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Executive Summary

Today the users of eye control systems are people with severely disabilities, such as ALS or locked-in syndrome. Only few systems are in use, maybe less than 2,000 users in Europe, and the system prices are relatively high, from 4,100 € to 17,900 €

If the market for eye control systems should grow, special attention should be paid to the following areas:

1. The *quality* of eye control systems should be improved; the systems should meet the *user requirements* (summarised from the COGAIN Deliverable 3.1 by Donegan et al., 2005), for instance:

- The speed at which the pointer/cursor is moved around the screen should be variable, to meet individual needs and abilities.
- The user should be able to calibrate and recalibrate the system easily and independently.
- The user should be allowed to move (or turn) away from the system and return to it without the need for recalibration.
- The user should be allowed to switch between different kinds of input and output modalities (multi-modal).
- It should be possible to access any Windows application, including internet browsing, email, assistive software (virtual keyboards, text-to-speech systems), computer games, education software etc.
- There should be no problem using the Eye Control System outside and in sunshine.
- The system should be more portable, i.e. easy to move around with the Eye Control System mounted on the wheelchair.
- The system should be flexible enough to accommodate a wide range of individual differences to meet the needs of as many users with complex physical or visual difficulties.
- It should be possible to move independently from application to the next (e.g. from social communication to email and back again).

2. The *prices* of the eye control systems should be lower.

Supply and demand are, after all, also regulating the assistive technology (AT) market. It means that if the prices would not be as high as they are today, people with wider variety of disabilities (other than ALS, locked-in syndrome and similar conditions where the functional level is very limited) could be included to the target group.

If the price were around 2,000 – 3,000 € the market would probably grow to include people with varying conditions, including e.g.:

- motor neuron disease (MND)/ amyotrophic lateral sclerosis (ALS)
- multiple Scleroses (MS)
- cerebral palsy (CP)
- spinal muscular atrophy (SMA)
- Werdnig-Hoffman syndrome
- Rett syndrome
- muscular dystrophy (MD)

- locked-in syndrome
- quadriplegia – spinal cord injury (SCI)
- brainstem stroke
- traumatic brain injury (TBI)
- repetitive strain injury (RSI)

If eye control systems were available for just 100 – 1000 € they could become one of the preferred mean of control for a very large group of people with special needs (Hansen et al., 2005).

3. A lot of attention should be put on *information dissemination*.

If the end-users or the AT professionals do not know about the eye control systems, they will not acquire them. Therefore, it is quite important to inform the end-users, the AT professionals and the public.

Different kind of dissemination activities (COGAIN Deliverable 7.1 by Jordansen et al., 2005) should take place, for instance:

- Participating in conferences, exhibitions, fairs and other key events
- Articles in magazines on AT
- Articles in newspapers
- Direct mail to end-user organizations
- Direct mail to information and resource centres on AT
- etc.

If the work within COGAIN is resulting in new and improved eye control systems with a lower price, and if the network is able to reach and inform the different target groups (end-users, AT professionals, general public), the market share could be considerable larger than today. It is estimated that there are about 571,250 persons in EU with physical impairments in need for alternative input devices. It is uncertain how many of those would need or prefer an eye control system rather than one of the other alternative solutions, but a market share on 5–10 percent might be realistic, meaning the market size in EU should be about 28,000–57,000 persons.

1 Objective and methods of the market study

The objective of the market study is to define the characteristics of the end-user population of eye control systems¹, including demographics, to ensure best allocation of resources within the COGAIN network. The market study will also include the business perspective.

When doing a market study on eye control systems, there are several issues to take into account. First, we need to define the target group. However, the target group depends largely on the quality (and the price) of the eye control systems. This means that, if the quality of the eye control systems is like most of the systems today then the target group will primary include people with amyotrophic lateral sclerosis and locked-in syndrome. On the other hand, if the quality of the eye control systems would become considerable better then the target group would maybe be much bigger and include people with other kind of disabilities too. Furthermore, it is possible that the market will also include people without any kind of disabilities if the quality of the eye control systems would be as good as standard keyboards and mice. Therefore, we need to define the user needs and requirements—what benefits the users are seeking—to know the required quality of the Eye Controls Systems.

In this study, we will only put attention on the market concerning *people with disabilities*, as this is the focus of COGAIN. How should we define *people with disabilities*? According to the International Classification of Functioning, Disability and Health (ICF, 2001) *disability* serves as an umbrella term for impairments, activity limitations or participation restrictions. In this study, *people with disabilities* are defined as people with impairments that result in activity limitations or participation restrictions according to the use of standard keyboard and standard mouse.

The study will also primary look at the market within EU (see Appendix A for further information about the member states in EU).

In spite of this delimitation, it is still not easy to define the characteristics, demographics and size of the end-user population. The primary reason for that is the lack of comparative data from the different European countries. The EU countries are using different diagnoses and/or words to describe the same condition and they also use different methods to estimate the severity of such condition. In addition, in many cases they do not estimate the severity at all.

In everyday talk, we normally use diagnoses to describe and classify particular conditions. However, that kind of classification is in many cases imprecise because the diagnoses normally do not say anything about the person's functional status or disability. In this study, it would be more useful to know the number of persons suffering from a specific impairment causing problems when using their hands and arms to access the standard keyboard and mouse than knowing the number of persons with a specific diagnosis. In spite of that we use the diagnoses in this study to classify the target groups because only very few countries are collecting data in any other way. It would be a great help if some researchers would put attention on that in the future.

In this market study, we first defined the target group primary as a summarization of those target users suffering from disabilities listed (for each eye control system) in the COGAIN catalogue of currently available eye trackers² (Ersbøll, 2005). Then, we gathered information about the condition, characteristics and progression of the diseases.

¹ There are a number of terms referring to the eye control systems, e.g. eye gaze systems, eye communication systems, gaze communication systems, eye-typing systems, or simply eye trackers, eye-tracking devices, or eye-tracking technologies. In this deliverable, we use the term eye control systems.

² <http://www.cogain.org/eyetrackers>

The size of the different disability groups is estimated by calculating the prevalence based on the population figures from each EU country. It is very difficult to get reliable and comparative data on the size or prevalence of the different diagnoses in each EU country. Lack of official statistics and varying legal definitions of disabilities make it particularly difficult to calculate accurate numbers. Furthermore, some figures (not available for Europe) were based on statistics from USA; the figures may be bigger for the US than for Europe. Therefore, the numbers presented in this study should be taken as a rough estimate only.

In addition, this study, especially the parts defining user needs, is also largely based on information from the COGAIN Deliverable 3.1 "User requirements report with observations of difficulties users are experiencing" (Donegan et al., 2005).

