIO 3 – **HYGIENE TASK**

A scenario to support a person with their personal care and hygiene was very important within the user requirements. To enable a person to complete some private tasks by themselves such as brushing their teeth, wiping their face, brushing their hair and washing their hands generated a lot of discussion. This scenario introduces the use of robotics for the first time and therefore has a significant level of complexity. The scenario will be developed to enable a person to wipe their face and brush their teeth. A task analysis was undertaken to consider the necessary steps and environmental factors that need to be considered if the user is to brush their teeth using the exoskeleton (See Appendix 2). After the initial feasibility testing of this task it will be refined and developed to include wiping a person's face.

SCENARIO 4 – **PREPARING AND EATING A MEAL**

The final scenario presented is to enable the user to prepare a meal within the kitchen, to eat and to drink. It is necessary to break this task up into smaller steps and try to achieve each step at different stages in the life cycle of the project. End user focus groups were asked to arrange the steps within this task in order of importance to help focus the development. Taking a drink and eating were most commonly viewed at the top of this hierarchy. Therefore, the very first step will be to enable the user to take a drink and secondly to eat. Within this task it is important to consider each users unique presentation as in order to eat a person need to have the ability to chew, move the muscles in their mouth, the ability to swallow, control their trachea, and pulse the muscles to move the food through their oesophagus. One of the end user group's had a discussion surrounded the desire to move and grasp as in a locked in state they were on a special food supplements so eating was not a priority.

A task analysis was undertaken within the therapist's groups and the complete tasks within the kitchen to prepare and eat a meal is presented in Appendix 3. In order to support the final complete kitchen task some preparation would be necessary in advance by the caregiver to reduce some of these steps. The caregiver is required to leave a meal with pre-cut food ready for the microwave in the fridge, a drink ready for person in the fridge, and a fork or spoon according to the users preference on the table. According to the preferences of target end users the first focus will be on eating and drinking.

11. A ROAD MAP OF USER REQUIREMENTS

To ensure a user centred approach is critical to the technical developments within the project and that the impact of stakeholder engagement is visible throughout the Work Packages, a Road Map of User Requirements was developed. The road map was defined from the target end users, therapists, and caregivers input. Identifications of these needs were then mapped against the systems specification and design solution, and how we will measure if this has been achieved. This road map will continue to evolve as we work with target end users and test the various components of the system in an iterative design approach supporting the link between the users, the technical team and the Work Packages. The Road Map is illustrated in Table 9.

	User Requirements	**Planned Technical Specification**	**Performance Measurements**
Signal Acquisition	**Ease of use:** The user should be able to establish and maintain control of the system easily	• The user's ability to control the system will be maximised through multiple input devices that can be customised according to the unique presentation of user and their preference to interact with it	User feedback during system set up and training Complete task by set protocol to establish: • Accuracy and Success rate (nº success(S), nº No detection(ND), nº errors(E)) • Functionality testing (0:unsuccessful; 1:acceptable; 2: completely functional)
	Effort: The workload required to interact with the system should be minimal	• Using two of the input system together creating a hybrid system will reduce effort needed to control the system. Additionally, the context awareness system to estimate the users intention will automate a number of steps in the control of the exoskeleton reducing workload	Set protocol: Estimation of user intention using EEG/ EoG/ EMG (signal used ☐ not used ☐) (nº success(S), nº No detection(ND), nº errors(E)) NASA TLX: subjective workload
Software	**Effectiveness:** The user should be able to control the system as accurately and completely as possible with a low error rate	• The adoption of the multi-level control architecture guarantees a great accuracy in task execution.	Set protocol: Time to complete tasks Accuracy and Success rate (nº success(S), nº No detection(ND), nº errors(E)) Functionality testing (0:unsuccessful; 1:acceptable; 2: completely functional) VAS- Satisfaction 0 (not at all satisfied) to 10 (absolutely satisfied)

	Easy to use: The system must be easy to operate; intuitive to navigate, and require minimal technical support	• Training will be provided to each user until they feel comfortable and in control of the system. • The user interface will display user friendly graphics to enable the user to navigate with ease.	Set protocol: Time to complete tasks Accuracy and Success rate (nº success(S), nº No detection(ND), nº errors(E)) Functionality testing (0:unsuccessful; 1:acceptable; 2: completely functional) VAS- Satisfaction 0 (not at all satisfied) to 10 (absolutely satisfied) QUEST 2.0 Custom usability questionnaire
	Reliable and robust: The system stable without malfunctions, crashes and errors	• The component-based approach, adopted for exchanging data among the subsystems, minimizes the risk of system malfunctioning by providing control nodes and consequently temporarily disabling faulty components without altering the functioning of the whole system. • The control system will run on a dedicated real-time processor in order to minimize crashes and malfunctions. • The control system will implement different actions to ensure the safety of the user when using the exoskeleton (e.g. speed limits, angle limits, enable/disable switches, integrity checks). • The control system will allow the user to abort the ongoing task at any times, by means of an intuitive interface.	A risk assessment of the whole system will be carried out. The risk assessment can be divided on: 1) risk analysis consists of (i) Determining the limits of the machinery/robot, (ii) Hazard identification and (iii) Estimating the risk; and 2) risk evaluation;. Risk reduction strategies will be implemented and then evaluated to assure that the acceptable level of risk is reached. Number of restarts required and errors will be recorded
	Functionality: The system should enable the user to do as many tasks independently as possible	• The control system will be programmed to allow the user to perform different actions independently, by referring different input signals to the execution of different actions, depending on the recognized context. • Applications available to users include communication tools, environmental control, Internet access, entertainment features and upper limb exoskeleton	Set protocol: Time to complete tasks Accuracy and Success rate (nº success(S), nº No detection(ND), nº errors(E)) Functionality testing (0:unsuccessful; 1:acceptable; 2: completely functional) VAS- Satisfaction 0 (not at all satisfied) to 10 (absolutely satisfied) QUEST 2.0 Custom usability questionnaire
	Personalisation for each user: The system needs to be customised for the needs to each user	• Choice of the components of AIDE multimodal interface; configuration of AIDE sensory system; Adaptation of HLC to each patient requirements; symbols for communication and use aspects of system i.e. communication if complex needs	VAS- Satisfaction 0 (not at all satisfied) to 10 (absolutely satisfied) QUEST 2.0 Custom usability questionnaire

Hardware	**Aesthetic Appearance:** The design of the system should be as user friendly and 'normal' looking as possible	• It is acknowledged that the system will have multiple wearable devices for the user to wear. It is challenging to increase the aesthetic appearance and not compromised functionality however users only need to wear the devices they are interacting with.	QUEST 2.0 Custom usability questionnaire
	Safety: The system must be safe and alleviate any fear target users might have	• The systems hardware is CE certified with the exception of the hand and upper limb exoskeleton. These two prototypes will be put through quality control within their organisations and specifications aligned to achieving certification. • A safety stop button will be integrated in the exoskeleton to ensure the possibility to stop its movement at any times. • Suitable participants will be selected to take part in evaluation e.g. a person with high muscle tone in their upper limbs will not be recruited to operate exoskeleton	A risk assessment of the whole system will be carried out. The risk assessment can be divided on: 1) risk analysis consists of (i) Determining the limits of the machinery/robot, (ii) Hazard identification and (iii) Estimating the risk; and 2) risk evaluation;. Risk reduction strategies will be implemented and then evaluated to assure that the acceptable level of risk is reached. Demographics in pre-testing interview and thorough explanation of technology and testing procedure
	Comfort, Weight and wearability: Any of the devices the users have to wear need to be comfortable, lights and not impact on them	• Shoulder and elbow exoskeleton: Double sided use, integrated onto wheelchair, minimal weight and encumbrance, weight compensation via software, adapts to size of user, several passive degrees of freedom to allow the robot axes self-alignment with human joint axes. • Hand exoskeleton: easy to attach, not bulky, minimal weight • Physiological signals acquisition: - EEG/EOG: comfortable solid-gel electrodes, no hair-washing is required afterwards and wireless - comfortable chest belt (ECG, respiration) - reusable electrodes for GSR/ disposable for EMG - Eye tracking: wireless communication, high wearability, free head movements	User feedback during system set up and training QUEST 2.0 Custom usability questionnaire
	Wheelchair: The wheelchair needs to be stable and not compromised in functionality or balance by the addition of large device	• A wheelchair has been selected to maximise safety by mounting the exoskeleton onto it ensuring the weight distribution and centre of gravity are correct • A custom frame will be designed to attach the exoskeleton onto the selected wheelchair. • A universal system to control the wheelchair movements using the AIDE multimodal interfaces has been developed	QUEST 2.0 Custom usability questionnaire

	Portability and size: The system needs to be portable so that it can be transported from the other project partners to be tested with end users. The portability and size will impact the ability for user to operate the system in different environments	• The exoskeletons will be designed to be quickly disassembled in his main parts, for transportation or maintenance.	QUEST 2.0 Custom usability questionnaire

Table 9: Road Map of User Requirements to support the User Centred development of the AIDE system

12. CONCLUSION

The development of the scenarios of use has emerged from extensive engagement with key stakeholders, underpinned by a theoretical framework. Target end users living with neurological conditions have a number of desires for the system and the technical team will now aim to achieve as many of these desires through the novel AIDE system. This document will continue to evolve as the project progresses to facilitate the ambition of the technology and as the user centred engagement continues. The User Requirements Road Map seeks to provide guidance and support the technical progress within the project

REFERENCES

Agree, E.M. Freedman, V.A. Cornman, J.C. Wolf, D.A. And Marcotte, J.E. 2005. Reconsidering substitution in long-term care: When does assistive technology take the place of personal care? *Journal of Gerontology*, **60**(5), pp. 272-280.

