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Communication by Gaze Interaction

Network of Excellence
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D3.3 Report of User Trials and Usability Studies

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Executive Summary

This report includes a description of user trials that have been carried out by the three COGAIN partners – DART/Sahlgrenska University Hospital (Gothenburg), The Politecnico di Torino (in partnership with the Torino ALS Centre) and The ACE Centre, Oxford. All of the results point to the huge potential benefits for the kinds of people who need it most.

The findings of the Politecnico di Torino in partnership with the Torino ALS Centre were as follows:

- The level of satisfaction and engagement gained from eye-control was relative to the level of the person's disability.
- Patients who were unable to speak or move any of their limbs were very motivated to learn a new method of communication and felt that eye-control gave them hope.
- The team felt, following the trial, that eye-control potentially offers great satisfaction for ALS patients once other methods of control (head-mouse, switches etc.) have failed.
- The majority of the ALS patients involved were not aware that is possible to write a letter, play chess, send an e-mail, or communicate needs, emotions, and problems just by eye-gaze alone.

From a technical point of view, the process of implementing the use of an eye control system with the majority of people with ALS is a comparatively straightforward process as most have good visual, cognitive and literacy skills. They do not have involuntary movement so they can potentially choose from a range of eye control systems, whether they are designed to accommodate head movement or not. On the other hand, ACE and DART deliberately chose to work with people who might also benefit greatly from eye control but who find it difficult because of involuntary head movement, visual difficulties and/or learning difficulties. Their aim was to use their clinical and technical skills and experience to see how best to accommodate their needs. They found that considerations when assessing for and implementing the use of an eye control system should include the following:

- Appropriate mounting and positioning of the system in relation to the end-user's needs, i.e. the system must be positioned for optimal comfort, function and visibility for the specific end-user.
- An appropriate eye-control system(s) that accommodates the end-user's physical and visual/perceptual needs, i.e. a system that is appropriate for the end-user, for example, a system that is able to accommodate involuntary head movement might be required.
- Appropriate on-screen visual representation (pictures, symbols, text, foreground/background colours, etc., i.e. ensure that visual images are presented in a way that is clearly visible and comprehensible to the end-user.
- Appropriate organisation of the images on the screen in relation to the visual abilities of the end-users to ensure that the visual images are arranged in a way that is most easily understood and controlled.
- More adaptable calibration procedures. Different users need different features, so a selection of options would be a useful tool that could make it possible for more people to try eye control.
- The development of a wide range of software to support initial trials and training for users with a wide range of physical, visual and cognitive abilities in the use of eye control. Software that is already widely used in schools and for leisure needs to be made accessible by eye control.

- A larger selection of software for communication is recommended. Several users already use communication programs and it is important to collaborate with developers to try to make these as 'eye-friendly' as possible so that they can continue using familiar programs.
- Appropriate auditory support and feedback is essential. It is important to ensure that the type of auditory support provided to the end-user gives them optimal support in relation to their needs and abilities.
- Enabling the user greater independence in changing the settings of both the system and software they are using.

1 Introduction

Deliverable 3.1 (Donegan et al. 2005) identified some of the key issues relating to user requirements. Deliverable 3.2 (Donegan et al. 2006) considered the relevance of these requirements to developers when considering which features to add, modify, incorporate or adapt in relation to the software they are using or developing. Many of the views expressed and recommendations made in these two deliverables were based on the user trials that have been carried out under COGAIN during its first 24 months. This document provides a description of the progress that has been made in relation to these COGAIN user trials so far. It includes:

- An introduction to the range of issues that need to be taken into account when measuring gaze performance. It provides a context for the descriptions of the various user trials that follow. It is intended to provide a reference point for those people who wish to carry out eye-control user trials in the future, whether they are within the COGAIN partnership or not.
- A description of user trials that are being carried out by three organisations involved in Work Package 3 – DART (Gothenburg, Sweden), ACE (Oxford, UK) and POLITO (Torino, Italy).

Key outcomes from the user trials include the following:

- Strong indications that this technology can have a positive impact on communication ability and, subsequently, quality of life.
- Valuable information on the conditions for successful initial assessment and subsequent implementation of eye control technology with the most complex users, e.g. those with visual difficulties, learning difficulties and involuntary head movement. This information is intended to benefit all involved whether they are (a) developing, adapting and selecting eye-control hardware and software or (b) requiring information on the techniques and modifications necessary to enable as many of those who need this technology as possible to use it as successfully as possible.

All of the research has involved close collaboration between the COGAIN partners concerned with the User Involvement work package. The methods adopted have been chosen in relation to the skills, interests and abilities of those involved in the trials and, of course, the specific aims of those trials. For example, a key issue for the joint Politecnico di Torino/Torino ALS Centre's trials was to discover the impact of this technology on the quality of life of a group of ALS patients. By contrast, much of the work carried out by DART and The ACE Centre involved a more open, exploratory approach that was appropriate to their own primary aim. This was, essentially, to focus on those for whom the use of eye control systems was difficult because of visual difficulties, learning difficulties or involuntary movement. The main aim was to "find a way into" eye control technology for such people with the most severe and complex accessing difficulties. As a result of this investigative, action research, a range of strategies, recommendations and specially developed software are being developed that are intended to (a) influence both hardware and software developers in making their systems more accessible to more people and (b) provide valuable information to professionals, carers and potential end-users who are considering taking up the use of eye control technology.

As the requirements of the most complex users have emerged from the user trials, WP3 has communicated these requirements to the eye tracking manufacturers. The response been encouraging and WP3 intends to continue and enhance the close collaboration, involving more manufacturers. It is much hoped that, with the arrival of the new commercial partners within COGAIN along with the new eye-control hardware anticipated

from partners in the near future, the results of the COGAIN user trials will continue to influence global development in relation to accommodating the needs of as many users who need this technology as possible. Indeed, the involvement of any software or hardware developer, commercial or otherwise, whether they are a member of the COGAIN network or not, is to be welcomed. **It is the responsibility of COGAIN and, in particular, Work Package 3 to provide a context within which such networking and subsequent collaboration can take place.**

In relation to eye-control friendly software, not only are the user trials designed to influence the way in which software developed within the project (e.g. Gazetalk) can be adapted and modified in order to meet more user requirements but also the way in which existing, widely available "framework" software can be adapted and modified to make it more "eye-friendly". Much encouraging work has already begun in this area as a result of the COGAIN project through collaboration with commercial software developers and companies. Eye-friendly activities are already being developed in collaboration with companies like Falck Vital (Norway) and Sensory Software (UK). These will be made freely available (as future deliverables) for use with commercial software, e.g. The Grid and Speaking Dynamically Pro, as well as for open source framework software such as SAW. Illustrations of these are provided later on in this document. Deliverables 3.1 and 3.2 have already provided information on the findings of the COGAIN user trials as they have emerged and, despite the limited number of eye control systems available to partners, the user trials have produced some influential outcomes. It is anticipated that the trials will be ongoing throughout the COGAIN Project. For example, future trials are planned to investigate systems and software from both within and outside the project as they emerge and these, too, will be reported in future deliverables.

Finally, it is worth noting that, wherever the work of partners involved in user trials has been presented, the interest in the special software and grid-sets developed under the project (e.g. Music activities, Reading Books, Personalised writing programs) has been very high. In addition, the level of interest in video case studies that provide information on techniques to assist the successful use of eye control technology has also been significant. There has been a great demand for copies of these resources. For this reason, future WP3 deliverables will not only include reports on user trials but also multimedia training materials and exemplar software resources (i.e. framework software grid-sets) to be made available for download from the COGAIN website (see Figure 1.1).

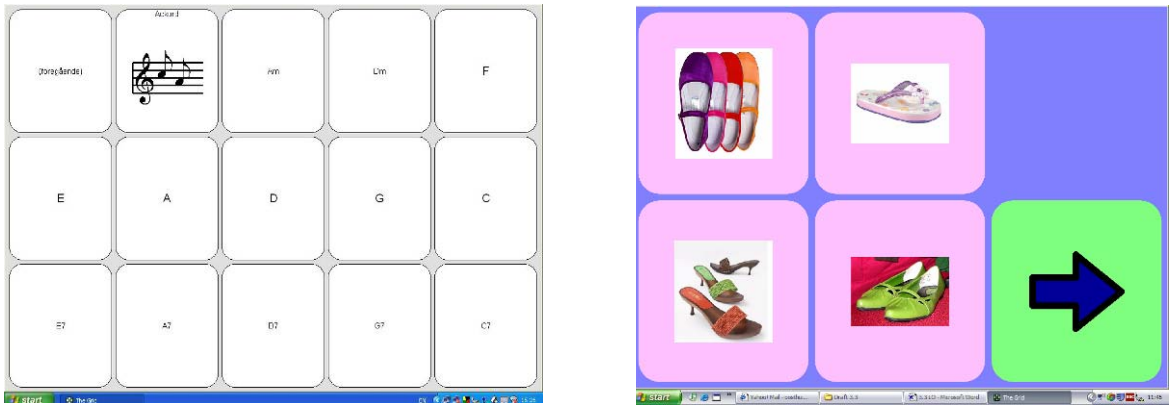

Figure 1.1. Examples of grid sets developed under user trials that will be made available for download in future WP3 Deliverables.

2 Measuring gaze communication performance

2.1 Assessing performance

This section introduces performance evaluation metrics that may be used to evaluate gaze based usability. These metrics are primarily aimed at people within COGAIN who can use gaze at high-performance levels and that are attempting to achieve high communication rates with on-screen keyboards and other typing aids, such as gaze-based control as a substitute for using a hand-based desktop mouse for example. This is presented as a companion to the KEE approach (detailed later, in section 4.5) that is designed for people who cannot or do not wish to use gaze at a high performance level, and where performance metrics are not suitable and the KEE approach can offer greater information and insight for end-users.

2.2 Communication rate

Previous work on methods of assessing the performance of gaze when used for communication, such as typing sequences on a graphical user interface (for example, Istance et al. 1996, Jacob 1991, Hansen et al. 2004, Majaranta et al. 2004) has shown that effective assessments may be made based on the end-user performing a small set of tasks or communication sequences. Often these tests only assess one type of interaction, such as typing on an on-screen keyboard, that occur on a real interface (Figure 2.1 – Majaranta et al. 2004). The data from these experiments is usually determined by the nature of the assessment task, for example words per minute for a typing task, but other metrics such as cursor paths, eye scan paths or user subjective reaction are often recorded, giving a richer data set. These test scenarios are often slower and more difficult to administer than more simple go/no-go type tests but possibly give more information as they attempt to assess detailed gaze-interaction behaviour.

Figure 2.1. Example typing assessment

The rationale behind these potentially complex test scenarios is that, although often time consuming and laborious to conduct, the true performance of gaze on a communication aid is revealed.

Unfortunately there appears to be no standard or commonly accepted test for assessing these tests. Typically tasks are designed to test or assess a particular element of interaction with specific interest, rather than the full range of interaction that is possible on a communication aid. In addition, the factors that are assessed and quantified vary due to the task undertaken, rather than using a common method, making comparison of results between studies difficult. Examining previous work conducted on eye based pointing found a range of different test scenarios: A brief, with only a small number of tasks, but wide ranging assessment of eye-based interaction with text entry, text editing, application and menu manipulation and limited internet browsing was found (Istance et al. 1996), however this interaction was carried out indirectly with the interface, via a virtual keyboard ('ECKey', Figure 2.2). In this work, performance metrics were the text entry rate in number of characters per minute, together with task times and task error rates.

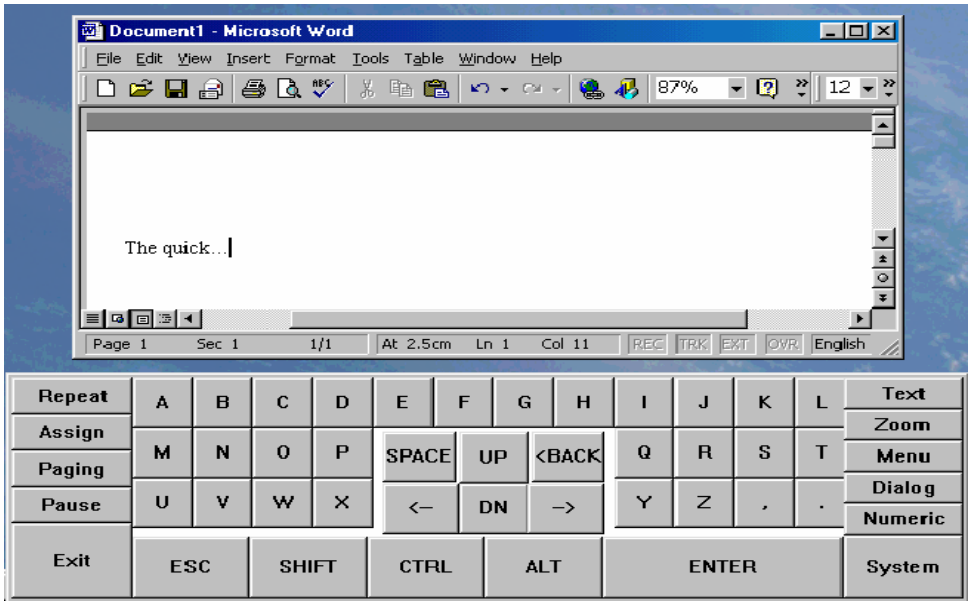

Figure 2.2. ECKey typing

Another attempt at a range of assessment scenarios for gaze based typing involved typing on a full-screen keyboard, typing on an environmental control with full screen keys, and playing a simple game; with metrics of simple success or failure of the tasks (Chapman 1991). Other assessments were based around text entry, typically with full-screen sized keyboards. Metrics for these studies were typing rate and subjective 'like' or 'dislike' of the overall system (Stampe and Reingold 1995), typing rate, error count, task time, gaze scan paths of the eye on the interface and subjective like or dislike of the system (Majaranta et al. 2004) and typing rate and user subjective qualification of typing efficiency and satisfaction with the system (Hansen et al. 2004).

Typing rate was common to these studies assessing keyboards, and this could be used to compare differing gaze based pointing devices if the same keyboards and text entry tasks were used, or if the same device was used and differing keyboards assessed for their efficacy.

2.3 Beyond typing rates

As we have seen, typically performance has been measured by the rate of communication, with some studies also measuring the time taken to complete a task and a basic task quality metric of the number of errors generated during the completion of the task. Although adequate, with a gaze system that has a shorter task completion time and a lower error rate (higher quality of interaction) during the task almost certainly being more suitable for the task than a system with a longer task time and higher error rate, these metrics are quite crude and do not offer great insight into the detailed performance of a gaze based communication device. Perhaps a device has a shorter task time but higher error rate than another device with a longer task time but lower error rate – which device is most suitable for the task? To resolve this problem, task times are typically used as the main comparator between pointing devices, with the error rates being reported separately (for example: MacKenzie 1992, Douglas and Kirkpatrick 1999) and the reader left to decide which metric is most important for their application of the results.

This is not completely satisfactory and a measurement scheme is required that would overcome this difficulty by taking into account both task times and error rates, or the quality of interaction, together with task success or failure, to form a composite objective metric of device performance on the test tasks.

To better gain a full understanding of the performance of a device it is regarded as not adequate to simply measure the objective performance of a device without also assessing the subjective reaction of the user when using the device (Bevan et al. 1991 and 1995). Perhaps a device performed well objectively, with low task times and error rates, but the user worked hard to control the device, or the device was uncomfortable to use. Would this device be more suitable to the task than a device that objectively performed less well but required less work from the user, or was more comfortable to use? This problem has been partially addressed previously, with differing questionnaires (for example: Douglas et al. 1999, Smith 1996). Typically, schemes addressed user 'workload' (Bates 1999, Brewster 1994); some also addressed user 'comfort' or 'ease of use' (Douglas et al. 1999, Murata 1991, Fernström and Ericson 1997). In a similar manner to the composite objective metric for the method, some form of subjective measurement is required that would encompass the elements of these assessment areas in a composite subjective metric of user reaction to a device. Together, these objective and subjective metrics would give an overall balanced assessment of a device, or in effect how 'usable' a gaze-based device is.

2.4 Objective and subjective metrics

As discussed, the assessment of a device can be expressed as two components: the objective performance of the device, and the subjective user reaction to that device. Together these enable the usability (Bevan 1991) of the device to be formally assessed. The objective performance may be measured as a composite of task times and task quality or errors during interaction, and subjective reaction in terms of the evaluation from the subject when using that device to perform tasks. Ideally, to gain maximum insight into the devices, these metrics should be multi-factor, detailed and hence complex to fully assess the performance of the device, but also composite to present the results in a simple manner, and validated to show that they measure what they claim to measure.

Looking for suitable methods of expression for these metrics for gaze based communication assessment leads to the definitions of device efficiency and satisfaction as stated in the European ESPRIT MUSiC (Metrics for Usability Standards in Computing) performance metrics method (Bevan et al. 1991 and 1995, MacLeod et al. 1997) and the recommendations outlined in the ISO 9241 Part 11 'Guidance on Usability' International Standard (Smith 1996). These metrics are defined in gaze based communication terms as follows:

- Efficiency: the objective performance of the device, expressed in terms of the amount and quality of communication with the device and the time taken to perform that communication.

- Satisfaction: the subjective acceptability of the device, expressed in terms of the user workload and comfort when using the device and the ease of use of the device.

