



IST-2003-511598 (NoE)

COGAIN

Communication by Gaze Interaction

Network of Excellence

Information Society Technologies

## D3.6 Final User Trials Report

Due date of deliverable: 31.08.2009

Actual submission date: 17.08.2009

Start date of project: 1.9.2004

Duration: 60 months

ACE Centre

Project co-funded by the European Commission within the Sixth Framework Programme (2002-2006)		
Dissemination Level		
<b>PU</b>	Public	x
<b>PP</b>	Restricted to other programme participants (including the Commission Services)	
<b>RE</b>	Restricted to a group specified by the consortium (including the Commission Services)	
<b>CO</b>	Confidential, only for members of the consortium (including the Commission Services)	

Donegan, M. et al. (2009) **D3.6 Final User Trials Report**. Communication by Gaze Interaction (COGAIN), IST-2003-511598: Deliverable 3.6. Available at <http://www.cogain.org/results/reports/COGAIN-D3.6.pdf>

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Our special thanks go staff at The Central Remedial Clinic (Dublin, Ireland), SCTCI (Glasgow, Scotland) for their involvement in the end-user trials, as well as the many members of the end-user community, especially in England, Scotland, Ireland, Germany, Finland, Sweden and Italy who have been so generous in their involvement in the end-user trials and their support for COGAIN. In particular, we would like to thank the staff at the Torino ALS Centre, including Prof. Adriano Chiò, Dott.sa Valentina Pasian, Dott. Alessandro Vignola, Dott. Paolo Ghiglione, Dott.sa Cristina Moglia, Dott.sa Anna Montuschi, Dott.sa Anna Terreni, Dott. Andrea Calvo.

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# 1 Introduction

In the previous COGAIN End-User Trials Report<sup>1</sup>, (Donegan et al. 2006), all of the evidence from the end-user trials that had been carried out by the three organisations involved: (1) DART; (2) POLITO/Torino Amyotrophic Lateral Sclerosis (ALS) Centre; and (3) the ACE Centre Advisory Trust, all pointed to the huge potential benefits of gaze control for people with disabilities who need it. There were already clear indications of the positive impact that this technology could have on motivation, communication and quality of life for a wide range of end-users who have severe and complex disabilities.

At the end of the report, a number of key recommendations were made that included the following:

- More adaptable calibration procedures. Different end-users need different features, so a selection of options would be a useful tool that could make it possible for more people to try gaze control.
- The development of a wide range of software to support initial trials and training for end-users with a wide range of motor, visual and cognitive abilities in the use of gaze control.
- A larger selection of software for communication is recommended. Several end-users already use communication systems and it is very important to collaborate with gaze control developers in order to try to make these as 'eye-friendly' as possible, so that they can seamlessly use familiar programs.

Since the first end-user trials report in 2006, it has been extremely encouraging to see positive developments in these very important areas. The COGAIN partners have been particularly proactive in encouraging gaze control developers to respond to such end-user needs. Deliverables 3.4 and 3.5 followed up the above recommendations by providing a range of resources and training materials to further encourage positive action based on our collective end-user trial findings.

This document reports on the additional trials that have been carried out since 2006, with occasional references to the previous end-user trials where appropriate. It makes further recommendations that, it is hoped, will build upon the ever increasing frequency and quality of use of gaze control not only throughout Europe, but on a global scale.

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<sup>1</sup> Donegan et al., 2006: D3.3 Report on user trials and usability studies <http://www.cogain.org/results/reports/COGAIN-D3.3.pdf>

## 2 DART End-User Trials

### 2.1 Introduction

During the time of the COGAIN partnership DART have organized various information dissemination activities concerning gaze control technology for people with disabilities. This has led to a number of contacts with end-users, their families and professionals involved in their care. Approximately fifty end-users with complex needs have been participating in our end-user trials, either as one-off sessions, or as trials over a more extended period of time. In order to carry out end-user trials with a variety of end-users, software adaptations for the introduction of gaze control were needed and this resulted in DART preparing several introductory activities, like playing music and games, writing and communicating with simple communication grids.

The trials with different end-users provided information on the need for the improvement and development of systems and software in order for gaze control to become an effective and efficient alternative for end-users with complex disabilities. Gaze control technology, especially for end-users with complex motor disorders, including considerable involuntary movement, visual and/or cognitive problems, is relatively new. The knowledge gathered within the COGAIN project has precipitated the possibility for many Swedish end-users to receive a gaze control system as a device.

An individual's *satisfaction with their life* depends on how well he or she is able to *achieve participation and perform meaningful activities*. To carry out assessments with people with disabilities which affect motor performance as well as communication and cognitive skills can be a complex and complicated matter. The fact that the outcome of an assessment may be the end-user's only way of achieving independent activity and communication makes **high quality** assessment **vital**. An essential prerequisite for carrying out high quality assessments is the approach of a trans-disciplinary team working towards a common goal. A client-centred approach is a basic condition for self-determination and the empowerment of the end-user in all assessment work.

DART's involvement in the COGAIN project started in the autumn of 2005 with the familiarisation of different gaze control systems and learning about their features and capabilities. Several non-disabled people, both children and adults, were involved in pilot tests in advance of the actual end-user trials. This provided good opportunities for us to learn about calibration techniques and how the systems functioned with different people, for example, people wearing glasses, different kinds of eye shapes, eye colours etc.

After several dissemination activities, the end-user trials started during the spring of 2006. The systems that have been used include the following: MyTobii, CompactRolltalk with ERICA and the Quick Glance/Eye Tech 3.



Figure 2.1: The above compilation of photographs show dissemination activities at DART

The one-off session end-user trials generally lasted between one and two hours. An introductory interview was conducted in order to establish an end-user profile and to ascertain the end-users' familiarity with computers. For the end-users involved in more extended time trials, the assessment was based on the more theoretical assessment method used in DART's regular client-centred work. For all of the end-users involved in extended time trials, the assessments have led to a prescription of a gaze control system as their personalized communication device. In Sweden Occupational Therapists and Speech and Language Therapists are able to prescribe computer access systems and communication aids. They are provided on loan to the end-user by his or her Local Authority.

The end-user trials began with finding a gaze control system that was likely to be the most suitable for the end-user, and the calibration process was completed. In the participant's first attempt to use gaze control, they were given simple applications which enabled them to learn how to operate the system and to understand how, for instance, the feature of 'dwell select' works. Only a few of our end-users have been able to use any other input method for a 'mouse click'.

On the basis of the end-user's physical and cognitive abilities, interests and age, various further applications were used e.g. choosing different "Eurovision Song Contest" music, playing, communicating face to face, writing with letters, writing with symbols, using e-mail or browsing the internet. The majority of the end-user trials were documented on videotape (with end-user consent). After the trial was completed, those end-users who were capable of participating were asked further questions about their experience and opinions about the gaze control system. The interviews were adapted to suit the end-user's level of communication and cognitive ability.

## 2.2 Participants and Methods

### 2.2.1 End-user profiles

Fifty two end-users have been involved in the trials at DART, twenty seven males (of a mixture of ages) and twenty five females (of a mixture of ages). They were born between the years 1944 and 2004, the oldest was in fact sixty two and the youngest was only two and a half years of age when they tried gaze control for the first time. Most of the end-users were adolescents and young grown-ups (please see Figure 2.2).

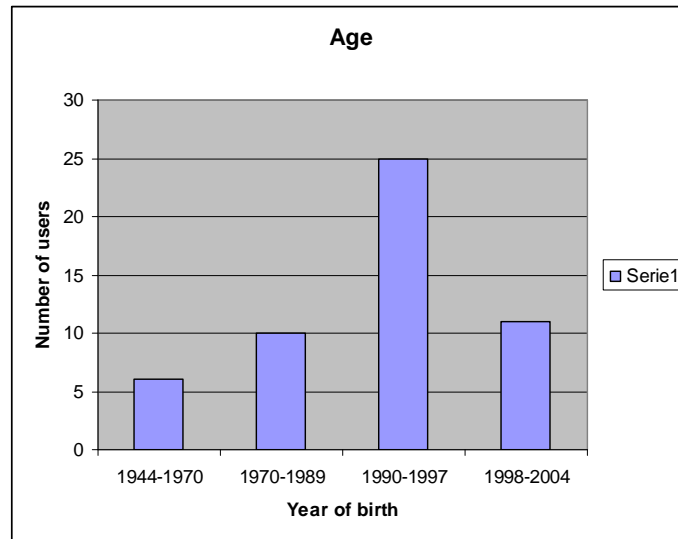


Figure 2.2: Distribution of age

Different types of diagnoses were represented (as shown by Figure 2.3 below) as well as a wide range of cognitive abilities. Thirteen end-users wore glasses, two of the end-users had restricted vision and four had poor vision. Eleven of the end-users had problems with eye movements, for example squinting<sup>2</sup>, spasticity<sup>3</sup> involving eye movements, nystagmus<sup>4</sup> and eye tremor.

<sup>2</sup> “A squint means the eyes stop working together as a pair and therefore do not look in the same direction. One eye may turn inwards, outwards or even upwards or downwards. The medical term for a squint is strabismus” [www.rnib.org.uk](http://www.rnib.org.uk)

<sup>3</sup> “Spasticity is a condition in which certain muscles are continuously contracted. This contraction causes stiffness or tightness of the muscles and may interfere with movement” [www.ninds.nih.gov/disorders/spasticity/spasticity.htm](http://www.ninds.nih.gov/disorders/spasticity/spasticity.htm)

<sup>4</sup> Nystagmus is “an uncontrolled movement of the eyes, usually from side to side, but sometimes the eyes swing up and down or even in a circular movement” [www.rnib.org.uk](http://www.rnib.org.uk)

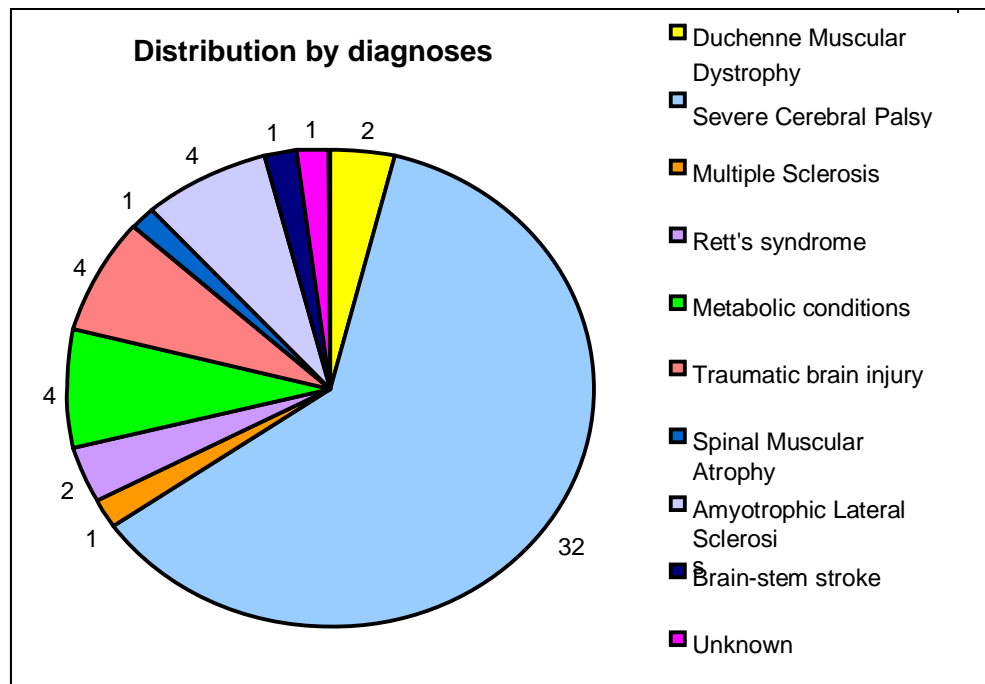


Figure 2.3. Pie Chart to illustrate the distribution by diagnoses

Only eight of the fifty two end-users used speech as their main means of communication. Three people used letter boards and thirty two used augmentative and alternative communication (AAC) with symbols such as PCS, bliss and signs. Nine used non formal AAC such as gestures, facial expression, sounds etc. About half of the AAC end-users were limited readers, while the other half were pre-literate. Only a couple were fluent readers.

Before the end-user trials, about fifteen percent of the end-users didn't use a computer due to not having an access method. For others the most common computer control methods included a single switch, head mouse and a trackerball. Almost all of the end-users needed assistance in order to be able to use the computer.

## 2.2.2 End-user evaluation interviews

Thirty five of the end-users participated in a questionnaire following the first trial. Four of these answered a more advanced questionnaire and thirty one answered a questionnaire that had been adapted for communication and cognitive disorders. The remaining seventeen were unable to answer because of their cognitive ability.

When asked for their opinion on using gaze control, twenty one of the thirty one end-users liked it a lot, six liked it, three thought it was average and one disliked it (please see Figure 2.4 below).



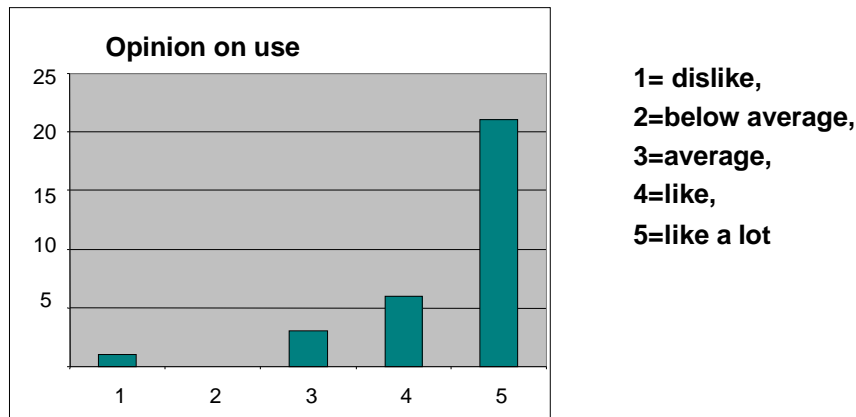


Figure 2.4. Opinion on using a gaze control system

When asked if they thought gaze control was easy to use, twelve answered very easy, three thought it was easy, seven thought it was average, five thought it was hard and two thought it was very hard. Two did not answer the question (please see Figure 2.5 below).

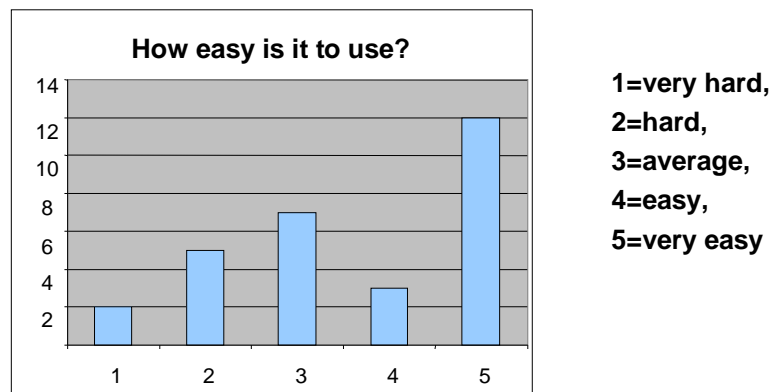


Figure 2.5. Ease of use

Some advantages with gaze control that were mentioned were as follows:

- you don't need to move your head
- you are able to manage on your own and to play music
- there are many options and opportunities
- it is easier than using another type of access method – even at the first attempt
- it is easier to adjust to changes in motor ability
- it provides more freedom
- it is a faster and easier method than scanning
- it is fun

Some disadvantages that were mentioned were as follows:

- it is hard to see
- it is sometimes hard to get a click

- your eyes become tired
- it is sometimes hard to look at the right spot

Twenty eight out of the thirty one end-users wanted to try gaze control again, and three didn't want to.

Some comments after the trial included;

- it is a much faster computer access method
- "I felt more relaxed when using gaze control"
- there is the need for a more portable gaze control system
- "Buy me one before Monday!"