Andlin-Sobocki, P., Jonsson, B., Wittchen, H.U. And Olesen, J., 2005. Cost of disorders of the brain in Europe. *European Journal of Neurology,***12** (Suppl. 1), pp. 1–27.

Ashman, T.A., Gorden, W.A., Cantor, J.B. And Hibbard, M.R., 2006 Neurobehavioral consequences of traumatic brain injury. *The Mount Sinai Journal of Medicine*, **73**(7), pp. 999-1005.

Benyon D, Macaulay C. 2002. Scenarios and the HCI-SE design problem. *Interacting with Computers*, **14**(4), pp. 397–405.

Brandt, A. Samuelsson, K. Toytari, O. And Salminen, A.L. 2011. Activity and participation, quality of life and user satisfaction outcomes of environmental control systems and smart home technology: A systematic review. *Disability and Rehabilitation: Assistive Technology*, **6**(3), pp. 189–206.

Hartigan, Irene. "A comparative review of the Katz ADL and the Barthel Index in assessing the activities of daily living of older people." *International journal of older people nursing* 2, no. 3 (2007): 204-212.

International Classication of Functioning Disability and Health: ICF. Geneva: World Health Organization, 2001.

Legg, Lynn, Avril Drummond, and Peter Langhorne. "Occupational therapy for patients with problems in activities of daily living after stroke." *The Cochrane Library* (2006).

Sellers, E.W., Vaughan, T.M. And Wolpaw, J.R. 2010. A brain computer interface for long term independent home use. *Amyotrophic Lateral Sclerosis*, **00**, pp. 1-7.

Trisolini, M., Honeycutt, A., Wiener, J. And Lesesne, S., 2010. *Global Economic Impact of Multiple Sclerosis.* London: Multiple Sclerosis International Federation.

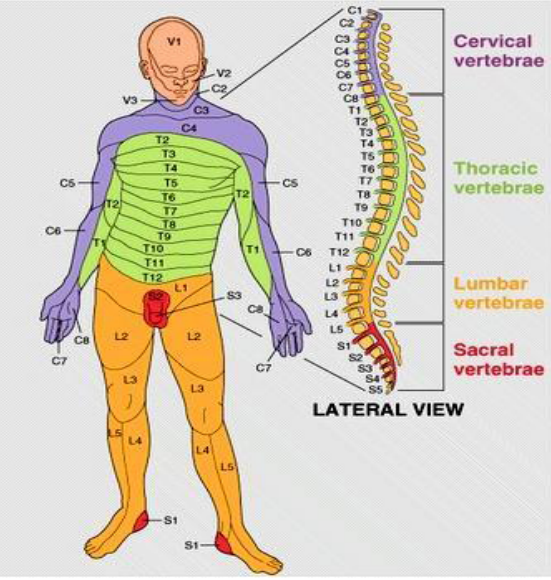
Wade D. (1992) Measurement in Neurological Rehabilitation. Oxford University Press, Oxford.

World Health Organization, 2006. *Neurological Disorders: Public Health Challenges*. Geneva: WHO.

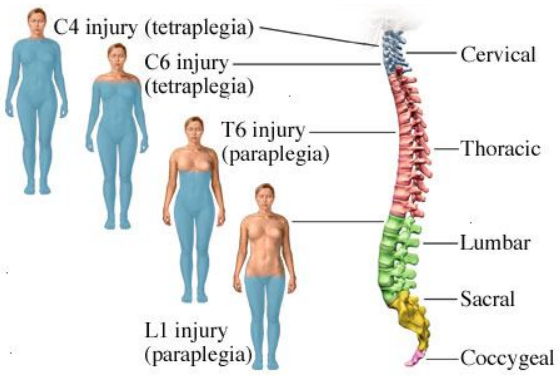
Widya, A., Bults, R. G., Sandsjö, L., Hermens, H. J., & Vollenbroek-Hutten, M. M. (2010). A scenario guideline for designing new teletreatments: a multidisciplinary approach. *Journal of telemedicine and telecare*, *16*(6), 302-307.

APPENDIX 1: DESCRIPTIONS OF TYPES OF NEUROLOGICAL CONDITIONS

SPC- Spinal Cord Injury :



A spinal cord injury (SCI) is an injury caused to the spinal cord as a result of trauma such as motor vehicle accident, falls, sport and violence (DeVivo and Chen, 2011). The extent of the injury depends on the location of the injury on the spinal column and the classification of a complete or incomplete injury. An incomplete injury can range from no impairment to intermittent loss of sensation or control below a persons injury. A complete injury classifies a total loss of function below the point of trauma. The location of the injury on the spinal cord can help infer the extent of paralysis and loss of function. The higher the level of injury on the spinal column the greater impairment in functioning, such as a cervical injury usually result in quadriplegia and an injury in the theoretic region can lead to paraplegia. Neurological changes following SCI can include impairment or loss of motor function, difficulty breathing, impaired control of body temperature, involuntary movement and chronic pain. Thus, a SCI can result in the long term dependence on wheelchairs, carer's, medication, bladder management and in high level cervical injuries the dependence on a ventilator. It is estimated that there are between 12.1 and 57.8 SCI cases per million in developed countries (Chiu et al., 2010; van den Berg et al., 2010). SCI has primarily affected young adults with most cases between 16 and 30 although the age is on the increase (DeVivo and Chen, 2011). Also, it has greater prevalence in the male population (van den Berg et al., 2010). The increasing life expectancy following a SCI due to improved acute management and long term rehabilitation adds a significant cost burden to health services in order to meet the needs of an aging SCI population (DeVivo and Chen, 2011).



MS- Multiple sclerosis

Multiple Sclerosis (MS) is an inflammatory disease where a persons immune system mistakes the myelin that protects the axons in the brain and spinal cord for foreign bodies and attacks it striping it off the nerve fibres either partially or completely leaving scars known as lesions or plaques. The condition is characterised by repeated relapses followed by partial or complete remission (Compston and Coles, 2008). The damage from the acute episodes can accumulate over time inhibiting the nerve cells in the brain and spinal cord from communicating effectively with each other. The neurological symptoms associated with MS include visual loss, sensory impairment, physical disability, fatigue, emotional disturbances, and cognitive impairment.

MS affects about two million people across the world and is characteristically diagnosed between the ages of twenty and forty (WHO and MSIF, 2008). A total of 4.3 cases per 100,000 are typically diagnosed in Europe and the prevalence rate is highest between 34-64 years (Pugliatti et al., 2006). MS is more prevalent in females than males (Alonso and Hernan, 2008). Risk factors for MS include genetic predisposition, environment, pregnancy and vaccinations (Koutsouraki, Costa and Baloyannis, 2012). The clinical course of MS usually evolves over several decades (Compston and Coles, 2008) and there is an approximate life expectancy of sixty five years of age (Hirst et al., 2008). MS is associated with a significant cost burden due to high prevalence, long duration, and incidents in young adults (Koutsouraki, Costa and Baloyannis, 2012; Pugliatti et al., 2006).

Motor Neurons Disease (MND) or ALS- Amyotrophic lateral sclerosis

Motor Neurons Disease (MND) or Amyotrophic lateral sclerosis (ALS) is a fatal disease of the nerve cells in the brain and spinal cord that control voluntary muscle movement (Wijesekera and Leigh, 2009). There are numerous presentations and types of MND however most result in the degeneration of the upper and lower motor neurons leading to progressive muscle weakness and paralysis (Kiernan et al., 2011). ALS is characterised by progressive paralysis, loss of speech and eventual respiratory failure (Logroscino et al., 2008). The cause of the condition is unknown however risk factors include genetic disposition, male gender and incidences increase rapidly after forty years of age (Logroscino et al., 2008). It is generally considered to have a survival rate of two to five years post diagnosis although this can vary (Holmes, 2005). It is estimated that 2.16 people per 100,000 a year received a diagnoses in Europe (Logrososcino et al., 2010). This debilitating condition is extremely complex and individuals have an increasing need for care as it progresses (Brown and Addington-Hall, 2008).