2.5 Measuring objective efficiency

Efficiency can be defined as a composite of the amount of a task accomplished, the quality of the communication during that task, and the time taken for the task. Examining the MUSiC performance definitions in detail (Bevan et al. 1991 and 1995, MacLeod et al. 1997) gave the following relationships (Figure 2.3):

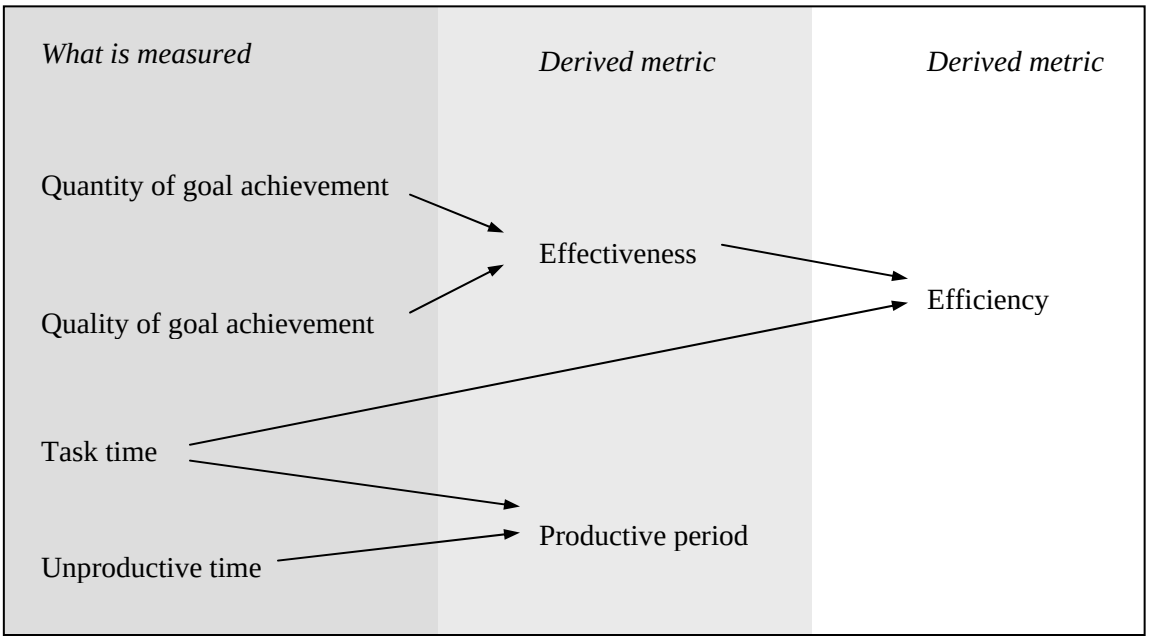

Figure 2.3. Relationship between measures and metrics

Here Efficiency is described as follows:

- 'The Efficiency with which users use a […] product/device is defined as the ratio between their Effectiveness in carrying out their task, and the time it takes them to complete the task'.

Where efficiency was defined as:

$$\text{Efficiency} = \frac{\text{Effectiveness}}{\text{Time taken for interaction}} \times \frac{100}{1} \%$$

Figure 2.4. Efficiency as effectiveness and time

And effectiveness is described as:

- 'The Effectiveness with which users […] carry out a task is defined as comprising two components, the quantity of the task attempted by the users, and the quality of the goals they achieve'.

This is defined as:

$$\text{Effectiveness} = \text{Quantity of interaction} \times \text{Quality of Interaction} \times \frac{100}{1}\ \%$$

Figure 2.5. Effectiveness as quantity and quality

Substituting the equations gives the final calculation for efficiency:

$$\text{Efficiency} = \frac{\text{Quantity of interaction} \times \text{Quality of Interaction}}{\text{Time taken for interaction}} \times \frac{100}{1}\ \%$$

Figure 2.6. Calculating Efficiency

2.5.1 Measuring task time

Task time is simple to quantify (Bevan et al. 1991 and 1995, MacLeod et al. 1997), and is defined as:

- 'The time a user spends using a system to perform the evaluation task'.

And is further described as:

- 'Task Time begins when the user starts to interact with the product […] and ends when the user indicates he or she has finished'.

With unproductive time defined as:

- 'How long the user took performing actions that did not contribute to the task output'

Hence productive time was defined as:

- 'The proportion of time the user spent performing actions that contributed to the task output'.

These are clear definitions, with the task time defined as the total time for a communication task, including any unproductive time, with the additional division of task time into productive and non-productive elements giving additional detail.

2.5.2 Measuring quantity

Quantity can be simply measured as the amount of a task completed in the time taken by the task. This can simply be the number of words produced, or the amount of a task done.

2.5.3 Measuring quality

As discussed in previously, this could typically be a count of errors generated during the task. However, this 'pass/fail' approach lack detail and would not give any great insight into what factors caused any errors that may be counted. A more subtle approach is needed.

Hence quality of interaction (Bevan et al. 1991 and 1995, MacLeod et al. 1997) is defined as:

- 'How good the attempt is'.

And is further described as:

- 'Quality is a measure of how good the task goals represented in the output are compared to their ideal representation. It is defined as the degree to which the task goals represented in the output have been achieved'.

A method was suggested for specifying quality (Bevan et al. 1991 and 1995, MacLeod et al. 1997):

- '1. Decide what constitutes an ideal output of each goal'.
- '2. Specify a scoring procedure for measuring how good the output of each goal is compared to its ideal, that also takes into account any output that was not asked for. If the task goals vary in importance, a weighting can be applied'

Hence, a scoring system can be developed to measure the quality of how well a system is aiding communication, for example. This could be the number of corrections of a spelling mistake due to mistyping or inaccurate gaze control due to a poor system. An example is shown in Figure 2.7.

Rating	*Meaning*	*Description*
0%	Very low	Incorrect typing, failed to communicate
25%	Low	Many corrections, but still had meaning
50%	Medium	Average corrections, clearly understood communication
75%	High	Small corrections, clear communication
100%	Very High	Perfect communication

Figure 2.7. A possible Quality rating

2.6 Measuring subjective satisfaction

In order to measure the subjective response of the user to the device, it is necessary to know by what factor and by what amount the user was influenced by the device:

- 'Measuring user satisfaction, or the acceptability of a system, requires knowledge of the internal state of the user'. (Bevan 1991)

There are a multitude of differing questionnaires applied to evaluation, all assessing some aspect of the subjective reaction of the user to a device (for example: ISO 1998, Smith 1996, Douglas et al. 1999). Parameters such as 'mental effort', 'physical effort', 'body fatigue' and 'body comfort' are used. However, none of these sources offered a comprehensive set of questionnaire factors that fully addressed the expected assessment needs of gaze based communication aids. For example, none assessed factors such as eye comfort, speed, frustration etc. The most appropriate course of action is to take the most suitable assessment factors from a range of questionnaires and assemble a new questionnaire assessment scheme suitable for the gaze based systems to be tested. This approach was not novel, with customised questionnaires being used previously for device assessment (Brewster 1994, Douglas et al. 1999).

Subjective 'satisfaction' can be defined as a composite of the amount of user workload exerted when using the device, the level of comfort experienced when using the device, and the ease of use of the device. Hence three areas need to be addressed:

- Workload
- Comfort
- Ease of use

2.6.1 Measuring workload

Searching for suitable workload factors, the MUSiC method (Bevan et al. 1991 and 1995, MacLeod et al. 1997) gives the following definition for workload:

- 'Measures of cognitive workload are provided by the SMEQ (Subjective Mental Effort Questionnaire), and TLX (Task load Index) questionnaires, and by heart rate variability measures'.

Of these three measures of workload, none are commonly used for gaze device assessment, but of these, the NASA Task load index (Hart et al. 1988) is perhaps the most simple, and non-invasive, to apply.

The NASA Task Load Index is based upon a multi-dimensional rating procedure that provides an overall workload score based on an average of ratings on six workload subscales: Mental, Physical, Temporal, Performance, Effort, and Frustration (Hart et al. 1988). In normal application the TLX requires two passes to apply paired comparisons and hence weightings to the ratings. However this appears to be unnecessary and a 'raw' form may be used, where the workload topics are treated as simple questionnaires with the result averaged and no second pass required (Byers et al. 1989), thus simplifying the application of the rating procedure. Thus, the following workload factors could be in the questionnaire (Figure 2.8):

- Physical effort
- Mental effort
- Time pressure
- Frustration
- Performance

Figure 2.8. Workload factors

2.6.2 Measuring comfort

Searching for suitable user comfort factors found suggestions in the ISO 9241 Part 9 'Non-keyboard Input Device Requirements' International Standard (ISO 1998, Smith 1996) and 'Testing Pointing Device Performance and use Assessment with the ISO9241, Part 9 Standard' (Douglas et al. 1999). In these, specific body areas were defined to suit the requirements of the test and subjects asked to rate their level of comfort (or discomfort) for these areas. Typical examples included 'headache', 'wrist ache' and 'finger ache' for a desktop hand mouse. With this precedence, and evaluating which areas gaze based communication would influence, and the abilities of the expected user groups, the following areas can be selected as factors for the questionnaire (Figure 2.9):

- Headache
- Eye discomfort
- Facial discomfort
- Mouth discomfort
- Neck discomfort

Figure 2.9. Comfort factors

Note that the facial and mouth factors were included to allow the questionnaire to be used to assess the performance of facial and mouth operated selection devices, such as eyebrow switches, eye blink switches, and sip-puff switches, that are often used with gaze based communication.

2.6.3 Measuring ease of use

Finally, searching for suitable device ease of use factors again found suggestions in the ISO 9241 Part 9 Standard (ISO 1998, Smith 1996, Douglas et al. 1999). In a similar manner to comfort specific device properties were defined to suit the requirements of any test and subjects asked to rate their perceived level of ease of use of the device for each property. Typical examples included 'speed of pointing' and 'ease of system control'. Again with this precedence, and evaluating which property the devices in this work are likely to exhibit, the following properties were selected as factors for the questionnaire (Figure 2.10):

- Accuracy of gaze pointing
- Speed of gaze pointing
- Accuracy of target selection
- Speed of target selection
- Ease of system control

Figure 2.10. Ease of use factors

2.6.4 A summary of questionnaire factors

At the most fundamental level each factor may be reported individually, in addition factors may be amalgamated (in the same manner as the NASA-tlx, by simple averaging) within their sections to give ratings for workload, comfort and ease of use (see Table 2.1). Note that aggregating all sections to form a single satisfaction result would be invalid, as each section assesses a different aspect of the subjective response of the subjects to the device.

Satisfaction assessment areas and factors			
Area	*Workload*	*Comfort*	*Ease of use*
Factors	Physical effort	Headache	Accuracy of pointing
	Mental effort	Eye discomfort	Speed of pointing
	Time pressure	Facial discomfort	Accuracy of selection
	Frustration	Mouth discomfort	Speed of selection
	Performance	Neck discomfort	Ease of system control

Table 2.1. Satisfaction assessment areas and factors

2.7 A summary of measuring gaze communication performance

This section gave an overview of a proposed detailed assessment method for measuring gaze communication performance that would compliment the KEE approach (detailed in section 4.5) for situations where the user of the system is able or wishes to communicate at higher speeds using on-screen based communication aids. It proposes the measurement of not only simple text entry rates as done previously, but also the objective efficiency of communication and the subjective reaction of the user during that communication.

It is hoped that as gaze based systems become more usable and give increased possibilities for high-performance communication that this system may be used through COGAIN for the detailed assessment of high-performance gaze based communication.

3 POLITO/Torino ALS Centre User Trials

3.1 Summary

COGAIN members from Politecnico di Torino (POLITO) do not usually work directly with people with disabilities and it was therefore decided that it would be necessary to find a partner that had both a group of willing participants with disabilities, and experience in working with this group. It was felt that knowledge and sensitivity about the issues involved in disability would be important to the success of the trials, and the Torino Amyotrophic Lateral Sclerosis (ALS) Centre agreed to take part in the eye-control trials. Based in the Neuroscience department at the San Giovanni Battista Hospital, a multi-disciplinary team of doctors, speech therapists and psychologists, supervised by Doctor Chiò, treat approximately one hundred patients with varying stages of ALS. The ALS Centre staff showed a great deal of enthusiasm for the idea of trialling an eye-control system with their patients.

Upon receiving the ERICA eye-control system (Eye Response Technologies), purchased under the COGAIN project, we began preliminary trials to familiarise ourselves with the features and capabilities of the system. It became very clear that in order to use this system successfully, the user would need to keep his/her head very still. ALS patients, therefore, who eventually have very limited movement, if any, seemed a potentially good group to trial this system with. The ALS Centre was given training on the use of the system and then began conducting eye-control trials.

3.2 Introduction

Eye-tracking technology is relatively new and in the Italian assistive technology market, like most other countries, knowledge about its existence and capabilities is limited. Consequently, Italian ALS patients are not even aware of the opportunities that this new technology could offer them, which was partly why staff at the ALS Centre were so enthusiastic about involving their patients. They felt that the trials could potentially have multiple benefits, including:

- Increasing Italian public interest/knowledge in eye-tracking technology
- Make ALS patients aware of eye-tracking technology
- Investigate how eye-tracking technology might improve the quality of life of ALS patients

Patients that were well motivated, willing and had a strong desire to investigate new possibilities were selected to take part in the trials. A major focus and motivation for our work has been to demonstrate that eye-tracking technology can have a profound effect on the improvement of quality of life for ALS patients.

3.3 Methods

The ERICA system was trialled with eight ALS patients (and still continues with others), for a one-week period each. Each participant was asked to sign a consent form once the project and their involvement had been explained (see Appendix 3.1). Patients were usually selected for participation by a neurologist, who discussed his choices with a speech therapist and psychologist. The choice of participant was based on:

- The patient's motivation
- The patient's experience of PC use
- The needs/requirements that had been expressed by patients during routine medical examinations

The neurologist provided a brief report on each patient, outlining the progression of their ALS, the level/severity of their disability etc. A date for the start of the trial week was then agreed with each patient. During the first meeting, the psychologist carried out a series of tests to evaluate the patient's perception of their quality of life. The McGill Scale, the Self-Perceived Burden scale, the SWLS (Satisfaction with Life Scale), and the Zung Self-Evaluation of Depression scale were used to gain an insight into the perceptions of this group of patients (see Appendices 3.3-3.6 for examples of these tests).

Using the McGill Scale (see Appendix 3.3), five factors were analysed: physical comfort, physical symptoms, psychological symptoms, existential comfort and support. SPSS 12.0 (see http://www.spss.com/spss/) was used for the statistical analysis of the data gathered. The T-Student test was applied to the results, with a significance level of less than 0.05. The speech therapist then provided each patient with training on use of the ERICA eye-control system. Patients were given both the ERICA on-screen keyboard, and personalised grids made with The Grid. Patients were able to contact either the speech therapist or the psychologist with any questions on either the software or technical questions regarding the system. The therapists, in collaboration with POLITO staff, provided the necessary support.

Approximately half way through each patient's trial, they would be contacted by either the speech therapist or the psychologist and asked for feedback on their progress. At the end of the trial week, the same set of tests (see above) were administered, as well as a COGAIN questionnaire[1] (The ACE Centre), and a questionnaire designed by the ALS Centre (see Appendix 3.2) that investigates qualitatively the experiences of both the patients and their families. The questions included whether they felt the systems had been easy to learn to operate, and whether they felt the system had met their needs.

3.4 Results

3.4.1 Participants' Background

- Six of the patients were male; two were female
- The average age of the patients was 54
- Three patients had a tracheotomy and five are PEG fed
- Four patients were completely unable to speak and four were dysarthric
- All patients had severe physical disabilities
- One patient had ataxia and consequently found use of the system very difficult
- All patients had a reasonable amount of experience of using a computer, gained from previous work experience or a hobby
- All patients showed great interest in eye-control technology

[1] The COGAIN Questionnaire on User Needs is available at http://www.cogain.org/user_involvement/

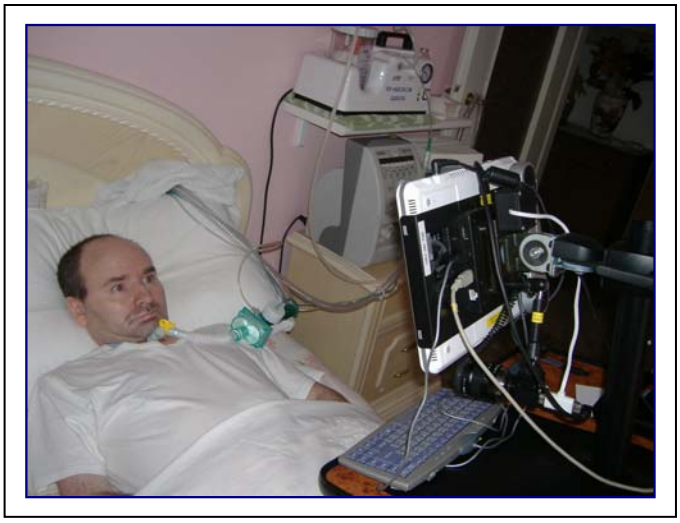

Figure 3.1. A patient from the ALS Centre using the ERICA eye-control system

3.4.2 McGill and SWLS

The test results showed a clear improvement in the perceived quality of life, in both the McGill and SWLS Scales (see Figure 3.2, Figure 3.3, and Table 3.1). A particularly noticeable improvement was shown in the patients' perceived overall psychological state, existential comfort and physical symptoms although the amount of support required by each patient, and their perceived depression did not show a significant change (less than 0,05).