The four end-users who answered the more advanced questionnaire after their first trial rated the gaze control system using a six graded scale (1 being poor – 6 being excellent):

User	Effectiveness	Efficiency	Satisfaction	Ease of use
A	6	5	6+	6
B	5	4	5	6
C	5	5	3	4
D	4	5	6	5

Four end-users who had received their own system participated in an interview (one had an ERICA gaze control system and three had a MyTobii gaze control system). They had had their systems for nearly one and a half years. The main advantages mentioned were as follows:

- Speed and precision
- Saves a lot of clicks
- Easier on the hands
- Much faster typing.

The person using the ERICA gaze control system made some comments about the calibration, saying that it was sometimes hard to get a good calibration and that the calibration process was sometimes frustrating.

One MyTobii end-user found the system harder to use in windows mode – otherwise the precision was very good, comfortable and provided opportunities for using the computer in ways that hadn't before been possible. One end-user was now able to use the internet and to chat, which was a goal that had been created during the 'set up' time and was something that had failed to work when using their other method of computer control.

Improvements needed were:

- Better integration with Windows and advanced applications

- Some "keys" were missing on the on-screen keyboard. Also there should be easier ways of saving and finding documents.

## 2.3 Findings and Issues

### 2.3.1 Prior to the trial:

In complex cases it is important to have a team approach and to plan the assessment process thoroughly. At DART we begin the process by identifying, describing and prioritising the issues. The end-user (with help from the team) decides which issues and activities are most important to them. If needed, the interview and discussions with the end-user must be adapted to suit his or her level of cognitive and physical ability. There are different approaches, depending on whether the end-user is an adult or a child and whether they have any cognitive and/or communication problems. For many of our end-users with communication and cognitive difficulties, the use of the "Talking Mats" method has been useful in helping the decision-making process (Murphy and Cameron 2006).

The individual's motivation is central for activity performance. There are also several other factors to consider, for instance physical abilities including: motor function; speech; vision; hearing; and other senses, as well as finding out whether the person has any problems with pain. One should also be aware of the person's emotional and social abilities which may affect the end-user's potential to succeed. It's important to consider the person's cognitive abilities which include the ability for abstract thinking, memory, attention and concentration, linguistic skills, as well as perceptual abilities. Common perceptual problems for people with cerebral palsy<sup>5</sup>, other congenital brain injury and acquired brain injuries include cerebral visual impairment (CVI)<sup>6</sup> and crowding<sup>7</sup>.

A motor assessment is often necessary. The first step is to assess the end-user's control of eye movements. The end-user needs to be able to control his or her eyes to some extent.

An assessment for access to technology should result in a list of useful motor functions and how to make the best use of them. Issues for consideration include whether or not there is a motor function that could be useful for a mouse click - this could be any deliberate movement of the hand, leg, foot, head, or indeed any other form of physical control. If possible, the capacity to use a manual mouse click instead of the dwell function (automatic mouse click) can provide the end-user with more control. It can also enable them to look at the screen without clicking, which may be less stressful for some end-users. It may also, for some end-users, be faster to manage. It is also important to know the end-user's level of strength and coordination, as well as their best working position. Can the end-user hold his or her head or is there need of a special headrest?

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<sup>5</sup> "Cerebral palsy is not a disease or an illness. It is a disability caused by damage to the brain that can take place before, during, or in the early days after birth" [www.bobath.org.uk](http://www.bobath.org.uk)

<sup>6</sup> "Cerebral visual impairment (CVI) is the term used to describe visual problems associated with difficulties in processing visual information. It arises from damage to the visual pathways and the part of the brain – the Visual Cortex – which is responsible for helping us to understand what we see and act upon it" <https://czone.eastsussex.gov.uk>

<sup>7</sup> The phenomenon of crowding occurs when "a shape presented in the visual periphery is harder to identify when it is surrounded by other shapes" van den Berg R, Roerdink J and Cornelissen Journal of Vision 2007 7(2):14, 1-11 [www.journalofvision.org](http://www.journalofvision.org)

## Prerequisites of the technology

It is necessary to systematically analyse the characteristics of the gaze control systems available, and how well these respond to the end-user's level of motor function, cognitive ability and the activities that it is needed for. For instance, if the end-user is not able to look at the whole screen, it is possible to adapt some systems to utilise only those areas that the end-user is able to see. Other end-users may have problems completing a standard calibration due to cognitive problems or extensive spasticity. This will lead to trials with a gaze control system with individualised calibration settings, as well as ensuring that there isn't the need to repeat the calibration process too often (see below).

## Prerequisites of the environment

Competence and the availability of support in the end-user's environment are critical factors that need to be considered when choosing a gaze control system. A supportive environment is often the key to success.

### 2.3.2 Calibration

For young children, people with learning disabilities or brain damage and CVI it can be difficult to perform the necessary calibration process. This may be due to motor problems such as spasticity interrupting the control of eye movements or the fact that the person doesn't understand how to perform the task. The calibration in some systems can be adjusted by changing the appearance, size and speed of the target. In the MyTobii system, it is also possible to time the movement of the target manually and to work with every target separately, which is useful in cases where end-users have problems following a moving target, or with timing. In some gaze control systems it is possible to choose the appearance of the target, using personal photos, pictures of favourite animals, a film clip with sounds, etc. (as illustrated in Figure 2.6). This can make the end-user more interested in the target and enable him or her to carry out the calibration process without verbal instructions or understanding the purpose. This feature of the MyTobii system was developed as a result of the cooperation between Tobii Technology and DART, working collaboratively with an end-user with complex brain injuries.

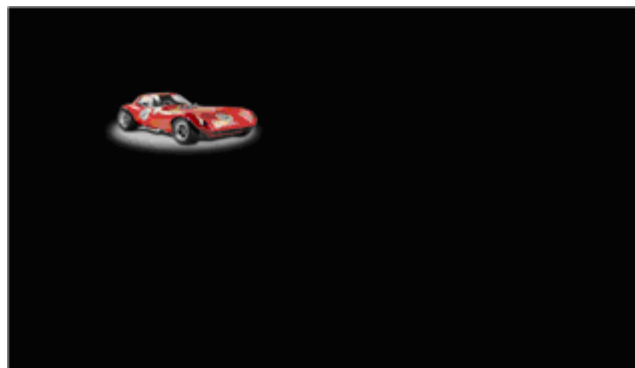


Figure 2.6: Personalised calibration using pictures of interest to the user

The calibration process is strenuous for many end-users who have complex needs and some can only complete it during several sessions with specialists. As many of the systems available demand that the end-user start every session with a new calibration, some of the systems are therefore hard or impossible to use for these people. To make gaze control technology available for as many end-users as possible, the systems need to have a selection of options in the calibration settings.

### 2.3.3 Initial use and training

#### Activities/tasks

When a person tries out a gaze control system for the first time it is advisable to start with easy tasks, preferably with a type of activity where a choice only generates a sound. It is essential during the early stages for the end-user to be presented with activities enabling him or her to build up his or her skills with this new tool, without making mistakes. To be able to succeed, the choice of activities and software must be appropriate for the end-user's interest and abilities. If the demands upon the end-user are too high or too low, he or she may lose interest and/or motivation. The activities are gradually changed so that they become more complex.

It is important to work in short sessions and to notice if the end-user shows any signs of fatigue. Beginners often become tired quite fast.

When "simple" applications are initially used it enables the end-user to experience the conditions applicable to gaze control, on their own, in an environment where there is no pressure to perform and where they don't need to worry about making mistakes. Also, importantly, this activity is fun for most people! This approach is especially useful for people who have difficulties in following verbal instructions (due to age, language disorders, learning difficulties, neurological disorders etc.) The amount of cells/choices and the size of the targets must be individually adapted to suit the end-user's cognitive skills and his or her level of gaze control performance.

All of our end-users (children as well as adults) have responded well to the initial use of "simple" musical grids. As well as being fun, these have made the end-user feel successful and have motivated them to continue with more demanding tasks. Many end-users have not been able to move on to writing applications (text or symbols) immediately, and they have needed to have a practice training period with suitable software.

In all likelihood, an end-user needs to have some cognitive understanding of how to make a choice using a gaze control system; choosing by looking at a picture/symbol and by looking for a certain amount of time. Many end-users with severe learning disabilities have been able to successfully handle a gaze control system with applications at an appropriate level for them. The aim of having adaptations available for people with severe learning disabilities, a very challenging group to find computer access for, is important. More effort needs to be put into making applications that are not too cognitively demanding for end-users who have different levels of learning difficulty.

#### Music and play

Play is a well known concept for learning and motivation (Reilly 1974; Kielhofner 2002). It is a powerful strategy when learning a new computer system and it helps to prevent feelings of insecurity and pressure. Music has the same advantages and is sometimes more age independent plus it is a suitable activity for the majority of end-users. Music and play are the two main foundations for initial use and training of assistive technology at DART.

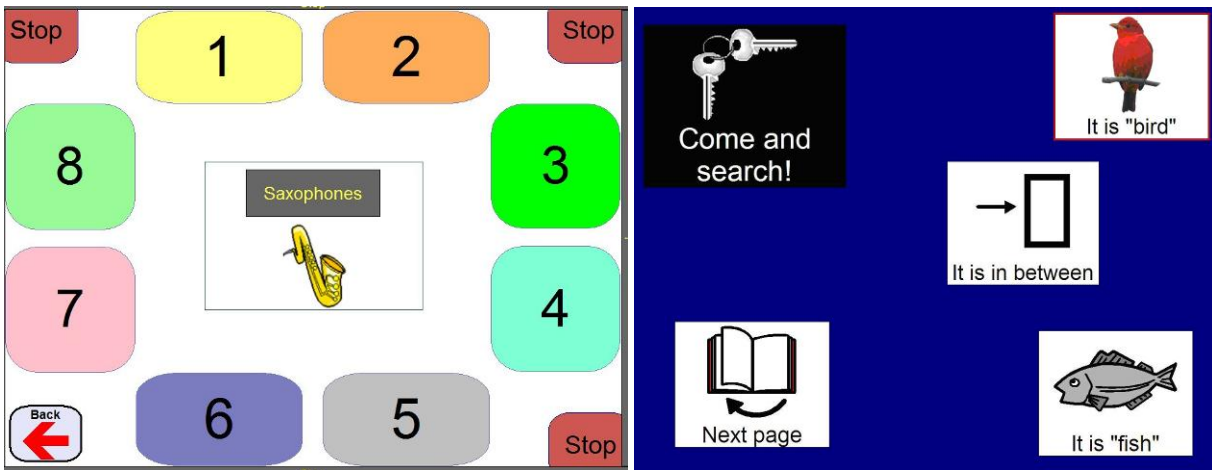


Figure 2.7: The above screen shots show an example of a musical and play activity. The top right picture shows a grid from the Swedish game "Hide the key" (a kind of treasure hunt) in which the child hides a key when the partner leaves the room. Then, when the partner comes back, the child can give clues to help him/her search for the key.

There are several things to consider when creating applications for end-users with complex needs. These are as follows:

- The appropriate on-screen visual representation (pictures, symbols, text, foreground/background colours, etc.), i.e. ensuring that visual images are presented in a way that is clearly visible and understandable to the end-user.
- The appropriate organisation of the images on the screen in accordance with the visual abilities of the end-users so that the visual images are arranged in such a way that they can be easily understood and controlled
- The appropriate auditory support and feedback is essential. It is important to ensure that the type of auditory support provided for the end-user gives them optimal support in relation to their needs and abilities.
- These are combined and integrated with other applications that the end-user may need or be familiar with.

At the gaze control system evaluation, after six months, all of the end-users taking part in the evaluation expressed that the period of training had had a great impact on their performance. Training enhances the end-users' strategies and memory which affects performance. Therefore, the lay-out of the application needs to be as consistent as possible.

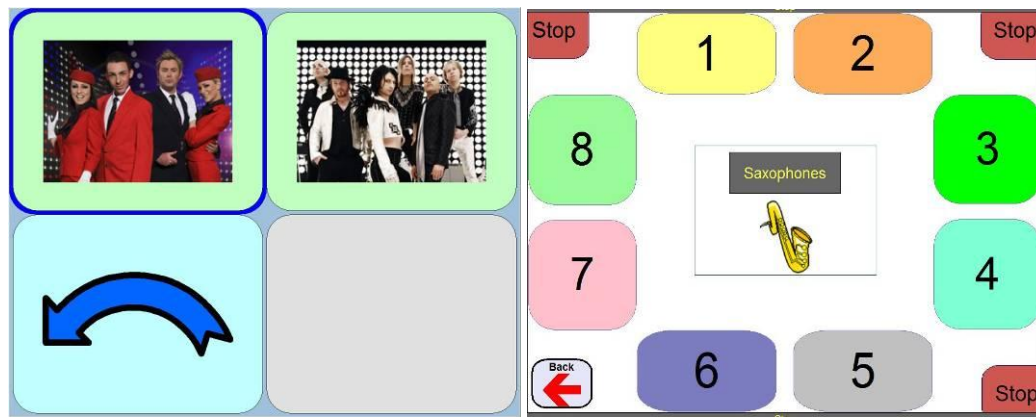


Figure 2.8: Some examples of grids that have been used during the introduction to gaze control and training period

The grid illustrated in Figure 2.8 on the left hand side presents two choices. The end-user starts the music by looking at their preferred choice. As soon as he or she looks at another cell, the music changes. A blank cell gives the end-user a spot in which to ‘rest’, a cell with no action. If you buy a record it would be possible to convert the music into a suitable format and to put it into the appropriate communication software. Pictures of musicians are generally easy to find on the internet.

The grid above on the right hand side shows an application for playing music where the instruments loop with the mouse pointer. This is a non-click application which is suitable for initial training and for playing music together.

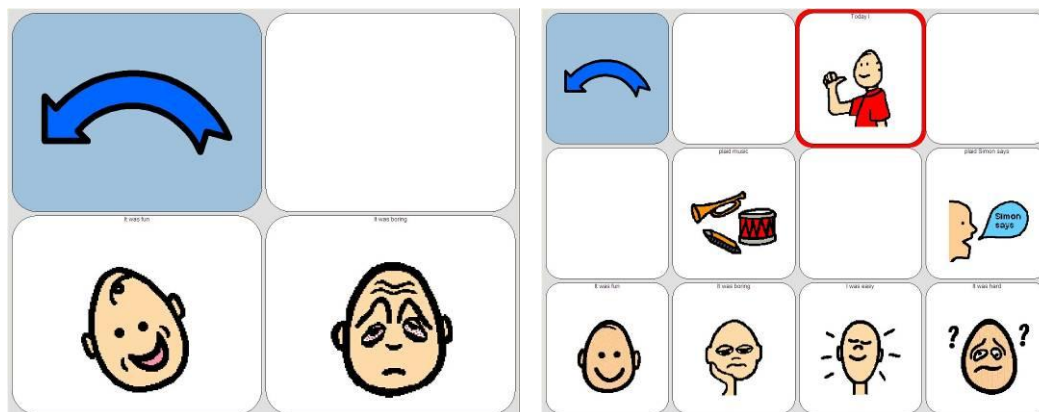


Figure 2.9: Examples of grids for commenting on gaze control activities

The first grid on the left hand side in Figure 2.9 is an example of a simple grid that presents two choices: “it was fun” and “it was boring” so that an end-user who is at an early introductory level can participate in evaluating activities. The second grid (Figure 2.9, on the right) is designed to enable the activities of the session to be evaluated. The end-user can say “today I...” and then choose the appropriate activities, shown here are “played music” and “played Simon says”. Then he or she can choose between the following opinions: (1) “it was fun”, (2) “it was boring”, (3) “it was easy” and (4) “it was hard”. This is a useful way to



explore the opinion of the end-user (in writing as well), and it can be used repeatedly by simply updating the list of activities.

### 2.3.4 Choice of access method

We have met numerous people whose severe involuntary movement means that finding computer access has been almost impossible for them. Gaze control has turned out to be the only way of achieving independent control of any activity. Some of the end-users had used other computer access methods before using a gaze control system, but these were difficult for them to manage, and much more energy demanding than gaze control. Also, even if the gaze control system is not a faster way then the end-user is still able to work in longer sessions and is able to perform more through it being less tiring. The most common way to make a comparison between different computer access methods, or settings, is to complete the same task using alternative methods or settings, while a score is kept on time and errors. This way, one can obtain an objective measure on what is most effective. In some cases this may not be possible due to the fluctuating performance of the end-user. In these cases video recordings can be used to analyse the alternatives. The most important information though, is definitely the opinion of the end-user!