Eye movement

People with ALS may have difficulty in generating voluntary fast movements of the eye. The speed of eye movement is slower in people with ALS.[27] Problems in generating smooth pursuit and convergence movements have also been noted.[27] Testing the vestibulo-ocular reflex should help in identifying these problems.[28] The

electrooculography (EOG) technique measures the resting potential of the retina. EOG findings in people with ALS show progressive changes that correlate with disorder progression, and provide a measurement for clinically evaluating the effects of disorder progression on oculomotor activity.[28] Additionally, EOG may allow earlier detection of problems with the eyes.

CP- Cerebral palsy

Cerebral palsy is the result of a brain injury or a brain malformation. Individuals with cerebral palsy were most likely born with the condition, although some acquire it later. An individual with cerebral palsy will likely show signs of physical impairment. However, the type of movement dysfunction, the location and number of limbs involved, as well as the extent of impairment, will vary from one individual to another. It can affect arms, legs, and even the face; it can affect one limb, several, or all. Cerebral palsy affects muscles and a person's ability to control them. Muscles can contract too much, too little, or all at the same time. Limbs can be stiff and forced into painful, awkward positions. Fluctuating muscle contractions can make limbs tremble, shake, or writhe. Balance, posture, and coordination can also be affected by cerebral palsy. Tasks such as walking, sitting, or tying shoes may be difficult for some, while others might have difficulty grasping objects. Other complications, such as intellectual impairment, seizures, and vision or hearing impairment also commonly accompany cerebral palsy.

Stroke

Stroke is considered the third biggest cause of death in the UK and largest single cause of acquired disability worldwide (WHO, 2006). Advancements in acute stroke care have reduced mortality but increased dependence on rehabilitation and long term care (Strong, Mathers and Bonita, 2007). A stroke is caused by a disruption to the blood supply in the brain generally as a result of a haemorrhage or brain ischaemia. Numerous risk factors are associated with strokes such as increased age, hypertension, high cholesterol, diabetes, smoking, obesity (WHO, 2006).

Traumatic Brain Injury

Traumatic Brain Injury (TBI) is injury to the brain from an external force to the skull. An estimated 5.3 million people in the United States of America (Langlois, Rutland-Brown, & Thomas, 2004) and 6.2 million people in the European Union (EU) are estimated to be living with some level of impairment as a result of a TBI (Tagliaferri, Compagnone, Korsic, Servadei and Kraus, 2006). The outcome from a TBI can range from a full recovery to permanent disability or death (Ashman, Gorden, Cantor and Hibbard, 2006). Debilitating consequences include communication difficulties (MacDonald and Wiseman-Hakes, 2010); impaired memory (Fish, Wilson, & Manly, 2010); inappropriate behaviour (Kelly, Brown, Todd and Kremer, 2008); and physical disability (Marshall et al., 2007). Research has indicated that the high risk population

for TBI are male adolescences and young adults and the elderly (Faul et al., 2010; Bruns and Hauser, 2003).

References:

Alonso, A. and Hernan, M. (2008) Temporal trends in the incidence of multiple sclerosis: A systematic review. Neurology, 71:2: 129-135.

Ashman, T.A., Gorden, W.A., Cantor, J.B., Hibbard, M.R., (2006) 'Neurobehavioral Consequences of Traumatic Brain Injury'. *The Mount Sinai Journal of Medicine, 73:*7: 999-1005.

Brown J. & Addington-Hall J. (2008) How people with motor neurone disease talk about living with their illness: a narrative study. Journal of Advanced Nursing 62(2), 200–208

Bruns, J. and Hauser, A.W. (2003) The epidemiology of TBI: A review. Epilepsia, 44(11), pp. 2-10.

Chiu, W.T., Lin, H.C., Lam, C., Chu, S.F., Chiang, Y.H., Tsai, S.H., 2010. Review paper: epidemiology of traumatic spinal cord injury: comparisons between developed and developing countries. Asia Pac. J. Public Health 22 (1), 9–18.

Compston, A. and Coles, A. (2008) Multiple sclerosis. Lancet, 372: 1502–1517

DeVivo, M.J. and Chen, Y. (2011) Trends in new injuries, prevalent cases, and aging with spinal cord injury. *Archives of Physical Medicine and Rehabilitation,* **92,** pp. 332-338.

Faul M, Xu L, Wald MM, Coronado VG. Traumatic brain injury in the United States: emergency department visits, hospitalizations, and deaths. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2010.

Fish, J., Wilson, B.A., Manly, T., (2010) 'The assessment and rehabilitation of prospective memory problems in people with neurological disorders: A review'. *Neuropsychological Rehabilitation, 2:* 2: 161-179.

Hirst, C. Swingler, R. Compston, D.A.S., Ben-Shlomo, Y. and Robertson, N.P. (2008) Survival and cause of death in multiple sclerosis: a prospective population-based study Journal of Neurology, Neurosurgery and Psychiatry, 79:1016–1021.

Holmes T. (2005) Motor neurone disease and the NSF for long-term neurological conditions. Primary Health Care 15(9), 27–31.

Kelly, G., Brown, S., Todd, J., Kremer, P. (2008) 'Challenging behaviour profiles of people with acquired brain injury living in community settings'. *Brain Injury, 22:* 6: 457-470.

Kiernan, M.C., Vucic, S., Cheah, B.C., Turner, M.R., Eisen, A., Hardiman, O., Burrell, J.R. and Zoing, M.C. (2011*)* Amyotrophic lateral sclerosis. Lancet, 377: 942-955.

Koutsouraki, E., Costa, V. and Baloyannis, S. (2010) Epidemiology of multiple sclerosis in Europe: A Review. *International Review of Psychiatry*, 22:1: 2–13.

Langlois, J., Rutland-Brown, W. and Thomas, K. (2004) Traumatic brain injury in the United States: emergency department visits, hopitalizations, and deaths. Centres for Disease Control and Prevention. Atlanta: Georgia.

Logroscino G, Traynor BJ, Hardiman O, Chiò, A., Mitchell, D., Swingler, R.J., Beghi, E. at EC 2010. Incidence of amyotrophic lateral sclerosis in Europe. Journal of Neurology Neurosurgery and Psychiatry, 81, pp. 385–90. Incidence of amyotrophic lateral sclerosis in Europe

Logroscino G, Traynor BJ, Hardiman Chiò, A., Couratier, P. Mitchell, D., Swingler, R.J., Beghi, E. and EURALS 2008. Descriptive epidemiology of amyotrophic lateral sclerosis: new evidence and unsolved issues. *Journal of Neurology Neurosurgery and Psychiatry*, **79**, pp. 6-11.

MacDonald, S., Wiseman-Hakes, C. (2010) 'Knowledge translation in ABI rehabilitation: A model for consolidating and applying the evidence for cognitive-communication interventions'. *Brain Injury, 24:* 3: 486-508.

Marshall S, Teasell R, Bayona N, Lippert C, Chundamala J, Villamere J, Mackie D, Cullen N, Bayley M: Motor impairment rehabilitation post acquired brain injury. *Brain Injury* 2007, 21:133-160.

Pugliatti, M., Rosati, G., Carton, H., Riise, T., Drulovic, J., Vecsei, L. et al. (2006). The epidemiology of multiple sclerosis in Europe. European Journal of Neurology, 13, 700–722.

Strong ,K., Mathers, C. and Bonita, R. (2007) Preventing stroke: saving lives around the world. *Lancet Neurology,* 6: 182–187.

Tagliaferri, F., Compagnone, C., Korsic, M., Servadei, F., Kraus, J. 2006. A systematic review of brain injury epidemiology in Europe. Acta Neurochir (Wien), 148, pp. 255-268.

van den Berg, M.E., Castellote, J.M., Mahillo-Fernandez, I., de Pedro-Cuesta, J., 2010. Incidence of spinal cord injury worldwide: a systematic review. Neuroepidemiology 34 (3), 184–192.

WHO and MSIF (2008) Multiple Sclerosis Resources in the World. London: Multiple Sclerosis International Federation, 2008. Available at: http://www.msif.org/en/about_msif/what_we_do/atlas_of_ms/index.html.