2 Description of the market for eye control systems

Eye control is a method of access to technology for people with disabilities. Today there exist different kind of eye control systems on the European market (for a list of available systems, see Ersbøll, 2005). However, at present, the systems can effectively meet only a limited range of what users with disabilities require of it. Furthermore, the systems can be used effectively only by a limited number of people with disabilities (Donegan et al., 2005).

2.1 Target groups for eye control systems

The target group for eye control systems includes everybody who for one reason or another is looking for alternative access methods to operate a computer or other kind of technology. In general, there is a wide range of user groups who may benefit from eye control. These user groups include :

- people with no disabilities who may have hands occupied with other tasks and wish to point with head or eye,
- people who may have some reluctance, difficulty or discomfort moving their hands or arms,
- people with different disabilities that cause paralysis or impairment of motor function at a high level on the body (such as cerebral palsy, brain injury, multiple sclerosis, spinal cord injuries),
- people who have little, if any, bodily movement (such as amyotrophic lateral sclerosis or motor neurone disease).

This market study focuses on people with different kind of disabilities. To classify the target group we use diagnosis groups. The diagnosis groups we are looking at are a summarization of the target users mentioned in the COGAIN Catalogue of currently available eye trackers (D5.1 by Ersbøll, 2005):

- motor neuron disease (MND) / amyotrophic lateral sclerosis (ALS)
- multiple sclerosis (MS)
- cerebral palsy (CP)
- spinal muscular atrophy (SMA)
- Werdnig-Hoffman syndrome
- Rett syndrome
- muscular dystrophy (MD)
- locked-in syndrome
- quadriplegia – spinal cord injury (SCI)
- brainstem stroke
- traumatic brain injury (TBI)
- repetitive strain injury (RSI)

Description of the condition, characteristic and progression of the different target disease groups according to their specific diagnoses are showing in Appendixes B and C.

2.2 What benefits does the user seek?

In connection with the COGAIN Deliverable 3.1 "User requirements report with observations of difficulties users are experiencing" (Donegan et al., 2005), there have been made a questionnaire to users and potential users of eye control system. The responses to the questionnaire provided an indication of the range of activities already achieved through certain eye control systems and those that users would *like* to achieve.

The range of activities carried out by the users from whom information was gathered included emailing, internet access, social communication, writing (i.e. not for emailing or social communication, e.g. for personal pleasure), instant messaging, playing games.

Those requirements, which users are not currently achieving through eye control but would *like* to, included: powered mobility, environmental control, possibility to play more video games and move independently from one application to another (e.g. from speaking dynamically pro to writing software).

This is not to say these activities cannot be achieved with a certain, appropriately set up eye control system. Nor does it suggest that the list of requirements is in any way comprehensive. However, it provides an important indication of some of the things that certain *existing* users would like to be able to achieve through eye control—but cannot, at the moment.

From the User requirements report and from feedback from the long-term eye-control users (Donegan et al., 2005) we can summarize some of the important *user requirements* when developing eye control systems:

- The speed at which the pointer/cursor is moved around the screen should be variable, to meet individual needs and abilities.
- The user should be able to calibrate and recalibrate the system easily and independently.
- The user should be allowed to move (or turn) away from the system and return to it without the need for recalibration.
- The user should be allowed to switch between different kinds of input and output modalities (multi-modal).
- It should be possible to access any Windows application, including internet browsing, email, assistive software (virtual keyboards, text-to-speech systems), computer games, education software etc.
- There should be no problem using the Eye Control System outside and in sunshine.
- The system should be more portable, i.e. easy to move around with the Eye Control System mounted on the wheelchair.
- The system should be flexible enough to accommodate a wide range of individual differences to meet the needs of as many users with complex physical or visual difficulties.
- It should be possible to move independently from application to the next (e.g. from social communication to email and back again).

The above-mentioned user requirements are those identified by people who are already using an eye control system. Not all users will have the same requirements; some users, for instance, will have more limited requirements for technology than others will, so it is also reasonable to acknowledge that not all users need to have a top-level eye control system with top-level assistive software (Donegan et al., 2005).

Different users may have different levels of demands for an eye control system. For example, a person who can already use some other kind of alternative input device (such as a headmouse, mouth joystick, or speech recognition) rather effectively, may have higher demands on the functionality and usability of the system than a person who does not yet have an effective solution of any kind.

2.3 What factors can affect the purchase or the use decision?

The market for assistive technology (AT), including eye control systems, is not the same as the "normal" consumer market. The factors, which can affect the purchase or use decision, are different from usual consumer models.

In some European countries, i.e. Denmark, Sweden, Norway, Finland etc., the assistive technology market is controlled by legislation (Deloitte and Touche, 2003). This means that in many cases the decision concerning which solution should be chosen is not made by the end-user alone but it is made in collaboration with professionals, for instance occupational therapists, speech therapists etc. from the authorities or private organisations. In some countries, the user will have the assistive technology free, paid by the authorities; in some countries, the users pay it themselves or have it paid by insurance companies, private foundations etc.

In those countries, which have a legislation giving the possibility to provide assistive technology, there will always be some kind of principles regulating who are included by the legislation and who are not. In general, no diagnosis in itself is enough to justify the acquisition of assistive technology. Instead, the conclusive criterion should be the degree on which the impairment influences in carrying out daily activities.

Factors, which in general have influence on the decision of using eye control systems, are among others: the level of service regulated by the legislation, the competitive solutions, the knowledge of eye control systems, the prices, the infrastructure and technological status (see Chapter 4 for more information). This means that the situation may be very different in different European countries.

2.4 What attitude does the user have about the products currently on the market?

Only few people in Europe in need for alternative access methods are using an eye control system. Most people prefer some other kind of input devices, because of (generally speaking) strong demands on the user, and lack of important features – issues that are still characterising the current eye control systems. For instance (Donegan et al., 2005; Jordansen, 2000):

- Hard, assistance dependent calibration procedure. Need for recalibration.
- Restricted tolerance to involuntary head and eye movements.
- Restricted tolerance to ambient light (sun light).
- Restricted tolerance to eye glasses and contact lenses.
- High demand on the user's ability to focus his/her eye gaze on an item. Need to have large items on screen (because of the low spatial accuracy), thus in most cases the user cannot access standard Windows applications.
- High demand on the user's motivation, patience and concentration. It takes time to be an effective eye gaze user.
- High demand also to the people around the user to spend time to assist the user when needed.
- Need for the user to accept that he or she has to focus his or her eyes on the monitor instead of using them to look around and to communicate as everybody else.
- Restricted usability in general, usability meaning the effectiveness, efficiency, and satisfaction with which specified users achieve specified goals in specified context of use (ISO 9241-11).

On the other hand, there are some quite satisfied eye-control users, such as, for example, Birger Bergmann Jeppesen from Denmark. He was the first user in Denmark: he has used Quick Glance eye control system since 1998, and has also written a book ("Is heaven a better place?") with the system. In addition, Birger Bergmann Jeppesen is constantly looking for new and better solutions.