Some end-users may have difficulties with managing a gaze control system in a very effective way, but compared with not having any possibilities for any self determined activity and with adaptations, the systems may work to an acceptable degree, even if it is not optimal. It is not possible beforehand to tell what development of skills could take place from a period of training.

### 2.3.5 Ergonomics

The use of a computer in a good ergonomic way requires a good seating and working position and a new method of computer access requires an assessment of seating and positioning. When using a gaze control system, compared with many other access methods, the end-user does not necessarily need to have as much controlled mobility and muscle function (strength, endurance and muscle tone) but, nonetheless, a good seating and working position is essential. From experience so far, an end-user who is hypertonic<sup>8</sup>, for example, with a great deal of involuntary movement and perhaps unwanted reflex actions often seems to be more relaxed when using a gaze control system as compared with other methods.

For a good ergonomic position, the key issues are stability, mobility and comfort. The seat, backrest and neck rest of the chair should provide comfortable postural support, allowing occasional variations in the seating position. Most end-users need a good neck rest when using a gaze control system. The screen should be positioned at a suitable distance and the top of the screen should be level with (or perhaps slightly lower than), the end-user's eyes. However, when using a gaze control system, some end-users may benefit from having the computer screen a bit higher than is generally advisable. This may be because the end-user opens his or her eyes more when looking up, allowing the gaze control system to recognise where the end-user is looking more easily. In these cases, it is important to be attentive to the end-user's neck to avoid pain and always use a good neck rest. For comfort during extended periods of use, the seating needs to be flexible. The end-user should be able to change position whenever he or she wants. The computer screen needs to be adjustable for different sitting positions, including the end- user leaning backwards, whether in an electric

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<sup>8</sup> Hypertonic is "having extreme muscular tension; spastic" <http://medical-dictionary>.



wheelchair or even when lying in bed. This is particularly relevant when using a gaze control system, as it often allows for a wider range of working positions.

### 2.3.6 Communication

If the end-user has a disability affecting communication skills it is important to have a low tech communication system available. The design of a new communication system should be built on the experiences from the earlier low tech or high tech solutions. There will always be the need for a well functioning, low tech alternative, for those situations when the gaze control system is not available, for example when at the beach or while eating.

## 2.4 Discussion and Recommendations

Almost all of DART's end-users had very severe motor disorders, many of them with involuntary head movement and the MyTobii has been a non-head worn gaze control system that has been able to tolerate head movement to a sufficiently significant extent. MyTobii worked to some degree for almost all of our end-users, but not with full functionality in all cases. The other systems have been more suitable for people who sit still, for example people with ALS, high spinal injuries etc. There are new gaze control systems on the market that have not been tested within the project at DART that are also designed to tolerate head movement.

Many of the end-users have needed especially adapted keyboards (in terms of colours, sizes etc). The option of auditory feedback when a choice is made is helpful for most of the end-users, especially initially. Functionality was also dependent on the end-user's visual ability and their sitting position, which affects head control and their field of vision. In some cases, when the end-user has problems with reaching targets across the whole screen, or perhaps has problems with targets in corners, it has been necessary to permit the end-user to work on only part of the screen.

In Sweden today, end-users who need gaze control systems for communication and/or environmental control have the possibility of obtaining one as a personal aid. All of the evidence suggests that the COGAIN project has helped in making this process faster. We have noticed an increased awareness and interest in the field of gaze control and we feel that end-user trials have been an important part of this project. There is widespread interest from end-users who wish to have their own systems at home, school or at work. If an end-user needs to have and to use the gaze control system in more than one place, for instance in school and at home, one solution in Sweden has been to let the end-user have two mounting systems and to move the gaze control computer from one place to another.

### 2.4.1 Case study - Anna

The key recommendations that have emerged from DART's end-user trials are best illustrated by describing the processes involved in assessing and implementing the successful use of gaze control with Anna, a young person involved in the trials.

Anna is eighteen years old and has severe cerebral palsy, which affects her speech and motor functions as well as her cognitive skills, and causes extensive problems with spasticity. During her early school years and up until now, several assessments have been made and Anna has tried out different computer access methods,

mainly with different kinds of switches, as well as an EEG/EMG-system<sup>9</sup>. Despite extensive efforts, up until now, it has not been possible to find a method for independent communication in daily life. Anna goes to a special school and is in a class for students who have severe communication problems.

Prior to the assessment, Anna's principal means of communication had been to answer yes and no by moving her eyes to the left or to the right. She had also used a communication book with eye-pointing in combination with scanning, but then only with a few skilled communication partners. As a result of COGAIN, Anna had the opportunity to try out a gaze control system using simple activity grids with large targets on one occasion. This was partly successful and it identified the need for a further assessment. A comprehensive communication assessment at the regional AAC-centre (DART) was thus initiated. This was carried out in accordance with the model already described above.

### Identification, description and a prioritisation of the issues

Often the assessment process starts with a meeting that gathers everyone involved - the end-user, family and staff from the rehabilitation team, school and personal assistants - in order to discuss the issues and to establish a consensus on goals. In this case it was considered too hard for Anna to express her own point of view in such a large meeting. Instead, the assessment process started up with a meeting with Anna, her mother, the Occupational Therapist and the Speech and Language Therapist from DART for an interview on Anna's thoughts and preferences concerning the forthcoming assessment. Talking Mats™ (Murphy and Cameron 2006) were used to interview Anna on her activity goals and preferences concerning an gaze system. Anna felt that there were several areas in which she would like to use a gaze control system and then prioritized them in order of importance. She wanted to be able to carry out the following activities: (1) choose and listen to music; (2) look at pictures; (3) write shopping lists; (4) listen to books/magazines; (5) write school work with symbols; (6) read and write e-mails; (7) use the internet; (8) be able to participate in planning her budget; (9) watch sport results; and (10) watch movies (see examples on Figure 2.10).



Figure 2.10: The result of the Talking Mats™ interview

After the interview, a meeting with all of the individuals who were involved was carried out, and a person from DART presented Anna's ideas and views.

### The selection of a theoretical approach

The theoretical approaches employed in this process can include theories, models or paradigms, all of which aim to guide further future actions, including assessments and implementation. In Anna's case, the team used

<sup>9</sup> EEG refers to electroencephalography and EMG refers to electromyography

a theoretical framework appropriate for her situation and condition. Here, the ICF (WHO 2001), client-centred models, CMOP (CAOT 1997), laws and praxis models concerning the prescription of technical devices could be applied.

### **A description of the factors required for gaze control activities**

During the meeting, factors concerning the activities and the environment were discussed. Anna's strengths and resources were highlighted, the resources in the environment concerning staff and where, how and with whom the different activities could be carried out were targeted. Guidance was underpinned by journal evidence and prior experience. Thus, the AAC-team from DART was able to provide information about the different, available gaze control systems, outlining their pros and cons.

### **A description of the targeted outcomes and the development of an action plan**

A discussion concerning the goals and how to achieve them was held, and with Anna's agreement, it was decided that the overall goal for Anna would be for her to be able to use gaze control for spoken and written communication, but there was a need for extensive training before such goals could be achieved. Therefore, several interim targets in areas which were considered to be good training activities were set up for the following six-month period:

These were as follows:

For Anna to be able to

- Choose and listen to music
- Look at pictures and give a presentation
- Make shopping plans
- Write some schoolwork tasks with symbols
- Write and read e-mail

Based on this, an action plan with six assessment sessions at DART was scheduled. Anna's assessment was planned to include: (1) three sessions for an gaze control assessment; (2) three sessions for choosing and finding the right strategies for using communication software; (3) a meeting to inform the team of the assessment results, including the prescription of an appropriate device and communication software; (4) The education of staff and family, as well as an introduction to and the setting up of the equipment were also planned. These plans were written up into a report.

### **The implementation of plans**

The first three sessions involved the assessment of seating and positioning, calibration and gaze recognition, target size and the method for mouse click.

The seating was assessed to be the best when Anna's wheelchair was tilted back into a position in which she could use the headrest, which had to be adapted for improved use. The gaze control equipment was positioned quite high in order to achieve the best eye recognition.

The calibration was completed in several different ways in order to find the best method. Anna had problems following a moving object and needed time to focus on it. A calibration procedure with targets that were moved manually by the Occupational Therapist in the AAC-team from DART gave the best results. The

calibration got better when pictures were used instead of the standard 'dots'. After this, Anna achieved a good calibration, but the recognition was still very sensitive to positioning and spasticity. Anna had to be made aware of how the recognition was affected by her facial expressions. For instance, when making a happy face her eyes squinted, and suddenly recognition was not possible. At every session the Occupational Therapist gave at least one briefing of how to relax her facial muscles and the effect this had. A mirror was used, but the best feedback was that Anna could see her eyes in the track status window, and of course, how well the system was working. During this part of the assessment, different available gaze control systems were tried and a system that was suitable for Anna's needs was chosen.

Appropriate target size was assessed using different applications, some that were included in the gaze control system, and some that were made by the AAC-team. This involved choosing popular music that Anna liked in applications that had targets of different sizes and positions. At the same time the mouse click method was tried out. Anna had a lot of involuntary movement so trying to activate some kind of switch for a mouse click was not a good solution because it would only increase her spasticity, which she was endeavouring to reduce. Dwell selection was chosen and different timings were tested in order to find the optimal time. The result from this assessment was that Anna's preferred target size would be to use grids containing targets that were arranged in a 5 by 6 layout. When the targets were placed side by side, the smaller targets worked well when gaps were created in between them. She had problems reaching targets on the lower side of the screen. Her preferred dwell time was 0.6 seconds in general. The target size and the dwell time depended on the activity and could change over time; therefore an evaluation of this was planned for later on.

An application was made by DART, based on the assessment findings and Anna's goals. This was tried out and trained for three sessions and the application was adapted after a trial based on the results of the trials and ideas from Anna's staff.

At this time the AAC-team from DART started to make their recommendations for appropriate equipment and software so that the rehabilitation team could make their prescription and order the equipment. This was done in a written report also specifying the results from the assessments. During the time whilst waiting for the delivery, DART organized for the family and staff to receive training though a one day course on how to adapt and use the communication software, as well as half a day on how the gaze control system was to be used.

The equipment was then introduced to Anna at school and the staff started to train her in the different activities. This was carried out for one hour every weekday, step by step, clearly and thoroughly timetabled (which was planned in a joint meeting), so that the training would be at the right level, and broken down into a few areas step by step. During this period the staff had support from DART on both the methodology as well as the technology.

An assessment on how to develop Anna's low-tech communication was also carried out at DART.

### **An evaluation of the outcomes**

After six months of implementation it was time for the scheduled evaluation. This was done through an interview with Anna as well as a meeting with Anna and everybody else involved. At DART, the team assessed whether Anna's occupational performance had improved or not, if the system functioned satisfactory, if there was a need for a further assessment and to what extent the goals had been met/reached. There was also the need to check whether any new issues had arisen.

Anna was very happy with her gaze control system. She had used the musical applications a lot and the staff had developed them in accordance with her wishes and ability. This was an activity that she herself was very happy with. They had also undertaken a great deal of work with picture albums, as well as making presentations for school work. It had worked very well. Another part of her school work involved writing with symbols using speech synthesis. Her skills and the amount of material used were slowly improving. There hadn't been any work on making shopping plans which did not concern Anna when she was asked. Writing and reading e-mails had not been practised yet due to problems with the internet connection at school. However, this problem was in the process of being resolved, and plans were being made to start using e-mails shortly.

Overall, Anna and the others involved were very satisfied with the level of goal attainment and thought that it was time to set up some new goals and to make further future plans. Anna wanted to be able to use the system at home too and to become a much more skilled end-user, both she and her family felt ready to do this. It was decided that her mother and her personal assistant should be with her at school in order to have some training sessions, refreshing their knowledge of the gaze control system and the communication software. A general consensus was reached on the subject of increasing the use of gaze control for communication. Therefore, it was the right time to introduce some more communication grids into the application. This was to be done by the AAC-team at DART in cooperation with Anna's local rehabilitation team. Practice with this was planned to be carried out at school as well as at home.

Finally, a new list of goals, schedules for training and who should be responsible for each part were documented in a report and a new meeting for the next evaluation was set to take place following a new six-month period.

## 3 POLITO/Torino ALS Centre End-User Trials

### 3.1 Introduction to PoLITO/Torino ALS Centre User Trials

People with Neurodegenerative Diseases, such as ALS, are affected by several kinds of symptoms and problems during the progression of their illness (sometimes over a span of many years). These have a severe impact upon their quality of life. In the advanced phases, both ALS and Multiple Sclerosis (MS) are characterized by the complete loss of the ability to communicate, even with common augmentative/substitutive systems, due to the complete loss of movement in the limbs, neck, etc, rendering the individual utterly dependent upon other people to carry out the common activities of daily life.

A great deal of research in the literature highlights various areas related to the care and to the improvement of the quality of life of these patients. Generally they propose and adopt the palliative care approach. In palliative care, it is fundamental to control pain, symptoms and social, psychological and spiritual problems. It is an approach that aims to improve the quality of life of patients and their families. This type of care must adapt, on a daily basis, to the needs of the patient and to those of his or her family.

All treatment needs to be re-examined on a continuous basis. From the literature we find that home is the ideal place in which to implement palliative care in the best way. The improvement or the facilitation of effective communication in ALS clearly falls within the realm of palliative care. Patients with a very severe disability, thanks to the existence of communication tools, are given an opportunity to re-enter their social and family life.

The potential for gaze control in ALS is extremely high, since these patients retain their full cognitive abilities, and while paralysis progresses fortunately eye movements are still controllable in most cases.

A deeper knowledge of the needs of real patients and their caregivers is therefore necessary in order to define and evaluate what are effective tools for AAC through gaze control. In this deliverable we report on the trials performed, over a span of two years, on a significant proportion of Italian ALS patients. The trials were conducted through the collaboration between the Politecnico di Torino, the hospital San Giovanni Battista and the University of Torino (dept. of Neuroscience). The aim of these trials has been to evaluate if and when the use of gaze control has had a positive impact on patients' lives.

### 3.2 Participants and Methods

The research was based on the following main principles:

- Adoption of Quality of Life assessment scales
- Trial with off-the-shelf devices



- Involving a large<sup>10</sup> end-user base.

A Multi-Disciplinary Team (MDT) composed of Neurologists, Psychologists, Speech and Language Therapists and Computer Science Engineers conducted the trials. The Neurologists selected the patients in accordance with the following recruitment criteria:

- From an ethical standpoint, patients had to be able to understand the aim of the study and to be able to give their informed consent.
- To ensure motivation, patients had to be unable to speak intelligibly and to have varying degrees of functional hand impairment.
- For reasons of efficacy, patients had to have a basic to a good level of computer literacy.

The patients used a gaze control system for a week in their own domestic environment.

The research team scheduled two visits and one contact by means of the telephone for each patient during the loan period of the gaze control system. The Speech and Language Therapists trained the patients and their caregivers in the calibration and use of the gaze control system. The training also included a brief course about using applications for writing, communication and internet browsing in gaze control mode. Other applications were installed in accordance with the end-users' needs and interests.

The Psychologists filled in the patients' assessment questionnaires just before the training phase. The questionnaires measured the Quality of Life (QoL), the satisfaction about Life, the Depression level, and the perception of representing a burden. The following international recognisable quantitative scales were adopted<sup>11</sup>:

- The McGill scale (MGS). This scale developed by McGills University analyses five factors: (1) physical comfort, (2) physical symptoms, (3) psychological symptoms, (4) existential comfort and (5) support.
- The Satisfaction with Life Scale (SWLS) which evaluates the satisfaction with life.
- The Zung Scale: self rating depression scale; it is fast, simple and it has quantitative results.
- The Self-Perceived Burden Scale (SPBS): this questionnaire consists of 25 statements about feelings the patients may or may not have about their relationships with caregivers.