Wijesekera, L.C. and Leigh, N.P. (2009) 'Amyotrophic lateral sclerosis. Orphanet Journal of Rare Diseases, 4:3: (3rd of February 2009) doi:10.1186/1750-1172-**4-3**

APPENDIX 2: TASK ANALYSIS OF TEETH BRUSHING SCENARIO

Task	Individual Steps	Environmental Factors	Risk factors
1. Go to the sink 2. Pick up prepared tooth brush and turn the electric toothbrush on 3. Position the brush moving occasionally 4. Put the brush down and spit out tooth paste	Control wheelchair and move it in front of the sink; Extend (robotic/ exoskeleton) arm and grasp handle of prepared toothbrush; TURN the toothbrush on Flex elbow pulling arm back towards body; extend elbow upwards towards mouth Position brush at the mouth and hold in position as the electric brush brushes teeth. Move hand forwards/ backwards occasionally to change position of the brush head against mouth. Retract arm from mouth and extend hand towards sink. Release the handle of the tooth brush. Position hand and using a lateral grip grasp the bowl on the sink. Flex elbow pulling arm back towards body; extend elbow upwards towards mouth. The user can spit the tooth paste into bowl. Retract arm from mouth and extend hand towards sink. Release the bowl to place it onto sink.	The user is in front of sink Specially adapted electric toothbrush How does the user spit out the tooth paste after brushing their teeth? (bowl) Does the toothbrush need to be a certain dimension in order to be grasped? What height does the sink need to be at? What position does the chair need to be in so that the exoskeleton is in the correct position side to carryout task? (Sidedness)	Spiting the tooth paste out so that it does not land on the users clothes Control of the exoskeleton/ toothbrush head so that it is not positioned to close to the user that it would hurt them

APPENDIX 3: TASK ANALYSIS OF THE KITCHEN SCENARIO INCLUDING EATING AND DRINKING

Task	Individual Steps	Environmental Factors	Risk factors
1. Go to the refrigerator 2. Open the refrigerator door 3. Grasp the prepared drink and leave the drink over on the table 4. Grasp a dish with a cold meal on it and leave it next to microwave 5. Close the refrigerator door	Control wheelchair and move it in front of the fridge; extend (robotic/ exoskeleton) arm and grasp handle of fridge with hook grasp; Flex elbow pulling back to open fridge door; Move wheelchair backwards while opening door; Release grip on door; Position wheelchair in front of fridge again; Extend arm/ elbow forward into fridge; Use a cylinder grip to grasp the glass/ cup; Move wheelchair and carry the glass/ cup across to table; release grip of bottle so it stands on table; Position wheelchair in front of fridge again; Extend arm forward into fridge; Use a lateral grip to grip the plate; Move wheelchair and carry plate to microwave; Place plate next to microwave and release grip; Move wheelchair back to fridge Extend robotics (arm) and grasp handle of fridge with hook grasp; Move wheelchair forwards while pushing the fridge door closed	The user is in the kitchen How does the user control the power wheelchair? Is there an easier way to open the fridge? Can the fridge door be automated? **Multitask- move wheelchair back and open fridge door Does the glass/ cup need to be a certain dimension in order to be grasped? **Multitask- move wheelchair and carry drink to table- can it be place somewhere for transit? Does the dish need to be a certain dimension in order to be grasped? **Multitask- move wheelchair and carry plate to microwave- can it be place somewhere for transit? What height does the refrigerator door handle need to be at? (Table &	Spillage of bottle/ food when carrying plate or glass Balance of user in chair if using exoskeleton Ability to complete dual/ simultaneous tasks Safety- reaching and carrying the glass (error rate would need to be low not to drop it) other material recommended (hard plastic)

		microwave also- does everything need to be at same height?) What position does the chair need to be so that the exoskeleton is in the correct position side to carryout task? (Sidedness)	
6. Open the microwave door 7. Grasp the dish with cold meal and put it in the microwave 8. Close the microwave door 9. Program the microwave with different cooking times and power level	Position the chair in front of the microwave; Extend arm with ____ grip (depending on how to open the microwave/ finger extension & apply force); Exert pressure on the mechanism to open the microwave door; Position chair to lift plate; Lift arm, extend elbow and outreach hand; Supination of wrist; Flex fingers to grasp dish; Flex elbow to lift plate; Reposition chair and carry plate so that arm is at the correct trajectory to the microwave; Extend arm with plate into microwave; Position plate in microwave and release grip; Retrieve hand by flexion in elbow; Reposition arm and flex elbow forward to close door; Again, reposition arm and flex index finger to chose required microwave setting*	Is there an easier way to open the microwave door? Can the door be automated? **Will it be possible to position correctly with robotics and environment to enable the person to remain still while lifting plate & put into microwave? Again with closing microwave door- positioning of chair & exoskeleton **Multitask- move wheelchair and carry plate How will microwave be programmed? Can it operated on ECS? Environment is important i.e. height	Requires lots of gross & fine motor skills; finger isolation; grip & strength; lifting & carrying; coordination; positioning Ability to programming microwave

		of workshops; positioning of wheelchair; transporting the plate	
10. (The meal is ready) Open the microwave door 11. Grasp the dish with hot meal and leave it next to microwave 12. Close the microwave door 13. Grasp the dish with hot meal and leave it over the table	Listen to hear microwave beep Position the chair in front of the microwave; Extend elbow/ arm and shoulder abduction with ____ grip (depending on how to open the microwave/ finger extension & apply force); Exert pressure on the mechanism to open the microwave door; Lift arm, extend elbow and outreach hand; Supination of wrist; Flex fingers to grasp dish; Flex elbow to lift (hot) plate; Retract arm from microwave; Position (exoskeleton) arm over wheelchair tray* so plate is resting on it; Gently release grip of plate; Reposition arm and flex elbow forward to close door; Maneuver wheelchair into position underneath table; Position (exoskeleton) arm over wheelchair tray* Flex fingers to grasp dish; Flex elbow to lift (hot) plate; Extend elbow forward to table so plate is	Does it matter to exoskeleton that plate will be hot? The environment is fundamental (lowered worktops/ space under table for wheelchair/ enough room to turn) Consider* if the wheelchair user has a tray to carry plate; glass etc- this will be in the way when trying to get close to the table (also might be in the way of exoskeleton's movements) need to consider as possible user could eat off of this tray…Also possible that there is an electronic mechanism to move this tray? However if no tray how will these items be transported?	Again- a number of multiple tasks required at the one time or in close sequence to each other (*arm extension; finger extension; plate grip; coordination; arm extension; muscle strength; plate grip; finger manipulation; cylindrical grip; arm flexion*) Coordination and positioning Not every user will be able to chew/ swallow Transporting items and moving wheelchair

	resting on table; Gently release grip of plate;		
14. Grasp the fork/spoon 15. Start eating the meal and drinking	Lift fork using pincher grip with hand; Extend elbow (holding fork) towards food; Flex fingers and wrist to make stabbing motion to put food onto fork; Flex elbow to bring food to mouth; (*Open and close mouth to break down food and swallow;)* Retract elbow down and release grip of fork; Extend arm/ elbow forward towards glass; Use a cylinder grip to grasp the glass; Flex elbow to bring glass to mouth; (*need straw to drink)* Retract elbow down to table position and release grip of glass; (*Repeat as necessary*)	Fork/ spoon with foam to support robotics lifting it	Coordination and positioning Not every user will be able to chew/ swallow

* The red text within the table outlines the times when the user is required to complete two tasks simultaneously; The green text means that the approach is unconfirmed until the environment is decided.

APPENDIX 4: CAREGIVERS QUESTIONNAIRE

We are developing a system within the AIDE project to enable people with no muscle movement to communicate, control their environment and wear an upper arm exoskeleton that will help them to do things like eat and drink. At this early stage of the project we are interested to know what caregiver's/ support workers think this type of technology would be useful for.

Please read the AIDE project leaflet and answer the following questions:

How many years have you been a caregiver/ support worker? _____

Age range (Please circle)

Under 25 Under 35 Under 45 Under 55 Under 65 Over 65

How do you think this type of technology could help you in your caring role?

_____

_____

_____

Can you think of any advantages to the people/person you support using a system with communication aids, environmental control and upper arm exoskeleton/ robotic arm?

_____

_____

_____

Can you think of any disadvantages to the people/person you support using a system with communication aids, environmental control and upper arm exoskeleton/ robotic arm?

_____

_____

_____

What characteristics would this system need to have so that it could fit into your daily support routine?

_____

_____

_____

Do you have any type of technology that supports your caring role currently?

_____

_____

_____

APPENDIX 5

1. Focus Group Presentation
2. Target User Information Sheet
3. Target User Consent form
4. Project leaflet for recruitment
5. Community based service provider information sheet
6. Community based service provider consent form

FOCUS GROUP PRESENTATION

AIDE

Adaptive Multimodal Interfaces to Assist Disabled People in Daily Activities

Jean Daly & Professor Suzanne Martin

Cedar Foundation

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 645322

Welcome

- The AIDE Project
- Emerging Technology
- The AIDE System
- Your Opinion

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 645322

The Aim of the AIDE Project

1. To create a breakthrough in multimodal technologies for empowering people with disabilities to participate in society

2. To incorporate user centred design principles to create an assistive technology in accordance to potential end users needs and preferences

3. To efficiently use highly sophisticated technologies that can adapt and be customised to the residual capabilities of the person living with a disability to enhance social inclusion, communication and participation

4. To strengthen Europe's capacity and competitiveness in the worldwide market of assistive ICT and assistive wearable robotics

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 645322

An *Emerging Technology* is a device or system that is currently in the <u>design and development stage</u> that aims to fill a current gap in the market place.