3 Market Metrics

Eye control technology is just one of many ways with which even the most disabled users can access the computer. There are many alternative computer input devices for people with disabilities. In general, there are three main groups: switches, keyboards and pointing devices (e.g. trackballs, joysticks, headmice).

For some people with disabilities eye control is their only method of independent control of technology. Many other people with disabilities, who today are using other kind of input devices, expect that eye control could provide a more effective, efficient and satisfying form of access. Their current method(s) of access to technology might be slow and/or effortful for them, whereas eye control technology might offer a much more direct and efficient form of access, at least for some of the applications they wish to use (Donegan et al., 2005).

Today there are still only few persons with disabilities in Europe using an eye control system for every day communication. In Denmark, for instance, there have been around 10 users from 1998 until now³ and the same figures are showing in the other Nordic countries too⁴. In the Nordic countries, nearly all of the users of eye control systems have been people with ALS or locked-in syndrome.

One of the aims of COGAIN is to develop eye control systems based on ordinary video cameras or web-cameras and to develop eye-tracking software that will run on a state-of-the-art PC. The plan is to develop eye control systems that can work with standard word processors, email systems and internet browsers. The price of the system will be low and the software distributed via the Internet.

On the assumption of these new and improved eye control systems, the potential market would be much larger than only people with ALS and locked-in syndrome. Then the potential market would probably also include many others from the identified target groups.

As already mentioned, it is rather difficult to gather information about the numbers of people with different diagnoses or disabilities. Another question is, how important it is for this purpose to know the exact number or prevalence of different diagnoses. More important would be to know the number of persons in need for alternative access methods. Unfortunately, it is not possible to get this kind of data, therefore we have to content with numbers on the different diagnoses. However, to give some idea of the total market for eye control systems within the "handicap-world", we have tried to find out the prevalence on different diagnoses in the European countries and then calculated the estimated figures for the total population in EU.

The lack of general statistics about prevalence of different diseases in Europe forced us to gather figures from several sources (e.g. from health professionals and disease associations). In addition, when figures from Europe were not available, figures from the US and from international sources were used to give a rough idea. However, some diseases may have prevalence that varies between the US and Europe, or even within Europe. For instance, MS is five times more prevalent in temperate climates, such as the northern United States, than in tropical regions. Another problem is that each diagnosis in many cases has certain subtypes but the different countries might use different methods to define and calculate the groups. **Therefore, the figures in Table 1 and 2 should be treated cautiously and only as estimates.**

³ Based on information from professionals from the regional Assistive Technology Centres in Denmark, <http://www.hmi.dk/index.asp?id=199>

⁴ Based on information from a Nordic network group working with advanced input devices, <http://www.aac-input.org/index.asp?id=43>

Target groups	Prevalence	Estimated total number in EU
Amyotrophic lateral sclerosis (ALS) / motor neuron disease (MND)	6 per 100,000 ¹	27,000
Multiple sclerosis (MS)	30 per 100,000 ²	135,000
Cerebral palsy (CP)	200 per 100,000 ³	900,000
Spinal cord injury	8 per 100 000 ⁴	36,000
Spinal muscular atrophy (SMA)	12 per 100,000 ⁵	54,000
Rett syndrome	6.66 per 100.000 ⁶	29,970
Muscular dystrophy (MD)	28 per 100.000 ⁷	126,000
Brainstem stroke	153 per 100,000 ⁸	688,500
Traumatic brain injury (TBI)	150 per 100.000 ⁹	675,000
Total		2,671,470

Table 1. Prevalence on different diagnoses and estimated total number in Europe.
(The total population in EU is 456,953,258 (July 2005 estimation)¹⁰)

Table 1 shows the prevalence numbers for different diseases and the estimated total numbers of people with the diseases in EU. The total numbers are calculated from prevalence numbers.

To offer a possibility to compare the number of persons with different diagnoses, we collected the prevalence numbers for Denmark, Finland and Spain (figures from all EU countries are calculated in Appendix D). Table 2 presents the estimated total numbers of people with the diseases in Denmark, Finland and Spain. The left column under each country contains figures collected from national sources and the right column contains figures calculated from the prevalence numbers in Table 1. Comparison between the columns (in Table 2) shows that there is a rather big inconsistency. In general, the numbers calculated with the general prevalence give higher estimated figures.

Target groups	Denmark		Finland		Spain	
Total Population	5,400,000		5,200,000		40,700,000	
Source of information	From disability organisations ¹¹	From general prevalence numbers	Different, see each below	From general prevalence numbers	From Spanish Statistics national Institute ¹²	From general prevalence numbers
Amyotrophic lateral sclerosis (ALS)	300	324	400 ¹³	312	31,724	2,442
Multiple sclerosis (MS)	7,000	1,620	6000 ¹⁴	1,560		12,210
Cerebral palsy (CP)	8,000 (?)	11,232	6500 ¹⁵	10,816	34,413	84,656
Spinal muscular atrophy (SMA)	80 (W-H S and K-W S)	65	50-60 ¹⁶	62		488
Rett syndrome	102	540	250 ¹⁷	520		4,070
Muscular dystrophy (MD)	3,000 (2,000 in need for support)				71,859	
Locked-In syndrome	10		10-100 ¹⁸			
Quadriplegia – spinal cord injury (SCI)	600, 70 – 80 with only head movements	216	55 ¹⁹	208	7,939	1,628
Brainstem stroke	20,000 ++ (12,000/year)	7.290		7,020	41,383	54,945
Traumatic brain injury (TBI)	20,000 ++ (10,000/year) 80% have mortal impairments	10.800	100,000 (15,000 – 20,000/year) ²⁰	10,400	25,638	81,400

Table 2. Estimated total numbers of diagnoses in Denmark, Finland and Spain. For each country, the left column shows numbers collected from national sources; the right column shows numbers estimated using the prevalence numbers in Table 1.

The potential market for eye control system does not include everybody from the target disease groups as stated above. As mentioned earlier the diagnosis in itself does not say much about the persons' function, neither if they need some kind of alternative input devices or not. In fact, most people with a diagnosis of some of the conditions mentioned in the table above do not need any kind of alternative input devices.

It is not possible to say what percent of the different target groups need some kind of alternative input devices. However, from a market study on the need for speech recognition (SR), conducted by Danish Centre in May 2001, we have some figures. We then asked some of the disability organisations in Denmark about the number of people that were using alternative input devices.

	Estimated number using alternative input devices in Denmark, May 2001
Multiple Scleroses (MS)	1,000
Muscular Dystrophy (MD)	500-1,000

Table 3. Estimated number of people with MS or MD using alternative input devices in Denmark, May 2001.