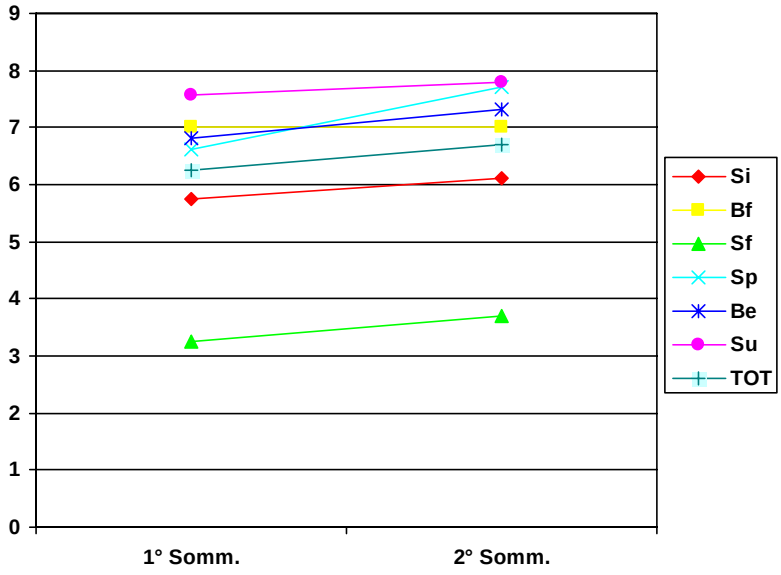

Figure 3.2. Score variation in perceived Quality of Life after 7 days

[Si = single item; Bf = physical comfort; Sf = physical symptoms; Sp = psychological symptoms; Be = existential comfort; Su = Support; 1° Somm. = first test; 2° Somm. = last test]

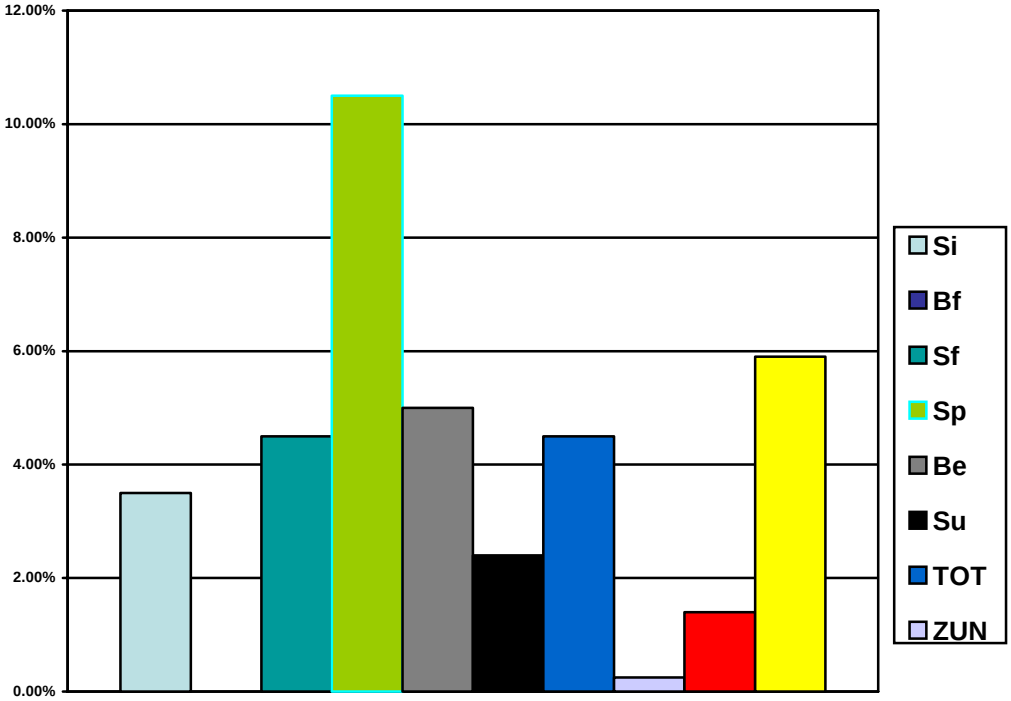

Figure 3.3. Percentage variation in Quality of Life, Depression; SPBS after 7 days

[Si = single item; Bf = physical comfort; Sf = physical symptoms; Sp = psychological symptoms; Be = existential comfort; Su = Support]

Scale	Factor analysis	First test	Last test	Variation	% Variation	T Student Test
		Average	Average			
MCGILL						
	Single item	5,75	6,125	0,35	3,50%	p<0.05
	Physical comfort	7	7	0	0	p<0.05
	Physical symptoms	3,25	3,7	0,45	4,50%	p<0.05
	Psychological symptoms	6,62	7,7	1.08	10,50%	p<0.05
	Existential comfort	6,8	7,31	0,5	5%	p<0.05
	Support	7,56	7,8	0,24	2,40%	Not significant
	Total	6,26	6,71	0,45	4,50%	p<0.05
ZUNG		43,6	43,8	0,2	0,25%	p<0.05
SPBS		76	77,8	1,8	1,40%	p<0.05
SWLS		19	21,5	2,5	5,90%	p<0.05

Table 3.1. Summary data test table

While it is important to bear in mind the very brief nature of each trial (seven days) the introduction of an eye-control system improved the perceived quality of life of the patients, as demonstrated by the following observations from the COGAIN and ALS Centre questionnaires:

3.4.3 COGAIN Questionnaire

The COGAIN Questionnaire is available at http://www.cogain.org/user_involvement/.

Responses to the questionnaire indicate that:

- The ERICA system was considered efficient and effective, and facilitated more complex communication. Patients commented that they were able to express more than only their primary needs.
- The ability of the patient to use applications independently, following the calibration procedure, was a positive aspect for all the patients. This is not possible with all other methods of communication, for example an E-Tran frame, which relies on a communication partner.
- One patient was able to communicate with a grandchild using the eye-control system.
- Patients were impressed with the prediction/vocabulary that enabled faster communication, and the synthesised speech was also well received.
- Patients had difficulties with the calibration procedure, which had to be repeated on many occasions, causing frustration and fatigue in many.
- Patients suggested that a device which maintained their head position might be useful, as well as software for communicating by telephone.

The ERICA on-screen keyboard (Figure 3.4) was the first application used by the majority of the patients.

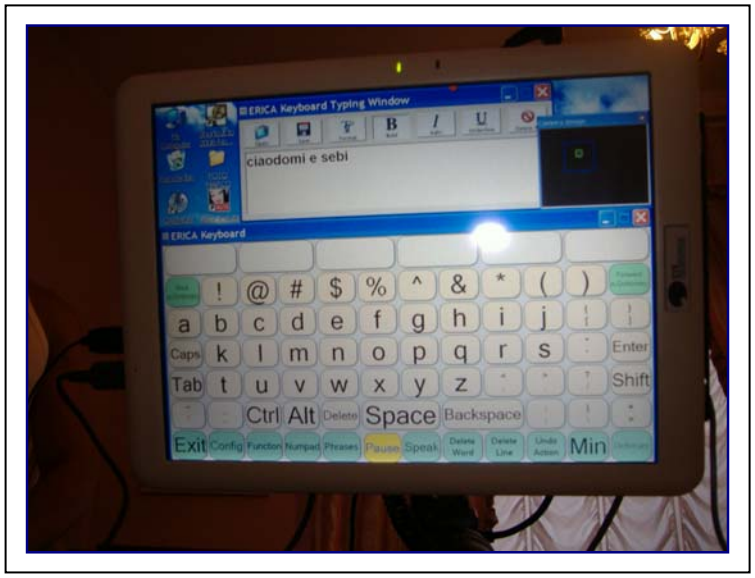

Figure 3.4. The ERICA keyboard in use by a patient

3.4.4 ALS Centre Questionnaire

See Appendix 3.2 for the questions in the ALS Centre Questionnaire.

The results for the questions are as follow.

1. Time:

During the trial week, 50% of patients used ERICA every day; 25% of patients used ERICA on 5 days and the remaining 25% of patients used the eye-control on 3 days.

50% used ERICA for 2 hours every day; 25% used the system for 1 hour; 12.5% used it for 30 minutes and the remaining 12.5% of patients used ERICA more than 2 hours every day.

2. Learning:

50% of patients said that the time it took to learn how to operate the ERICA was acceptable; 25% said that it took too long; and the remaining 25% said that it had been very quick to learn how to operate the system.

For 25% of patients, learning to control the ERICA was difficult; for 25% it was a little complicated; for 25% it was not easy, but not too difficult; for 12.5% it was possible and for the remaining 12.5% it was easy.

At the end of trial, 37.5% of the patients felt they were able to use the ERICA quite well; 37.5% felt they could use it well; 12.5% felt they did not use it well; and the remaining 12.5% felt they didn't use it well, but not badly either.

The biggest problems were: concentration (37.5%); technical difficulties (25%) and managing the eye control hardware (12.5%).

Other problems included difficulty in maintaining head position (50%), eye fatigue (25%) and being too slow (12.5%).

3. Satisfaction:

For 37.5% of patients, the satisfaction level was quite high; for 37.5% satisfaction was medium and for 25% poor.

It was felt that easier communication made it easier to accept the consequences of having a disability because it was possible to say/do things that might not otherwise have been possible.

It was also felt that eye-control was comfortable and flexible, and required relatively little effort.

3.5 Discussion and Recommendations

The medical team's initial impressions were very positive. They felt that the level of satisfaction and engagement gained from eye-control was relative to the level of the person's disability. Patients that were unable to speak or move any limb (typical of the middle stage of ALS) were very motivated to learn a new method of communication and felt that eye-control gave them hope. The team felt, following the trial, that eye-control is a real option for ALS patients once other methods of control (head-mouse, switches etc.) have failed.

Currently in Italy, few people use eye-control systems, even though for many, this is the only access method that will work. Reasons for this include the high price of systems and the extensive support required for successful use. The Italian health service also does not currently assist with the costs of purchasing expensive eye-control equipment.

It is hoped that this sort of eye-control trial will contribute to an improvement in the situation in the following ways:

- The Italian assistive technology market can receive input directly from disabled people who are interested in eye-control – some of the patients expressed a great interest in contacting assistive technology companies and pursuing the provision of this technology.
- The assistive technology market will eventually have more interest in this technology as sales increase.
- Eventually, the Italian health service may realise the need for their participation in this process.

The majority of ALS patients are not aware that is possible to write a letter, play chess, send an e-mail, or communicate needs, emotions, and problems with only eye-gaze, and the COGAIN project, and in particular, user trials, are a starting point for a positive change in the current situation in Italy.

4 ACE Centre User Trials

4.1 Summary

The ACE Centre, the leader of Work Package 3, adopted a case-study-based action-research methodology to investigate conditions for successful use of eye control technology by end-users with complex visual and physical difficulties. By comparative analysis of the performance and progress of a range of participants, a number of conditions emerged which were perceived as having an impact on enhancing even the most complex end-users' chances of successful access to this technology and optimising its usability. This chapter will discuss the results of these case-study-based user trials and provide recommendations for those wishing to achieve success with complex end-users from the outset.

4.2 Introduction

At the time COGAIN started, very little had been written about eye control in relation to the needs of those with visual difficulties and severe involuntary head movement. Therefore, it was necessary to take the widest possible perspective in order to find out, in the first instance, what the issues that needed to be explored further actually *were* if the needs of those end-users with complex visual and/or physical difficulties were to be accommodated. A case-study-based approach was therefore adopted which focused on a range of individuals with complex needs, abilities and disabilities. The aim, through comparative analysis of the case studies (Edwards and Talbot 1994, Hammersley and Gomm 2000) was to use Grounded Theory (Glaser and Strauss 1967) in order to identify common themes that provided an insight into the conditions necessary to enable them to achieve success with eye control technology. Once an insight had been gained, it was planned to produce a set of recommendations. It is acknowledged that, because of the level of complexity of the individuals involved, the numbers are not large. Nonetheless, common themes *have* emerged that add to the knowledge base of how well currently available eye-control technology meets the needs of complex end-users and what needs to be done in order for it to meet their needs more effectively. It is hoped that the results of this research provide a basis for further, more specific investigation. At the time the COGAIN project began it was evident that there were a number of people whose complex physical difficulties (e.g. severe involuntary head movement) and/or complex visual difficulties (e.g. severe nystagmus) made it difficult for them to use eye control technology. This issue was illustrated in Deliverable 3.1 using the following Diagram in Figure 4.1.

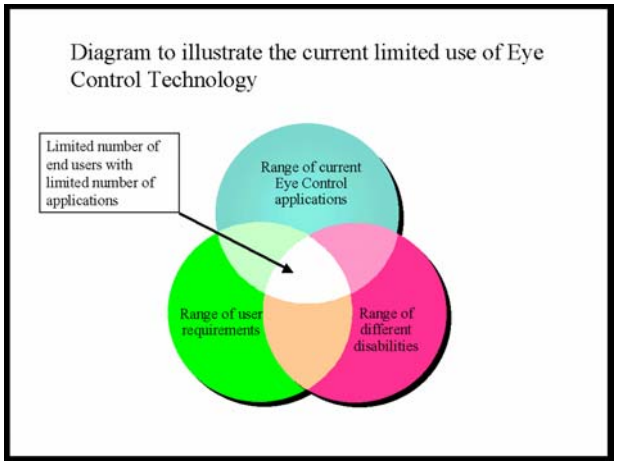

Figure 4.1. Diagram taken from Deliverable 3.1 to illustrate the range of users who are currently excluded from using eye control technology.

As described in Deliverables 3.1 and 3.2, the people with disabilities who were able to use eye control successfully were usually people who could write well and had good eye-control. The group of people with disabilities who were *not* using eye control included many of those who, for example, were not literate and/or had severe involuntary head movement and/or had complex visual difficulties. However, it was this *latter*, 'excluded'group which caused the greatest concern amongst professionals that contacted The ACE Centre in relation to the COGAIN project. Even before the project started, several professionals and carers responsible for meeting the needs of such people had already contacted The ACE Centre with requests to be involved in the COGAIN user trials.

The choice, therefore, for The ACE Centre was clear - either to carry out trials with a community of end-users who could already access this technology or to carry out trials with those people who were experiencing difficulties in accessing it and yet who could, potentially, benefit just as much as those who could use it already. A choice was made for The ACE Centre to focus on the latter group and to explore ways of making eye-control technology as accessible to this 'excluded' group as possible.

The challenge that needed to be addressed was to explore and highlight the ways in which eye-control systems and/or applications could be adapted in order to try to meet the needs of this particular group of end-users. It was planned that the information gathered from the research could then be fed back to stakeholders for them to take into account in the future. Tobii were already a partner in the COGAIN project. With more commercial partners joining the COGAIN project during 2006, it was anticipated that there would be an even greater opportunity for the findings of the COGAIN user trials to influence developments in this field on a wider scale. To explore the needs of complex end-users for whom the effective use of any form of eye-control seemed difficult or impossible, the following decisions were made:

- To work with a range of complex end-users to explore the ways in which the available systems and software needed to be modified or adapted in order to meet their needs.
- As a result of working with these end-users, to communicate what these difficulties were to eye-control stakeholders, i.e. potential end-users, researchers and developers, professionals and those supplying and developing eye control systems and software. (By "software" this included not only software specifically written for eye-control but, very importantly, software that could, potentially, be adapted for eye-control.)

During these first two years of the COGAIN project, therefore, the approach of The ACE Centre has been to:

Work with a range of complex end-users to gain an insight into the ways in which both systems and software need to be adapted.

- Collaborate with researchers, developers and manufacturers already involved in this field to modify and develop systems and software to better accommodate the needs of end-users as they emerged.
- Publicise the issues involved as they have emerged, through publications, Deliverables and presentations at conferences, etc., in order to increase awareness and influence change.
- To use case study material to provide exemplars of end-user needs in order to illustrate (i) the types of end-user need which are not currently being met (ii) to illustrate the potential benefits of adapting/utilising/modifying this technology and (iii) to illustrate the wide range of issues which need to be taken into account when introducing/implementing this technology.

4.3 Methods

As described above, the challenge presented by our user trials has been to identify the conditions necessary for eye-control software to be used as successfully as possible by as wide a range of end-users as possible. Essentially, this challenge involved an exploration of two main areas:

- The conditions necessary to achieve as successful a *calibration* as possible with a varied selection of the most complex end-users.
- The conditions necessary to achieve a successful *implementation* of the use of eye control technology once as good a calibration as possible had been achieved.

In this context, the term *implementation* covers all of the activities that end-users carried out on the computer following the initial calibration trial. For some, this involved a brief trial with a limited range of software specifically focused on gaining an insight into their potential functional use of it. For others, however, the implementation trials took place over a longer period that, in certain cases, involved extensive personalisation, modification and programming. Because the people selected for this enhanced level of involvement were amongst the most complex and, as a result, the customisation process was very labour-intensive, the number of people involved in these extended implementation trials was limited. Nonetheless, the information gained was valuable and many of the obstacles to their successful use of this technology have already been reported in earlier Deliverables and action subsequently been taken by the commercial partner whose system was used (Tobii) to overcome them. Furthermore, the personalised applications designed for these people during the action research process are already providing valuable exemplars for manufacturers, developers and those carrying out eye-control assessments.

4.3.1 Participants

- A range of end-users with complex physical and/or visual difficulties. Some were involved in a one-off trial involving calibration and a brief trial of the system only. Others were involved in longer-term implementation trials. They included end-users already known to The ACE Centre for whom it was felt that eye-control could be beneficial, combined with a group of end-users who were referred to us as a direct result of the project. The aim was to work with a cross section of end-users with a variety of the types of difficulties that can make control of eye-control systems either difficult or impossible. Those people who were involved in the trials were provided with information relating to the COGAIN project and a questionnaire to ensure that they understood the purpose of the trials and their level of commitment and involvement. (Appendices 4.1 and 4.2)

As well as a range of disabilities, there was also a wide geographical spread. The participants included end-users from the following locations:

- Three adults with high-level spinal injuries (The Spinal Injuries Unit, Glasgow)
- Three children with cerebral palsy and/or visual difficulties (at a special school in Newcastle, in the North East of England)
- Seven people, aged seven to adults, with cerebral palsy and/or visual difficulties (The Central Remedial Clinic, Ireland)
- Two people, a child and an adult, both with athetoid cerebral palsy (SCTCI, Scotland)
- 17 people with a range of complex accessing difficulties, aged 10 to adults, either selected by, or referred to, The ACE Centre for involvement in the user trials. These included people with complex physical and/or visual difficulties resulting from multiple sclerosis, athetoid cerebral palsy, a rare metabolic disorder, an unknown degenerative condition, head injury, locked-in syndrome and brainstem stroke. One end-user was from Finland and another end-user was from Germany. The rest were from the UK.

In addition, valuable additional experience and information has been gained by trialling eye-control systems with people both with and without disabilities at conferences, presentations, exhibitions, etc.

4.3.2 Data collection

Methods for data collection for both calibration and implementation trials included:

- In advance of a trial – Discussions with the end-user (where possible) and/or those involved in their support (e.g., parents, professionals, etc) to help to plan and prepare.
- Video material
- Field notes
- Informal interviews in relation to the performance of the eye-control systems and software, leading to subsequent modifications as appropriate.

In the case of the longer-term implementation trials that involved personalisation of the software, the data collected also helped form part of a cyclical process that involved an ongoing review of the success of the system and software trialled in order to improve its performance over time. Additional information on the methods adopted is provided in Appendix 4.3

4.3.3 Calibration trials - aim and planned outcomes

Aim

To gain an insight into the ability of different systems' calibration processes to accommodate different individuals.

Planned outcomes

- Observations on any features which present a barrier to calibration
- Observations on any features which assist calibration
- As a result of the above, produce guidelines on desirable features.

4.3.4 Implementation Trials - aim and planned outcomes

In this context, the term "implementation" covers all of the activities that end-users carried out once the calibration process was finished and as effective a calibration as possible had been achieved. This includes all eye *control* activities ranging from a brief one-off session to a loan or sequence of loans over a longer-term period - anything from several days to several weeks, depending on the individual, their situation and equipment availability.

Aim

To gain an insight into the issues and strategies involved in enabling and adapting eye-control technology to accommodate the eye-control needs of individuals with complex accessing difficulties, e.g. involuntary head movement or visual difficulties.

Planned Outcomes

Highlight issues relating to the process of adaptation of hardware and software to individual needs.

- Hardware issues – mounting, positioning etc.
- Software issues – adaptations that are necessary or recommended in order to meet individual needs.

4.4 Results

A range of issues emerged relating to the conditions for successful use of eye control technology by the kinds of complex end-users described above. These included the following:

4.4.1 Issues related to achieving a successful calibration

A wide range of issues that influence successful calibration emerged, relating not just to the features available in the eye-control system and application software used but also a range of external factors such as environmental conditions.