The questionnaires were proposed again at the end of the evaluation period with the purpose of verifying the impact of the gaze control system on the measured parameters. A questionnaire, developed by the ALS centre, was also proposed for the end of the loan period. The ALS questionnaire focused upon qualitative aspects and feelings, and analysed the time that had been spent with the gaze control system, the training process, the level of subjective satisfaction and the influence upon quality of life.

### 3.3 Findings and Issues - Phase 1

The gaze control system that was used in the first part of the trial was the Eye Response Technology's ERICA Standard System. It was provided with the relevant assistive and communication software including the ERICA keyboard, mouse emulators and Sensory Software's The Grid 2 as standard.

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<sup>10</sup> For a rare disease such as ALS, "large" should be compared with the actual number of affected patients in the considered region.

<sup>11</sup> Copies of these questionnaires are provided in COGAIN Deliverable 3.3. [www.cogain.org](http://www.cogain.org)

In the second part of the trial we used a MyTobii P10 with the Italian software called **iAble**, The Grid 2 and windows and internet applications. Case studies have been used below to give a qualitative outlook on the impact of gaze control on ALS patients. Permission to publish this information, in a partially anonymous form, was obtained.

When comparing the results before and after the trial week, a particularly noticeable improvement was shown in the patients' perception of their condition overall, including their psychological well-being and their physical symptoms, although the amount of support required by each patient and their perceived depression did not show a significant change. However, it must be remembered that these results were achieved over a relatively short trial period of seven days.

### 3.3.1 Case Study - Pietro

Pietro is 52 years and lives at home with his wife. Before the illness he was a web designer. He still is. During the initial trials he was still able to use a mouse (plus a separate switch) as an alternative method to gaze control. He does not use a communication aid socially because he still uses labial<sup>12</sup> movements successfully in order to communicate with his family. He uses many programs for his work, and has tried them all on the Erica system. The results of his involvement in the Torino/ALS Centre end-user trials were positive.

Some time after the initial trial however, he lost the ability to use a mouse as an input device, and he applied to The Health Service for funding for the purchase of a gaze control system. Having done a great deal of research, and having tried out a range of systems, he decided that an EyeTech TM3 most appropriately met his needs. In the past he had tried other gaze control systems but he didn't like them because they didn't work well with the web design programs he wished to use. As well as the accuracy afforded by the EyeTech TM3, he also finds that the end-user interface is particularly appropriate in meeting his needs. In addition, the EyeTech TM3 can be used with any windows computer, and Pietro needs a powerful system for his graphic design and music applications.

## 3.4 Findings and Issues – Phase 2

After the first phase we decided to change the trial methodology by broadening the set of analysed cases and conditions. In particular, in the second phase we aimed to analyse different types of patients with ALS or other conditions or disabilities and to understand their needs. Gaze control became one tool, but the whole set of communication and assistive technologies were considered. For this phase of the trial we would like to acknowledge the support of the association for ALS patients in Piedmont (APASLA)<sup>13</sup>.

In this way, we were able to evaluate the impact of gaze control systems on real patient need. The results would be of a qualitative nature because we were faced with a significant variation in patient conditions. This enabled us to make strides in practice within the general assessment field.

This phase was possible too because we were able to adopt a different gaze control system: the MyTobii P10 device. We found it to be more versatile and more adaptable to a wider range of cases, including individuals who had either involuntary eye or head movement, or both. It also meant that we were much better placed to

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<sup>12</sup> labial refers to the lips.

<sup>13</sup> <http://web.tiscali.it/slatorino/>



compare the differences between the two different gaze control systems used in both phases of the end-user trials.

The P10 device, lent through the COGAIN project, was reconfigured, thanks to the kind co-operation of the Italian reseller (SRLabs). The SRLabs software, 'iAble' uses the 'centralised cell-select' feature, a technique described in detail under the ACE Centre end-user trials, below. This software is a much more sophisticated end-user interface, currently available in Italian, only. It makes gaze control more effective, and more appreciated, by literate and advanced end-users. The new interface, called iAble, uses a different layout that clearly separates areas "to look at" from areas "to act upon", i.e., where a gaze is taken as a command action. With this separation, much more complex interfaces may be designed, and have been integrated into the iAble framework. Depending on the end-user, and on their former computer knowledge, we chose whether to propose the simpler MyTobii grid, or the new iAble interface. End-users were able to test both interfaces and to change their choice autonomously, during the lending period.

The new gaze control system was immediately appreciated for having a substantially easier and less convoluted calibration and initialization procedure, both for the end-user and for the caregiver. This was very important in creating a more relaxed approach to the new device.

As a first, partial result of this phase of the trial, out of three trialled patients with ALS, all three had already started the process with their relevant Health Authority to receive a gaze control system.

### 3.4.1 Case Study - Alessandra

Alessandra is a woman aged 56, affected by ALS for a period of 2 years at the time of writing. Within a short space of time, Alessandra had been given a percutaneous endoscopic gastrostomy (PEG) feeding tube<sup>14</sup> and a tracheostomy<sup>15</sup>, and she currently resides in a residential care centre. She is still able to speak, even if she has an endotracheal tube<sup>16</sup>, since she still has good articulation movements.

The Neurologist caring for her asked for a further evaluation by the COGAIN team, since her ability to speak depended on the position of the endotracheal tube. When the tube was not totally cuffed (i.e., inflated), she was able to speak, however she was at risk of pulmonary infections and she was subject to an excessive quantity of secretions from her mouth entering her lungs. The care centre at this time lacked a satisfactory call-for-help system, and the only way to call for help was for Alessandra to shout into the microphone beside her bed. But, during the night the tube had to remain cuffed and inflated, which prevented her from speaking and therefore Alessandra constantly lived in the worry of not being able to call for help.

When we first met Alessandra we evaluated her swallowing ability (whether she was able to eat), her sound articulation abilities, her residual arm movements and we collected information related to her needs and desires.

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<sup>14</sup> A percutaneous endoscopic gastrostomy (PEG) feeding tube enables the individual to maintain adequate nutrition when there are difficulties with oral intake, e.g. the patient is unable to swallow ([www.patient.co.uk](http://www.patient.co.uk)). An opening is made into the stomach enabling individuals to be provided with fluids and nutrition directly into the stomach

<sup>15</sup> A tracheotomy is described, by the Merck Manual ([www.merck.com](http://www.merck.com)), as "surgery to create an opening into the trachea (windpipe) through the neck"

<sup>16</sup> An endotracheal tube is a tube that is inserted into the trachea that serves as an open passage through the upper airway in order to permit air to pass freely to and from the lungs serving to ventilate the lungs [www.medicinenet.com](http://www.medicinenet.com)

Our evaluation showed that she still had a sufficient level of swallowing ability, an effective movement of the index finger of her right hand and, during a test with the eye tracker, very good ability in interacting with software interfaces. The Speech and Language Therapist and the Neurologist worked with an Engineer and with the personnel of the care centre, as well as with the family caregivers, and after the multi disciplinary work, we had been able to:

- Modify the button to call for help, by devising a new version and by hand-crafting it. The previous button needed to be pushed, and with a force higher than her strength. The new version of the button required a much smaller force (0.07 N), and was activated by *lifting* her finger (rather than pressing it), which was a much easier movement for this individual to make.
- Try the MyTobii eye tracker, and change her eyeglasses (multifocal ones were a problem for reliable use of the gaze control system). At this time, the paperwork for obtaining a gaze control system had already been started.
- Evaluate her swallowing capabilities and ascertain that Alessandra was able to feed (in small quantities) by mouth, as long as the tube was not totally inflated. When the tube was cuffed she was unable to speak, and the gaze control system was necessary for communication.

### 3.4.2 Phase 1

End-user comments agreed that the system was efficient and effective, and allowed more complex communication, beyond the expression of primary needs. In fact, the majority of patients used the system every day with a high level of satisfaction. It was felt that gaze control was comfortable and flexible and required relatively little effort. A great perceived advantage was that, after calibration, the end-user was independent in using applications (compared with Plexiglas tables commonly used for eye-contact dialogs, which relied on a communication partner). For typing applications, end-users appreciated the prediction dictionary and the voice synthesis features. On the other hand, some patients expressed negative comments, which were mainly due to a loss of motivation after some initial technical problems, or due to the difficulty in calibration or the need to repeat the calibration procedure too often.

Some patients who used multi focal lenses could not calibrate the system, but this was solved by changing his or her glasses. For end-users who were less expert with computers, learning to use the onscreen keyboard was fairly difficult. Finally, patients who had some residual movement in certain parts of their body had difficulties in keeping their head perfectly still.

### 3.4.3 Phase 2

The new gaze control system was immediately appreciated for having a substantially easier and less convoluted calibration and initialization process, both for the end-user and for the caregiver. These initial features were very important in creating a more relaxed approach to the new device. As a first partial result of this phase of the trial, out of three patients with ALS who were trialled, all three of them had already started the process with the relevant Health Authority to receive a gaze control system.

## 4 ACE Centre End-User Trials

### 4.1 Introduction to ACE Centre User Trials

The COGAIN deliverable 3.3 “Report on User Trials and Usability Studies” (2006), downloadable from the COGAIN website, ([www.cogain.org/results/reports/COGAIN-D3.3pdf](http://www.cogain.org/results/reports/COGAIN-D3.3pdf)), highlighted a number of ACE Centre end-user trial findings that had emerged as being significant to successful gaze control at that stage of the project. Rather than incorporate these findings already described in the 2006 document in detail, this chapter highlights only the new ACE findings that have emerged *since* 2006. For a full appreciation of the key issues that have emerged over the project as a whole, therefore, this chapter is meant to be read in conjunction with the ACE Centre findings from this earlier deliverable.

### 4.2 Participants and Methods

During the five years of the COGAIN project, we have worked with over one hundred end-users. Some of these have been involved in an investigation into the calibration process only, on a one-off basis. On the other hand, our investigations have also involved almost twenty detailed longitudinal studies, most frequently involving people who have very complex difficulties from a gaze control prospective, including locked-in syndrome<sup>17</sup>, stroke patients, rare metabolic disorders, nystagmus, athetoid cerebral palsy, etc.

During the COGAIN project, the ACE Centre has chosen to focus primarily on people with the most complex physical difficulties, including individuals who often have associated visual difficulties. It was felt that, if we could overcome the difficulties experienced by the most complex end-users then we would overcome many of the difficulties experienced by everyone who wished to use gaze control.

Unsurprisingly therefore, it was these end-users who presented the greatest challenge in terms of gaze control technology due to having visual difficulties, severe involuntary movement or a combination of both

Nonetheless, working to overcome the difficulties experienced by this group of people did in fact cast light upon many of the issues that should be taken into account when assessing and implementing successful use of gaze control for all. Therefore, if at least some of this very complex group's difficulties could be resolved, then it was anticipated that gaze control could become a more satisfying and successful process for many more end-users whose difficulties were less complex.

As with Deliverable 3.3, the previous end-user trials report, the issues focused on related to the key areas of calibration (during the assessment process) and implementation.

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<sup>17</sup> Locked-in syndrome is described by The Merck Manual as being “a state of awareness with quadriplegia and paralysis of the lower cranial nerves, resulting in an inability to show facial expression, move, speak or communicate except by coded eye movements. Vertical eye movement is possible; patients can open and close their eyes or blink to answer questions [www.merck.com](http://www.merck.com)

## 4.3 Findings and Issues

A number of key end-user trial findings and associated issues are discussed below:

### 4.3.1 Calibration Issues

There is a need for a variety of calibration methods depending on the end-user's abilities and difficulties.

#### **Seating and positioning issues during calibration**

Please refer to section 4.4.1.3 of the earlier report entitled 'Issues relating to seating and positioning' (Donegan et al, 2006). In addition, please see section 2.3.5 of this report entitled 'Ergonomics', completed by DART, which also discusses seating and positioning in greater depth. Both documents highlight the importance of being 'well supported and comfortable' for communication and computer control.

This case illustrates the importance of implementing a client-centred approach for the calibration process. A twenty year old end-user with athetoid cerebral palsy illustrated the distinction between seating and positioning in order to achieve a successful calibration, and the long term aim of appropriate seating and positioning for optimal postural management. While her seating and postural needs were an issue (she was soon due to attend a seating appointment), it was essential that they were addressed at an engaging and palatable pace, otherwise she could have become easily alienated from using the technology.

Gaze control was new to her and it involved learning. Grading of the activity was important. At this early stage therefore, the main goal was to achieve a good calibration. Her Speech and Language Therapist aimed to ensure that she felt relaxed not pressurised nor overwhelmed by having to concentrate on too many things at once. Both comfort and being relaxed, it has emerged through the ACE Centre end-user trials, naturally aid calibration. The focus was to kindle her motivation by ensuring her introduction to gaze control was an unequivocal success. It was the early groundwork that made all the difference. Her specialist Speech and Language Therapist ultimately wanted her to be able to use gaze control with an improved posture. The end-user was then able to gradually work on her posture, and the positioning of her equipment has subsequently changed considerably.

From an initial, no pressure successful introductory period, a subsequent process of intervention resulted in the equipment of one end-user being optimally set up. His seventeen inch monitor screen was made as easy and as comfortable as it could be for him to see. The computer was also connected to a large flat screen television, placed on some shelves opposite him on the facing wall. Not only could he see what he was writing, but so too could other people in the room. This enabled them, including those people he did not know well, to be able to comfortably and naturally see the screen and interact more easily. A different end-user once said "it would be nice to be able to look at my communication partner when talking, instead of staring at a screen". In a sense, this situation was partly addressed by the television because the people with whom he was conversing were also able to also share a view of the screen (Figure 4.1).



Figure 4.1: The equipment was set up in such a way that it was not only empowering for the end-user, but its high quality enabled him to function at his level of ability both recreationally and for work purposes.

End-users involved in the ACE Centre end-user trials usually have a preference as to where they feel most comfortable and best able to concentrate. This is influenced to a large extent by their physical ability. It is important to manoeuvre the equipment into the individuals' preferred position, and not to ask the end-user to twist to see the monitor screen. Information and assistance to help the end-user select the most appropriate equipment to aid comfort, posture and pressure care is available, if they are eligible, from their local health or social care professionals. Certainly, a gaze control system doesn't involve as much anticipation of movement as many other computer control methods. The end-user is less likely to experience frustration and reliance upon using abnormal postural patterns of movement. However, even when lying in bed, there may be some equipment to further promote postural alignment, symmetry and circulation particularly if the end-user is in the same position for a long period of time. An end-user may adopt an asymmetrical position in order to use gaze control. For example, one complex end-user "always has his head turned to the left side."

There are many variations in seated and/ or lying positions. The monitor screen is typically tilted sideways for someone in side lying. It tends to be placed above the person, faced downwards, parallel to and straight in front of an individual who is lying in supine, like Russell. He is able to use his system seated at a table, but he prefers to use it lying in bed. This is where he feels most comfortable when focusing on the monitor screen.

Height adjustable and tilt in space wheelchairs are often helpful. During the ACE Centre end-user trials, difficulties arising with seating and positioning have mainly occurred when an end-user has been unable to achieve an open, full pupil of the eye (please see issues relating to visual difficulties below for further information about this). In these cases, it has often been necessary to spend time on finding a good position, through adjusting the equipment as appropriate, at least in the initial stages.

This was the case for one young end-user attending primary school who had long eyelashes, (see issues relating to long eyelashes and visual difficulties below), combined with cerebral palsy - type dystonic athetosis, which was characterised by a sudden increase in tone (i.e. spasm). The type of spasms experienced included (1) an extensor spasm, i.e. the whole body extended, precipitated as a result of trying to lift his head

and the anticipation of movement, as well as (2) a flexor spasm, whereby his hips pulled into flexion and adduction. He almost had to learn to let go of his spasm in order to achieve more control. At an emotional level it helped to prevent frustration by being relaxed and learning to reduce the anticipation of movement. Several hours were spent in a motivating and non pressurised way, manoeuvring the equipment so that the device was able to register his eyes, and the calibration could be improved.