In 1999, the Danish Centre for Assistive Technology made a survey on the status of providing assistive technology in Denmark. We found that in 1998 the total number of alternative input devices provided was 223. Among those, there were two eye-control systems. In Denmark, we have some of the best service delivery systems so these numbers say something about the market size.

John Gill and Tony Shipley (1999) from the Royal National Institute of the Blind in UK have written a telephone guideline: Telephones – What features do disabled people need. There they estimate the number of people with different disabilities, and they use, among others, a category called "Persons with limited use of their hands or arms". The definition is "people who may not be able to use a standard telephone keypad". They estimate the prevalence to be 1,250 per million. People who cannot use a telephone keypad are expected to be the same group as the group of people who cannot use a standard computer keyboard. If the estimated number is reliable then we may say there should be about *571,250 persons in EU with physical impairments in need for alternative input devices*. How many of those, who would need or prefer an eye control system, would purchase one, largely depends on the quality of the systems, the prices, the alternative solutions and the knowledge of the eye control systems.

4 Competitive Analysis

4.1 Eye control systems on the market

Today there exist at least eight different eye trackers on the European market, which are available for interactive applications within AAC⁵:

- EagleEyes (<http://www.bc.edu/schools/csom/eagleeyes>)
- Eye Response Technologies ERICA (<http://www.eyeresponse.com>)
- EyeTech Digital Systems Quick Glance (<http://www.eyetechds.com>)
- H.K. EyeCan VisioKey (<http://www.eyecan.ca>)
- LC Technologies Eyegaze (<http://www.eyegaze.com>)
- Metrovision VISIOBOARD (<http://www.metrovision.fr/>)
- TechnoWorks TE-9100 Nursing System (<http://www.t-works.co.jp/page011.html>)
- Tobii Technologies MyTobii (<http://www.tobii.com/>).

Each of these systems has its own particular advantages and disadvantages: some of the systems should be mounted on the users head, some of them do not allow involuntary head or eye movements, some of them can only be used with dedicated communication software, etc.

4.2 Number of eye control systems in use

From the COGAIN Deliverable 5.1 "Catalogue of currently available eye trackers" (Ersbøll, 2005), we have some information about the number of systems in use:

- EagleEyes: 10 – 50
- LC Technologies Eyegaze: 500 - 1000
- Metrovision VISIOBOARD: 10 - 50
- TechnoWorks TE-9100 Nursing System: 100 - 500
- Tobii Technologies MyTobii: not known (both in Denmark and Norway there are 4 users)

Based on this information (average maybe 100 systems) COGAIN estimates that about 2000 – 3000 systems are in use in Europe (including the TechnoWorks system from Japan).

If most (or all) of the requirements identified in Chapter 2.2 "What benefit do the user seek?", were met then the market size would probably grow considerable. Not only people with ALS and locked-in syndrome, who are already using eye control systems today, but also many other target disease groups in need for alternative access (as mentioned in Chapter 2.1, "Target groups for eye control systems") would then be able to use an eye control system.

⁵ COGAIN catalogue of currently available eye trackers, <http://www.cogain.org/eyetrackers>

4.3 Alternative to eye control - competitive solutions

There are a range of access devices available for people with disabilities to use as alternatives to eye control, including switches, pointer-based interfaces (e.g. trackballs, joysticks, headmice) and electrical interaction (e.g. brain-computer interface and muscle EMG). The factors involved in choosing an appropriate input device (or devices) are complex and depend on a range of issues, including safety, reliability, independence, ease of use, etc.

As the (severity) level of motor disability increases, the number of possible usable computer input devices, or input modalities (such as eye, head or hand pointing), decreases dramatically; with the majority of input devices becoming unusable once the hand function is lost (Donegan et al., 2005).

It depends on each person's disability or level of function, which input devices are competitive in each case. For some people with disabilities eye control is their only method of independent control of technology. In those cases, different eye control systems would be competitive solutions.

In other cases, when the person, for instance, can control the movement of his or her head (e.g. quadriplegia) then headmice, where head movements control the mouse, or joysticks (joystick mice) controlled by chin or mouth, or switches controlled with head movements, would be competitive solutions.

In those cases, when the person has limited mobility or reduced strength in his or her arms, or maybe pain caused by e.g. arthritis, then competitive solutions would also include trackballs, joysticks controlled with a hand, mini keyboard, etc.

More information about the possible modalities and methods that may be most usable for a user can be found in the COGAIN Deliverable 3.1 "User requirements report with observations of difficulties users are experiencing" (Donegan et al., 2005).

In general, it is important to bear in mind that the alternative competitive solutions do not only include all the other eye control systems on the market but in most cases include more or less the total market on alternative input devices. For example, the Danish Centre for Assistive Technology runs a national database on assistive technology where almost all AT products on the Danish market are registered. Totally there are (registered) 36 different kind of keyboards (including visual keyboard), 89 different kind of computer mice (including standard mouse and pen mouse, trackballs, mouse trappers and touch pads, joystick mice, touch screen, eye-gaze systems, headmice, switch adapted mice, foot mice, EEG- and EMG-controlled mice) and 72 different kind of switches. As the example list shows, the selection of alternative input devices is large and varied.

4.4 Knowledge on eye control systems

Information and marketing on eye control is quite important. The professionals involved with providing AT to the end-user should have good knowledge on eye control systems. The COGAIN eye tracker catalogue (<http://www.cogain.org/eyetrackers>) aims to spread information on the possibilities. The catalogue contains information about currently available eye trackers for interactive applications within AAC, including:

- general information about each eye control system
- who can use the system
- what features does the system have
- technical specifications
- setup and system requirements
- contact information

Furthermore, the AT professionals need some information about who (disability, diagnoses) is actually using the different eye control systems, and, what benefits do the users attain? To meet these requirements it might

be suitable to add (to the catalogue) a possibility for the actual users of the systems to tell about their experiences concerning the use of eye control systems.

The AT professionals also need the possibility to see and try the eye control systems and for that reason it is important for COGAIN to participate in conferences, exhibitions etc., for the professionals, such as AAATE, ISAAC, RESNA (Jordansen et al., 2005).

Furthermore, the end-users and the public should be informed and made aware of the systems, if the goal were to increase the demand on eye control systems. For that purpose success stories in newspapers and magazines are quite effective, as well as COGAIN participation in conferences and meetings aimed for the users, such as Muscular Dystrophy Association Summer Camp, the International Symposium on ALS/MND and CSUN, International Conference on Technology and Persons with Disabilities. In addition, Trade shows, such as CeBIT or REHACARE would be relevant to attend, too.