4.4.1.1 Impact of the environment in which calibration takes place

Environmental issues included the following:

Lighting conditions

The positioning of the eye control system in relation to the window(s) and the amount of sunlight coming through the window(s) could have a significant impact on success. In one room, which had full-length windows down either side, no calibration at all was possible with the high-level eye-control system used. Similarly, the type of electric lighting used and the angle of reflection if the end-user were wearing glasses, could also have an adverse effect. Careful positioning of the end-user and the equipment in relation to the ambient lighting conditions was found to be critical to increasing the chances of success.

Attendees at the initial user trial

It was found that the number and composition of those people who attended the user trial and the way in which they behaved during the session could have a significant impact on the success of the calibration and subsequent use of the system. Because of the high level of interest in this new technology, there could be a tendency for those attending the user trial to become a "crowd" unless steps are taken to prevent this. It was observed that the larger the number of people attending, the greater the potential risk of the person either being distracted or put under unnecessary stress due to a perceived requirement to "perform", thus increasing

the likelihood of involuntary movement, for example. Certain trial end-users understood this potential difficulty well and even before the trials had begun had requested that the numbers were kept to a minimum, including one young person who requested that her parents be kept out of the room during the initial stages of the trial.

4.4.1.2 Potential benefits of repeating the calibration process

In several cases, it was found that a person's calibration could be significantly improved by either repeating the whole calibration process or, alternatively, using the facility to improve poorly calibrated areas of the screen, where this facility was available.

It is unknown whether or not this was due to the end-user becoming more familiar with, and therefore more relaxed with, the calibration process or for another reason or reasons. Whatever the reason(s), though, from our own experience it is recommended that repeating either some or all of the calibration process is well worth trying if a less than optimal calibration is achieved.

4.4.1.3 Issues relating to seating and positioning

Ensuring that the end-user was well supported and comfortably seated was also a contributory factor to a successful calibration. In addition to this, it was important that the system was in an optimal position for the end-user to operate the system comfortably. Having a flexible mounting system that enabled the eye-control system to be moved forwards, backwards, sideways and rotated was necessary in all cases.

Figure 4.2. A fully adjustable Ergotron mounting arm, used here with the LC Binocular Eye Control System.

4.4.1.4 Issues relating to involuntary head movement

One of the systems used for the trials was designed to accommodate involuntary head movement. With a number of end-users who had involuntary head movement using this system, the following observations were made:

- The amount of involuntary movement involved in their use of eye control, in comparison with their usual access method was, in some cases, severely reduced.
- Some of the end-users with severe involuntary head movement felt that, in comparison with their usual access method, eye control might prove to be less tiring. One end-user, Kathrin, who trialled the system for a month, reported that she was able to do more homework because it was less tiring for her than using her switches and, as a result, she was able to write on the computer for longer periods of time.

- In certain cases, too, it was observed that, even after a relatively short period of time, the amount of involuntary head movement that occurred when using the eye-control system decreased over time as the end-user became accustomed to the process.

In certain cases, the eye position of end-users with very severe involuntary head movement went beyond the range that even an eye-control system *designed* to cope with such movement could pick up. In these cases, it was necessary to spend time waiting for such end-users to become as relaxed and comfortable as possible before adjusting the eye-control system so that the system could pick up their eye movement for as much of the time as possible. In this way, the amount of time when the system was not able to pick up the end-user's eye movement was kept to a minimum.

Effect of involuntary head movement on the functionality of the eye-control system

Using the eye-control system designed to accommodate involuntary head movement, a functional calibration was achieved with many of the trialists who had severe involuntary head movement. Indeed, in several cases, the quality of calibration achieved was indistinguishable from someone without severe involuntary head movement. However, it was also found that the degree of accuracy that could be achieved in relation to the end-users *control* of the system could be adversely affected in relation to the severity of their involuntary head movement. As a result, however good a calibration had been achieved *per se*, the accuracy with which certain end-users involved were able to *control* the computer using their eyes was less than optimal. This issue had implications for the design of the software they were able to use and is discussed further under "Implementation" below.

4.4.1.5 Issues relating to visual abilities and difficulties

Choice of calibration with one eye or both eyes.

It is generally accepted that eye-control systems that can be operated by accommodating the movement of both eyes simultaneously offer the potential to be more accurate than systems designed for controlled by one eye only. However, the option of *choosing* to use either one eye or both eyes was found to be at least helpful, if not essential, with certain end-users:

- **People who only have the use of one eye** – One of the end-users, for example, who was described as having "locked-in syndrome", had one of his eyes permanently closed. As a result, it was impossible for him to use anything other than a system that had the option of working with one eye.
- **People with strabismus** – certain end-users with strabismus (or a “squint") were found to require a system that offered an option of a one-eye calibration. It was interesting to note that *neither* of the eyes of some of these end-users was picked up by the system used that was designed for calibration with two eyes only. (This system has since been modified to provide a "single eye calibration").
- **People whose eye dominance fluctuated** – there were certain end-users who, despite the fact that, to the untrained observer, both eyes appeared to move normally and simultaneously, their eye dominance was found to fluctuate, depending on which part of the screen they were looking at. Depending on which eye was dominant at any specific time, the position of the cursor could vary by several centimetres in relation to the position of the target. For such end-users, it was found that a single eye calibration was far more accurate for them than using both eyes.
- **People with difficulties with visual acuity in one of their eyes** – there were certain end-users who, even though (a) both eyes worked perfectly simultaneously and (b) had no fluctuations in eye dominance, still experienced difficulties in achieving a successful binocular calibration with eye control systems designed to be used with both eyes. If this was the case, the cause was frequently found to be due to a "weakness" of some kind in one eye in relation to the other. For example, one

end-user who had no difficulties whatsoever with moving both eyes simultaneously, could only control the cursor on the left-hand side of the screen and found it impossible to move the cursor beyond the middle of it, apparently due to what she described as "poor vision" in her right eye.

4.4.2 Issues Related to Implementation

As described above, in this context, the term *implementation* covers all of the activities that end-users carried out once the calibration process was finished and as effective a calibration as possible had been achieved.

4.4.2.1 Impact of the level of difficulty of the task

It was observed that, once the calibration process was finished and the end-user was presented with the opportunity to control the system with their eyes, the level of difficulty of the activity presented to them on the screen seemed to have a direct impact on their performance. As with the difficulties that might result from too many observers, described above, the result could be increased involuntary movement and, consequently, reduced control. The kinds of demands that had an adverse effect on performance included the following:

- Beginning with the dwell-select option turned on, especially if the speed of the dwell-select was found to be too quick.
- Targets that were too small to be accessed easily in relation to the end-user's calibration (for example, the size of the cells containing letters on an on-screen keyboard).
- Software that was difficult to understand or control when seen for the first time.
- Eye-control system software that was unpredictable or difficult to control - for example (a) if the end-user could not easily switch off eye-control independently or (b) if it caused unexpected things to happen, such as the appearance of on-screen mouse buttons when they were not required.

As a result, The ACE Centre team have begun to develop a range of carefully designed activities that it intends to use as exemplars for others wishing to introduce eye control technology to complex end-users. Below, for example, is a screen from a grid set designed to introduce the user to eye control for the first time (Figure 4.3). With this screen, nothing actually happens. The user cannot ‘select’ any of the items on the screen. As a result, they cannot ‘fail.’ All that it is designed to do is provide the user with a successful initial introduction to eye control by giving them visual feedback of which cell they are looking at. When the screen below is used with the special MyTobii dwell-select feature illustrated in Figure 4.10, when the user looks at a particular face, the MyTobii dwell-select visual feedback appears in the middle of the cell.

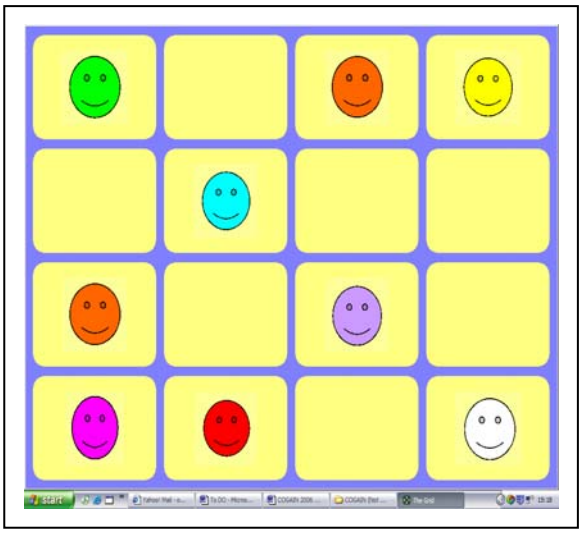

Figure 4.3. An introductory, 'failure-proof' eye-control grid[2] – nothing happens other than the user gains a gentle introduction to eye control through visual feedback of where s/he is looking at.

4.4.2.2 The impact of increasing the size of the end-user's application targets

As described above, regardless of how good a calibration could be achieved, involuntary head movement sometimes had an adverse effect on their ability to control the system, even if the system was *designed* to accommodate such movement. However, if using a grid-based system, this problem was overcome by designing grids with appropriately sized targets.

With several end-users, despite the fact that they could successfully access smaller targets, they chose to use larger targets, despite the fact that, as a result, the software used was less efficient and required more 'hits', therefore taking more time to use.

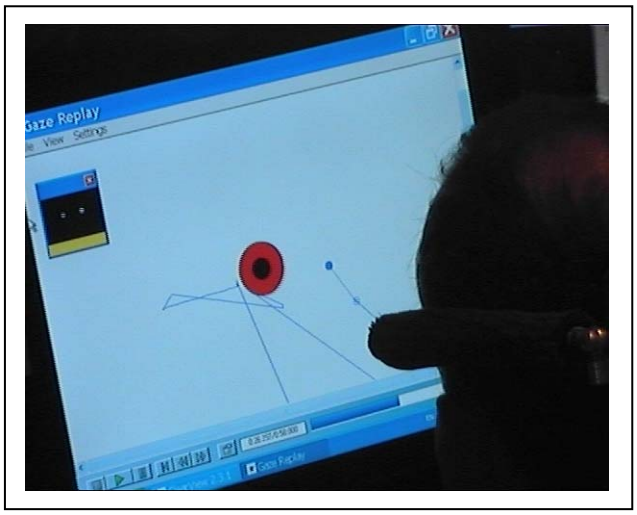

Figure 4.4. Due to his involuntary head and eye movement (nystagmus) Michael experienced difficulties tracking the slowly moving red ball. The blue line represents his involuntary eye movement over a period of approximately one second.

[2] 'The Grid' from Sensory Software was used to make the grid shown in Figure 4.3, as well as many others such as grids shown in figures 4.6, 4.7, 4.12, 4.13.

A similar preference was expressed by an end-user who had a combination of involuntary head and eye movement (nystagmus). Even though he could successfully access cells in a 2 x 4 grid, he preferred to access larger cells in a 2 x 2 grid because he did not have to "work as hard" in controlling either his head or his eyes in order to "hit" the required target (see Figure 4.5).

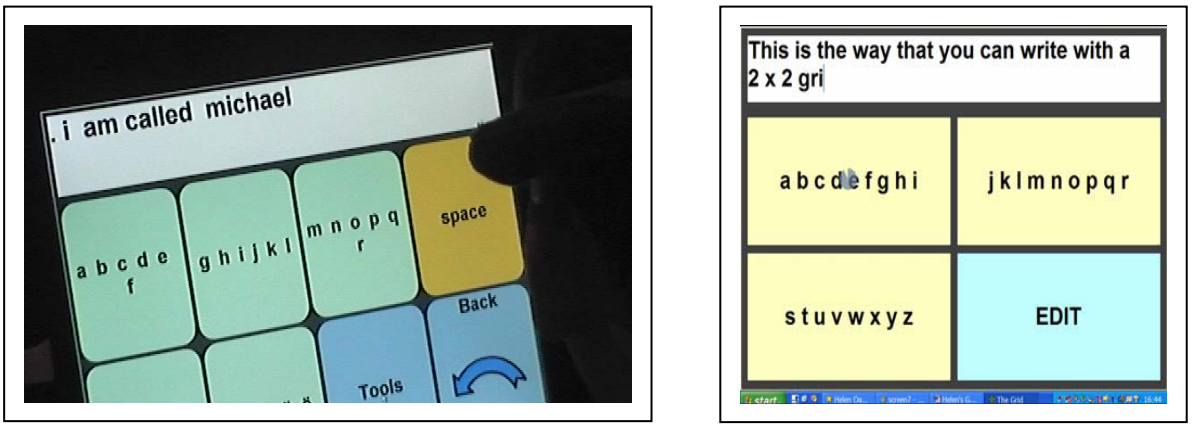

Figure 4.5. Despite the fact that Michael was able to write using the more efficient grid set (left), he preferred to write using the less efficient grid set (right) because it required less effort from him.

4.4.2.3 Issues relating to the positioning of interface targets

The positioning of the end-user's interface targets was also found to be an issue requiring careful attention for certain end-users with visual difficulties. For example, amongst the end-users involved in the trials who were described as having "locked-in syndrome", there were two people who could only move their eyes in one 'plane'. One end-user, Russell, could only move his eyes in the vertical plane (i.e. up and down). The other end-user, Steve, could only move his eyes in the horizontal plane (i.e. side to side). For these people, their user interface had to be designed so that it was presented to them on the areas of the screen that they *could* access in relation to their visual scanning ability.

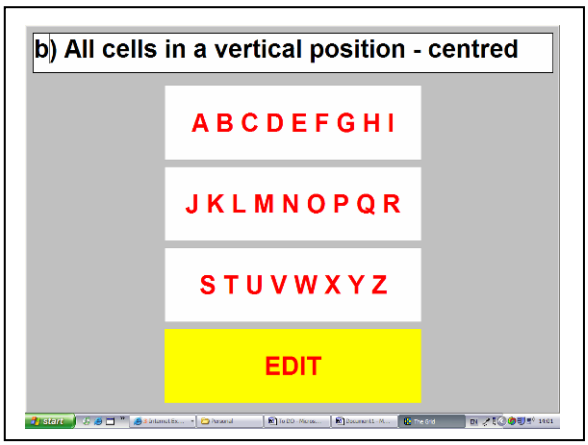

Figure 4.6. Russell's writing grid was similar to Michaels 2 x 2 grid (above), but the cells were presented in a way that he could access them using his vertical eye movement.

4.4.2.4 Building on the end-user's abilities and interests

As described above, carefully graded 'failure-proof' activities were found to be helpful in the early stages of implementation. In addition, it was found that enjoyable, non-challenging user-focused activities, based the interests and abilities of the user involved, also had a motivating and relaxing effect in comparison with more challenging activities. With Sarah – a teenager, for example, a 'shopping' activity was designed which presented her with a range of shopping items from which to choose. In the example below, there are four items from which she can choose. She was asked which of the items was her favourite. Nothing happened when she looked at the item other than it being highlighted by the dwell-select feature used. Thus, she was able to scan the items in a stress-free manner until she settled on the one she wished to choose. Then, when she had finished indicating the item she preferred, she was independently able to turn the page by dwell clicking on the forward arrow.

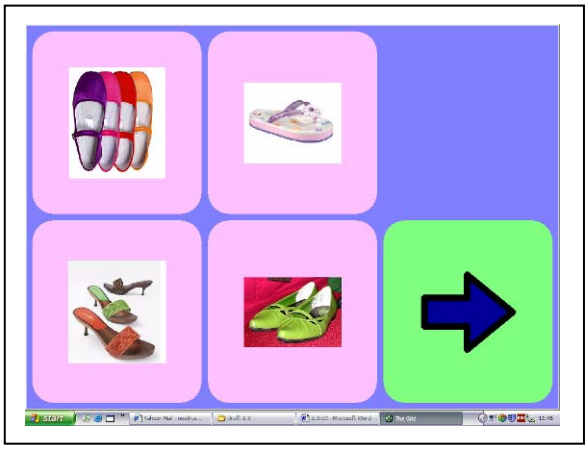

Figure 4.7. Example from a ' failure-proof' grid set designed to taking account of the interests and abilities of a specific user.

4.4.2.5 Having a choice of visual feedback in relation to cursor position

The importance of auditory support has been described in detail in Deliverables 3.1 and 3.2 and was used, as appropriate, as a matter of course in the trials. During the trials, too, the nature of the visual feedback provided to inform the end-user which part of the screen they were looking at was also emphasised and was found to have an equally important, if not critical, effect on their control of the system. Much of the currently available software that is used for eye-control by people with disabilities who have no visual difficulties or involuntary head control is accessed by an on-screen pointer (or cursor) of some kind and provides direct visual feedback of where the eye is looking.

For example, Bjorn Andre (in Figure 4.8.) operates the computer from a side-lying position. His eye-control is excellent and he maintains a very stable head position. He controls the on-screen pointer using his eyes in the same way that others use a mouse. All he needs is an on-screen keyboard and the mouse control utility provided within his eye-control system software and he is able to carry out all of the tasks he wishes to on his computer in the same way as anyone else. Many end-users like Bjorn who are able to use pointer control, develop the skill to compensate for any slight variations between the point at which they are looking on the screen and where the cursor is positioned by simply adjusting the point at which they are looking.

Figure 4.8. Bjorn Andre's eye-control is so good and his head is so still that he is able to have full control over all Windows applications, by using direct control of the on-screen pointer using his eyes, combined with a small on-screen keyboard.

However, for several of the end-users with involuntary head and/or eye-movement we worked with, pointer control of this kind was difficult due to the extent to which the cursor position varied from the point on the screen they were actually looking at. For those experiencing this difficulty, for example Helen, in Figure 4.9 below, the appearance of a cursor within her peripheral vision constantly caused her to try to see what it was. The result of this was, in effect, to 'chase' the cursor off the screen.

Figure 4.9. Helen, whose involuntary head movement made control and visual tracking of a standard pointer (or cursor) difficult. She needed a special form of cursor feedback to be able to control the computer effectively.

Direct pointer control for Helen was, therefore, difficult. However, by utilising a special dwell-select feature, currently available for the MyTobii system, Helen was able to focus on, and subsequently select, targets on the screen without a problem. This feature, also described in deliverable 3.2, highlights the centre of the cell only when the computer interprets that the eye is looking anywhere within a cell. Evidence from the user trials suggest that one of the potential advantages of this feature for those who do not achieve a particularly good calibration is the centre of a cell is highlighted, thus encouraging them to maintain their gaze on it while that particular cell is being selected (Majaranta et al., 2003b). As a result, even though the calibration might

not be particularly accurate, as far as the end-user is concerned, this is not noticed and does not cause a problem with their control. From the end-user's perspective, they are looking at the middle of the cell and it is the middle of the cell that is giving them visual feedback (as in Figure 4.10). As far as the end-user is concerned it appears to be a perfect calibration.