In addition, it was important for the Teacher and Teaching Assistant to be given plenty of opportunities to practice repositioning the equipment. This meant they would be able to easily recognise when the eyes were not being tracked and to confidently reposition the device appropriately, safely and independently as required when they had the device on loan. Different systems have their own style of visual feedback to show how well the system is able to track both eyes. It indicates whether the system needs to be moved to the right, left, forwards or backwards. Some systems enable this tool to appear automatically when the software starts running. Only resizing and repositioning of the track status box is then required.

Despite using standard positioning equipment like a height adjustable table, a mounting arm or a rolling mount, there have been times at assessments when it has not been possible to position the device high enough for the end-user to be able to open their eyes fully and for the device to be able to pick up the entire pupil of the eye. On these occasions someone has been required to hold the device in order to find the optimum place (please see figure 4.2 below). Obviously, it may be possible to employ a wall mounted mounting arm when a more permanent solution is required. However, for assessment purposes, especially those not being held in an assessment centre but in another environment, (like the client's home), it is helpful to be able to have a versatile range of mounting equipment and options readily available.

## Issues relating to visual difficulties

### *Droopy eyelids*

For most gaze control systems, the full, round pupil needs to be visible to the camera. Even if for most people these are visible to the camera, the gaze control system may still have difficulties in responding to eye movement. If the end-user finds it difficult to open their eyes sufficiently for the full pupil to be visible, as described in the section above and also by DART, careful positioning of the gaze control system can sometimes overcome this problem. Depending on the individual, it is worth trying to raise both the height of the system in relation to the end-user's position and lowering it to see which position results in the best signal.

LC technologies have addressed this issue by providing a 'droopy eyelid' setting in their software for those who need it. It is a feature that, wherever possible, should be offered by all gaze control developers. However, with some end-users, *none* of the available gaze control systems could accommodate their eye movements:

### **Case Study - Frank**

Frank, for example, is a man who is aged in his sixties and who has been described as having locked-in syndrome<sup>18</sup>. Like five other people who we have worked with during the ACE Centre end-user trials, he could only move his eyes up and down. However, this simple movement was accurate and consistent. In the

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<sup>18</sup> Locked-in syndrome is described by the Merck Manual as being 'a state of wakefulness and awareness with quadriplegia and paralysis of the lower cranial nerves, resulting in an inability to show facial expression, move, speak, or communicate, except by coded eye movements'.



case of some other end-users, we were able to accommodate their difficulties by designing an on-screen keyboard with selections placed in a vertical position.



Figure 4.2: No matter where the gaze control system was positioned, it could not pick up Frank's eye movement consistently when he looked upward, his only controlled eye movement. Frank is someone for whom the development of an appropriate 'gesture recognition' system might be of benefit.

However, in the case of Frank, whenever he looked up, he was unable to open his eyelid at the same time. As a result, his pupil disappeared behind his eyelid and the gaze control system was no longer able to track his eye movement. Like many of those people with locked-in syndrome that we have worked with, Frank's upward eye movement was very good and he used it for a confirmation "yes" when communicating. It was very unfortunate that this particular, decisive movement could not be capitalised upon by gaze control technology (Figure 4.2). This inability of gaze control technology led us to believe that there could be both a need and an advantage in developing a 'gesture recognition' system specifically for eye movement. Even if, as in Frank's case, his upward eye movements were simply interpreted as a single switch press, he is so quick and reliable with this movement that, with appropriate software, this method could soon become an efficient means of independent computer control.

### *Long eyelashes*

Several end-users involved found it difficult or impossible to use gaze control due to having long eyelashes. The result is similar to the problem described above in that the performance of the gaze control system is

adversely affected due to the system not being able to locate a full, round pupil. Obviously, it is *not* recommended that the eyelashes be trimmed! However, in addition to the ‘droopy eyelid’ problem this is a problem that remains one for many gaze control developers to address.

### ***Involuntary eye movement***

Several of the end-users involved in the ACE Centre trials that had experienced a stroke had involuntary eye movement (illustrated in Figure 4.3, on the left). In many cases this resulted in blurred vision. It was also noted that amongst those who had involuntary eye movement, the eyes did not always move together. For example, the involuntary movement of one eye might be greater than the other. Also, in some cases, each eye might move in different directions.

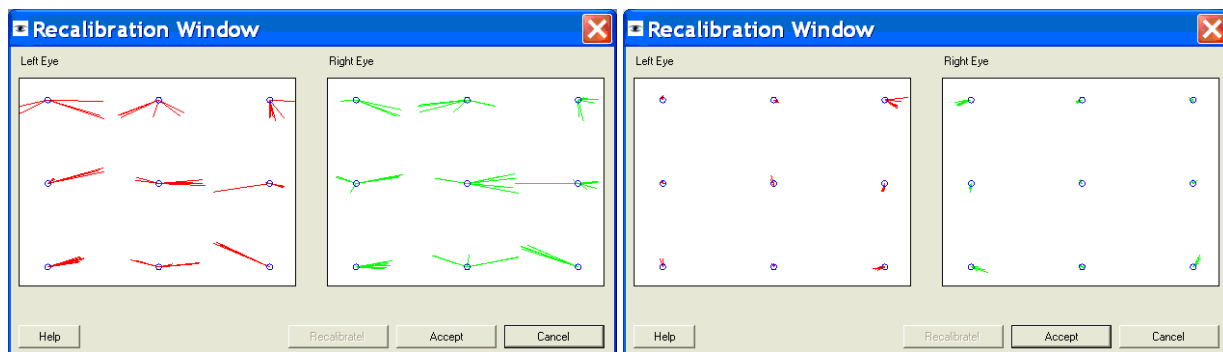


Figure 4.3: The calibration results on the left are of someone who has involuntary eye movement. On the right: the calibration of someone without involuntary eye moment. The straight lines in the figure on the left illustrate the direction of involuntary movement of each eye when trying to focus on a particular calibration target for a short period of time.

As a result, with those gaze control systems that allowed it, it was often helpful to try the effectiveness of the three available settings to see which one was the most successful. These settings were:

- both eyes
- left eye only
- right eye only

Of course, these settings did not affect the end-user at all in the way they used their eyes. However, in several cases, it was surprising what a difference it made to their ability to control the computer. Nonetheless, none of the end-users with involuntary eye movement were able to use direct pointer control and had to use a grid-based system and framework software that offered the option of a “centralised cell-select”<sup>19</sup> feature.

### ***Squint (or Strabismus)***

Those end-users who had a squint<sup>20</sup> did not necessarily experience significant difficulties in achieving a successful calibration. In the majority of cases, even when one or both eyes had a significant convergent or divergent squint, the individual experienced no difficulties with achieving a successful calibration, unless the squint was combined with fluctuating eye dominance (see below).

<sup>19</sup> The term ‘centralised cell-select’ is used here to describe a feature that is especially helpful for people with involuntary movement or visual difficulties which reduces the need for accuracy. For further information, please refer to the section entitled ‘centralised cell-select’ below.

<sup>20</sup> In this context, ‘squint’ means a failure of the eyes to align properly to focus on an object. The affected eye may deviate in any direction, including inward (cross-eye) or outward (walleye).



### ***Fluctuating eye dominance combined with a squint***

In a small number of cases, a problem with calibration resulted when the end-users eye dominance<sup>21</sup> fluctuated between one eye and the other eye and if this were combined with a squint<sup>22</sup>. In one case, Joanne, her eye dominance appeared to change very frequently. The result of this was that it was extremely difficult to achieve a successful calibration. The problem was that, during any given calibration, some of the calibration points would be calibrated when the left eye was dominant and the other calibration points would be calibrated when the right eye was dominant. One result was, of course, a poor, 'hybrid' calibration. However, even if a calibration could have been achieved that corresponded to the dominance of one eye or the other eye, the gaze control system would still have presented problems because it could only have been used at those moments when that particular eye was dominant. For this type of end-user, it was felt that an eye gesture system could be a more effective type of control method. Such a system has not yet been developed. Hence it is discussed below under discussion and recommendations.

### **Difficulties with glasses / contact lenses**

Results with contact lenses varied. Whereas some end-users' could use contact lenses successfully, others often resulted in an inaccurate calibration and a difficulty in the gaze control system being used to pick up a consistent signal, illustrated by a 'flickering' effect in the 'Track Status' window<sup>23</sup>. Please refer to the advice under discussion and recommendations at the end of this chapter.

### ***Infrared reflection***

More and more commercially available gaze control systems are following the trend to position two infrared light sources in line with the camera. In some cases, this resulted in problems caused by reflection. This only occurred when the angle of the glasses was completely parallel with the infrared light sources on the gaze control device and the problem could be overcome by tilting the glasses slightly. However, strategies like this are not only inconvenient, but they can also be very difficult for many of those people who need to use gaze control systems. This problem was not found to occur with gaze control systems that had head light sources both at the bottom and at the top of the screen, such as the MyTobii P10 and D10.

### ***Size and shape of glasses***

The size and/or shape of glasses frequently had an influence on the success of the calibration process. The most frequent problems occurred if the glasses were too small or too narrow. The result was that the gaze control system found particular difficulties in tracking the eye movement towards the edges of the screen.

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<sup>21</sup> Eye dominance is the tendency to prefer visual input from one eye to the other

<sup>22</sup> Sometimes called strabismus - a condition in which the eyes are not aligned with each other and point in different directions.

<sup>23</sup> 'Track Status' window is the term used in this document that describes the window that gives visual feedback relating to the position of the eyes in relation to the camera and how successful a 'signal' is being picked up by the gaze control system.



Figure 4.4: Wide glasses used by Angela in preference to narrow ones which can have an adverse effect on gaze control

### **Testing the efficacy of the calibration process successfully**

As already highlighted in the section completed by DART, the ACE Centre also found that great care is needed in relation to the choice of gaze control activities to be used during the remainder of the initial calibration and assessment process. Appropriate gaze control activities to maintain the end-user's motivation and interest were, therefore, essential in order to (a) judge the success of the calibration and (b) provide an opportunity to improve the calibration. The careful design of such activities was therefore found to be an integral part of the calibration process. This gentle introduction to gaze control was found to be important for any person using gaze control for the first time, whether they had a disability or not. Up until their first gaze controlled trial, the end-users would have spent their whole lives using their eye movement to *absorb* information, whereas during the trial, for the first time ever, they were *controlling* information. The chance to spend some time simply becoming used to the idea of simply moving a cursor, before combining movement with selection, is therefore highly recommended.

### ***Direct pointer control without selecting***

For those end-users who showed sufficient potential to be able to try to use direct pointer control, it was found that an opportunity to become accustomed to pointer movement only - *without* emulating mouse button control - was a helpful and important stage to go through. One way of doing this was to present a photograph or a cartoon picture for the end-user to explore. It was found to be helpful if the picture contained a number of easily recognizable focal points. For example, a cartoon character or a celebrity of some kind would provide an opportunity for the end-user to look at features such as a nose, eyes, fingers, ears, shoes, etc. This was, of course, found to be more appropriate than a screen containing no obvious focal points such as a bland landscape or a picture of clouds in the sky. *Without* such a gentle introduction to gaze control by simply exploring a screen rather than trying to control it, end-users were more likely to become disengaged. The result of this could be an increase in involuntary movement or a decrease in motivation.

### ***Centralised cell-select without selecting***

For younger end-users and those with complex physical difficulties who required a 'centralised cell-select' feature it was found that activities that guaranteed success were most effective in order to 'dwell only', when no selection is made but which can give invaluable feedback to both the end-user themselves and those carrying out the assessment. The MyTobii has, in fact, incorporated this technique into its 'grid size test'.

For literate end-users, the ACE Centre has a number of letter-based grids to help discover those areas of the screen that the end-user can access reliably (Figure 4.5).

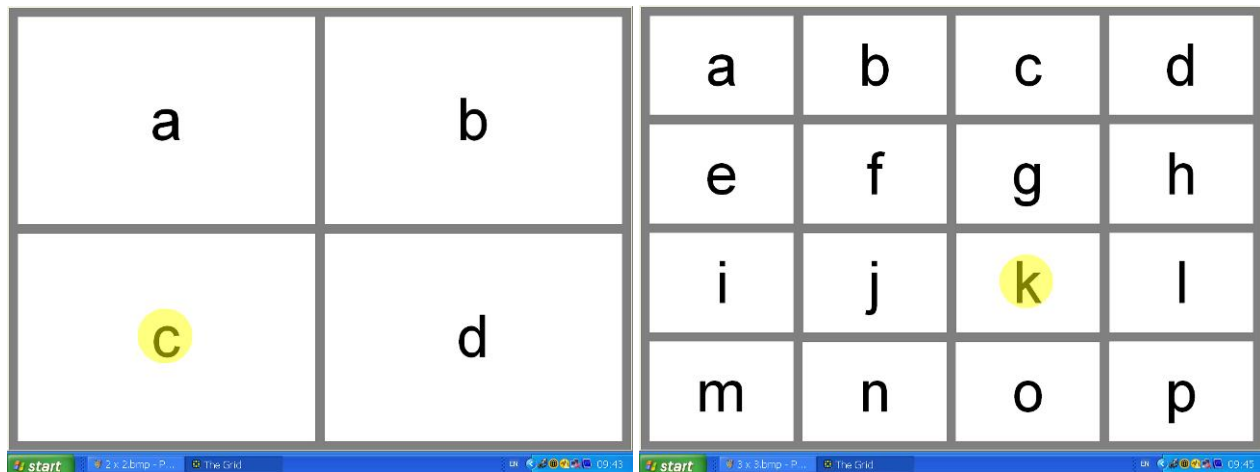


Figure 4.5: Two examples of ACE Centre grids to help find out which areas of the screen can be accessed through gaze control.

### Choice of visual/auditory stimuli during calibration

As described by DART above, it is important that a range of visual and auditory stimuli are available during calibration in order to attract the attention of people with a range of either learning or visual difficulties. At the time when the COGAIN project started, this option was not available. However, developers are beginning to include a range of visual and auditory stimuli that can be personalised to meet the needs and interests of a specific end-user. A choice of foreground and background colours and the option to change the size of the target has been found to be effective for some end-users involved in the trials with a visual impairment. For young people and people with learning difficulties, the option of a picture or a video of something that interests them, along with the option of a stimulating sound file has been found to be helpful in attracting and maintaining attention. For example, a photograph of a child's mother, combined with their voice may well be more stimulating than a simple abstract target and more likely to attract their attention. However, it was also noted that, in most cases, the option to play video to attract attention during calibration had not been helpful, especially if the 'video calibration point' has changed size as well as moved. The result was that it was found to be confusing to end-users who struggled to make sense of the constantly expanding, contracting and 'wandering' calibration point.

### Choice of speeds with automatic calibration

If the calibration process has the option to take place at a preset speed, automatically, then there should be a variety of automatic speeds offered. It has been found that many of the end-users we have worked with who have involuntary movement need to have a slower speed of automatic calibration so that they have more time to track and focus on the moving target. In addition, if the target 'glided' across the screen from one calibration point to another it was found to be more effective at retaining the visual attention of many end-users who had visual difficulties or involuntary movement compared with gaze control systems where the calibration point disappeared completely and 'popped up' at another point on the screen. This was because many of the end-users with visual difficulties or involuntary movement experienced visual scanning difficulties and had difficulty in locating a target on the screen unless it was preceded by some kind of movement to assist their visual tracking.

## The ‘wait until the end-user looks’ calibration option

It has been encouraging to see an increase in the number of gaze control systems which offer an option for the calibration points to wait until the end-user is looking before moving on to the next calibration point. This is particularly helpful for end-users with involuntary movement or attention difficulties.

For example, if the end-user looks away from the screen due to a spasm, or if they are distracted momentarily, then the calibration point will remain fixed and the system will wait until they look at the screen once again. Sarah, for example, who had a stroke sometimes goes into spasm and therefore cannot help looking away from the screen during the calibration process. Currently, with a My Tobii P10, the person carrying out the calibration has to wait until Sarah is looking at the screen again. If her P10 had the feature of ‘waiting until the end-user looks’ option, then the success of the calibration would (a) not be dependent on a combination of luck and the timing skills of the person carrying out the calibration and (b) it would enable Sarah to be able to recalibrate the gaze control system independently.