4.5 Prices of eye control systems

Eye control systems available for people with disabilities cost more than most people can afford (often more than 5000 €), and authorities that would normally supply citizens with communications aids may be reluctant to invest such high amount of money if the final effectiveness is uncertain. The high price is due to the fact that the eye tracker industry only sells tens or hundreds of systems in a year. This makes it difficult to invest in the large engineering effort that is required to develop a really good, inexpensive unit. However, without such a unit, the market will continue to be limited – a kind of "chicken and egg" problem.

For example, the eye control system MyTobii was introduced on the Danish market in December 2004. Its price is 17,900 € and today, August 2005, there are four users who have the system granted from the Danish Service Delivery System. This indicates that if the quality of the eye control system were considerable better than the quality of the competitive solutions then, in some cases, the eye control system would be granted even if the price were high. In most cases, however, when the person can control any other part of the body than the eyes, it is possible to choose an alternative solution, which is cheaper and maybe better. In Denmark only a very few alternative input devices cost more than 1,400 € and most of those expensive systems are eye control systems⁶. In general, the prices of eye control systems on the European market are from 4,100 – 17,900 € (Ersbøll, 2005).

Obviously, in countries where there are no possibilities to get the system from the authorities, the high price is a significant obstacle.

The intention within COGAIN is to develop eye control systems based on ordinary video cameras or web cameras and to develop eye-tracking software that will run on a state-of-the-art PC. The plan is to develop eye control systems that can be used with standard word processors, email systems and internet browsers. The price of the system will be low and the software distributed via the Internet. With that goal in mind a price not higher than 2,000 – 3,000 € should be considered.

However, there is also another strategy. Hansen, et al. (2005) describe a possible development of the gaze tracking market. The idea is to not only focus on the market for assistive technology but also use gaze trackers in computer games, in ergonomic workplace adaptation with displays, in videoconference rooms or for hands-free interaction with mobile displays. Figure 1 depicts their prediction of the market evolution from today's small volumes to a mass market.

⁶ Hjaelpemiddel Institutet, <http://www.hmi-basen.dk/r8x.asp?include=00000&linktype=iso&linkinfo=2410>

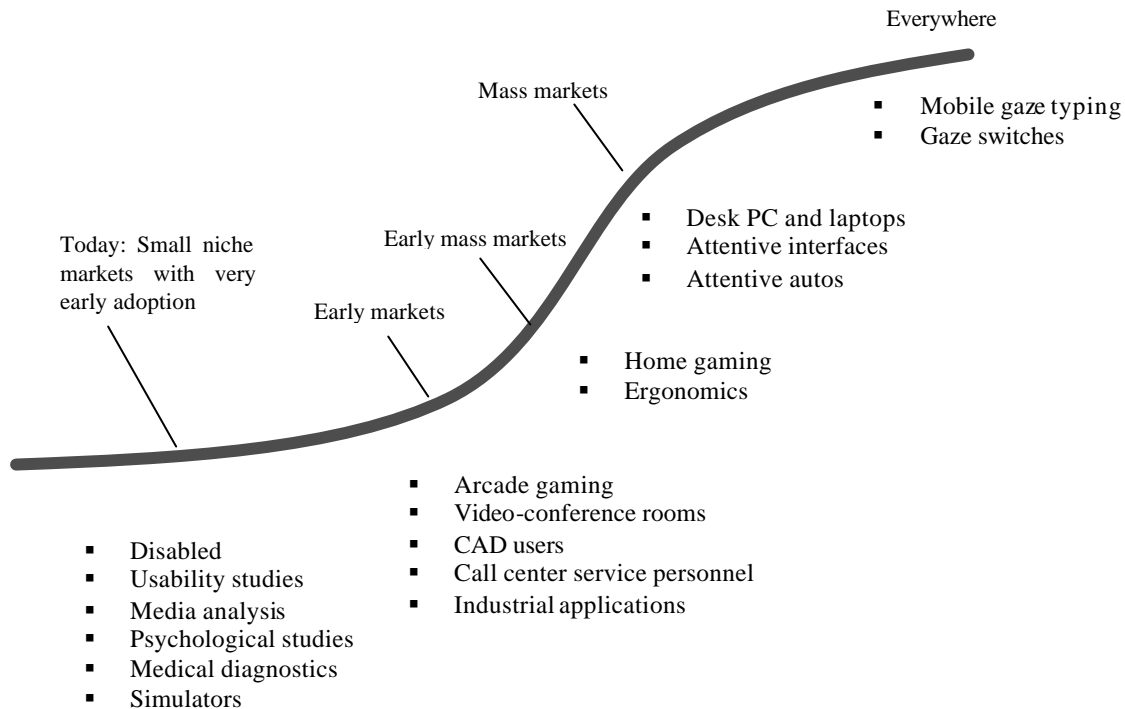


Figure 1. Possible development of the gaze tracking market(Hansen et al., 2005)

If gaze interaction were available for just 100 – 1000 €, it could become one of the preferred means of control for a very large group of people with special needs, not just for people in a lock-in condition, who have been the main user group until now. To reach that price level, a market volume of a million units is needed. As shown in the Figure 1, home gaming and ergonomics might be the applications to make sales take off.

4.6 Infrastructure and technological status

The infrastructure and the technological status in different European countries may also have impact on the market size for eye control systems. The more technological the country is and the more the authorities are using e-communication, the greater the demand is on effective, alternative access systems, including eye control systems.

In recent years, the EU has seen a rapid increase in the use of mobile phones. In 1990, only about one person in every hundred used one; in 2002, the number had risen to about 78% and it reached 80% in 2003. The EU-15 is ahead of both the United States and Japan in this respect – partly because European countries lead the field in manufacturing mobile phone technology⁷.

⁷ EUROSTAT http://europa.eu.int/abc/keyfigures/living/tools/index_animated_en.htm

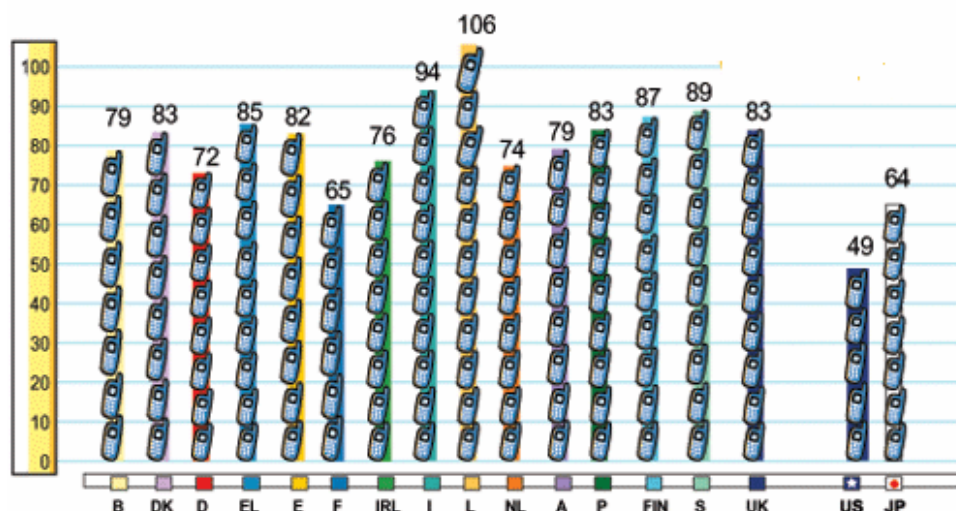


Figure 2. Number of mobile phone subscribers per 100 people, 2002 (EUROSTAT).