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AIDE-GA 645322

Emerging Technology

Human- Machine Interaction

'Hybrid system'

'An adaptive modular and multimodal interface'

'A state of the art modular multimodal perception system'

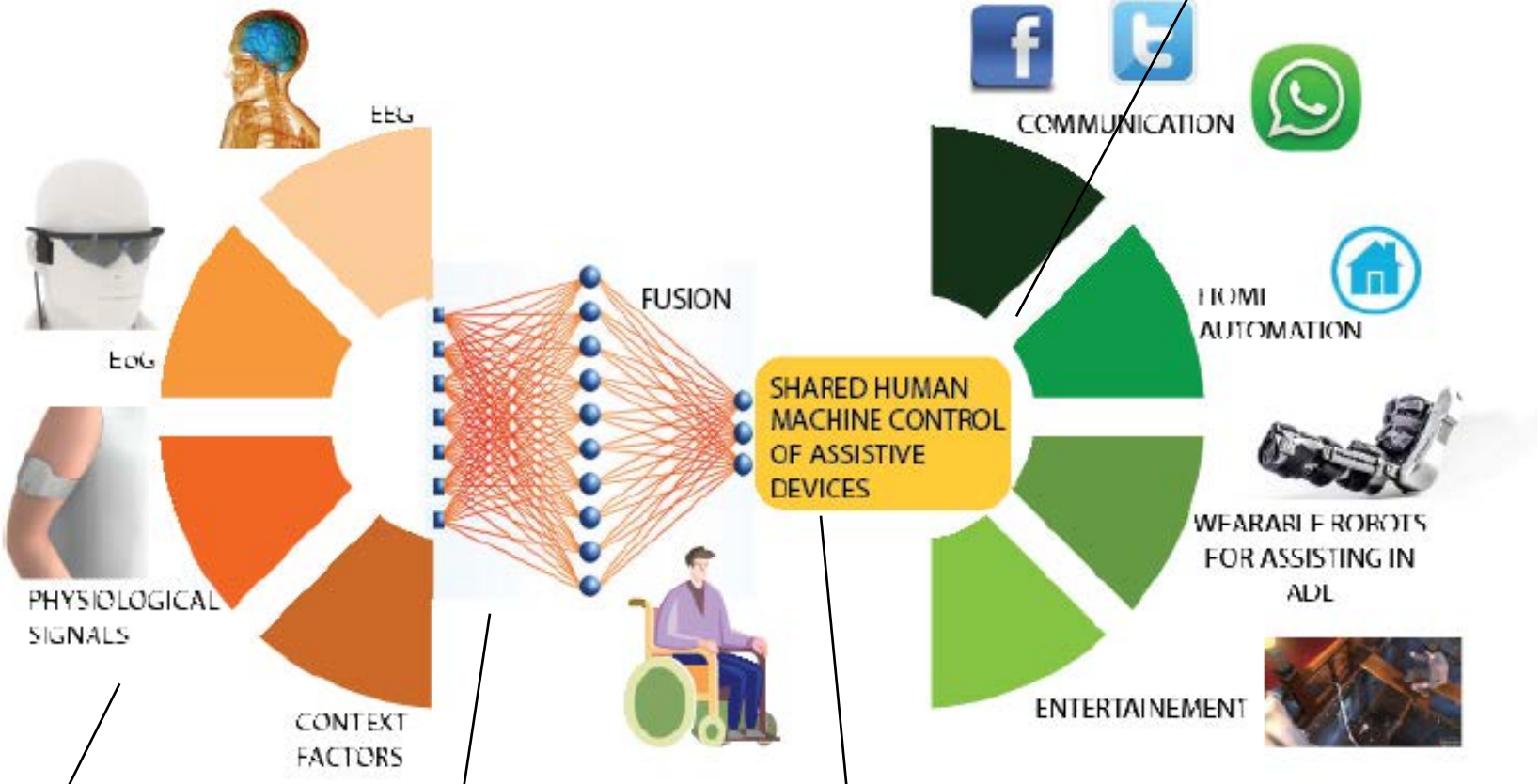
But what does this mean….

and what do you want from emerging technologies…

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 645322

The AIDE Platform

Application areas (ADL)



Signal Acquisition

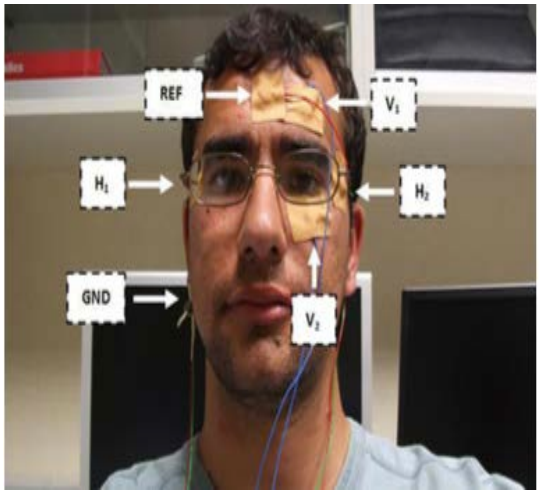
Classification and fusion

Shared Human-Machine Control of Assistive Devices

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 645322

Signal's from your Eyes

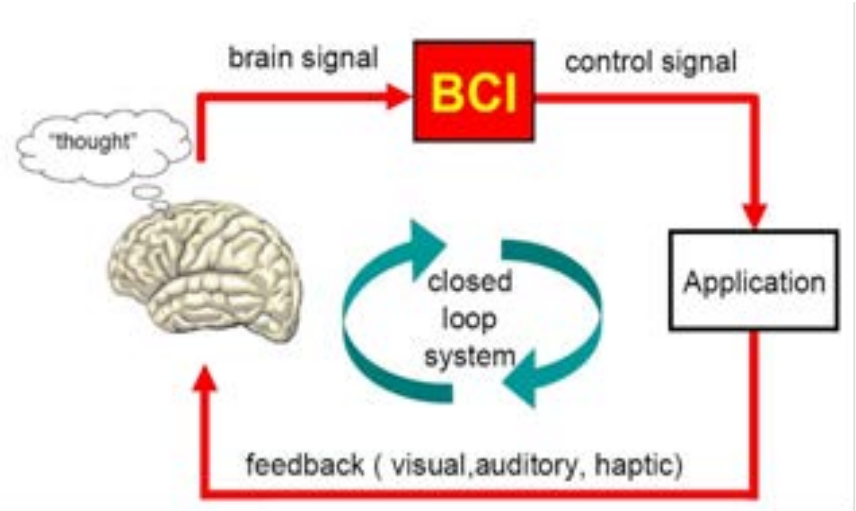
- Sensor's can detect the movements of the eyes



- A camera can detect what a person wants from where they are looking

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 645322

Signal's from your Brain



Brain waves are collected by electrodes in a cap

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 645322

Brain Computer Interface (BCI)

Can…	Cannot…
• Interpret signals from the brain when a person has voluntarily chosen to undertake a task • Collect waves in real time • Work with any device that is electrical	• See memories • Hear thoughts • Work without a person's knowledge • Implant thoughts or images

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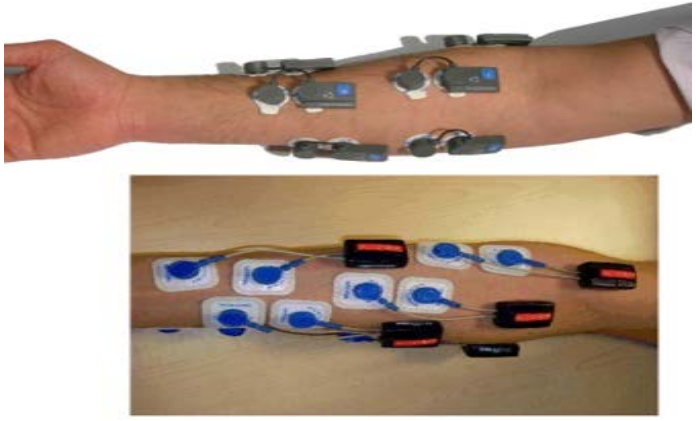
Signals from Muscles

The smallest twitch from a muscle anywhere in the body can be collected by electrodes place on that muscle



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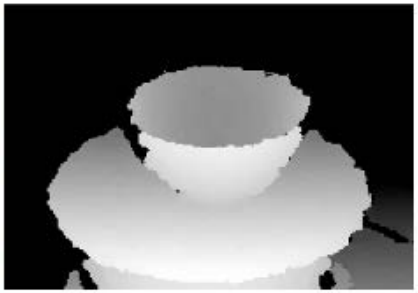
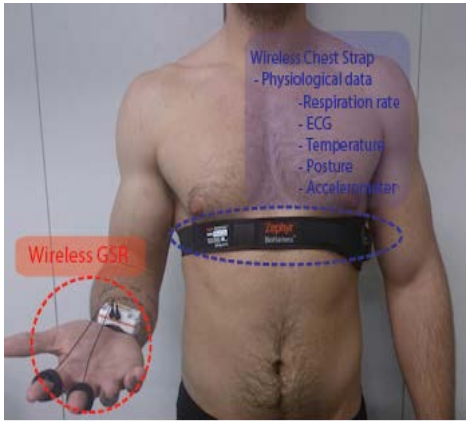
CAMERAS: CONTEXT & ENVIRONMENT