Figure 4.6: The LC technologies calibration process incorporates both movement to help end-users to track the calibration points and also the ‘wait until the end-user looks’ feature described above

## Techniques to overcome a failed calibration...

Despite all the improvements in the calibration process provided by several gaze control systems and despite taking account of all the advice and recommendations described above, some end-users have still failed to achieve any calibration at all. In this case, there were certain strategies that were adopted which, whilst not providing a perfect calibration by any means, nonetheless allowed several such end-users to have a certain level of access to gaze control technology.

### *‘Borrowing’ a calibration for end-users who fail to calibrate successfully*

For those people who couldn't achieve any calibration at all, a technique was developed that involved using the gaze control system's ‘default’ calibration as a starting point. For those gaze control systems that permitted it, an attempt was then made to improve one calibration point at a time. By carrying out this process, the more calibration points that were achieved by the individual end-user, the closer the calibration became to being their own. For those end-users who had the patience, an even better result could be achieved by using this technique not only with the default calibration, but with a selection of different end-user's stored calibrations as a starting point. Once this had been done, each of these ‘personalised’ calibrations was tested to find the one which was the most successful.

### ***Choosing the size and position of a calibration area***

In some cases, certain end-users could only interpret visual information that was presented on a certain area of the screen due to having cognitive or visual difficulties. Calibration, therefore, was difficult for them, as the default calibration for most gaze control systems requires the end-user to be able to focus on targets positioned on each side of the screen, as well as the top and bottom. The LC Technologies software allows the assessor to position the calibration points wherever they wish. The MyTobii software, too, enables the assessor to decide on the area to be calibrated in relation to the end-user's visual abilities.

For example, if the end-user is only able to interpret information from one side of the screen, due to hemianopia<sup>24</sup>, or if they are only able to move their eyes up and down due to having locked-in syndrome, the option to reduce and reposition the area for calibration, enabled them to calibrate within the restricted screen area that they would be able to use, once calibration is completed. This enabled them not only to complete a calibration involving as many calibration points as the system allowed but it also enabled them to achieve an accurate calibration for that area of the screen they would be using, once calibration had been completed

### **4.3.2 Issues related to implementation**

Once as successful a calibration as possible had been achieved during the assessment process, the next key issue was to implement the successful use of the gaze control system. In the case of the ACE Centre, it was those end-users who had the most complex disabilities that required the most careful and considered support if they were to use this technology successfully.

#### **Software techniques to improve accuracy**

##### ***Centralised cell-select***

It was interesting to note that many of the end-users who experienced severe involuntary movement were able to achieve a very good or even an excellent calibration, especially if they were able to repeat individual calibration points until each calibration point was successful. As far as the calibration was concerned, there was little difference between them and end-users that did *not* experience involuntary movement, for example, those with ALS/MND. As a result, if they were simply required to look at a target *without* selecting it, their level of accuracy and control were as high as for anyone else.

However, in all cases trialled, there *was* a difference when they were required to make a specific *selection* using pointer control. Apparently, the extra demands (whether cognitive, visual or physical) involved in this process resulted in a higher degree of involuntary movement which, in turn, resulted in a failure to make the required selection. As a result, over the short term at least, it was found helpful to use the 'centralised cell-select' feature available in some, but by no means all, gaze control systems. It must be noted that, whilst none of those end-users involved in the trials that used the 'centralised cell-select' feature progressed onto direct pointer control, this may well be possible over a period of time with practice.

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<sup>24</sup> The Merck Manual describes hemianopia as a "defective vision or blindness in half the visual field of one or both eyes" [www.merck.com](http://www.merck.com)

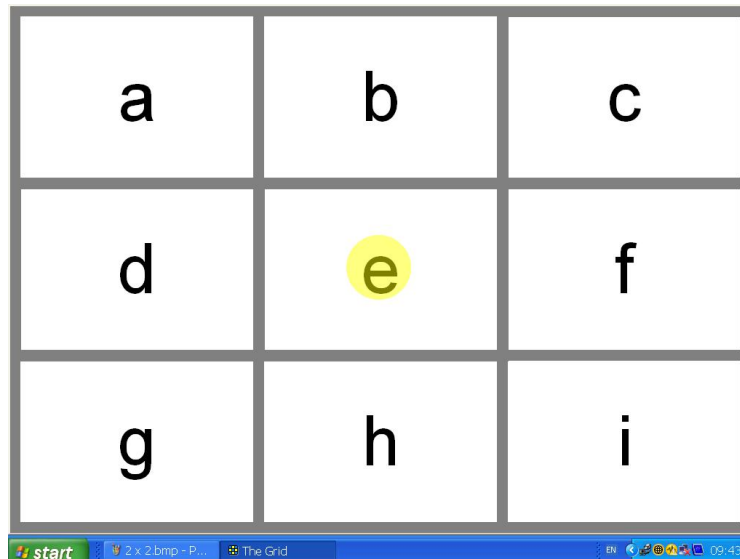


Figure 4.7: 'Centralised Cell-Select' in action on the cell containing the letter 'e' - this feature is becoming increasingly common in more and more gaze control systems and software.

The 'centralised cell-select' feature (see Figure 4.7) is becoming available for an increasing number of gaze control systems and software. For example, The Grid 2 has settings that will also enable the 'centralised cell-select' feature to be used with an increasing number of gaze control systems, e.g. The LC 'Edge', The Quick Glance 3 / TM3 and the ALEA IG-30.

### ***'Tagged' Dwell Selection***

However, even with a 'centralised cell-select', the end-user is unable to relax when scanning the screen before making a potential selection because, from the moment they begin to look at it, the 'countdown' to their selection begins. As a result, the only choice for many end-users who wish to make selections without being rushed is to use either a blink or switch to make a selection.



Figure 4.8: The iAble software is designed so as to enable the end-user to combine dwell-select with the ability to take as much time as they wish to visually scan on-screen icons.



One interesting software feature that has emerged in order to overcome this problem is now available from iAble (see Figure 4.8). It is combined with a MyTobii and has also been described in the section of this report completed by the Politio/Torino ALS end-user trials above. On the screenshot below, for example, each of the three potential selections on the right-hand side of the screen are labelled on a 'tag' positioned to the right-hand side of the active 'centralised cell-select' area. As a result, the end-user is able to spend as much time as they like visually scanning each of the tags before making their selection by looking at the active 'centralised cell-select' area, positioned to the left of the tag. This new gaze control feature has only recently emerged, so it is difficult to judge its efficacy at this early stage. However, Marcello, an end-user with ALS/MND who has been using the iABLE software for several months, reports that he uses the software almost continuously for sixteen hours a day without finding it visually tiring.

### ***Magnification***

The magnification option, when used in combination with direct pointer control, is one that has been found to be of potential benefit to all end-users, regardless of whether they have involuntary movement or not. In the previous end-user trials report it was already known that those end-users who were not accurate relied on this option to provide the accuracy they needed. However, since these initial trials it has been found that, for many very accurate end-users, the option to magnify a target before selecting it is their preferred option. Because it reduces the need for precision it is chosen by many end-users because they find the selection process less demanding.

Pietro, who was involved in the Torino/ALS Centre end-user trials referred to above uses an Eyetech TM3 and is extremely accurate. His ability to calibrate the system is so good that he could, if he wished, easily manage without magnification. However, for the first majority of tasks he chooses to use a special option available on the TM3 that enables him to use automatic magnification (Figure 4.9).

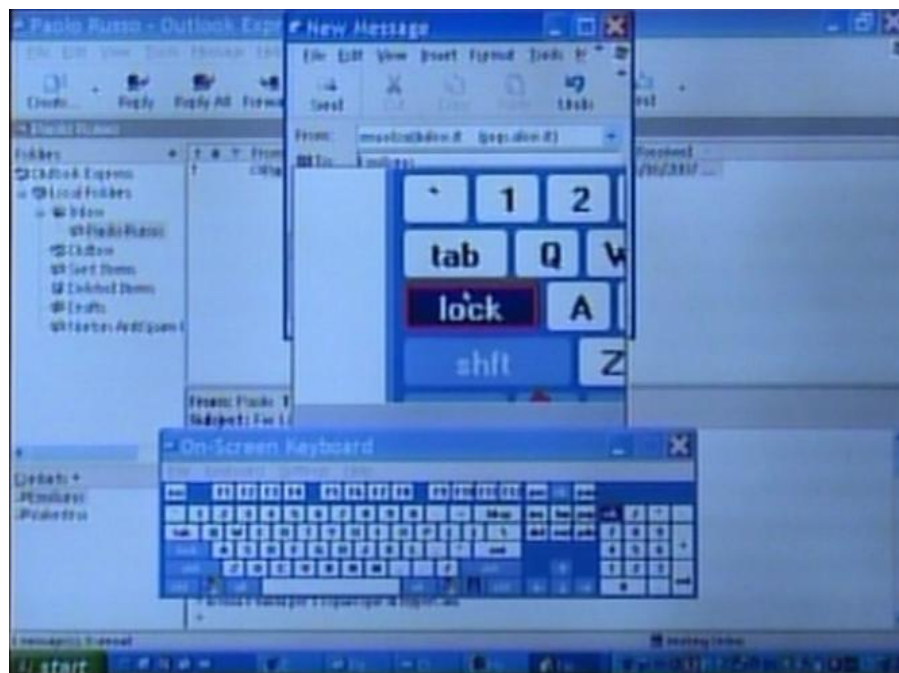


Figure 4.9: By combining the magnification option with direct pointer control, Pietro is able to use even the small 'windows' keyboard to write successfully.

With this option, *every* target that he looks at is automatically magnified enabling him to relax and not to be concerned about precision. Even though this process requires two actions for each selection (i.e. magnification then selection) it is not only easier for him but it is also more or less equally efficient in terms of the time that it takes him.

Another end-user, who has involuntary head movement however, finds that through the use of magnification that she is able to independently access parts of the computer that are important to her – files and folders for example. But, despite having the interface enlarged, she feels that she is able to access these areas slower than she would like to be. Therefore, it would potentially be of benefit to her to have an automatic magnification feature, but this is not currently available on her gaze control system.

## Grid-based software or direct pointer control?

The calibration process provides an indication of whether or not the end-user will be able to use direct pointer control or will need to use grid-based software. For those end-users who had high levels of motivation, accurate pointer control and were literate, the implementation process could be very straightforward. As long as an on-screen keyboard was available, combined with a utility to emulate the mouse buttons and magnification, many end-users were able to begin independent use of gaze control almost immediately. The Erica, for example, is one of the gaze control systems where all of these features are available (see Figure 4.10)

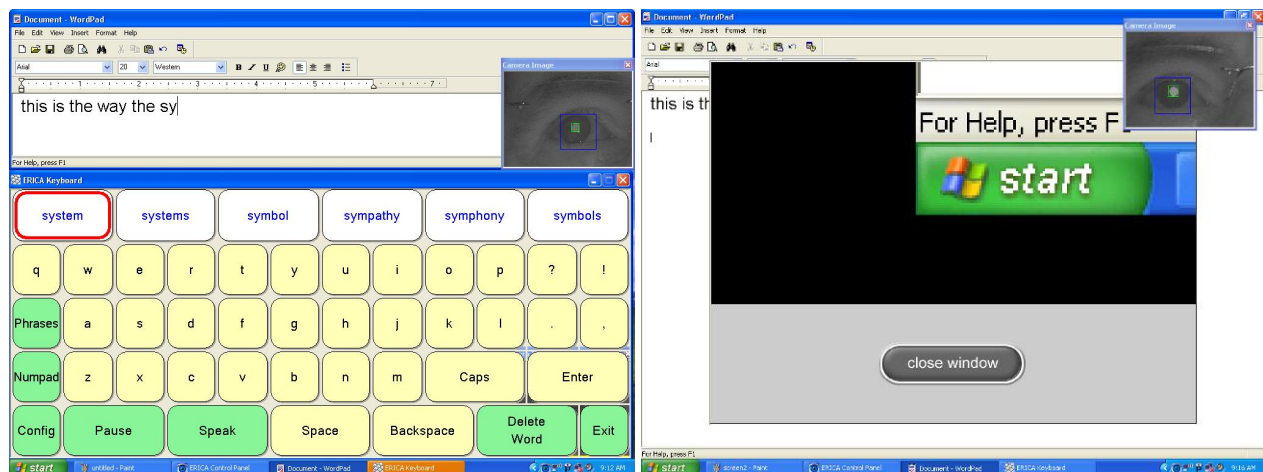


Figure 4.10: The Erica has a built-in on-screen keyboard (left) which, combined with its magnification utility (right) is able to meet the needs of many literate end-users in terms of direct pointer control of Windows applications.

For those end-users who required the ‘centralised cell-select’ feature, the implementation process could involve considerably more work. This process has been described in deliverable 3.3 and is also explained in some detail in ‘The KEE Approach’ (Donegan and Oosthuizen. 2006). The KEE Approach (Knowledge-based, End-user focused and Evolutionary) is based on three elements that have been found to be essential if the implementation process is to be a success.

1. **Knowledge-based** - The initial calibration and assessment should be based on as much background information and knowledge of the end-users’ visual and physical abilities as possible.



2. **End-user focused** - The assessment and implementation should be based on the needs and interests of the end-user. For example, if environmental control is a priority then this should be included in the framework software that is developed, adapted and modified for individual use.
3. **Evolutionary** - the grid that is developed for the individual end-user should evolve in relation to the end-user's needs and abilities.

One of our end-users, Peter, provides an excellent example of this process in action.

### Peter

We first met Peter when he was in intensive care, following a traumatic illness. He was paralysed and only able to breathe with the help of a ventilator. It was clear from the information that we had gathered in advance that he was still fully cognitively able. However, our investigations also suggested that there were some visual difficulties which might impact on his ability to use the gaze control system. We were told that the most important thing for Peter was to be able to communicate and, as he was still literate, we made sure that a range of differently sized grid-based keyboards were available to try out on the gaze control system.

When we arrived to carry out the trial at the hospital, we were prepared with the necessary background information and the calibration and assessment process went according to plan. We did, indeed, find that, due to his nystagmus, that the calibration process was not easy and several points had to be recalibrated before he achieved a calibration that could be used functionally. Once as successful a calibration as possible had been achieved, we found that Peter not only needed the 'centralised cell-select' feature but, at that point in time, he was only accurate enough to be able to access a 2 x 4 grid. As a result, he was trialled with a 'two-hit' letter grid to use for his written communication (in Figure 4.11).

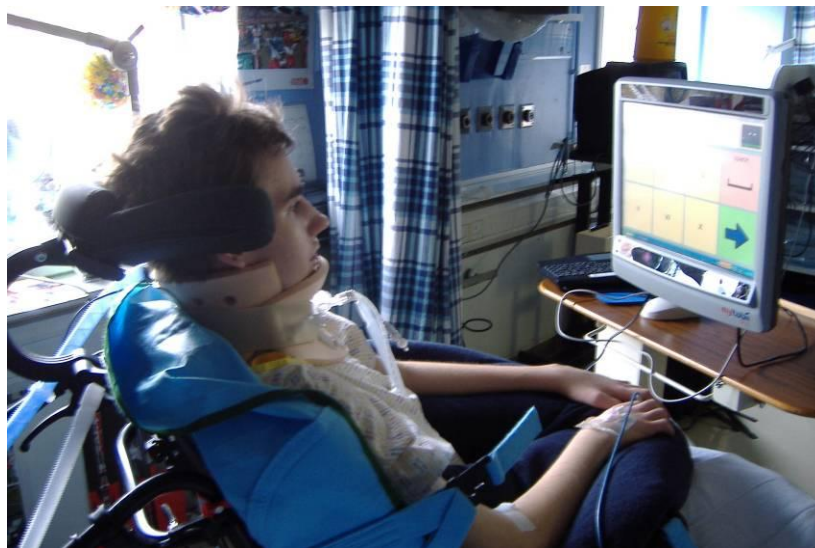


Figure 4.11: Peter

Following the loan of the gaze control system, Peter's condition improved in several areas. For example, the nystagmus reduced and, as his speech returned to enable him to communicate effectively without the gaze control system, both his accuracy with gaze control and his interests changed. As a result of the improvement in gaze control, support was required to reduce the size of the cells on his gaze control grid. In addition, using the computer for recreation became increasingly important and, with an improvement in his accuracy, he showed not only the interest but also, indeed, the potential to be able to access gaze controlled games that

required direct pointer control. Those people supporting him would be able to find that, with very few modifications, a range of games could be found which would meet his evolving requirements, such as ‘racer’<sup>25</sup>, a mainstream Formula 1 game.