Figure 4.10. Screenshot to illustrate the MyTobii dwell-select option for use with cells in grid software.

In Helen's case (see Figure 4.11 below), a combination of this dwell-select feature *plus* specially designed grids with large cells resulted in her achieving successful access and control over her eye control system.

Figure 4.11. Helen is successfully reading a book and turning the page with her eyes, thanks to a combination of large targets and a special dwell-select feature that prevents her from being distracted by a pointer in her peripheral vision.

4.4.2.6 Impact of a graded or developmental approach

As described above, presenting the end-user with activities that were too challenging at the outset could have an adverse effect on their chance of achieving success. With end-users who were trialling systems over an extended period, too, it was found to be helpful if the activities were “graded” i.e. beginning with "fun" activities that gradually became more challenging over time. We began trialling the MyTobii system with Helen, for example, when she was aged nine. At that time, both her reading and spelling ages were described as being within the normal range. As a result, during her initial two-week loan, a number of grids were designed for her with literacy based activities, such as providing her with large letters that she could, in

principle, easily access using eye control, in order to spell out her name. However, at that early stage in her use of eye-control, the opportunity to 'write' in this way had no appeal for her and she simply chose letters at random. The activities she enjoyed more were the games and stories that had also been prepared for her, such as the example below, Figure 4.12.

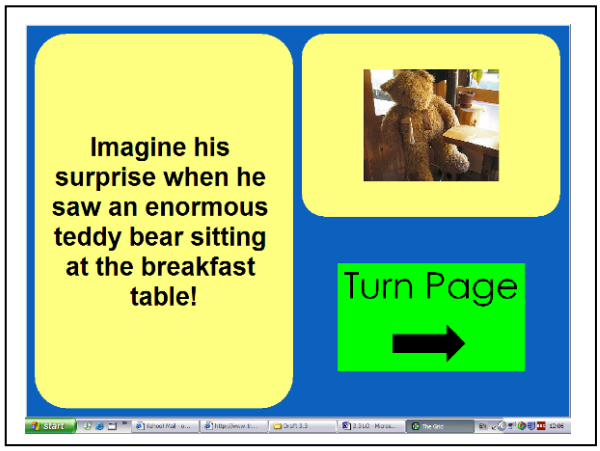

Figure 4.12. An example of the graded activities which helped to develop the eye-control skills of an end-user.

In fact, it took nearly a year of carefully graded and personalised activities and a sequence of two-week loans before Helen began to use the literacy skills that everyone knew she had, in order to write functionally 'letter-by-letter' and not just with whole words and phrases. The turning point was when those working with her informed us that one of Helen's favourite activities was to dictate and receive emails. For this reason a personalised, eye-controlled emailing utility was designed for her using The Grid. This, combined with encouragement and support from her Teaching Assistant resulted in her successfully using eye-control to write her emails. Because of her involuntary head movement, it was necessary for her to use larger targets, so she needed two "hits" to select each letter that she wanted. For example, as can be seen in from the examples in Figure 4.13, to write the letter 'b' she had to initially select the group of letters containing the letter b', and subsequently select the letter she wanted from the grid of individual letters that subsequently appeared.

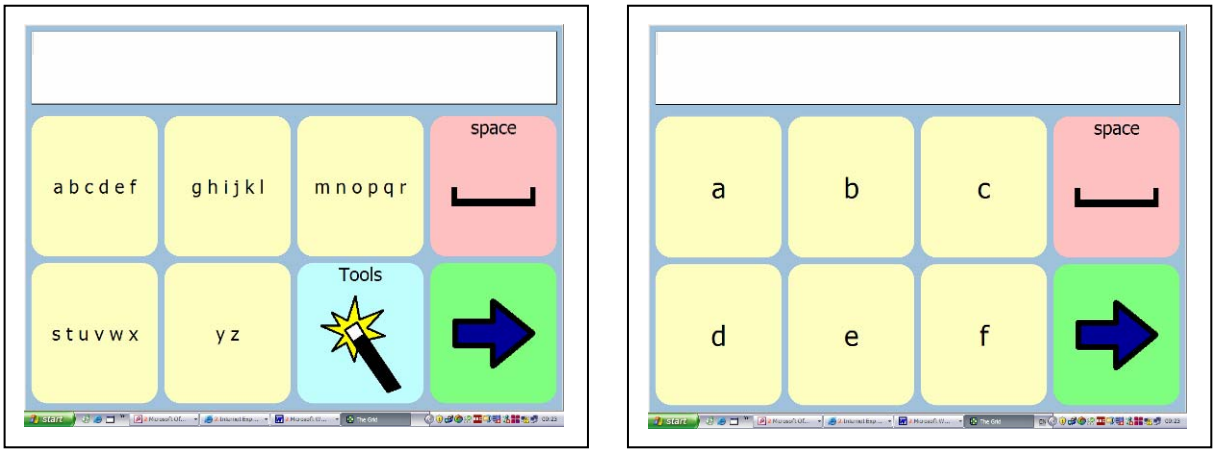

Figure 4.13. With this grid set, Helen could write, using large targets, with two 'hits'. By selecting the 'a-f'' cell for example (left), the individual letters appeared with which to write (right).

4.4.2.7 Physical impact of using eye control for end-users with involuntary head movement

There were indications that the use of eye-control might offer a less physically demanding control method than some others, for certain people with severe involuntary movement. For example, from our observations of several end-users, the use of eye movement as a form of control alone did not trigger off the same degree of involuntary movement as with some other more commonly used access methods.

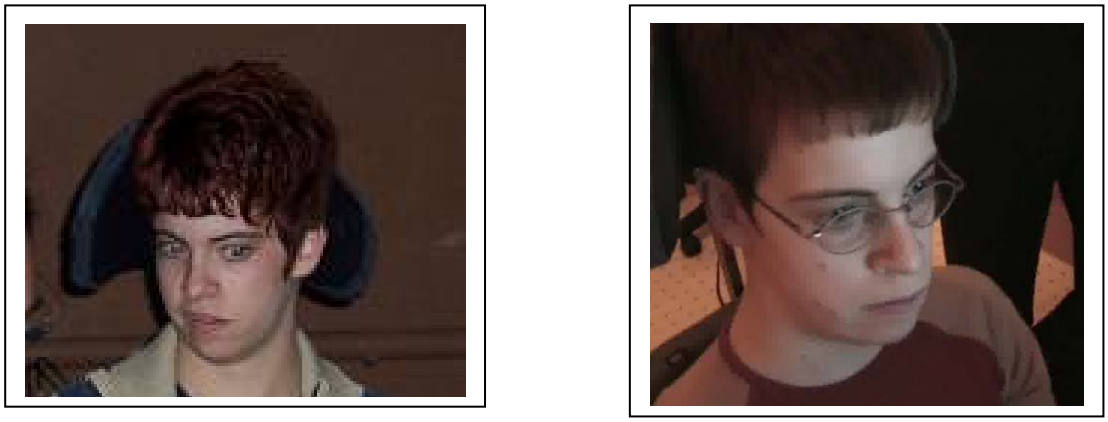

Figure 4.14. Kathrin's usual way of writing (left) involved the use of four switches, three in her headrest and one operated by her knee. During her month's trial, she felt that eye control (using similar, adapted software) was less tiring for her and she could continue using it for longer.

The result of this, in the opinion of Kathrin (Figure 4.14), who has athetoid cerebral palsy, was that she was able to retain sufficient energy to write for longer periods of time. To enable her to compare eye-control with her existing switch control method more easily, an eye-controlled version of her specially written, customised switch software, 'ERIC' (Figure 4.15), was developed in partnership with her programmer.

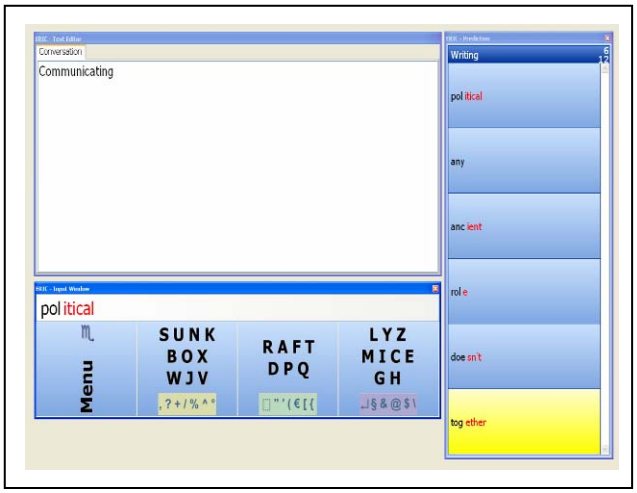

Figure 4.15. The 'eye-friendly' version of 'Eric' written in partnership with Jorn Garbe and adapted for eye control in collaboration with The ACE Centre.

Having trialled eye-control for a month, the outcome was that she considered eye-control to be less tiring than her usual method. This is what Kathrin wrote following the month-long trial:

> "With switches, even software as efficient as ERIC can be very tiring over long periods. This is why I have been amazed by my use of eye-control. In contrast to switch-based input I can now write long texts with ERIC without getting sore muscles. Often hours passed by. My texts grew even longer. The longer I wrote, the more relaxed my body became. At the same time, my speed improved on a daily basis. After one month I had the feeling that I was at least as fast as with my switches. I was thrilled: longer text in the same time with less stress. This was a huge step forward."

It must be emphasised that no trials have yet taken place specifically to investigate the physical impact of eye-control in comparison with other access methods. However, it is felt that this is an area that merits further investigation in the future. If, as is suggested from our initial observations, eye-control can be less physically demanding than other access methods, then eye-control would not just be considered as an access method for those who cannot use anything else, but could potentially become the *choice* of a wider range of end-users, subject to the necessary funding being available.

4.5 Discussion and Recommendations

The approach that was found to enhance the chances of successful use of eye-control technology with end-users who had complex disabilities during the course of the user trials can be summarised under three headings:

- **K**nowledge-based
- **E**nd-user focused
- **E**volutionary

We refer to this process as the *'KEE' approach* to trialling and implementing eye control technology.

4.5.1 Knowledge-based

The *Knowledge-based* approach was founded on what was known of the end-user's physical and cognitive abilities in relation to what was known about the ability of the range of hardware and software available to meet them.

Background information relating to the abilities and needs of the end-user can provide a valuable backdrop to the way in which a user trial is carried out. As with preparing for any technology control assessment, issues such as comprehension, level of literacy, interests, current technology control method, low- and high-tech communication system, etc. need to be taken into account. In addition, only if those conducting the trial can complement this information with a *detailed* knowledge of the systems and software available will it be possible to give the person the best opportunity to use an appropriate eye-control system to optimal effect.

4.5.2 End-user focused

The term *End-user focused* relates to the importance of developing and adapting applications specifically designed to meet the particular end-user's interests and needs.

There are various important factors to consider when deciding on which activities to present to an end-user during an eye control trial. It has been our experience so far that many of the physically complex end-users involved in our trials also have complex visual/perceptual difficulties which may not be fully diagnosed or understood. For this reason, the trials begin with a range of undemanding activities designed simply to gain an insight into what our participants are able to see and understand, to complement what has been learnt about these abilities before the trial. Even for those end-users who may well have been ready to start eye-typing immediately, there is no harm in starting with a less demanding activity initially to make the participant feel

confident and relaxed. It must be remembered that, even for fully literate, visually and cognitively able end-users, controlling a cursor with their eyes is still a new skill. At the other extreme, many end-users with a physical and/or visual impairment have complex difficulties that could be exposed by their use of eye control. The concept of dwelling on an item in order to make a selection is unfamiliar to most people and it can be very disconcerting to make unexpected and/or unwanted selections. Not being familiar with software or knowing how to navigate from area to area can also be confusing and/or frustrating. For many of the people who took part in the trials, increased emotional anxiety seemed to be very closely linked to increased involuntary physical movement, which subsequently adversely affected eye control. This, in turn, could increase frustration and further increase involuntary movement – a vicious circle.

It has become apparent during many of our trials that eye control is often suggested when almost all other options have failed or have become impractical. Because of this, even when it was made clear that any work being done was project-related and of an exploratory nature (rather than an assessment of any kind), there could still be very high expectations of the trial. It is recommended therefore, that if the trial is unsuccessful, it should be made clear to those involved that it is not the fault of the end-user. Rather, it is the fault of the currently available technology and/or software at this moment in time. If this view is understood, there is a greater chance of the end-user retaining a positive attitude for any future trials with this technology.

4.5.3 Evolutionary

The term *Evolutionary*, in this context, means that the design of the application software trials should evolve and change, when necessary, in relation to the end-user's response to eye-control technology and application software used in a graded or developmental fashion.

A carefully planned progression of personalised activities can enhance the chances of a successful and positive experience for the end-user during their trial. During our own initial trials, we regard it as our role to explore whether or not eye control can *potentially* be achieved and, if not, adjust or modify the software and/or hardware available to us to enhance the chances of success in subsequent trials. If necessary, this might involve working in partnership with manufacturers and developers. As a result, changes can be made with the aim of making the system more accessible to a specific end-user. In the best traditions of action research methodology, this is an evolutionary, cyclical process where each modification or set of modifications is re-trialled, with the end-user involved with the ultimate aim of acquiring a personalised eye-control system for the person involved.

As a result of this 'KEE' approach, a different way of unlocking the door to eye-control technology can be found for each end-user. One end-user, for example, might prefer to use an on-screen cursor/pointer and to access Windows directly, whilst another might need or prefer to control the computer via a grid. The examples below (Figures 4.16 and 4.17) show two sharply contrasting interfaces for producing text.

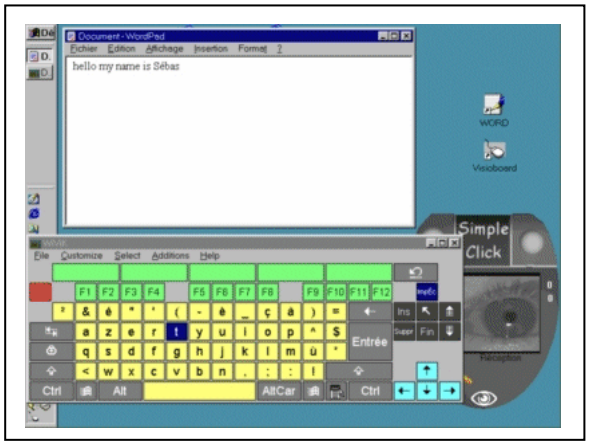

Figure 4.16. An on-screen keyboard writing grid on the Metrovision system designed for someone who wishes to access the computer by direct pointer control.

The writing grid system above is designed for someone who wishes to access the computer by direct control over the cursor/pointer, i.e. by using their eye(s) to carry out the same function as a hand would in controlling a mouse. Instead of a real keyboard, he/she prefers to use a small on-screen keyboard. In this way, he/she can access and use the computer in a very similar way to everyone else. On the other hand, another end-user might require a completely different 'KEE' approach. Someone who has severe involuntary movement, for example, might not be able to control an on-screen pointer well enough to access a standard on-screen keyboard. As a result, he/she might need to use an interface in the form of an on-screen grid with large cells and prediction (see Figure 4.17 below). Even though the system below requires three 'hits', it does enable such an end-user to produce final results that are just as successful as the keyboard illustrated on the Metrovision system.

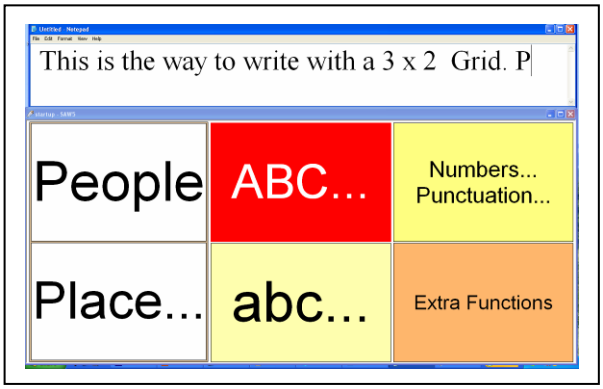

Figure 4.17. A text-based grid with large cells made using SAW (www.ace-centre.org.uk) incorporating prediction ('Prophet'), designed for an end-user who had achieved a poor calibration.

Considerations when taking the 'KEE' approach include the following:

- An appropriate eye-control system(s) that accommodates the end-user's physical and visual/perceptual needs, i.e. a system that is appropriate for the end-user. For some, a system that is able to accommodate involuntary head movement might be required. For others, this might be unnecessary and a cheaper, smaller system can be considered.
- Appropriate mounting and positioning of the system in relation to the end-user's needs, i.e. the system must be positioned for optimal comfort, function and visibility for the specific end-user.
- Appropriate on-screen visual representation (pictures, symbols, text, foreground/background colours, etc.), i.e. ensure that visual images are presented in a way that is clearly visible and comprehensible to the end-user.
- Appropriate organisation of the images on the screen in relation to the visual abilities of the end-users (e.g. visual scanning ability, range/direction of eye movement), i.e. ensure that the visual images are arranged in a way that is most easily understood and controlled by the end-user.
- Appropriate auditory support and feedback, i.e. ensure that the type of auditory support provided to the end-user gives them optimal support in relation to their needs and abilities, i.e. what kinds of sound should be used to assist the end-user in accessing the correct symbols, letters, words or pictures? (Speech, music, etc.)

In some cases, this can take months or even years, depending on the levels of complexity involved and the speed with which the available hardware and software can be adapted or modified. However, if the KEE approach is followed when designing/planning eye control applications and activities for an end-user, The ACE Centre's experiences have indicated that that there is a greater chance of success over the longer term.

5 DART User Trials

5.1 Summary

During our first year of COGAIN partnership DART have organized various information dissemination activities concerning eye gaze technology for people with disabilities. This has led to a number of contacts with users, their families and professionals involved in their care. So far, 14 users with complex disabilities have been involved in our user trials. The interest in user trials continues and we will continue to conduct these, some of which will be in the form of longitudinal trials. In order to carry out user trials with a variety of users, software activities for the introduction of eye gaze control were needed and this resulted in DART having to prepare several introductory activities, like playing music etc. The trials with different users provided information on the need for improvement and development of systems and software in order for eye control to be an effective and efficient alternative for users with complex disabilities.

5.2 Introduction

As the regional centre for AAC and computer access in western Sweden, DART have been involved in the development of methods of computer access for people with severe motor disabilities. DART staff have extensive experience of users with profound physical and communication difficulties and have on-going contact with them. Before the COGAIN project started, we had already discussed the concept of accessing a computer with eye control, and the opportunity to be involved in the COGAIN project was welcomed by staff, users and their families.