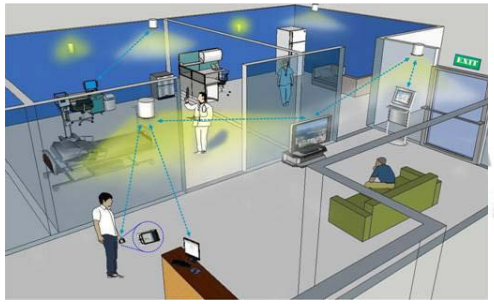


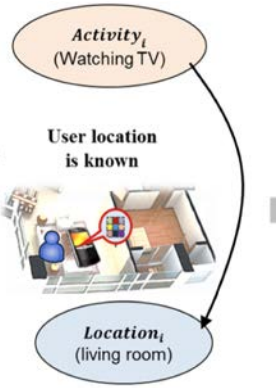
Body signals: heart rate, skin conduction level, temperature or respiration rate



Voice recognition

Room locator





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These signal's are collected so you can control…

Wearable Exoskeleton

Robotics

Communicate

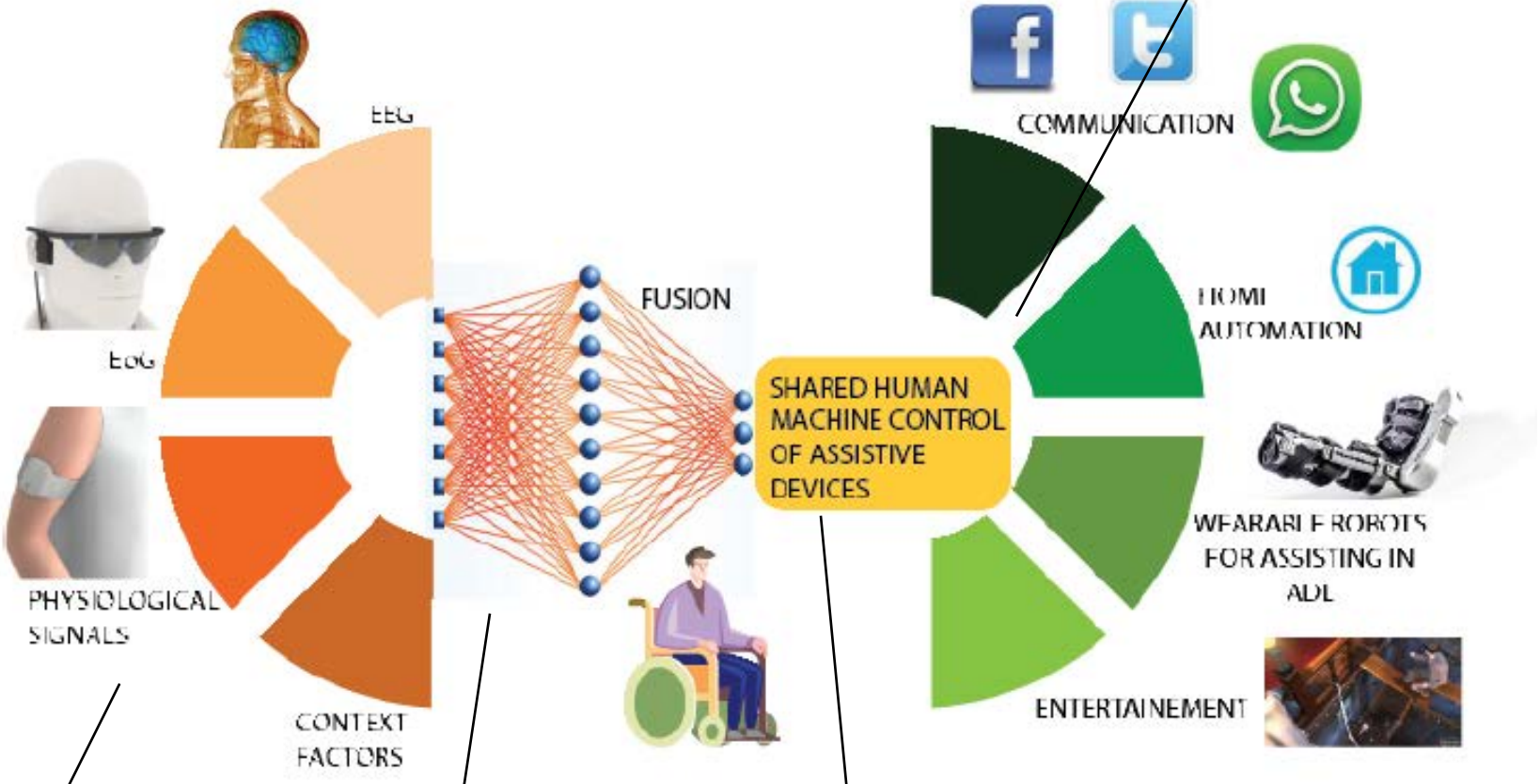
Home

Computer- Entertainment and leisure

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 645322

The AIDE Platform

Application areas (ADL)



Signal Acquisition

Classification and fusion

Shared Human-Machine Control of Assistive Devices

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Question 1

What are the key things that are important to you in your daily life to be able to do yourself?

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Question 2

What would you like this system to enable you to do independently?

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Question 3

What would be your favourite way to control the system?

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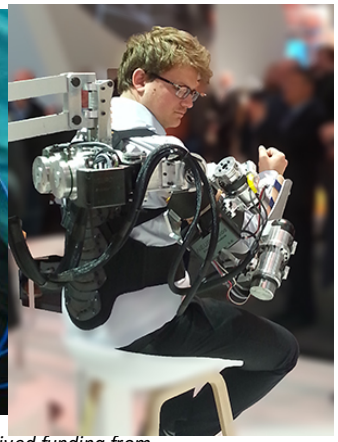
Question 4

Exoskeleton or robotic arm?



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AIDE-GA 645322

Finally, which of these tasks would be most important for you to do?

Please put into order of importance

1. Grasp objects from the refrigerator or the cupboard and bring them to the table
2. Heat a meal in the microwave
3. Eat a meal with spoon/ fork
4. Eat a sandwich with hands
5. Pour the water in a glass and drink from the glass
6. Drink from the straw
7. Move around the kitchen to reach different areas (such as to the refrigerator, cupboard, microwave)

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 645322

Thank you for taking part in the AIDE focus group

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 645322

TARGET USER INFORMATION SHEET

AIDE Project: Target User Information Sheet

You are being invited to take part in a research study called AIDE. Before you decide whether or not to take part, it is important that you understand what the research is for and what you will be asked to do.

You will have the opportunity to read through this information with the researcher and to ask questions about anything that might not be clear to you. Make sure that you are happy before making a decision.

Thank you for taking the time to consider this invitation.

What is the study about?

The big aim of the project is to develop systems that allow people to control devices in their environment. It will enable people who have difficulty with some physical tasks to use the system for assistance. The system has a number of parts to it, but it is customisable and you may not need to use them all. For example, people might use their brainwaves, their eyes or their voice to control the system. We want a system that is flexible in terms of how people interact with it depending on their needs. There are also a number of applications to control such as using a robotic arm, smart home environmental control, access the Internet and social media applications. The ultimate goal is that the AIDE system could support people with neurological conditions such as acquired brain injury, multiple sclerosis, and spinal cord injuries complete a number of tasks independently.

We understand that you might not be familiar with this type of technology. We would like to invite you to a focus group where we could tell you more about this and the AIDE project. We also want to know what you think about the AIDE system using a range of new technologies and what you think it would be useful for. For example, what do you find useful? Do you think the AIDE system could

support you at home? We want to know about your experience of using assistive technology and computer systems also.

Do I have to take part?

You have been invited to take part in the study, as you are currently involved with community based services that support your neurological condition or have made yourself known to us and said your are interested in the AIDE project. It is up to you to decide whether or not to take part. If you choose not to take part it will have no effect on any services you receive.

If you do decide to take part, you will be given this information sheet to keep. You will also be asked to sign a consent form or the individual with the legal authority who routinely provides consent may do so. After telling you about the project we will ask you to think about whether you would like to take part or not and your keyworker will contact you after one week to find out what your decision is. If you choose to take part, and later change your mind, you can withdraw from the study without giving a reason at any time. The data you contribute will be included in the study up to the point you withdraw.

The research team can arrange transport to and from the focus groups for you if necessary. Additionally, millage expenses will be covered for you to attend the focus group if you attend by car. This can be discussed and arranged in advance with Jean or Suzanne.

What will taking part involve?