### Mounting and mobility issues

Equipment for mounting gaze control systems ranges widely. There are height adjustable tables, wall and desk mounting arms, desktop stands, rolling and wheelchair mounts, etc. (some examples are shown in Figure 4.12).



Figure 4.12: Mounting options

The ease and safety of mounting the equipment depends upon the weight, screen size, style, robustness and portability of the device. The mounting equipment needs to be clearly visible to carers /personal assistants, especially when it is relatively large and presents as a potential trip hazard. For example, this may involve placing fluorescent tape onto the base of the rolling mount. It may involve removing a rug from underneath the base or nearby, if appropriate etc. Obviously all mounting equipment needs to be stable and its base should be in total contact with the supporting surface (table, floor etc).

How and where the device will be used is important, it could be in the home, classroom, office or hospital setting for example. The end-user and their family should be as comfortable as possible with the appearance and location of the mounting equipment when it is being used in their own home. It shouldn't damage any furniture, nor restrict the positioning of the end-user. For example, someone who wishes to rest their arms on a dining room table/ desk for extra comfort or support would need the space in which to be able to do so. In addition, when mounting equipment is to be fixed or placed on a table, it is important not to mark the surface. It may be appropriate to place a small piece of material (like non slip dycem<sup>26</sup> or a table cloth), in between the equipment and the piece of furniture. Some end-users may not want to use their equipment in certain rooms of their house.

End-users who are in a lying position may like their mounting system to be light and easy to swing out of the way. They may find it more comfortable when their device is out of view, especially when the device is not being used. Creating such space may enable the end-user to be more easily positioned themselves (e.g. during

<sup>25</sup> This game is available for download at [www.racer.nl/](http://www.racer.nl/)

<sup>26</sup> [www.dycem-ns.com](http://www.dycem-ns.com)

transfers with/ without a hoist). An end-user is generally reliant upon an able bodied person to move their equipment for them, but some would like to be able to do so independently.

One end-user designed a highly mobile wall mount for himself which also attached to an Ergotron<sup>27</sup> mounting arm. He commissioned a local tradesman to make it for a relatively low cost (see Figure 4.13).



Figure 4.13: shows an easily manoeuvred, bespoke mounting arm which provided the end-user with optimal positioning which did not obstruct his view of his room, or television.

Many people with disabilities change environments during the day. An end-user in Sweden, DART state above, may be given two mounting systems if they need to move their system easily from one environment into another.

There may be some specific occasions when end-users change from their preferred position, for example, when they go on holiday. An end-user may comfortably use their system all year round in lying except for an annual break when they use a wheelchair. There are those who normally prefer to use their system in sitting, but who need a period of temporary bed rest. It is for occasions like these when being able to access an inexpensive (ideally free) bank of mounting equipment would be beneficial. Without such a resource some end-users are unable to use their device. If they had the option, they may prefer to be able to use their device in all situations.

Many end-users also have powered mobility. Points to consider for wheelchair end-users, like any wheelchair mounted communication device, include the make, model, material and size of the wheelchair. The width, when the gaze control system is mounted needs to be smaller than a typical doorway. This is easier with the increasing availability of smaller and lighter devices. End-users require a clear and unobstructed view of the way ahead for safety reasons. Also, ruggedised casing helps to protect the device from wear and tear. Tightening up the mounting screws may be required periodically. Some end-users with powered mobility

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<sup>27</sup> [www.ergotron.com](http://www.ergotron.com)

may like to be able to use their system out of doors, in which case they would (currently) need a multi-modal approach, described in more detail below.

For individual assessors who are visiting the end-user away from an assessment centre, mounting equipment needs to be able to fit into a car boot or rest on a car seat easily. If the assessor/ trainer is sent a picture of the room in which the device is likely to be mounted, including furniture, it will help them to anticipate and reduce any potential problems that may arise. For example, it is often possible to mount a device on a table using a mounting arm. However, it is worth noting that the depth of tables often varies and some do not accommodate the base of the mounting arm. When the budget for mounting equipment is limited, or the demand for assessment mounting equipment is high, the rolling mount is often a versatile option - health and safety principles apply to this piece of equipment like any other. It enables the end-user to be able to control the device in either a seated or a lying position. There are a range of 'clamps' for this type of mount which also enable the device to be pivoted forwards, backwards or sideways.

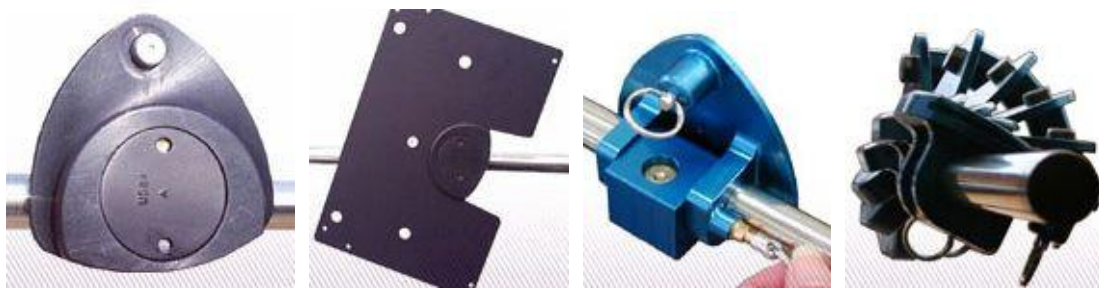


Figure 4.14: Special parts for safe mounting

### The need for Independent recalibration

Many end-users who used direct pointer control were found to require built-in interface software that enabled them to recalibrate independently. There were a variety of reasons why recalibration might be required. These included:

- A change in the head position of the end-user in relation to the position of the gaze control system, due to a shift in seating position as a result of involuntary side to side or forwards and backwards movements.
- A change in head position in relation to the gaze control system due to the end-user sliding down in a wheelchair.
- A change in the position of the gaze control system itself due, for example, to a desire of those supporting the end-user to achieve a 'stronger' signal in the 'Track Status' window.

As described above, some end-users, for example those with ALS/MND used their gaze control systems for between fourteen and sixteen hours a day, every day, almost continuously. They might need to recalibrate at any time during the day and it would, of course, not only be unfeasible and unreasonable to expect someone supporting them to be on hand to recalibrate the system for them, but it would also impact on the end-user's independence. One end-user stated "it would be great to be able to adjust my computer independently".

### The need for multimodal input

Despite improvements in gaze control technology overall, there can still be difficulties in using certain gaze control systems out of doors. Therefore, for those people who need to use their gaze controlled system in *any*



situation, they will need to use a 'multimodal' access method. In this case, 'multimodal' simply means one or more alternative computer control methods in addition to gaze control, such as a switch, glide pad, etc. As a result, whichever gaze controlled software the end-user utilises for indoor use there should be a straightforward method for them to be able to independently switch to an alternative method. It should also include being able to turn the device on and off independently.

### Case study

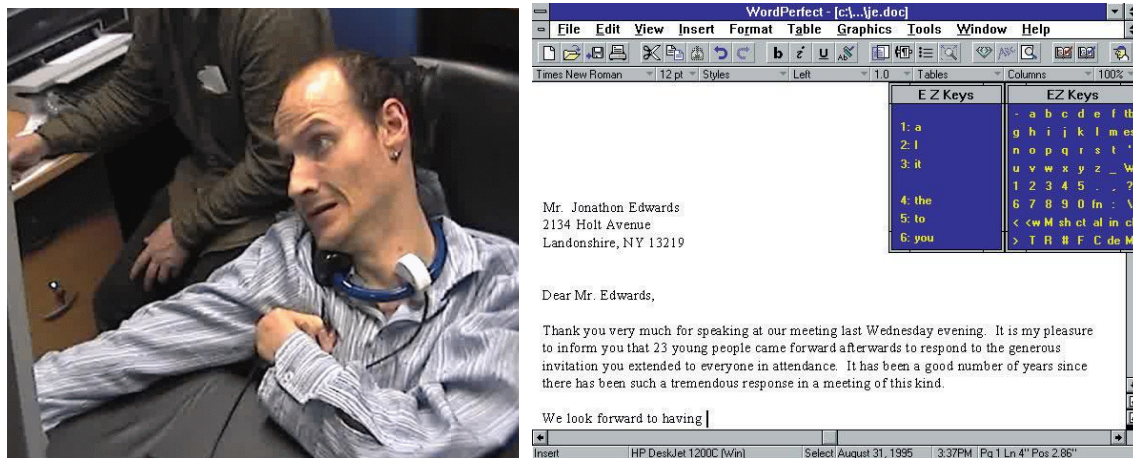


Figure 4.15: Anthony uses necklace switches in combination with 'WIVIK' right.

Anthony is non-speaking and has athetoid cerebral palsy. At present, he uses a chin activated switch to control his laptop computer, combined with Wivik, a switch control utility with which he can not only communicate socially but also through which he can access and control all of the software he needs to use on his computer (Figure 4.15). Because he finds using the chin switch is tiring and painful when used over long periods he wishes to purchase a gaze control system. Once he gets his gaze control system, it is highly likely that it will be mounted onto Anthony's wheelchair.

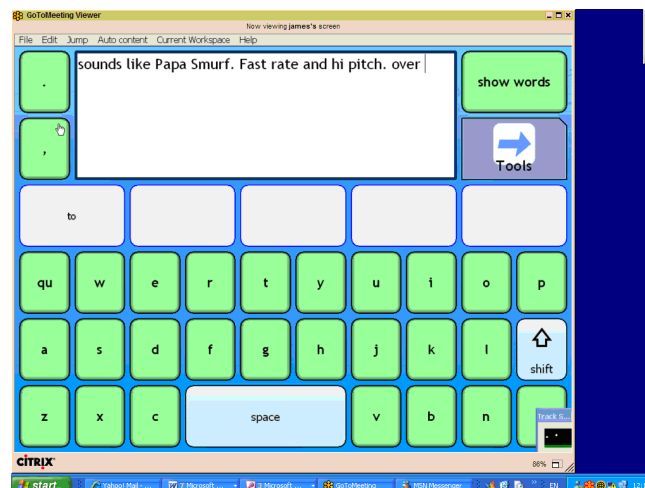


Figure 4.16: Anthony's gaze controlled interface for writing, using 'The Grid 2' application. When he has an eye-controlled computer mounted on his wheelchair, he will need to have a 'seamless' and independent way of switching from one access method and application (gaze control + The Grid 2) to another (switch control + WIVIK).

Anthony needed to use his neck activated switch (Figure 4.15) on occasions when gaze control (Figure 4.16) would not work (for example, during outdoor use). From trials already conducted, it seemed likely that he would need to use framework software such as The Grid 2, combined with a 'centralised cell-select' feature. For those times when gaze control was not possible, due to Anthony being out of doors or suffering from an eye infection, etc, he would need to integrate an easy way of exiting The Grid 2 in order to enable him to quickly and easily switch to Wivik, which he controlled with his chin activated switch. In addition, of course, he will also need an easy way to independently exit from Wivik and return to gaze control.

### Issues relating to the choice of selection method – blink, dwell or switch?

For most gaze control systems, the end-user has a choice of blink, dwell-select or pressing a switch in order to select a particular item on the screen.

**Blink** - this method of selection involves a process of deliberately keeping the eye closed for longer than for an ordinary blink whilst looking at a target in order to make a selection. The length of the blink time can be adjusted to suit individual abilities.

**Dwell** – dwell selection requires the end-user to maintain their gaze on a particular item for a predetermined length of time until it has been selected. The length of dwell time can again be adjusted in order to suit individual abilities.

**Switch** – switch selection requires the end-user to press a switch in order to make a selection whilst they are looking at a particular target. The switch can be activated by any part of the body.

The vast majority of end-users who have severe involuntary eye or head movement had no other choice but to use dwell-select. It was either difficult or impossible for them to press the switch at the same time as fixing their gaze on an item on the screen. Similarly, it was very difficult for them to blink in a controlled way for a specific length of time. For them, the benefit of dwell-selection was that they simply had to look at a target and wait.

Many end-users who did *not* have difficulties with involuntary movement, such as those with a spinal cord injury and those with ALS/MND, still chose dwell select, even though most of them had a choice between all three selection methods. The overriding reason for this, they said, was because it was less tiring for them. This was particularly true for those who used their system primarily for communication and writing. The decision is perfectly understandable, bearing in mind that some end-users involved in the trials were selecting letters from an on-screen grid at a rate of more than sixty per minute. For these end-users, pressing a switch or blinking this frequently was considered to be too tiring.

However, there were a small number of notable exceptions to this rule. One of them is Pietro, who participated in the Torino/ ALS Centre end-user trials referred to above. He uses gaze control for fourteen hours a day. He uses it for a range of activities, including social networking (Facebook), writing music (Cubase) and web design. He chooses to use blinking as his favoured method of target selection. When asked, he said that there were two reasons for this:

1. Most of his computer use is graphics based. It involves visually scanning graphic items on the screen and manipulating them. For example, he might be editing pictures, moving slider controls, etc. In comparison with his graphics work, only a relatively small amount of his computer use involves text. Using blinking, rather than dwell select, allows him to visually scan the screen and to think before



- making a deliberate selection, rather than the gaze control system making automatic selections for him – a problem sometimes referred to the ‘Midas Touch’ (Hansen et al, 2004)
2. Pietro’s second reason is that he feels that, with blink-selection, his eyes are automatically kept moist. On occasions when he has tried dwell-select his eyes have become dry because of the necessity to *stop* them blinking in order to make a selection.

Pietro’s experience emphasises the need to keep the eyes moist and using ‘blink-select’ is a natural way to do this. For those who use dwell-select, consideration might be given to using appropriate eye-drops. However, medical advice should be sought before taking this decision. Alternatively, the end-user may choose to ‘pause’ gaze control and use this time to look away from the screen, close and rest their eyes.

## Physical impact of using gaze control for end-users

Please refer to sections 2.2.1 entitled ‘end-user profiles’, 2.2.2 called ‘end-user evaluation interviews and 2.3.5. headed ‘choice of access method’ written by DART above.

The end-users described below have used gaze control for varying lengths of time, all during, and none before the start of COGAIN project.

A range of end-users were asked what it physically felt like to use a gaze control system. End-users varied in how tiring they found it to be for their eyes. One experienced end-user with cerebral palsy who typically uses gaze control for eight hours a day, six days a week, said it is exhausting for her eyes after eight hours of continuous use. It isn’t possible to comment on her interface, or ways to make it easier, except to say that the feature of magnification is very important to her. Indeed, if the gaze control system had an automatic magnification feature like the one described above, it could potentially be less effortful for her eyes. A different end-user with cerebral palsy felt that switch use was equally tiring as using gaze control for her eyes. When using switches she felt that she had to “concentrate for too long” on finding the letters that she needed. All the while trying to remember what she wanted to write, which she had to hold in her head for longer than the average person. These two end-users had involuntary head movement

In contrast, two end-users with ALS, who do not have involuntary head movement, said that they do not experience eye fatigue. One used his system for fourteen hours every day and the other used it for sixteen hours each day.

An end-user with locked-in syndrome and nystagmus typically uses gaze control for four hours a day each weekday. Loosing focus in his right eye occurs when he becomes tired. He is aware of no other signs of tiredness, but unsurprisingly, gaze control becomes more effortful to use afterwards.

An individual with complex disabilities may benefit from pacing their gaze control activities by taking breaks, considering the task demands, taking the time of the day or other physical changes into account, etc. Individuals experiencing unpredictable peaks and troughs in gaze control activity may benefit from doing little and often, and stopping before the eyes become tired. This may have positive and replenishing effects upon future sessions, as opposed to having one very good long session, but struggling in later sessions due to experiencing the residual effects of fatigue. DART, in section 2.3.3, have found that it can be important to work in short sessions and to notice whether the end-user shows any signs of fatigue, and also the fact that beginners often become tired quite quickly. It is fair to suggest that the individual may be able to build up their eye stamina through practice, if they are able to manage their eye fatigue more effectively.