At DART our work with users is client-centred and based on OPPM: Occupation Performance Process Model (Townsend 1997), Collaborative Problem Solving in Communication Intervention (Björck-Åkesson, Granlund and Olsson 1996) and BATS: The Bain Assistive Technology System (Bain & Leger, 1997). In the BATS model, components such as the communication aid, the environment and what activity the user would like to perform, combine to form the basis for the user achieving success. When testing computer access methods for individuals with disabilities, there is a need to assess the user's cognitive capacity as well as the components of the communication aid and the environment. Together with colleagues at other computer access centres in Sweden, the occupational therapists at DART have written a book about the ways in which individuals with motor disabilities can access the computer, which helps professionals to prepare adequate assessment tools (Aktiv Med Dator – Möjligheter för Personer med Rörelsehinder; *Active with Computer – Possibilities for People with Motor Disorders* 2005). This book is used at universities for the education of occupational therapists and as reference literature in various other courses concerning assessment of assistive technology. There is also a user-oriented version of the book on the Internet[3] with information and user stories, presented in plain text, symbols and with speech synthesis. The theories and assessment methods described in the book are very relevant when assessing eye control in the COGAIN user trials.

DART's involvement in the COGAIN project started during the autumn of 2005 and in November 2005 we went to The ACE Centre to get more information on the work of WP3 (described in Chapter 1 – ACE Centre User Trials) and to discuss how we could conduct these trials in Sweden.

[3] Online version of "Activ Med Dator" is available at http://www.hi.se:8080/aktivmeddator/default.shtm

By the start of 2006, two eye control systems were at DART and we began familiarising ourselves with the systems and learning about their features and capabilities. We also had several non-disabled people, including children and adults, involved in pilot tests in advance of the actual user trials. This provided good opportunities for us to learn about calibration techniques and how the systems functioned with different people, e.g., people with glasses, different kinds of eye shapes, eye colours etc. User contact began with a two day COGAIN exhibition at DART, with about 70 visitors each day. Further information about COGAIN has been provided and demonstrations of eye control systems have been carried out on seven different occasions. On those occasions, we also gathered information about what the expectations of eye control were, from users, people in their environment and from professionals working with users.

We estimate that information was given to about 340 people including users, parents/family and professionals (who made up the largest group). This led to an article in one of Sweden's major daily newspapers (Göteborgs Posten[4]). A national e-mail circular was sent using DART's address register, with information about the current work in the project and with an invitation to participate in user trials. The COGAIN brochure was translated into Swedish and was used in these information activities. Applications for participation soon started to arrive. All the applicants were given an appointment for a user trial, and anybody that could not make the proposed appointment (e.g. for a health reason) were offered another appointment in autumn 2006. We also contacted occupational therapists that work with users who already have an eye control system at home, in order to arrange interviews with these users. Currently, one interview has been completed. To our knowledge, there are four users in western Sweden who have their own eye control systems, all with Amyotrophic Lateral Scleroses (ALS).

The systems used in the trials during the spring of 2006 have been: MyTobii, CompactRolltalk with ERICA and the QuickGlance. MyTobii and the Quick Glance were purchased with COGAIN equipment funds and were lent to DART for the trials and CompactRolltalk with ERICA was a loan from a company in Norway (IGEL).

5.3 Methods

User trials during spring/early summer 2006 included 14 users, aged between 2 and 63 years old, with varying disabilities. 10 had severe Cerebral Palsy, mainly dyskinetic syndrome and 2 with severe diplegia. One person had Multiple Scleroses, one had Amyotrophic Lateral Scleroses, one had Spinal Muscular Atrophy and one person had severe brain damage after a drowning accident.

Before the user trials, the participants were given written information, and consent forms were signed (Appendix 5.1). The user trials lasted between one and two hours, and we began by giving information to the user and her/his carers/companions. An introductory interview was conducted to establish a user profile and ascertain the users' familiarity with computers (Appendix 5.2). The trial started with an eye control system likely to be most suitable for the user and the calibration process was completed.

In the participant's first attempt to use eye control, they were given a simple music application (Figure 5.1) which helped them to learn how to operate the system and to understand how a 'dwell select' works. This kind of simple applications enable the user to experience the conditions particular to eye control, on their own, in an environment where there is no pressure of performance and where the don't need to worry about making mistakes. Also, importantly, this activity was fun! This approach is especially useful with people who have difficulties following verbal instructions (due to age, language disorders, learning difficulties, neurological disorders etc.)

[4] Kristiansson, T. (2006-03-24). Ny hjälp med ögonstyrd dator. Göteborgs-Posten. Göteborg: 14.

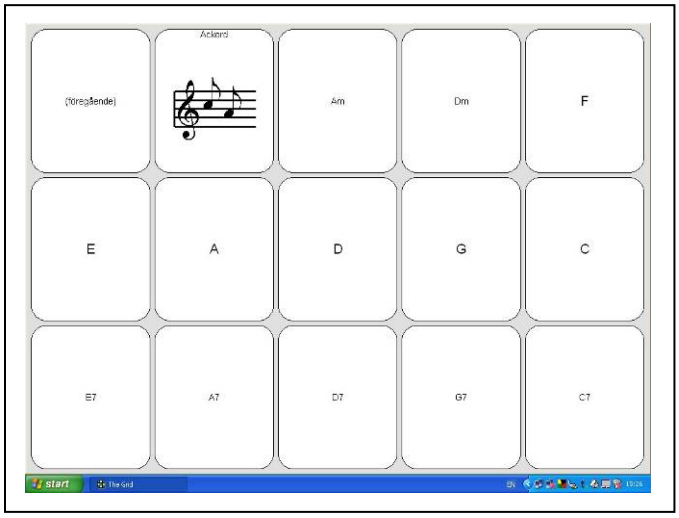

Figure 5.1. Simple music application

On the basis of the user's capacity, interests and age, various further applications were used e.g. choosing different Eurovision Song Contest music, writing with letters, writing with symbols or using e-mail. The majority of the trials were documented on videotape (with user consent). After the trial was completed, further questions about their experience and opinions about the system were asked. The interviews were adapted to suit the user's communicative and cognitive skills (Appendices 5.3 and 5.4), including a special grid for discussing users' opinions on the activities in the trial (Figure 5.2).

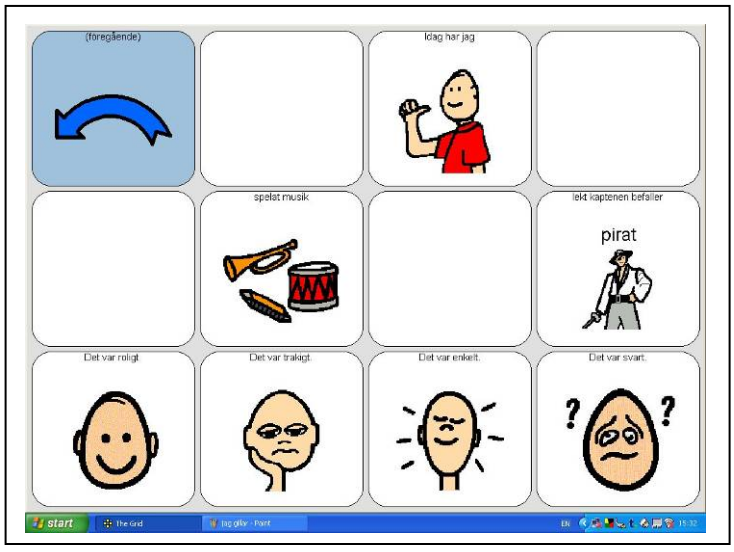

Figure 5.2. Grid application used to discuss the users' opinions on the activities in the trial (mainly for children)

5.3.1 Participants

1. Adult with Multiple Sclerosis, 63 years old

- Equipment: MyTobii and ERICA, both worked satisfactorily.
- Calibration: The calibration with MyTobii needed improvement once.
- Performance: Initially, it took some time for the participant to learn how the system and the dwell select worked.
- Problems: Participant had visual problems and difficulties seeing the letters when writing with MyTobii. It was also difficult to access the letters in the corners of the screen.
- Other reflections: Needed a layout with bigger letters, and a different colour scheme. Also needed auditory feedback when writing.
- The user currently has no independent access to the computer but uses the computer several times each day with the help of an assistant. This user was very positive about the eye control trial.

2. Child with Spinal Muscular Atrophy, 2 years and 3 months old

- Equipment: MyTobii, which worked very well.
- Calibration: Standard settings worked well.
- Performance: Despite the child's age, he had a good understanding of how to operate the system and the dwell function. He was positioned leaning backwards (see Figure 5.3), with the screen above his face. He played music and a game.
- Other reflections: There is a lack of software adapted for MyTobii for young children (using the Windows control mode with direct pointer control is more difficult for children).

Figure 5.3. Kevin playing "Simon Says"

3. Child with Dyskinetic Cerebral Palsy, 11 years old

- Equipment: MyTobii
- Performance: Child had used a head mouse previously, with his head supported by somebody, so he was familiar with the dwell function.

- Problems: The system had some difficulty with finding his eyes - most of the time only one eye was 'visible'. This was probably caused by the fact that the user often held his head to the right. This was improved when a person helped to support his head. There was some involuntary clicking, when the child was simply trying to look at parts of the screen rather than make selections.
- Other reflections: The child felt that eye control worked very well.

4. Young adult with Cerebral Palsy and learning disabilities, 19 years old

- Equipment: MyTobii.
- Calibration: It was difficult to do a calibration. This person did not cooperate.
- Other reflections: The difficulty with calibration could have been because this person did not understand what was expected of him, or perhaps he was not interested in participating that day.

5. Child with Dyskinetic Cerebral Palsy, 12 years old

- Equipment: MyTobii.
- Performance: Managed to play a few notes of music.
- Problems: It was difficult to know exactly how the child was using his eyes. He has a squint, and we were unsure if he was alternating dominance. He did not have a good sitting position, which led to problems raising his head, and consequently seeing the top part of the screen.
- Other reflections: The child found the experience difficult on the whole, and thought that it was difficult to make choices with his eyes.

6. Child with Dyskinetic Cerebral Pares, 16 years of age

- Equipment: MyTobii.
- Calibration: It was difficult to get a useful calibration.
- Problems: It was difficult to know exactly how the child was using his eyes. He has a squint, and we were unsure if he was alternating dominance. He had a hard time seeing what was on the screen.
- Other reflections**:** The child had tried eye control approximately 2 years ago, and felt it worked better this time. On the whole he felt that eye control worked well and was easy, but that he struggled to see what was presented to him.

7. Child with Cerebral Palsy, 16 years old

- Equipment: MyTobii.
- Calibration: Calibration was successful.
- Performance: The system worked well. The participant wrote with symbols, played a game and music.
- Other reflections: The child thought that eye control worked very well and was very easy to use.

8. Child with Dyskinetic Cerebral Palsy, learning disabilities, 10 years old

- Equipment: MyTobii.
- Problems: The child was not interested in the calibration process. Perhaps he was not interested, perhaps it was a sign of protest, or perhaps he did not understand what was expected of him.

- Other reflections**:** At the end of the session, the child felt that it worked 'OK'.

9. Child with Dyskinetic Cerebral Palsy, 16 years old

- Equipment: MyTobii.
- Calibration: The calibration worked, but two calibration points were not successfully calibrated, which led to problems for the user to reach some parts of the screen.
- Performance: Despite the two missing fields, the system worked well. The child wrote using symbols.
- Other reflections: The child thought it worked well and was easy to use.

10. Child with Dyskinetic Cerebral Palsy, 14 years old

- Equipment: MyTobii.
- Performance: The system worked well, but sometimes the control was a bit difficult. This child needed a very short dwell time (0.7 seconds) but also needed more time to learn the location of letters etc.
- Problems: The child has lots of involuntary movement and pathological reflexes (ATNR) that affected how well the system tracks the eyes. There were some problems with reaching the letters in the corners of the screen.
- Other reflections: The child thought the system worked well and was easy to use. This child usually uses a head mouse for accessing the computer and is used to the dwell function. He finds the head mouse tiring and difficult to use.

Figure 5.4. Lina writing with MyTobii's letterboard.

11. Adult with Dyskinetic Cerebral Palsy, 31 years old

- Equipment: MyTobii.
- Problems: In the beginning, the system struggled to recognise his eyes. His eyes are almost closed when he smiles and this made eye tracking harder. He also has a lot of involuntary movement in his facial muscles. The button for 'Pause' appeared regularly (unintentionally) and it was difficult to know whether the system was on or off. We preferred the old version of the software, which indicated this with a red or green cell.

- Other reflections: This person currently has no access to the computer. He thought it worked well and was easy to use. We have always struggled to find a functional access method for this person and eye control appears to be a potential way of him accessing the computer independently, even though there were some problems.

Figure 5.5. Fredrik choosing his favourite song

12. Child with severe brain damage, 12 years old

- This child has no voluntary motor control, apart from his eyes.
- Equipment: CompactRolltalk with ERICA:
- Problems: The user could not complete the calibration process on this system. Equipment: MyTobii
- Calibration: The child managed a manual calibration, with a lot of prompting and support. The system had difficulty in recognising his eyes because of his squint, but some functional tracking was achieved. At a second trial, with the new version of the MyTobii software, the child was unable to complete the calibration process (perhaps not interesting enough?) but the default system calibration worked anyway.
- Performance: He played music and enjoyed it.
- Other reflections: This user would have benefited from more flexible and more individual calibration options, like pictures and sounds to raise his interest and motivation. He currently has no access to the computer.

Figure 5.6. Fredrik, concentrating hard on playing guitar with the computer

13. Child with Dyskinetic Cerebral Palsy, 11 years old

- Equipment: MyTobii, on two occasions, being compared with a Headmouse Extreme.
- Calibration: The 'step through' calibration was used.
- Performance: Initially the tracker worked well. After a while, as the child became more involved and more excited, his spasticity increased, and the system became less successful at tracking his eyes. The lower half of the screen was most accurate. The child used the system to communicate (using The Grid).
- Other reflections: Presently, the child uses two switches, with difficulty, and these trigger a lot of involuntary movement. We feel that the problems caused with eye recognition due to his excitement, would be overcome with practice. Using the MyTobii was much less tiring than using a headmouse, which also triggered involuntary movement.

14. Adult with ALS, 52 years old

- Equipment: MyTobii and ERICA.
- Calibration: MyTobii worked well, but it was not possible to calibrate with the ERICA. This was probably due to movement caused by heavy breathing.
- Performance: The user worked with all Tobii applications and successfully navigated on the Internet too.
- Other reflections: The user currently has no computer access and has great difficulty with communication.

5.4 Results

All our trials so far have been conducted in DART's premises, in a room without windows and with good lighting. Therefore, at this stage, we have no knowledge of how the systems would work outdoors or in rooms with fluorescent lights etc.

MyTobii worked to some degree for all our users, but not with full functionality in all cases.

Only one of the users successfully used the CompactRolltalk with ERIKA. Almost all of our users had very severe motor disorders with involuntary head movement and the MyTobii is one of only two non head-worn eye control systems we are aware of that can currently tolerate head movement to such a significant extent. The other is the LC EyeFollower though we have not yet tried this system at DART.

5.4.1 Calibration

The calibration with MyTobii could be adjusted by changing the size and speed of the target. It is also possible to time the movement of the target manually, which is useful in cases where users have problems following a moving target, or with timing. With young children, people with learning disabilities or brain damage it can be difficult to perform the calibration process. Some people do not understand the task, or why they are being asked to watch a target. With the CompactRolltalk with ERICA system you can choose the appearance of the target, using personal photos, pictures of favourite animals etc. This makes the user interested in the target and he/she can carry out the calibration without verbal instructions or understanding the purpose. MyTobii has a short calibration (there are only 5 calibration points) and the calibration does not always need to be repeated. This is a benefit for most users.

5.4.2 Initial use and training

All our users (children as well as adults) responded well to the initial use of “simple” music grids. As well as being fun, it makes the user feel successful and motivates the user to continue with more demanding tasks. We must not forget the importance of having fun and feeling successful!

Many users could not move on to writing applications (text or symbols) immediately and would need a training period with suitable software. The lack of access to this kind of software is a problem. There are several suitable programs already available but they are not integrated with the eye gaze system. They can only be used in “Windows mode” with the cursor visible, and this is not a suitable means of access for users at this level of training.

5.4.3 Users’ needs

Users who tried MyTobii had problems with the appearance of the “button” for turning on and off the dwell function. They also needed specially adapted keyboards (colours, sizes etc). The option of auditory feedback when a choice is made would also have been very helpful for most of the users.

Functionality was also dependent on the user’s visual ability and their seating position, which affects head control. In some cases it might be necessary to allow the user to choose to work with only a part of the screen.

It is necessary to have mounting systems that allow the position of the screen to be adjusted according to the seating position. There is also a need for mounting systems that allow the users to have their system with them in different situations: sitting in an armchair, lying in bed etc.

5.5 Discussion and recommendations

During our user trials, we found a need for more adaptable calibration procedures. Different users need different features, so a selection of options would be a useful tool that could make it possible for more people to try eye control.

There is a need for software to support initial trials and training in the use of eye control (such as the example grid in Figure 5.7). Software that is already widely used in schools and for leisure needs to be accessible by eye control.

A larger selection of ‘eye-friendly’ software for communication is recommended. Several of our users already use communication programs and it is important that they can continue using familiar programs.

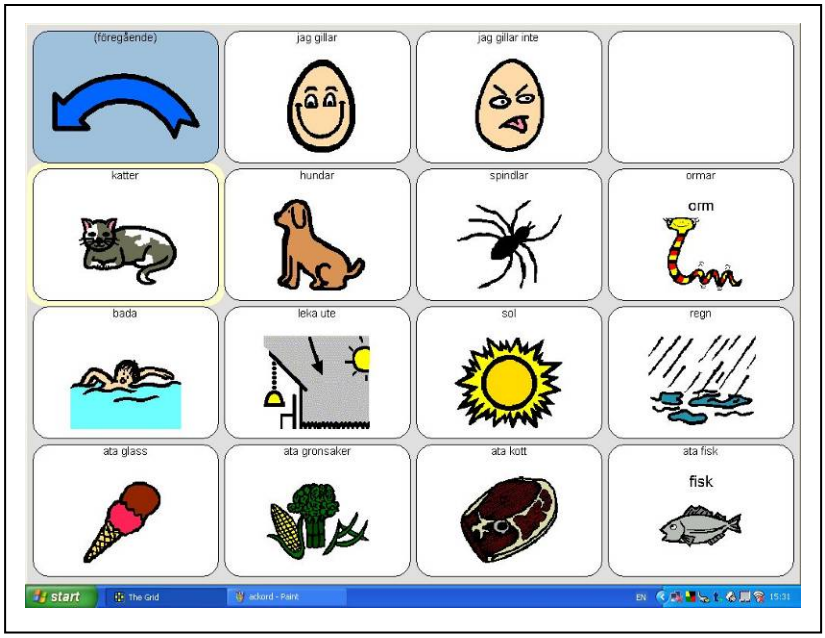

Figure 5.7. An example of a grid for initial use and training. The user can say what she/he likes and dislikes.