The ownership and use of personal computers (PCs) is also increasing in Europe, but Europeans as a whole lag well behind US citizens in owning PCs and using the internet.

Greater use of the internet is a key to modern education and new jobs, so one EU priority is to get its citizens online as fast as possible and to train both school pupils and older workers in computer skills⁸.

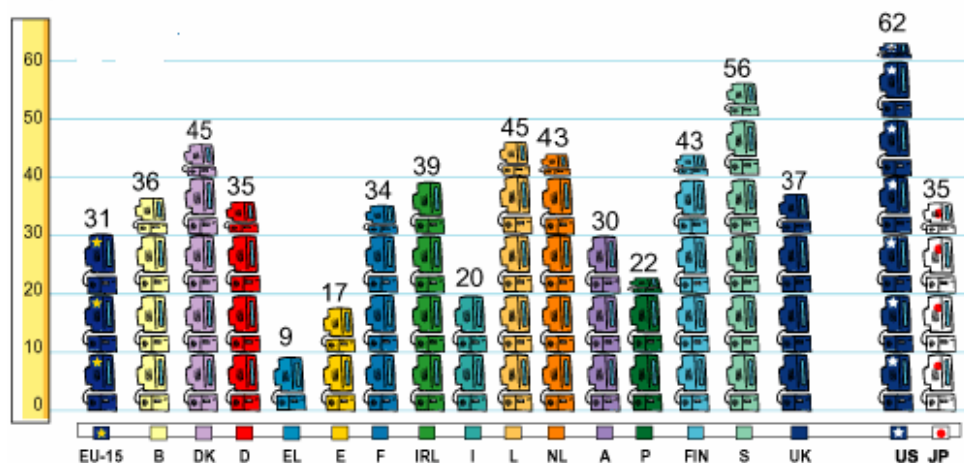


Figure 3: Number of personal computers per 100 people, 2001 (EUROSTAT).

The social development in itself is resulting in a greater demand on eye-gaze system. Naturally, the demand depends on the functionality, usability, price etc. of the system.

⁸ EUROSTAT http://europa.eu.int/abc/keyfigures/living/tools/index_animated_en.htm

5 Conclusion

Today the users of eye control systems are people with severely disabilities, such as ALS or locked-in syndrome. Only few systems are in use, maybe less than 2,000 users in Europe, and the system prices are relatively high, from 4,100 € to 17,900 €

If the market for eye control systems should grow, special attention should be paid to the following areas:

4. The *quality* of eye control systems should be improved; the systems should meet the *user requirements* (summarised from the COGAIN Deliverable 3.1 by Donegan et al., 2005), for instance:
 - The speed at which the pointer/cursor is moved around the screen should be variable, to meet individual needs and abilities.
 - The user should be able to calibrate and recalibrate the system easily and independently.
 - The user should be allowed to move (or turn) away from the system and return to it without the need for recalibration.
 - The user should be allowed to switch between different kinds of input and output modalities (multi-modal).
 - It should be possible to access any Windows application, including internet browsing, email, assistive software (virtual keyboards, text-to-speech systems), computer games, education software etc.
 - There should be no problem using the Eye Control System outside and in sunshine.
 - The system should be more portable, i.e. easy to move around with the Eye Control System mounted on the wheelchair.
 - The system should be flexible enough to accommodate a wide range of individual differences to meet the needs of as many users with complex physical or visual difficulties.
 - It should be possible to move independently from application to the next (e.g. from social communication to email and back again).
5. The *prices* of the eye control systems should be lower.

Supply and demand are, after all, also regulating the assistive technology (AT) market. It means that if the prices would not be as high as they are today, people with wider variety of disabilities (other than ALS, locked-in syndrome and similar conditions where the functional level is very limited) could be included to the target group.

If the price were around 2,000– 3,000 € the market would probably grow to include people with varying conditions, including e.g.:

- motor neuron disease (MND)/ amyotrophic lateral sclerosis (ALS)
- multiple Scleroses (MS)
- cerebral palsy (CP)
- spinal muscular atrophy (SMA)
- Werdnig-Hoffman syndrome
- Rett syndrome
- muscular dystrophy (MD)

- locked-in syndrome
- quadriplegia – spinal cord injury (SCI)
- brainstem stroke
- traumatic brain injury (TBI)
- repetitive strain injury (RSI)

If eye control systems were available for just 100 – 1000 € they could become one of the preferred mean of control for a very large group of people with special needs (Hansen et al., 2005).

6. A lot of attention should be put on *information dissemination*.

If the end-users or the AT professionals do not know about the eye control systems, they will not acquire them. Therefore, it is quite important to inform the end-users, the AT professionals and the public.

Different kind of dissemination activities (COGAIN Deliverable 7.1 by Jordansen et al., 2005) should take place, for instance:

- Participating in conferences, exhibitions, fairs and other key events
- Articles in magazines on AT
- Articles in newspapers
- Direct mail to end-user organizations
- Direct mail to information and resource centres on AT
- etc.

If the work within COGAIN is resulting in new and improved eye control systems with a lower price, and if the network is able to reach and inform the different target groups (end-users, AT professionals, general public), the market share could be considerable larger than today. It is estimated that there are about 571,250 persons in EU with physical impairments in need for alternative input devices. It is uncertain how many of those would need or prefer an eye control system rather than one of the other alternative solutions, but a market share on 5 – 10 percent might be realistic, meaning the market size in EU should be about 28,000 – 57,000 persons.