During the initial phase of the project we really just want to talk to you to and describe the system we are planning to develop. We are keen to hear your views. If you want to find out more about the project or about getting involved after reading this information please contact the research team or ask someone to contact us for you. Once we have heard from you we will answer any questions

you have and collect the signed consent form. We will then invite you to attend a focus group with approximately four other people. You are welcome to bring your caregiver, family member or key worker to this meeting also. During the focus group we will tell you all about the project and show you pictures and videos about the types of technologies we hope to include within the AIDE system. We will ask you to discuss the technology within the group and how you think it might be useful. We would also like to know if you could recommend other uses for the systems and ways for this type of system to be used in every day life. The focus groups will last no more than one hour. We want to record the focus groups so we are able to keep track of all the helpful information and discussion during the session. Afterwards this will be written out word for word and any names or information that could identify you will be removed so that you remain anonymous. We also want to take some photographs and short shots of video. We will ask you at the beginning of the session if you are happy with this and you can choose not be included in the photographs or video if you wish.

After the session and once we have removed any identifying information we let the other members of our research team know what the general views are. We do NOT share any names or information that would allow someone to recognise you, just themes. No preparation is required by you prior to attending the focus group.

Are there any known risks to taking part?

There are no known risks to taking part. We are inviting you to share your opinion on a very new piece of emerging technology. This is the first stage in the development, design, and evaluation of the AIDE system. Participation in the focus group does not mean you consent to take part in all aspects of the evaluation of the system nor does it mean that you will be guaranteed to evaluate future iterations of the system. Each stage of the project will have an inclusion and exclusion criteria that will be strictly adhered too. However, participants are invited to indicate their interest if they would like future updates on the progress

of the project.

Will my information be confidential?

All of your information will be kept confidential. Only the researchers in Cedar will have access to your contact details and any data that is collected during the project.

We may want to record the focus group using audio, video or photographs. We will only do this with your full consent.

How will the information gathered be used?

All information gathered will be held anonymously and will be shared with the designers of the prototype in the wider consortium for AIDE. The findings will be used to develop and learn how to improve the prototype. The reports at each stage of development will be published, but no names of participants will be used. The data collected will be stored for 10 years after the project has been completed in order to comply with Ulster University policy.

Who do I contact if I have more questions?

Jean and Suzanne are responsible for the day-to-day activities within the project. If you have any questions about the research in advance of the focus groups and would like to find out more please contact one of them.

Jean Daly
(Researcher)
Email: j.daly@cedar-foundation.org
Contact details removed

Professor Suzanne Martin
(Occupational Therapist)
Contact details removed

Mrs Joanne Barnes is on the senior management team in Cedar. If you would like to have an independent view on the project please contact her.

Mrs Joanne Barnes Co-Head of Organisational Development
Contact details removed

TARGET USER CONSENT FORM

AIDE Target User Consent Form

You are invited to take part in the AIDE project. The Cedar Foundation are the local partners in this European Commission funded project.

The overall aim at the end of the project is to develop a system using new technologies that would enable a person with limited functional ability to complete activities of daily living tasks independently. The system will adopt different methods of determining the users desired command depending on their preferences and abilities such as brain computer interface, eye gaze, and voice command. There are also options about what parts of the system you would use depending on your needs for example it might be a robotic arm, environmental control, or access to Internet and social media applications. The ultimate goal is that the AIDE system could enable people with neurological conditions such as acquired brain injury, multiple sclerosis, and spinal cord injuries undertake tasks on their own and to engage in their community.

We are hoping you will work with us to let us know what you like and don't like about this type of system. We will first identify the preferences of people who might use this type of system in the future and pass this information onto the technical developers. The system will then be developed in three stages, producing a model, generally referred to as the prototype at the end of each stage. Additionally 'mock-up' or individual components of the system will be tested in Cedar at various stages of the project.

The project will last for 3 years. Initially we would like you to attend a focus group and contribute by:

1. Letting us know your thoughts on the type of system we are developing and how useful it could be for the tasks you might like to do on a daily bases

When we share information with our technical and service partners we will not identify anybody personally at any stage. You do not have to take part in this study and can withdraw at any stage without explanation. All information will be treated in strict confidence and all data recorded will be protected under the Data Protection Act (1998) and Ulster University policies. No person who has participated will be identified in any publications or reports produced as a result of this work. Participation in this project will not provide financial benefits or rights to the intellectual property generated by it.

I (Name)……

Please initial each of the below statements to confirm:
I have read and understand the information provided in the information sheet and above and I consent to:
(a) take part in the above project
(b) allow video, photographs and/or tape recording of me taking part in the focus group.
(c) I am satisfied with the information and any questions I wished to ask have been answered to my satisfaction.
(d) I understand I may withdraw at any stage without necessarily giving a reason for doing so.

Signed (Volunteer)……Date……

(Next of Kin or Carer)……Date……

(Investigator)……Date……

You keep a copy of this and we keep a copy.

Contact Information:

Jean and Suzanne are responsible for the day-to-day activities within the project. If you have any questions about the research in advance of the focus groups and would like to find out more please contact one of them.

Jean Daly
(Researcher)
Email: j.daly@cedar-foundation.org
Contact details removed

Professor Suzanne Martin
(Occupational Therapist)
Contact details removed

Mrs Joanne Barnes is on the senior management team in Cedar. If you would like to have an independent view on the project please contact her.

Mrs Joanne Barnes Co-Head of Organisational Development
Contact details removed

PROJECT LEAFLET FOR RECRUITMENT

The Expected Outcome of AIDE

- To create a breakthrough in multimodal technologies for empowering people with disabilities to participate in society

- To incorporate user centred design principles to create an assistive technology in accordance to potential end users needs and preferences

- To efficiently use highly sophisticated technologies that can adapt and be customised to the residual capabilities of the person living with a disability to enhance social inclusion, communication and participation

- To strengthen Europe's capacity and competitiveness in the worldwide market of assistive ICT and assistive wearable robotics

The AIDE consortium is led by Universidad Miguel Hernández and includes nine groups from Spain, Germany, Italy and the UK

This Project has been funded by the European Union's Horizon 2020 Research and Innovation Programme under Grant Agreement No. 645322

European Commission | Horizon 2020 European Union funding for Research & Innovation

AIDE

Adaptive Multimodal Interfaces to Assist Disabled People in Daily Activities

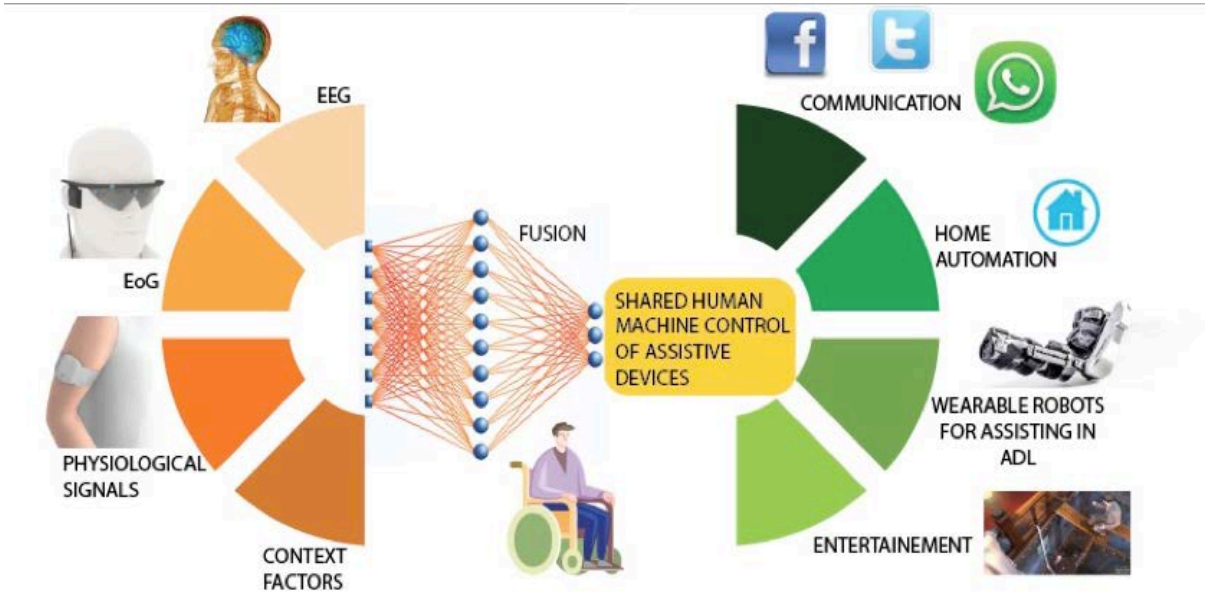
Cedar A better future for people with disabilities

EUROPEAN COMMISSION

Ulster University

What is the AIDE Project?

The AIDE project aims to develop a novel state of the art modular multimodal perception system that can be customized and adapted to the needs of people with complex disabilities. It is described as an adaptive modular and multimodal interface because it will use lots of different ways of picking up the commands from the user and this is incorporated with a range of technologies to enable the user to establish control over the applications or services they want. The systems will be customisable and will use different ways of picking up commands from the user depending on their preference, abilities and level of impairment. For example, one user might use the brain computer interface (EEG) to control the exoskeleton arm and another user might use the eye gaze (EoG). The functions of the system will include controlling an exoskeleton arm to pick up objects; to interact with their smart home environment; to enable communication through services such as email, Skype, social media and WhatsApp; and to access entertainment activities such as watch a movie. The ultimate goal is that the AIDE system could enable people with neurological conditions such as acquired brain injury, multiple sclerosis, and spinal cord injury to fully participate in society.