Other features also need further development:

- Auditory feedback
- Turning the dwell feature on and off
- Enabling the user to change settings.

We think that the users need to have some cognitive understanding of how to operate the system, including possibly having adaptations available for people with severe learning disabilities, e.g. Retts syndrome – a very challenging group to find computer access for. This has not been tested at DART yet, but is planned for fall 2006.

MyTobii is the system we have used the most. The other systems are currently more suitable for people who sit still, for example people with ALS, high spinal injuries etc. The majority of our users have involuntary movements, and therefore the Tobii was most suitable for them.

We have met numerous people with such severe involuntary movement that finding computer access for them was almost impossible. For them, eye control can be the only way of having independent control of any activity. In Sweden, nobody with this type of disability owns an eye control system yet.

5.5.1 Future plans

In August, more appointments for user trials will be offered. We will also offer 4 people the opportunity to participate in longitudinal testing during the fall. We plan to continue the user trials with those who are interested, and also offer additional opportunities for longitudinal involvement. This will involve regular visits to DART, approximately once a week, over an extended period. The schedule for this period will be planned with the user, whose needs will be accommodated as much as possible. During this period, further interviews will be held and individually tailored applications will be prepared.

We have noticed an increased awareness and interest in the field of eye control and we feel that user trials are an important part of the project and should be continued. There is widespread interest from users who wish to have their own systems at home or at school but there are very limited possibilities for this at present. In Sweden there is a system which would enable therapists to 'prescribe' an eye control system for a user, and it would not cost that user anything, but for this to become a reality, more information, and more reliable systems will be necessary, as well as age appropriate and adaptable software.

6 Conclusion

All of the evidence from the user trials that have been carried out by the three organisations involved, DART, POLITO/Torino ALS Centre and ACE, points to the huge potential benefits for the kinds of people who need it most:

Politecnico di Torino/ Torino ALS Centre

Even though these trials have only been going on with a relatively small number of patients, the medical team's initial impressions have been very positive.

- The level of satisfaction and engagement gained from eye-control was relative to the level of the person's disability.
- Patients who were unable to speak or move any of their limbs were very motivated to learn a new method of communication and felt that eye-control gave them hope.
- The team felt, following the trial, that eye-control potentially offers great satisfaction for ALS patients once other methods of control (head-mouse, switches etc.) have failed.

The ALS Centre's team notes that currently, in Italy, few people use eye-control systems, even though, for many, this is the only access method that they could potentially use. The reasons they give for this include:

- The high price.
- The extensive support required for successful use.
- The Italian health service also does not currently assist with the cost of purchasing expensive eye-control equipment.

Finally, the ALS Centre's team noted that the majority of ALS patients were not aware that it is possible to write a letter, play chess, send an e-mail, or communicate needs, emotions, and problems just by eye-gaze alone. They felt that the COGAIN project and, in particular, the user trials, are a starting point for raising awareness and bringing about a positive change to this situation in Italy.

The ACE Centre (Oxford) and DART

Both The ACE Centre and DART found that there were a number of conditions that needed to be met when introducing eye control to people with complex physical and visual difficulties. These conditions can be summarised as the 'KEE' approach to calibration and implementation, 'Knowledge-based, End-user focused and Evolutionary. Both DART and ACE's findings so far have been remarkably similar and both organisations subscribe to the following key points:

Considerations when assessing for and implementing the use of an eye control system should include the following:

- An appropriate eye-control system(s) that accommodates the end-user's physical and visual/perceptual needs, i.e. a system that is appropriate for the end-user, for example, a system that is able to accommodate involuntary head movement might be required.
- Appropriate mounting and positioning of the system in relation to the end-user's needs, i.e. the system must be positioned for optimal comfort, function and visibility for the specific end-user.
- Appropriate on-screen visual representation (pictures, symbols, text, foreground/background colours, etc.), i.e. ensure that visual images are presented in a way that is clearly visible and comprehensible to the end-user.
- Appropriate organisation of the images on the screen in relation to the visual abilities of the end-users to ensure that the visual images are arranged in a way that is most easily understood and controlled.

There is also a need for:

- More adaptable calibration procedures. Different users need different features, so a selection of options would be a useful tool that could make it possible for more people to try eye control.
- The development of a wide range of software to support initial trials and training for users with a wide range of physical, visual and cognitive abilities in the use of eye control. Software that is already widely used in schools and for leisure needs to be made accessible by eye control.
- A larger selection of software for communication is recommended. Several users already use communication programs and it is important to collaborate with developers to try to make these as 'eye-friendly' as possible so that they can continue using familiar programs.

Other features also need further development:

- Appropriate auditory support and feedback is essential. It is important to ensure that the type of auditory support provided to the end-user gives them optimal support in relation to their needs and abilities.
- Enabling the user greater independence in changing the settings.

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Appendices

Appendices related to Chapter 3 (POLITO/Torino ALS Centre trials) include:

- Appendix 3.1: Consent Form
- Appendix 3.2: User Questionnaire
- Appendix 3.3: The McGill Scale
- Appendix 3.4: The Self-Perceived Burden scale
- Appendix 3.5: The SWLS (Satisfaction with Life Scale)
- Appendix 3.6: The Zung Self-Evaluation of Depression scale

Appendices related to Chapter 4 (The ACE Centre trials) include:

- Appendix 4.1: Information Sheet and Consent Form for children
- Appendix 4.2: Information Sheet and Consent Form (for adults)
- Appendix 4.3: Types of User Trials and Methods

Appendices related to Chapter 5 (DART trials) include:

- Appendix 5.1: Information and Consent Form
- Appendix 5.2: Questionnaire on familiarity with computers
- Appendix 5.3: Questionnaire on user's experiences
- Appendix 5.4: Questionnaire on user's opinions

Appendix 3.1: Consent Form

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UNIVERSITA' DEGLI STUDI DI TORINO
…Dipartimento di Neuroscienze…..….
Via Cherasco 15, 10126 - Torino
Prof. Mutani……..
Prof. Adriano Chiò

INFORMED AGREEMENT FORM

The undersigned declares that he understood the information given by Dot._____ about communication system trial (PC + applications).

The reason of this trial is the storage of data about eye-tracking system effectiveness in quality of life improvement when patient has serious language difficulties.

An appropriate system (hardware and software) is given for a week. During this period the patient will learn the system use and he will verify its usefulness in making communication easy.

Al the end of the week the user will write out a questionnaire to transmit its opinions and comments.

Data gathered will be spread between partners involved in the project and they will become subject of papers and analysis for evaluating quality of live improvement.

The undersigned declares that he received satisfying answer to its explanation requests.

So, after exhaustive information and a good understanding of it he:

ACCEPTS / DOESN'T ACCEPT

TO BE INVOLVED IN THE TRIAL.

For further explanations, call from ____ to ____ the number: 011 _____.

Name …… Surname..……..

Birthplace…….. Birth date .....……

Address…..…….....……

Telephone. ……

Torino, ……. Signature. ……

Doctor/Psychologist providing information…….....…..

I GIVE MY CONSENT AND AUTHORIZE my personal data processing as provided in the 675/96 laws, exclusively for this research.

Torino, …… SIGNATURE……

Appendix 3.2: User Questionnaire

DATE _____ SURNAME AND NAME_____

Eye-tracking system: USER QUESTIONNAIRE

1_ Time spent with the system

1	During this week I used the system	1 day	2 days	3 days	5 days	Every day
2	Every day my system use average was	15 minutes	30 minutes	1 hour	2 hours	More than 2 hours
3	In the future I think my system use average would be	15 minutes	30 minutes	1 hour	2 hours	More than 2 hours

2_ Training

1	Time necessary to learn using system was	Very much time	Much time	Right time	Quite time	Little time
2	In general to learn system using I think was	Difficult	Quite complicated	Not easy, but not difficult	With some difficulties, but possible	Easy
3	I think to learn the system using was	Bad	Not too bad	More or less	Quite well	Well
4	In general I think that the system is (answer YES or NOT for all the options)	Easy and it doesn't tire me YES-NO	Simple and intuitive YES-NO	Easy to understand, independently from user experience YES_NO	Easy to use, independently from language knowledge and capabilities YES_NO	Easy to use, independently from concentration capabilities YES-NO
5	Which kind of difficulties did you have	Technical (ex. computer managing)	Concentration	Understanding	Handiness	Other
6	The main problems were	Eyes become tired	Posture weariness	System technical feature (ex. system slowness)	Problems for the disease (ex. difficult in concentration)	Other

3_ Satisfaction

1	My level of satisfaction for the system is	Very high	Quite high	Medium	Poor	Very low
2	This depends from (answer YES or NOT for all the options)	It helps me to accept easier my condition YES-NO	It gives me the possibility to do thing that I can't do any more YES-NO	It asks me a low physical effort YES-NO	Its use is suitable for every kind of user YES-NO	It's a comfortable and flexible device YES-NO
3	People close to me had difficulties with the new system	Absolutely no	A little	More or less	Sufficiently	Very much

4_ Influence on life quality

1	My life quality became better in this week	Very much	Sufficiently	More or less	A little	Absolutely no
2	I was able to say/do what I wanted	Completely	Sufficiently	More or less	A little	Absolutely no
3	My mood became better during the period I used the system	Very much	Sufficiently	More or less	A little	Absolutely no
4	Sometimes I felt frustrated because (answer YES or NOT for all the options)	I missed the eye contact with people YES-NO	I wasn't able to communicate my emotions with the system YES-NO	I had difficulties to maintain concentration during communication YES-NO	After a little time I felt tired YES-NO	Sometimes I found difficult to find words I wanted use YES-NO
						I noticed that I made a lot of mistakes YES-NO

More questions in addition:

1. What weren’t you able to do/communicate?

_____

2. What kind of difficulties did you have?

_____

3. What would you change in the system?

_____

Appendix 3.3: The McGill Scale

McGill Quality of Life Questionnaire (MQOL)

Keywords:

Quality of Life

Background:

The McGill Quality of Life Questionnaire is designed to measure quality of life for people with life-threatening illness. While the scale was reported in 1995 (Cohen et al., 1995), the version here (16-item) is as the scale appears in Cohen et al., 1996.

Developer(s):

S. Robin Cohen, Balfour M. Mount, Michael G. Strobel, France Bui, and McGill University

Copyright:

Subscales:

Four subscales were identified through factor analysis (Cohen et al., 1996):

1. Physical: items 1-4
2. Psychological: items 5-8
3. Existential: items 9-14
4. Support domains: items 15, 16

Reliability:

Internal consistency: Cronbach alpha

Whole scale = 0.83
Physical symptoms = 0.84
Psychological symptoms = 0.77
Existential well-being = 0.86
Support domains: 0.83 (Cohen et al., 1996)

Assessment:

Scale items:

1. One troublesome symptom is...	no problem/tremendous problem
2. Another troublesome symptom is...	no problem/tremendous problem
3. A third troublesome symptom is...	no problem/tremendous problem
4. Physically, I felt...	terrible/well
5. I was depressed...	not at all/extremely
6. I was nervous or worried...	not at all/extremely
7. How much of the time do you feel sad?	Never/always
8. When I think about the future, I am...	not afraid/constantly terrified
9. My personal existence is...	utterly meaningless and without purpose/very purposeful and meaningful
10. In achieving life goals, I have...	made no progress whatsoever/progressed to complete fulfillment
11. My life to this point has been...	completely worthless/very worthwhile
12. I have...	no control over my life/complete control over my life
13. I feel good about myself as a person.	Completely agree/completely disagree
14. To me, every day seems to be...	a burden/a gift
15. The world is...	an impersonal, unfeeling place/caring and responsive to my needs

16. I feel supported. Not at all/completely

USE THE FOLLOWING RESPONSE CATEGORIES.

Use an 11 point scale (0-10) anchored by the categories presented to the right of each item. Instruct the respondent to circle the number that best corresponds with their thoughts or feelings.

Example:

4. Physically, I felt..

terrible 0 1 2 3 4 5 6 7 8 9 10 well

References:

- Cohen, S.R., Hassan, S.A., Lapointe, B.J., and Mount, B.M. (1996). Quality of life in HIV disease by the McGill quality of life questionnaire. AIDS, 10, 1421-1427.
- Cohen, S.R., Mount, B.M., Strobel, M.G., and Bui, F. (1995) The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability, Palliative Medicine, 9, 207-219.

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Appendix 3.4: The Self-Perceived Burden scale

The Self-Perceived Burden Scale

We are interested in how you feel about the relationship that you have with the person (or people) who helps you out with your day-to-day activities. You may need a little bit of help with things like shoveling snow and carrying groceries, or a lot of help, like driving you to dialysis or preparing meals. We are interested in all the different kinds of help that you receive.

The person who helps you may be a friend, neighbor, or a member of your family, such as a spouse, son or daughter. For the purpose of this questionnaire, we will refer to this person (or people) as your caregiver. We are interested right now only in the people who are NOT paid to help you – this means that housekeepers, nurses and driving services would not be considered caregivers.

This questinonaire consists of 25 statements about feelings you may or may not have about your relationship with your caregiver. Please rate each statement on a scale of how often you feel this way, from "none of the time" to "all of the time". Please consider your answers carefully – we would like you to be as honest as possible.

The response scale for each item was
- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

1. I am concerned that my caregiver will "wear out" because of the demands of caring for me

2. I worry that the health of my caregiver could suffer as a result of caring for me

3. I worry that my caregiver is overextending him/herself in helping me

4. I am concerned that it costs my caregiver a lot of money to care for me

5. I worry that my caregiver has to take time away from other things in order to help me

6. I am concerned that I won’t be able to "repay" my caregiver for all they’ve done for me

7. I feel guilty about the demands that I make on my caregiver

8. I worry about my caregiver because they have to take on too much responsibility for me

9. I feel guilty that my caregiver has to change their plans in order to help me

10. I worry that my caregiver has lost control of their life due to caring for me

11. I’m concerned that my needs are so great that my caregiver can’t handle them

12. I am concerned that if I ask for help it will put too much pressure on my caregiver

13. I am concerned that because of all they do for me, the person caring for me may not be able to do so much longer

14. I am concerned that my caregiver is helping me beyond their capacity

15. I find it easier to ask my caregiver for help when I feel that I can give something in return

16. I am concerned that the demands of my care have strained my relationship with my caregiver

17. I am concerned that I am "too much trouble" to my caregiver

18. Receiving help from others makes me feel that they care for me

19. I am concerned that because of my illness, my caregiver is trying to do too many things at once

20. I am concerned about the negative effects of my illness on those around me

21. I am confident that my caregiver can handle the demands of caring for me

22. I find it easier to accept help when it’s offered, rather than when I have to ask

23. I am concerned that because of caring for me, my caregiver is being pulled in too many directions

24. I think that I make things hard on my caregiver

25. I feel that I am a burden to my caregiver

Appendix 3.5: The SWLS (Satisfaction with Life Scale)

Satisfaction With Life Scale

Diener, E., Emmons, R., Larsen, J., & Griffin, S. (1985). The Satisfaction With Life Scale. *J Personality Assessment*, 49(1), 71-75.

Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding. The 7-point scale is as follows:

1 = strongly disagree

2 = disagree

3 = slightly disagree

4 = neither agree nor disagree

5 = slightly agree

6 = agree

7 = strongly agree

__ 1. In most ways my life is close to my ideal.

__ 2. The conditions of my life are excellent.

__ 3. I am satisfied with my life.

__ 4. So far I have gotten the important things I want in life.

__ 5. If I could live my life over, I would change almost nothing.

Appendix 3.6: The Zung Self-Evaluation of Depression scale

Zung Self-Rating Depression Scale

(Adapted for patients in treatment for opioid dependence)

Adapted from:

Zung, W.W. (1965). A Self-rating Depression Scale. ***Archives of General Psychiatry 12*****: 63-70.**

ZUNG SELF-RATING SCALE

Please read each statement and decide how much of the time the statement describes how you have been feeling during the **month before you began treatment** for opioid dependence.

Make check mark (✔) in appropriate column.		A little of the time	Some of the time	Good part of the time	Most of the time
1.	I feel down-hearted and blue				
2.	Morning is when I feel the best				
3.	I have crying spells or feel like it				
4.	I have trouble sleeping at night				
5.	I eat as much as I used to				
6.	I still enjoy sex				
7.	I notice that I am losing weight				
8.	I have trouble with constipation				
9.	My heart beats faster than usual				
10.	I get tired for no reason				
11.	My mind is as clear as it used to be				
12.	I find it easy to do the things I used to				
13.	I am restless and can't keep still				
14.	I feel hopeful about the future				
15.	I am more irritable than usual				
16.	I find it easy to make decisions				
17.	I feel that I am useful and needed				
18.	My life is pretty full				
19.	I feel that others would be better off if I were dead				
20.	I still enjoy the things I used to do				

[Office use only: **21. TOTAL ZUNG SCORE =** _____]

Appendix 4.1: Information Sheet and Consent Form for children

INFORMATION SHEET

COGAIN (Communication by Gaze Interaction) is a European project involving a network of experts in the fields of eye tracking, hardware and software interfaces, disability and research. Started in 2004, this 5-year project aims to improve and increase the selection of hardware and software options available for eye tracking, lower the price of the technology and make eye control a real option for as many people who might benefit from its use as possible.

The involvement of potential users is critical to the success and validity of the project. By trying various systems with a range of people, we gain important feedback for the development of improved systems. Your child's participation would be greatly valued.