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Appendix A: Member states in EU

In 2004 there were 15 members of the European Union. This was called the EU-15. From May 2004 there have been 25 members of the EU.²¹

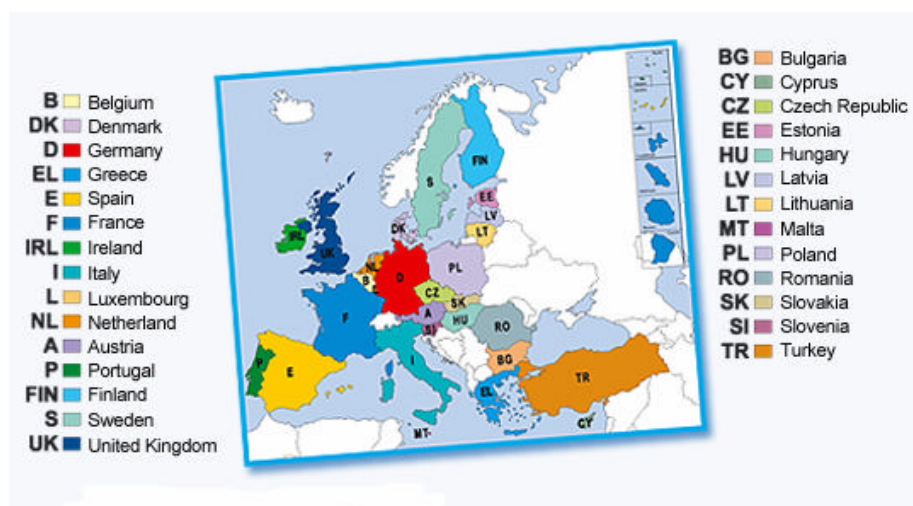


Figure 4. The 15 old and 10 new members of the EU incl. the three candidates (Bulgaria, Romania and Turkey)⁹

The EU-15 has nearly 380 million inhabitants – which is roughly 6% of the total world population. EU-25 has about 457 million inhabitants.

Seen on a map of the world, the EU is not a huge area. However, it has the world's third largest population, after China and India. The United States covers an area nearly three times bigger than the EU, but it has fewer people.

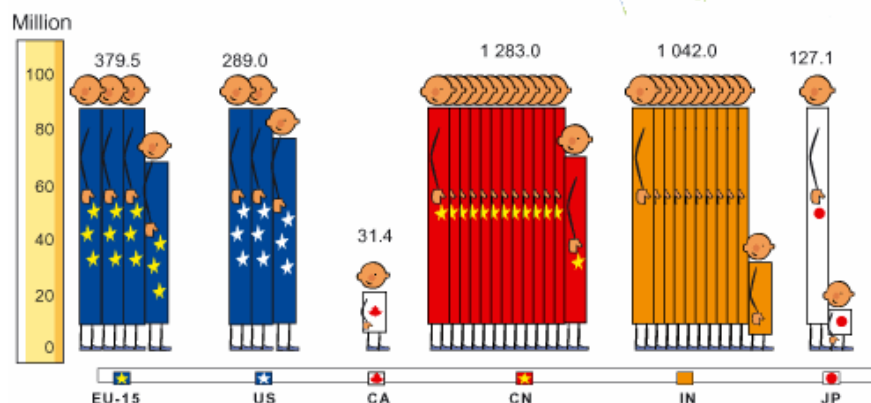


Figure 5. Population of the EU-15 and five other countries in 2003, measured in millions of people¹⁰.

⁹ http://europa.eu.int/abc/keyfigures/index_en.htm

¹⁰ http://europa.eu.int/abc/keyfigures/sizeandpopulation/compare/index_animated_en.htm

Appendix B: Target groups, characteristics

Target group	Brief definition of condition	Characteristics with Influence on the use of Eye Trackers
Motor Neurone Disease (MND) and Amyotrophic Lateral Sclerosis (ALS)	<p>Motor Neurone Disease (MND) is the name given to a group of related diseases affecting the motor neurones in the brain and spinal cord. Motor neurones are the nerve cells along which the brain sends instructions, in the form of electrical impulses, to muscles. http://www.mndassociation.org/full-site/what/index.htm</p> <p>When these neurones do not function properly, they don't activate the muscles, which gradually weaken and waste. The patterns of weakness vary from person to person. http://www.mnd.asn.au/whatis.html</p>	<p>In the majority of cases the intellect and memory are not affected, nor are the senses of sight, hearing, taste, smell and sensation. http://www.mnd.asn.au/whatis.html</p> <p>The wasting of muscles generally occurs in arms or legs initially, some groups of muscles being affected more than others. Some people may develop weakness and wasting of the muscles in the face and throat, causing problems with speech and difficulty chewing and swallowing. http://www.mndassociation.org/full-site/what/index.htm</p> <p>Use of the hands for lifting, eating, computer access etc can become increasingly difficult and tiring. Ultimately, eye movement can become the only method of communicating.</p>
Multiple sclerosis (MS)	<p>MS is thought to be an autoimmune disease that affects the central nervous system (CNS). The CNS consists of the brain, spinal cord, and the optic nerves. Surrounding and protecting the nerve fibres of the CNS is a fatty tissue called myelin, which helps nerve fibres conduct electrical impulses. In MS, myelin is lost in multiple areas, leaving scar tissue called sclerosis. These damaged areas are also known as plaques or lesions. Sometimes the nerve fibre itself is damaged or broken. Myelin not only protects nerve fibres but also makes their job possible. When myelin or the nerve fibre is destroyed or damaged, the ability of the nerves to conduct electrical impulses to and from the brain is disrupted, and this produces the various symptoms of MS. http://www.nationalmssociety.org/Sourcebook-Speech.asp</p>	<p>Numbness of the face, body, or extremities (arms and legs) is one of the most common symptoms of MS. Spasticity refers to feelings of stiffness and a wide range of involuntary muscle spasms, sustained muscle contractions or sudden movements. It is one of the more common symptoms of MS. Spasticity may be as mild as the feeling of tightness of muscles or may be so severe as to produce painful uncontrollable spasms of extremities, usually of the legs. Fatigue is one of the most common symptoms of MS, occurring in about 80% of people. Fatigue can significantly interfere with a person's ability to function at home and at work, and may be the most prominent symptom in a person who otherwise has minimal activity limitations.</p> <p>Speech disorders are also fairly common in MS. http://www.nationalmssociety.org/Sourcebook-Speech.asp</p>