Cedar
A better future for people with disabilities

Cedar's role in the project is to engage with and represent the views, expectations and requirements of people living with a neurological condition and their desires for the proposed system. Cedar will also work with therapists and NGO's who provide community-based services in order to gain a range of perspectives on the needs and preferences of their clients in terms of rehabilitation, technology and social inclusion. This will inform the technical design and development of the AIDE system. Cedar is also responsible for conducting evaluations and usability tests with end users at various stages of the design process before a final testing phase towards the end of the AIDE project.

The AIDE project will run from February 2015 until February 2018.

Cedar's Team in the AIDE project is:

Eileen Thompson	Joanne Barnes	Professor Suzanne Martin	Jean Daly
Deputy Chief Executive	*Co-Head of Organisational Development*	*Ulster University*	*Researcher*

For more information please contact:

Jean Daly
Balmoral Training & Resource Centre
1 Upper Lisburn Road
Belfast BT10 0GW
Telephone: (028) 9061 2424
Email: j.daly@cedar-foundation.org
www.cedar-foundation.org

Project Website:
www.aideproject.eu

COMMUNITY BASED SERVICE PROVIDER INFORMATION SHEET

AIDE Project: Community based Service Providers Information Sheet

You are being invited to take part in a research study called AIDE. Before you decide whether or not to take part, it is important that you understand what the research is for and what you will be asked to do.

You will have the opportunity to read through this information with the researcher and to ask questions about anything that might not be clear to you. Make sure that you are happy before making a decision.

Thank you for taking the time to consider this invitation.

What is the study about?

The big aim of the project is to develop systems that allow people to control devices in their environment. It will enable people who have difficulty with some physical tasks to use the system for assistance. The system has a number of parts to it, but it is customisable and you may not need to use them all. For example, people might use their brainwaves, their eyes or their voice to control the system. We want a system that is flexible in terms of how people interact with it depending on their needs. There are also a number of applications to control such as using a robotic arm, smart home environmental control, access the Internet and social media applications. The ultimate goal is that the AIDE system could support people with neurological conditions such as acquired brain injury, multiple sclerosis, and spinal cord injuries complete a number of tasks independently.

We understand that you might not be familiar with this type of technology. We would like to invite you to a focus group where we could tell you more about this and the AIDE project. We also want to know what you think about the AIDE system using a range of new technologies and what aspects do you think would be useful for your clients. For example, what kind of tasks could the systems help

your clients with neurological conditions complete? Do you think the AIDE system could support your client at home?

Do I have to take part?

You have been invited to take part in the study, as you are currently working with clients living with a neurological condition who are accessing community-based services. It is up to you to decide whether or not to take part.

If you do decide to take part, you will be given this information sheet to keep. You will also be asked to sign a consent form. We will not ask you to sign the consent form straight away. After telling you about the project we will ask you to think about whether you would like to take part or not and we will contact you after one week to find out what your decision is. If you choose to take part, and later change your mind, you can withdraw from the study without giving a reason at any time. The data you contribute will be included in the study up to the point you withdraw.

The research team can arrange transport to and from the focus groups for you if necessary. Additionally, millage expenses will be covered for you to attend the focus group if you attend by car. This can be discussed and arranged in advance with Jean or Suzanne.

What will taking part involve?

During the initial phase of the project we really just want to talk to you to and describe the system we are planning to develop. We are keen to hear your views. If you want to find out more about the project or about getting involved after reading this information please contact the research team or ask someone to contact us for you. Once we have heard from you we will answer any questions you have and collect the signed consent form. We will then invite you to attend a

focus group with other people who are working in a similar area to you. During the focus group we will tell you all about the project and show you pictures and videos about the types of technologies we hope to include within the AIDE system. We will ask you to discuss the technology within the group and how you think it might be useful for your clients. We would also like to know if you could recommend other uses for the systems and ways for this type of system to be to support clients in daily life. The focus groups will last no more than one hour. We want to record the focus groups so we are able to keep track of all the helpful information and discussion during the session. Afterwards this will be written out word for word and any names or information that could identify you will be removed so that you remain anonymous. We also want to take some photographs and short shots of video. We will ask you at the beginning of the session if you are happy with this and you can choose not be included in the photographs or video if you wish.

After the session and once we have removed any identifying information we let the other members of our research team know what the general views are. We do NOT share any names or information that would allow someone to recognise you, just themes. No preparation is required by you prior to attending the focus group.

Are there any known risks to taking part?

There are no known risks to taking part. We are inviting you to share your opinion on a very new piece of emerging technology. This is the first stage in the development, design, and evaluation of the AIDE system. Participation in the focus group does not mean you consent to take part in all aspects of the evaluation of the system nor does it mean that you will be guaranteed to evaluate future iterations of the system. Each stage of the project will have an inclusion and exclusion criteria that will be strictly adhered too. However, participants are invited to indicate their interest if they would like future updates on the progress of the project.

Will my information be confidential?

All of your information will be kept confidential. Only the researchers in Cedar will have access to your contact details and any data that is collected during the project. We may want to record the focus group using audio, video or photographs. We will only do this with your full consent.

How will the information gathered be used?

All information gathered will be held anonymously and will be shared with the designers of the prototype in the wider consortium for AIDE. The findings will be used to develop and learn how to improve the prototype. The reports at each stage of development will be published, but no names of participants will be used. The data collected will be stored for 10 years after the project has been completed in order to comply with Ulster University policy.

Who do I contact if I have more questions?

Jean and Suzanne are responsible for the day-to-day activities within the project. If you have any questions about the research in advance of the focus groups and would like to find out more please contact one of them.

Jean Daly
(Researcher)
Email: j.daly@cedar-foundation.org
Contact details removed

Professor Suzanne Martin
(Occupational Therapist)
Contact details removed

Mrs Joanne Barnes is on the senior management team in Cedar. If you would like to have an independent view on the project please contact her.

Mrs Joanne Barnes Co-Head of Organisational Development
Contact details removed

COMMUNITY BASED SERVICE PROVIDER CONSENT FORM

AIDE Project
Version 4: 27/10/2015

AIDE Community based Service Provider Consent Form

You are invited to take part in the AIDE project. The Cedar Foundation are the local partners in this European Commission funded project.

The overall aim at the end of the project is to develop a system using new technologies that would enable a person with limited functional ability to complete activities of daily living tasks independently. The system will adopt different methods of determining the users desired command depending on their preferences and abilities such as brain computer interface, eye gaze, and voice command. There are also options about what parts of the system you would use depending on your needs for example it might be a robotic arm, environmental control, or access to Internet and social media applications. The ultimate goal is that the AIDE system could enable people with neurological conditions such as acquired brain injury, multiple sclerosis, and spinal cord injuries undertake tasks on their own and to engage in their community.

We are hoping you will work with us to let us know what you think would be useful for your client group on the system. We want to know what you like and don't like about this type of assistive technology. We will first identify the preferences of people who might use this type of system in the future, their therapists and those who work closely supporting them and pass this information onto the technical developers. The system will then be developed in three stages, producing a model, generally referred to as the prototype at the end of each stage. Additionally 'mock-up' or individual components of the system will be tested in Cedar at various stages of the project.

The project will last for 3 years. Initially we would like you to attend a focus group and contribute by:

1. Letting us know your thoughts on the type of system we are developing and how useful it could be for your clients

When we share information with our technical and service partners we will not identify anybody personally at any stage. You do not have to take part in this study and can withdraw at any stage without explanation. All information will be treated in strict confidence and all data recorded will be protected under the Data Protection Act (1998) and Ulster University policies. No person who has participated will be identified in any publications or reports produced as a result of this work. Participation in this project will not provide financial benefits or rights to the intellectual property generated by it.

Cedar
A better future for people with disabilities

Ulster University

EUROPEAN COMMISSION

I (Name)……

Please initial each of the below statements to confirm:
I have read and understand the information provided in the information sheet and above and I consent to:
(a) take part in the above project
(b) allow video, photographs and/or tape recording of me taking part in the focus group.
(c) I am satisfied with the information and any questions I wished to ask have been answered to my satisfaction.
(d) I understand I may withdraw at any stage without necessarily giving a reason for doing so.

Signed (Participant)……Date……

Place of work: ……

(Investigator)……Date……

You keep a copy of this and we keep a copy.

Contact Information:
Jean and Suzanne are responsible for the day-to-day activities within the project. If you have any questions about the research in advance of the focus groups and would like to find out more please contact one of them.

Jean Daly
(Researcher)
Email: j.daly@cedar-foundation.org
Contact details removed

Professor Suzanne Martin
(Occupational Therapist)
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Mrs Joanne Barnes is on the senior management team in Cedar. If you would like to have an independent view on the project please contact her.

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Contact details removed