Many end-users said they had to build up their eye stamina when they first began to use gaze control. One end-user said: “it’s important not to expect too much at first”, but that it was encouraging, nonetheless, to be shown what he might be able to do with a gaze control system in the future, with practice. It can be seen that suppliers do sometimes post suggestions of activities for developing eye stamina onto their end-user community websites. Even so, for this purpose, it would be ideal to have a wider selection of available customisable games that are able to work with a centralised cell-select feature, apart from those that can be created in framework software. End-users need to be able to have a choice of a wide variety of games and leisure activities to match their interests, cognitive abilities and wish for social interaction.

The important features of such games include the ability to adjust the target/window size and position on screen, on screen colours and style of auditory feedback, etc. For example, end-users without horizontal eye movement are usually unable to target corners. The intrinsic physical and mental benefits of being purposefully engaged in meaningful activity are wide and far reaching. For example, one end-user said that by being able to enjoy and concentrate on an activity that he found interesting meant that he felt calmer, more settled and less likely to cough. In turn this reduced the amount of repositioning he needed...“it is the repositioning that takes the time”. This influenced his ability to feel relaxed.

An end-user with a high spinal injury found that sometimes having excess moisture in his eyes made it slightly uncomfortable for him to use gaze control. An individual with locked-in syndrome and nystagmus had a painful scratch on the lens of his eye and needed a short period of rest in order to give his eye an opportunity to heal, after which he could use it again without pain. Another end-user is prone to catching eye lashes in his eyes. Despite the fact that (apart from the first end-user above) other end-users have said that gaze control has not been painful for their eyes, vigilant eye care is important, including having regular eyesight tests for those who regularly look at a computer screen

A complex end-user with locked-in syndrome and nystagmus said using gaze control was not painful for his body, nor did he experience any increase in muscle tension. However, he did, through making small repetitive movements, find it physically tiring to use. It was not relaxing because it was physically demanding, too effortful and he was often unsuccessful. Unfortunately he had experienced intermittent problems with the technology itself. However, he was determined to persevere, even though he said that all types of activities were difficult. It was important for him to be able to give feedback through the COGAIN project, and he preferred to have direct access for writing instead of switch scanning. Improved accuracy, privacy and independence from writing emails were his reason and motivation for using gaze control.

Someone with similar disabilities said they did not find gaze control physically tiring to use. Other end-users said they did not experience physical pain, tiredness or an increase in muscle tension. However, an end-user said she felt increased muscle tension when using switches, while another described her use of switches as being “extremely tiring and slow”. She had activated a switch positioned on a table with her elbow throughout her school and college life. (It is not possible to comment upon the position of these, or how it could have been improved upon). She stated she could only just about keep up with her school work. Consequently, she decided to take on a personal assistant to type up the majority of her work at college. She felt it was impossible to use a switch at University and decided that having someone to type up her work was the only suitable method. Once the other person was familiar with her speech, she felt, it was quite a fast, easy and comfortable method. For most of the time she was able to concentrate well and felt that using this method was spontaneous. However, it lacked privacy which was important for her, hence her interest in gaze control in order to be able to send and read emails.

An end-user who is able to use gaze control for up to five hours a day also decided not to use switches, though he had tried many different types. The positioning, he felt, was too difficult, especially when he coughed. He also felt they were uncomfortable and made him “stand out...and feel different”. He feels “very relaxed” when using gaze control. When he is using the computer he is “able to pretend that he is not disabled. He can tax his brain”. He knows technology is fallible, but feels it is possible to fix problems. However, he becomes frustrated when his communication partner is not up to speed when conversing via his low tech system because he knows that this should be a fast and relatively simple method of communication. Whereas he needs a communication partner to be able to use his low tech system, using his gaze control system to read and write emails gives him a small degree of privacy and independence that would otherwise not be possible, and which he values highly.

## **The impact of the End-user’s environment during the implementation phase**

### ***Skill, training and attitude of carers/ personal assistants to gaze control***

End-users range widely in age from those attending primary school, or younger, to people of retirement age. Individual circumstances, support networks and expectations vary considerably.

An important time for a youngster using Assistive Technology (AT) at school is during the time of transition from one school to another. This phase was very carefully implemented for a complex end-user with involuntary movement.

In her particular case, this young girl moved from a mainstream primary school into a mainstream secondary school. Her new Teaching Assistant was able to invest a whole term at her feeder school so that expertise could be handed over in the most practical and effective way. The Teaching Assistant was able to get to know the end-user, her requirements and the gaze control hardware and software. Being able to practice in an organized, respectful and informal way built comfort, confidence and motivation, as well as developed her skills.

The Advisory Teacher felt end-users of gaze control could be successfully supported at school when Teaching Assistants have confidence in using computers, are given ongoing training, have time away from the pupil to set up grids/ page sets, are able to access good quality and quickly available technical support and when there is clear and direct information from teachers about lesson content, aims and expectations about what the pupil needs to produce in plenty of time. For example, this particular end-user would have benefited from having topic vocabulary lists; and these would need to be created by her Teaching Assistant prior to the lesson. It would also be beneficial, the Advisory Teacher felt, to have contact with other end-users with similar issues for future ideas and problem solving, as well as a back up Teaching Assistant who could be trained up in case of the event of illness.

For adults with complex disabilities living at home, two end users with locked-in syndrome and nystagmus have benefited from working with a motivated personal assistant, who has the ability to understand their computer control needs.

Supporting such personal assistants has involved a large investment of time by the assessor/ trainer. Tasks undertaken have included: modeling what the equipment is able to do; explaining decisions as they occur over a number of sessions as appropriate; support in the use of gaze control and in customising the software; providing opportunities for extended practice (e.g. during a loan); ensuring they are able to access technical help if needed, etc.

Indeed, enabling the personal assistant to be able to successfully carry out the basic details enables them to become more proficient at refining details over time. The personal assistant may or may not be a close family relative. Being able to carry out activities away from a close relative with privacy, space and independence may be valuable for both parties and expand the end-user's opportunities for social contact. The investment of time required to effectively set up a complex end-user to be able to use gaze control may/ may not be easier to do with someone outside the family. In light of the time involved, a family member may feel more comfortable using their low tech system because it is faster and "normal conversational speed is important, we can get to the bottom of things, have a proper conversation and discussion".

For a bright and technically literate end-user, the effect of not having designated support to assist with technology is that it is a priority for him to have an easy and as independent a set up time as possible. Even though he experiences painful tremors using a head mouse he does not wish to switch to gaze control despite its relative comfort. He feels his carers, whose time is allocated to other tasks, need only assist with putting a silver dot on his forehead. In his view and in light of what else they need to do, he feels it is not realistic to ask them to set up a gaze control system on a daily basis. As technology is his principal mode of communication he says he has to feel confident that he will be able to use it consistently, reliably and as independently as possible at home.

## 4.4 Discussion and recommendations

Throughout the end-user trials, a range of gaze control computers have been used by the ACE Centre. Whilst many end-users and those who support them are keen to know which is the best control system overall, this question remains impossible to answer. All of these systems have different merits in terms of size, power, how well they deal with involuntary movement, end-user interface, etc. For this reason, whilst it is not relevant or appropriate to ask the question which is the best system overall, it is *absolutely* appropriate for an end-user to ask 'Which is the best gaze control system for *me*'? Time and time again in the end-user trials different systems were found to be better than others, depending on the end-user needs. Whilst the price of some gaze control systems seems to coming down and, in general, their quality improving as competition heightens, they remain an extremely expensive piece of computer control equipment. For this reason, whilst the end-user trials above have been carried out in a range of different settings and with a range of different people with different disabilities there are certain recommendations which, we feel, will help people to make the most of what is potentially a life changing investment.

1. End-users should have the opportunity to try a range of different systems before deciding. Those at suppliers who sell one system only should make sure that customers are aware of the alternatives.
2. End-users who have the potential to use direct pointer control, as opposed to 'centralised cell-select' should have the opportunity to try out direct pointer control on a range of systems before deciding which is the best for their needs. As described above, some end-users will be using their systems all day every day, possibly for the rest of their lives, so choosing the best system to meet their needs is extremely important.
3. The initial calibration and assessment for a gaze control system should be carried out with great care and preparation, with reference to guidelines such as those described above. If the conditions are not right, a life changing opportunity could be wasted.

4. Once a system is purchased, it is essential that training is provided both for the end-user and those supporting them. Regular review is also essential, in response to changing end-user needs and requirements, in relation to technical developments.
5. During the review, attention needs to be given to any improvements in the end-user's accuracy with gaze control. If they are using a grid-based application with 'centralised cell-select' then the reviewer should consider whether or not they are ready for either (a) a revised, more powerful grid with a greater number of smaller cells or (b) whether to consider direct pointer control.

## 4.5 Conclusion - Future directions for gaze control

Gaze control had already been utilised successfully for at least two decades before the COGAIN project started. However, the numbers benefiting from this technology, globally, were relatively small, in relation to those who could potentially benefit from it. There can be little doubt that the COGAIN project has been a catalyst in moving gaze control forward as a computer access method. The range and numbers of people using this technology have increased dramatically, not only in Europe but across the whole world. One particularly dramatic development that has taken place during COGAIN has been the evolution of gaze control systems that, combined with the appropriate software, can enable people with severe involuntary head movement or visual difficulties to use gaze control, given the appropriate support and personalised software.

### *Gaze controlled environments*

Not only has great progress been made in terms of communication for this very complex group but also in terms of environmental control. Indeed, environmental control is an integral part of *several* gaze control-compatible applications, eg. The Grid 2, Tobii Communicator, iABLE, Gazetalk, etc

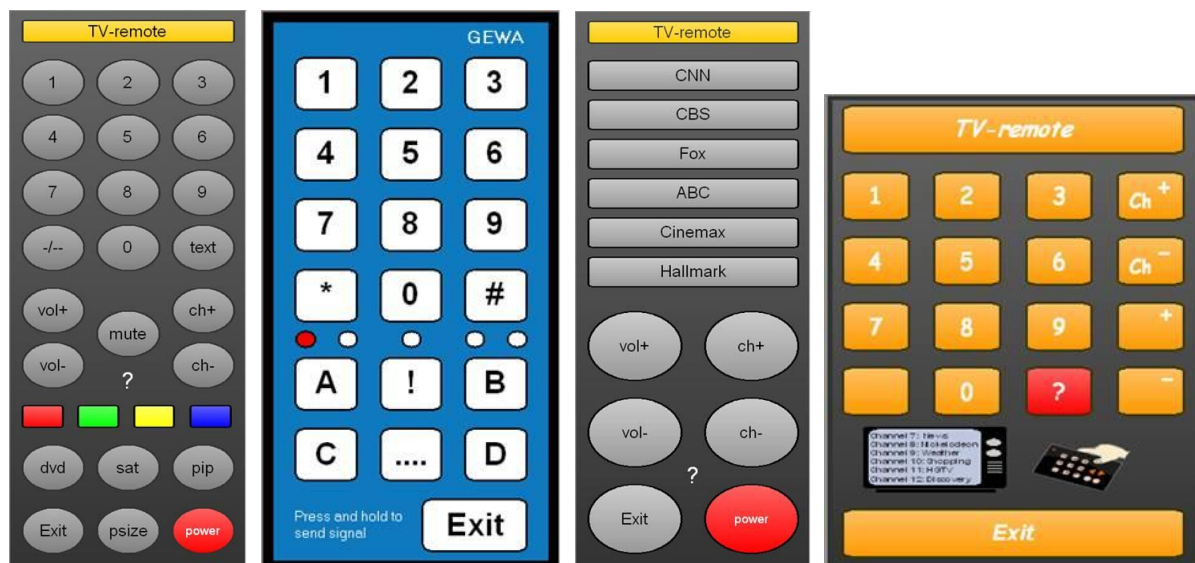


Figure 4.17: A range of Eye controlled interfaces for television control from Tobii Communicator



At present, the only commercially available environmental control systems require the end-user to look at an interface on a gaze-controlled screen. However, there is some very promising work that is being carried out by a number of researchers, including COGAIN partners. For example, The University of Derby is investigating the process of the end-user looking directly at electrical items in order to operate them, thereby bypassing the need for an on-screen interface for those who do not need one (Shi et al., 2007).

### *Gaze-controlled mobility*



Figure 4.18: Luis Figueiredo using gaze control for powered mobility via a gaze control camera mounted at the front of the wheelchair<sup>28</sup>.

Whilst considerable progress has been made in the areas of gaze controlled communication, computer control and environmental control, gaze controlled mobility remains a challenging area. This is not so much because of technical difficulties, but rather due to health and safety issues. Technically, Figueiredo et al (2008) have demonstrated how successfully a wheelchair can be operated through gaze control by a physically and cognitively able end-user under the COGAIN project. Novak et al. (2008) have also made great progress with the I4Control head-worn system that can be used both for computer control and direct wheelchair control without a computer interface. The significant challenges that remain are (a) to develop *failsafe* gaze-controlled mobility interfaces for people with a range of physical, visual and learning disabilities, including individuals with the most complex disabilities who wish to adjust their positioning independently, and (b) to develop a gaze controlled system that can be used reliably out of doors. Whereas a computer based application such as word-processor, can be very annoying, the consequences of an eye-powered mobility system crashing could be fatal.

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<sup>28</sup> See the full video at [http://www.cogain.org/cogain2008/cogain2008-videos/magicwheelchairhd.wmv/file\\_view](http://www.cogain.org/cogain2008/cogain2008-videos/magicwheelchairhd.wmv/file_view)



### ***Gaze Gesture control***

As described above, several end-users described as having locked-in syndrome were unable to use a gaze control system, despite the fact that they *were* able to control their eye movement, albeit in a single direction.

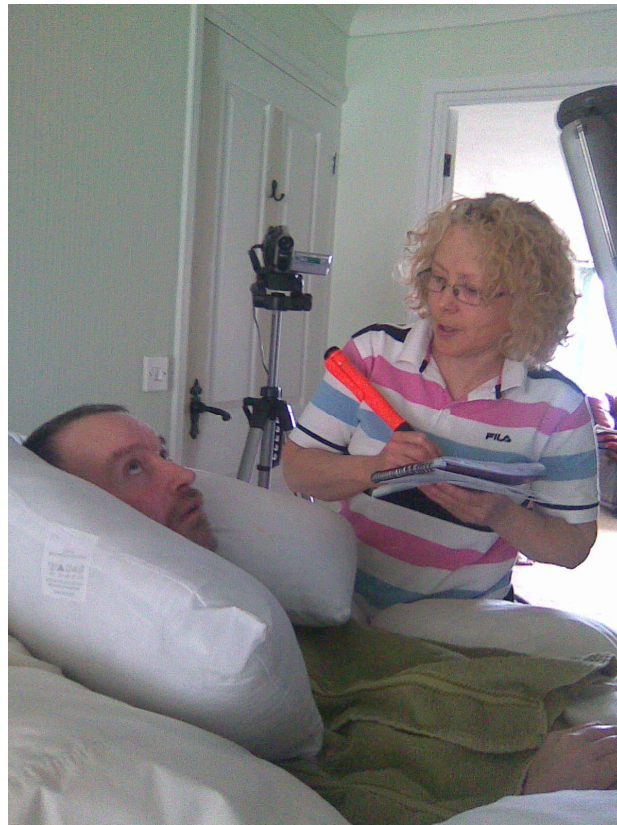


Figure 4.19: Russ looking up

This was due to the fact that many gaze controlled computers require the full pupil to be visible to the camera and their eyelids were partly covering their pupil(s). It is recommended that gesture recognition is investigated in order to capitalise upon what is, for many people with such disabilities, a quick, positive and deliberate movement.



Figure 4.20: Eye-gesture control used for online games (Vickers et al., 2008)

It is encouraging to see that work is already being undertaken in this area, for example by Vickers et al (2008) where eye gestures are being used to simulate standard games input methods in as quick and efficient way as possible.

All in all, while much has already been achieved, there is still much work to do to ensure that as many people as possible whose preferred, or only, method of computer control is eye movement. It is confidently anticipated that the COGAIN Association will continue to build on the groundbreaking work of the COGAIN network of excellence.

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