We would ask you to take note of the following:

- While there is no specific benefit to your child of participating in these trials, he/she will be helping to inform the development of future eye control systems, and gaining first-hand experience of the possible benefits of this technology.
- His/Her participation is voluntary and he/she can withdraw from participating at any stage.
- Eye control is a relatively new technology, so the available systems are still expensive and some is not even commercially available yet. It is therefore important to bear two things in mind:
  - We cannot guarantee that a successful trial will be achieved with everybody.
  - If a successful trial is achieved, this equipment is not currently available through existing statutory funding.
- Most Eye control systems work by directing low-level infrared lights at the pupils. We are assured by the manufacturers that the infrared levels comply with safety regulations.
- The duration of your child's participation in the project will either be a 'one-off' session, or by mutual agreement, a longer study which could continue over a few months.
- We may want to show and share video/photos of your child using the equipment. Doing so can help us share what we learn with others and could be in a presentation at a conference, in a publication, for training purposes, or on our websites etc. If you would rather we didn't use video/photos of your child, just let us know. He/she can still take part in the project.
- In accordance with the Data Protection Act, his/her information will be stored on a secure server and contact details will not be shared without permission
- If you have any questions about the research or your child's involvement, please contact Mick Donegan. Email: donegan@ace-centre.org.uk

You will be given a copy of this Information Sheet and a signed copy of the Consent Form to keep, prior to taking part in the research.

Thank you for your time!

CONSENT FORM

COGAIN (Communication by Gaze Interaction)

	YES	NO
Have you read and understood the Information Sheet?		
Has somebody explained the project to you?		
Have you had the opportunity to ask questions and discuss the project?		
Have you received satisfactory answers to all your questions?		
Have you received enough information about the project?		
Do you understand that your child is free to withdraw from the project at any stage?		
Are you happy for us to share our findings with any relevant parties?		
Are you happy for us to show and share video footage and photographs of you/ your child?		
Are you happy for us to quote you/ your child?		
Do you agree for your child to take part in the project?		

_____
Name of child

_____	_____	_____
Name of Parent	Date	Signature
_____	_____	_____
Name of Parent	Date	Signature
_____	_____	_____
Name of researcher	Date	Signature

The Parents should keep one signed copy of this consent form, and a copy of the Information sheet.

Thank you for taking part in this project!

Consent form for Children
(To be completed by the child and their parent/guardian)

COGAIN Eye Control project

Please circle Yes/No (or a parent/guardian can do so for you).

- Have you read (or had read to you) about this project? Yes / No
- Has somebody explained this project to you? Yes / No
- Do you understand what this project is about? Yes / No
- Have you asked any questions you would like to? Yes / No
- Have your questions been answered in a way you understand? Yes / No
- Do you understand it's OK to stop taking part at any time? Yes / No
- Are you happy to take part? Yes / No
- Is it OK if we show photos and videos of you to other people? Yes / No

If ANY answers are 'No' or you DON'T want to take part, DON'T write your name!

If you DO want to take part, please write your name and today's date (or a parent/guardian can do so for you).

Your name: _____ Date: _____

Your parent/guardian must sign their name here too if they are happy for you to do the project.

Parent Name: _____ Date: _____

Signature of researcher: _____

You can keep a signed copy of this page.

Thank you for your help!

Appendix 4.2: Information Sheet and Consent Form (for adults)

INFORMATION SHEET

COGAIN (Communication by Gaze Interaction) is a European project involving a network of experts in the fields of eye tracking, hardware and software interfaces, disability and research. Started in 2004, this 5-year project aims to improve and increase the selection of hardware and software options available for eye tracking, lower the price of the technology and make eye control a real option for as many people who might benefit from its use as possible.

The involvement of potential users is critical to the success and validity of the project. By trying various systems with a range of people, we gain important feedback for the development of improved systems. Your participation would be greatly valued.

Please take note of the following:

- While there is no specific benefit to you of participating in these trials, you will be helping to inform the development of future eye control systems, and gaining first-hand experience of the possible benefits of this technology.
- You participation is voluntary and you can withdraw from participating at any stage.
- Eye control is a relatively new technology so most of the equipment is still very expensive and some is not even commercially available yet. It is therefore important to bear two things in mind:
  - We cannot guarantee that a successful trial will be achieved with everybody.
  - If a successful trial is achieved, this equipment is not currently available through existing statutory funding.
- Most Eye control systems work by directing low-level infrared lights at the pupils. We are assured by the manufacturers that the infrared levels comply with safety regulations.
- The duration of your participation in the project will either be a 'one-off' session, or by mutual agreement, a longer study which could continue over a few months.
- We may want to show and share video/photos of you using the equipment. Doing so can help us to share what we learn with others and might be in a presentation at a conference, in a publication, for training purposes, or on our websites etc. If you would rather we didn't use video/photos of you, just let us know. You can still take part in the project.
- In accordance with the Data Protection Act, your information will be stored on a secure server and your contact details will not be shared without your permission.
- If you have any questions about the research or your involvement, please contact Mick Donegan. Email: donegan@ace-centre.org.uk

You will be given a copy of this Information Sheet and a signed copy of the Consent Form to keep, if you decide to take part.

Thank you for your time!

CONSENT FORM

COGAIN (Communication by Gaze Interaction)

	YES	NO
Have you read and understood the Information Sheet?		
Has somebody explained the project to you?		
Have you had the opportunity to ask questions and discuss the project?		
Have you received satisfactory answers to all your questions?		
Have you received enough information about the project?		
Do you understand that you are free to withdraw from the project without any penalty at any stage?		
Are you happy for us to share our results with any relevant parties? *(This could include, among others, fellow professionals, project partners and other participants/parents. It may be at conferences, during training, online or in publications.)		
Are you happy for us to show and share video footage and photographs of you? (This could be to a varied audience in a variety of ways. See above.*)		
Are you happy for us to quote you?		
Do you agree to take part in the project?		

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of researcher	Date	Signature

The participant may keep one signed copy of this consent form, and a copy of the Information sheet.

Thank you for taking part in this project!

Appendix 4.3: Types of User Trials and Methods

Types of User Trials and Methods – ACE Centre

Calibration-only trials

Individuals Involved

- Any person with a complex physical disability

Aim

- To gain an insight into the ability of different systems' calibration processes to accommodate different individuals.

Length of Trial

- 'One-off' session

Outcomes

- Observations on any features which present a barrier to calibration
- Observations on any features which assist calibration
- As a result of the above, produce guidelines on desirable features.

Implementation Trials

Individuals Involved

- Very complex users whose needs, at present, are difficult to accommodate through eye control technology – (eg. Locked-in, severe involuntary movement, visual difficulties.)

Aim

- To gain an insight into the issues and strategies involved in enabling and adapting eye-control technology to accommodate the needs of individuals' with complex accessing difficulties, e.g. involuntary head movement or visual difficulties.

Length of Trial

- A loan or sequence of loans over a long-term (anything from weeks to several months, depending on individual, their situation and equipment availability).

Outcomes

- Calibration Outcomes
    - Observations on any features which presented a barrier to calibration
    - Observations on any features which assisted calibration
    - As a result of the above, produce guidelines of desirable features.

- Highlight issues relating to of the process of adaptation of hardware and software to individual needs.
    - Hardware issues – mounting, positioning
    - Software issues – adaptations that are necessary or recommended in order to meet individual needs.
    - A summary of key issues – illustrated with exemplar material.

- This will include exemplar case-study material, e.g. video, examples of software & hardware adaptation, modification & design software, etc., to assist developers in meeting a wider range of needs more effectively.

Data Collection Methods

The following suggestions are based on standard methods for gathering data through case study. By selecting from these methods, as appropriate, information on issues that are considered to have a significant impact on the participant's successful use of eye-control technology was gathered for subsequent comparative analysis across case studies :

- In advance of a trial - Discussions with the enduser (where possible) and/or those involved in their support (eg. parents, professionals, etc) to help to plan and prepare.
- Video material
- Field notes
- Informal interviews in relation to the performance of the eye-control systems and software, leading to subsequent modifications as appropriate.

Content analysis

As involvement with a participant progressed, the information gathered was added to each case study as events unfolded. An ongoing process of content analysis for each individual case study as a whole should be carried out. The process involved the following:

- Collect and collate data from all sources of potential relevance to the study, on an ongoing basis, over an extended period of time, using a range of methods (see above).
- Analyse the information on an ongoing basis, focusing in particular on critical events, issues or situations perceived as influencing successful use of the technology used.
- At the end of the data collection process, condense the data relating to each individual into a coherent, chronological case study, editing and adding annotations as appropriate.

All information should be cross-referenced, using triangulation, in order to take into account the varying perspectives of those involved. In effect, all information gained should be regarded as 'hearsay' until endorsed through this approach.

Comparative Analysis

The way in which Glaser and Strauss (1967)[1] use 'comparative analysis' is in order to generate theory. They argue that, as with experimental and statistical methods, comparative analysis is also a method that involves the logic of comparison. As a strategic method for generating theory they consider that it can be used on social units of any size, large or small, ranging from individuals, or their roles, up to nations or even whole continents. Based on a comparison of evidence collected, the data can be

[1] Glaser, B. and Strauss, A. (1967*) The Discovery of Grounded Theory*, Chicago: Aldine

used to check whether or not the initial evidence was correct. If facts are replicated within comparative evidence, either internally (within the study), externally (outside the study), or both, they add strength to the arguments underlying the theory generated. The analysis of comparative data, they point out, continually checks out his theory as the data pour in. Hammersley *et al.* (2000)[2], argue that comparative analysis across case studies is potentially more effective than the examination of a single study, no matter how detailed. Examining the idea that general conclusions can be drawn from case studies by means of theoretical inference, they consider the two approaches. The first assumes that, through an in-depth study of a single case study, direct causal relationships can be uncovered by relying on ' direct perception' and/or empathy. They argue that this assumption is false and that only through the second approach, comparative analysis, can a sound basis for theoretical conclusions be drawn.

The method suggested for the COGAIN longitudinal case studies is that each individual case study should be examined carefully in order to highlight issues related to successful use of eye-control systems as they unfold, using content analysis. Then, comparative analysis should be used to discover any relevant issues that are common *across* the case studies. If similar issues were noted for across the studies in this way there is an increased likelihood that that the issue will have relevance to others with similar needs. Significant issues or themes thus identified, therefore, should be included in the overall Findings. Such an approach is intended to capitalise on the rich, evidence-based material that we are able to gather in order to generate theory.

> The comparative analysis of cases takes us beyond the notion of the case study being illustrative. When data from similar situations are compared common themes and patterns can be elicited, hypotheses generated and theory developed. The examination of themes is important in all case studies, but particularly important if the research demands comparative analysis.
>
> Edwards & Talbot (1994, pg.45)[3]

The approach to comparative analysis of the case studies then should involve:

- cross-referencing the information gathered across all case studies to identify factors that influenced success for more than one participant.
- a consideration of whether or not the factors identified both within and across the case studies have sufficient in common to be identified as a general 'theme' which might have implications for others who might wish to use this technology

An example of a strong theme that is already emerging across case studies is the evident reduction in involuntary movement among certain participants when using eye control in comparison with other access methods.

---

[2] Hammersley, M. and Gomm, R. (2000) 'Introduction' in Hammersley, M., Gomm, R. and Foster, P. (eds) *Case Study Method,* London: Sage Publications

[3] Edwards, A. and Talbot, R., (1994) *The Hard Pressed Researcher*, London: Longman Group

Procedure for informal interview
The informal interview structure below was used when a visit was made to someone who was part of an implementation case study.

Date:

Attendees:

Intervention

Intervention	Description of Change	Rationale	Observations	Feedback on the Change
adjusting the size of cells on the on-screen grid designed for writing using text.	Reducing number of cells from 8 to 4. More 'hits' are now required to select a letter (3 instead of 2).	X is experiencing mishits and it was hoped that by having fewer cells with larger targets, the errors would be reduced	X appeared to be more relaxed when making selections	X reported that he was happy with this change and prepared to try it.

Interview (Carried out after the system had been trialled over a period of time).

Questions Asked	Response
e.g. How do you feel now that the cell-size changes we made the last time we were here?	X: I feel much more relaxed using it. I am also making less mistakes. Spouse: He now uses it for u[p to 90 minutes at a time. It was only half an hour or so before.

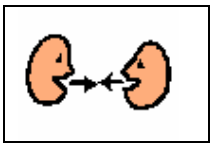
Appendix 5.1: Information and Consent Form

Projektet “COGAIN”
Communication by Gaze Interaction

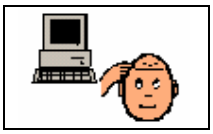
Personens namn:

Välj ett alternativ

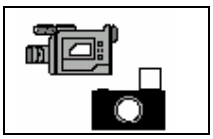
Ja **Nej**



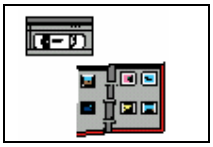
Jag/vi tillåter att ni intervjuar mig/mitt barn för COGAIN-projektet



Jag/vi accepterar att vara delaktig i projektet samt använda och utvärdera COGAINs produkter

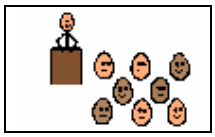


Jag/vi tillåter att ni videofilmar och fotograferar mig/mitt barn i samband med COGAIN



Jag/vi tillåter att videofilmer och fotografier av mig/mitt barn i samband med COGAIN-projektet används för:

- träning av yrkesverksamma inom området



- föreläsning/träning för allmänheten

-publicering av arbetet inom COGAIN

Vänligen skriv specifika anmärkningar här:

_____

_____

_____

Jag _____ medger att ovanstående projekts syfte har förklarats för mig, och jag har tagit till mig ovanstående information. Jag har klart för mig att jag kan dra mig ur projektet när helst jag önskar.

SIGNATUR _____

Datum_____

Kontaktuppgifter

Namn_____

Adress _____

Postnummer_____ Ort _____

Telefon _____

E-post _____

Appendix 5.2: Questionnaire on familiarity with computers

Namn …… **Intervjuare .....**
Datum.....

Tidigare erfarenhet av COGAIN:

……

Tillgänglig teknisk support? (beskriv vad som är överenskommet):

……

Har du hört talas om ögonstyrning/provat ögonstyrning tidigare:

Hur ofta använder du dator idag?

Aldrig .....
.....☐
Cirka en gg/vecka .....
.....☐
Mellan 1 och 5 ggr/vecka .....☐
Mer än 5 ggr /vecka .....☐

Använder du dator
självständigt .....☐
med hjälp .....☐

Om du använder dator, vilka program använder du?

.....

Vad använder du dator till?
Underhållning..... ☐
Skolarbete ..... …..☐
Hobby/fritid..... ☐
E-post ..... ☐
Annat: ……

Appendix 5.3: Questionnaire on user's experiences

Brukar - tester

Baserad på EU:s definition om användbarhet (ISO DIS 9241-11)
(" den nivå en brukare effektivt, funktionellt och på ett tillfredsställande sätt kan nå ett specifikt mål in en specifik miljö")

Test-upplägg

Personer involverade
- Person med eller utan funktionshinder

Syfte
- Att få insikt i effektivitet för specifika applikationer med tanke på brukar-tillgänglighet

Tid
- Beroende på svårighetsgrad i programvaran (t ex kan ett program som Dasher ta längre tid att lära sig jämförelsevis med ett enkelt skärmtangentbord).

Resultat
- Rekommendationer relaterade till tillgänglighet I de testade applikationerna – såsom hastighet, hur behagligt och pålitligt systemet är att använda

Observera:
Som tillägg till detta intervjuformulär kan det vara bra (dock inte nödvändigt) att samla in följande:

- Exempel på vad deltagaren åstadkommit med systemet – både med test och symboler, d v s utskrifter av producerat material, skärmdumpar av använda programvaror, skärmdumpar av producerat arbete med systemet

- videomaterial – under förutsättning att tillåtelse har givits till detta, bör forskaren sträva efter att med en digital videokamera filma deltagarna när de använder systemet. Bra att ha med både det som sker på skärmen och på individen i arbete. Det skulle också vara till hjälp att filma med de styrsätt och metoder som används innan ögonstyrning introduceras. Alla video filmer ska noga märkas och beskrivas.

Namn och kontakt till personen som utför intervjun	
Uppgifter om personen som testar programvaran…	
Namn och kontakt	
Typ av funktionshinder, om aktuellt:	
Namn på använt ögonstyrningssystem (eller annat system)	
Hur länge har du använt ditt ögonsstyrningssystem	
Namn på använd programvara – och beskrivning av denna	
Använder du något annat styrsätt till datorn än ögonsstyrning?	
(Effektivitet…) Hur bra lyckas du “träffa rätt” på önskade föremål på bildskärmen på en skala mellan 1-6? (1 är dåligt, 6 är utmärkt)	
Beskriv varför du sätter den siffran	
(Efficiency…) Hur funktionellt tycker du att ögonstyrningssystemet är på en skala mellan 1-6? (Till exempel, om du använder ett skärmtangentbord för ögonen, hur snabbt kan du skriva?) (1 är dåligt, 6 är utmärkt)	

Beskriv varför du sätter den siffran	
(Tillfredsställelse) Hur komfortabelt tycker du att systemet är att använda, på en skala mellan 1-6? (1 är dåligt, 6 är utmärkt)	
Beskriv varför du sätter den siffran	
Hur enkelt tycker du systemet är att använda, på en skala mellan 1-6? (1 är dåligt, 6 är utmärkt)	
Sammantaget, vad tycker du om systemet?	
På vilket/vilka sätt tycker du att systemet skulle kunna förbättras?	
Hur tycker du att detta sätt att styra datorn är jämfört med andra styrsätt?	

Övriga kommentarer:	

För personen som ansvarar för testningen	
Har brukaren några fysiska eller visuella svårigheter/problem som, enligt din åsikt, påverkade hur personen lyckades?	
Hur bra tycker du att användningen fungerade på en skala mellan 1-6? (1 är dåligt, 6 är utmärkt)	
Beskriv varför du sätter den siffran	
Lyckades brukaren använda systemet funktionellt (ja/nej)	
Har du ytterligare observationer/idéer om hur systemet skulle kunna förbättras?	
Tycker du att några ändringar i programmet berhövs med tanke på brukarens, och/eller dina egna observationer? Om så, vänligen se nästa sida (appendix B)	

Appendix 5.4: Questionnaire on user's opinions

UTVÄRDERING EFTER PROVTILLFÄLLE

1. **Tyckte du om ögonstyrningen?**

Några kommentarer:

2. **Hur enkelt var det att använda?**

Några kommentarer:

3. **Vad tycker du om utseendet/användargränssnittet?**

Några kommentarer:

4. **Hur enkelt tyckte du det var att välja med ögonen?**

Några kommentarer:

5. **Tror du/tycker du att ögonstyrning kan uppfylla dina behov?**

6. **Är det något du speciellt tycker om med ögonstyrningen?**

7. **Är det något du tycker fungerar dåligt med ögonstyrningen?**

8. **Är det några förbättringar du tycker vi ska göra? Ja ☐ Nej ☐**

Förklara:

9. **Skulle du vilja prova ögonstyrningen igen?**

10. **Några övriga kommentarer:**