<p>Cerebral palsy (CP)</p>	<p>Cerebral palsy is a term used to describe a group of chronic disorders that are characterised by an inability to fully control motor function, particularly muscle control and coordination.</p> <p>http://www.ninds.nih.gov/disorders/cerebral_palsy/cerebral_palsy.htm</p> <p>http://www.about-cerebral-palsy.org/definition/involuntary-movement.html</p>	<p>Symptoms of cerebral palsy include difficulty with fine motor tasks (such as writing or using scissors), difficulty maintaining balance or walking, involuntary movements. The symptoms differ from person to person and may change over time.</p> <p>http://www.ninds.nih.gov/disorders/cerebral_palsy/cerebral_palsy.htm</p> <p>Depending on which areas of the brain have been damaged, one or more of the following may occur: muscle tightness or spasm, involuntary movement disturbance in gait and mobility, abnormal sensation and perception, impairment of sight, hearing or speech and seizures.</p> <p>http://www.about-cerebral-palsy.org/definition/involuntary-movement.html</p>
<p>Spinal muscular atrophy (SMA)</p>	<p>Spinal muscular atrophy (SMA) is a condition that affects the nerves in an area of the spinal cord called the anterior horn. These nerve cells become damaged, breaking the link between the brain and the muscles. As a result, the muscles can't be used and become wasted or atrophied.</p> <p>http://www.bbc.co.uk/health/conditions/spinalmuscularatrophy1.shtml</p>	<p>SMA affects the voluntary muscles (especially those closest to the trunk of the body) used for activities such as crawling, walking, head and neck control and swallowing. There are several different types of spinal muscular atrophy. Type I (severe), also known as Werdnig-Hoffmann syndrome, type II (intermediate) and type III (mild) also known as Kugelberg-Welander disease affect children, while there are a variety of types of adult-onset SMA that develop later in life. Unlike types I, II and III, which aren't usually progressive, adult-onset SMA tends to progress very slowly, although it's not usually life-threatening. Symptoms are variable and depend on the muscles affected.</p> <p>http://www.bbc.co.uk/health/conditions/spinalmuscularatrophy1.shtml</p>
<p>Werdnig-Hoffman syndrome</p> <p>Rett syndrome</p>	<p>See above (Type I)</p> <p>Rett syndrome is a childhood neurodevelopmental disorder characterized by normal early development followed by loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, gait abnormalities, seizures, and cognitive dysfunction. It affects females almost exclusively.</p> <p>http://www.ninds.nih.gov/disorders/rett/detail_rett.htm</p>	<p>See above (Type I)</p> <p>The inability to perform motor functions (apraxia) is a feature of Rett Syndrome that interferes with every body movement, including eye control and speech. There are four stages of Rett Syndrome. The last stage, stage IV — called the <i>late motor deterioration stage</i> — can last for years or decades and is characterized by reduced mobility. Muscle weakness, rigidity (stiffness), spasticity, dystonia (increased muscle tone with abnormal posturing of extremity or trunk), and scoliosis (curvature of the spine) are other prominent features. Generally, there is no decline in cognition, communication, or hand skills in stage IV. Repetitive hand movements may decrease, and eye control usually improves.</p> <p>http://www.ninds.nih.gov/disorders/rett/detail_rett.htm</p>

<p>Muscular dystrophy (MD)</p>	<p>The muscular dystrophies (MD) are a group of genetic diseases characterized by progressive weakness and degeneration of the skeletal muscles that control movement. There are many forms of muscular dystrophy, some noticeable at birth (congenital muscular dystrophy), others in adolescence (Becker MD), but the 3 most common types are Duchenne, facioscapulohumeral and myotonic. These three types differ in terms of pattern of inheritance, age of onset, rate of progression, and distribution of weakness.</p> <p>http://www.ninds.nih.gov/disorders/md/md.htm</p>	<p>Duchenne MD - primarily affects boys. Onset is between 3-5 years and progresses rapidly. Most boys become unable to walk at 12, and by 20 have to use a respirator to breathe.</p> <p>Facioscapulohumeral MD - appears in adolescence and causes progressive weakness in facial muscles and certain muscles in the arms and legs. It progresses slowly and can vary in symptoms from mild to disabling.</p> <p>Myotonic MD - varies in the age of onset and is characterized by myotonia (prolonged muscle spasm) in the fingers and facial muscles. Cataracts are another characteristic with an effect on eye control. Individuals with myotonic MD usually have long faces and drooping eyelids.</p> <p>http://www.ninds.nih.gov/disorders/md/md.htm</p> <p>For many people with muscular dystrophy, computer access using their hands can become very tiring, making eye control a potentially easier option in certain cases.</p>
<p>Locked-in syndrome</p>	<p>Locked-in syndrome is a rare neurological disorder characterized by complete paralysis of voluntary muscles in all parts of the body except for those that control eye movement. It may result from traumatic brain injury, diseases of the circulatory system, diseases that destroy the myelin sheath surrounding nerve cells, or medication overdose.</p> <p>http://www.ninds.nih.gov/disorders/lockedinsyndrome/lockedinsyndrome.htm</p>	<p>Individuals with locked-in syndrome are conscious and can think and reason, but are unable to speak or move. The disorder leaves individuals completely unable to talk and totally paralyzed.</p> <p>http://www.ninds.nih.gov/disorders/lockedinsyndrome/lockedinsyndrome.htm</p> <p>Because eye movement of some kind is often the only deliberate movement, eye control might be the only means of accessing technology available.</p>
<p>Quadriplegia – spinal cord injury</p>	<p>When a person suffers a spinal cord injury, generally the spinal nerves joining the cord below the level of injury will be either completely or partially cut off from the brain, resulting in Quadriplegia or Paraplegia. The body will still be trying to send messages from below the level of injury to the brain, however these messages will be blocked by the damaged spinal cord. Nerves joining the spinal cord above the level of injury will be unaffected and continue to work as normal.</p> <p>http://www.apparelyzed.com/paralysis.html</p>	<p>Quadriplegia/Tetraplegia is when a person has a spinal cord injury above the first thoracic vertebra and paralysis usually affects the cervical spinal nerves resulting in paralysis of all four limbs. In addition to the arms and legs being paralysed, the abdominal and chest muscles will also be affected resulting in weakened breathing and the inability to properly cough and clear the chest.</p> <p>http://www.apparelyzed.com/paralysis.html</p> <p>Eye movement might be the only (or easiest) method to control a computer for some quadriplegics.</p>

<p>Brainstem stroke</p>	<p>There are two types of stroke: <i>Ischemic</i> stroke, the most common type of stroke happens when there is a sudden lack of blood flow to some part of the brain, usually due to a blood clot blocking an artery or blood vessel. <i>Hemorrhagic</i> strokes happen when there is bleeding in the brain from a broken or leaking blood vessel. Either type of stroke can cause brain cells to die. This brain damage may cause a person to lose control of certain functions, such as speech, movement, and memory. http://www.4woman.gov/faq/stroke.htm#1</p>	<p>Each area of the brain is responsible for a particular function or ability. Depending on where the stroke happens, there can be different effects. Strokes that occur in the brain stem are especially damaging. The brain stem is the area of the brain that controls all of our involuntary "life-support" functions, such as breathing rate, blood pressure and heartbeat. The brain stem also controls abilities such as eye movements, hearing, speech and swallowing. Since impulses generated in the brain's hemispheres must travel through the brain stem on their way to the arms and legs, people with a brain stem stroke may also develop paralysis in one or both sides of the body. http://www.4woman.gov/faq/stroke.htm#1</p>
<p>Traumatic brain injury</p>	<p>A traumatic brain injury occurs when an outside force affects the head hard enough to cause the brain to move within the skull or if the force causes the skull to break and directly damages the brain. http://www.biausa.org/Pages/types_of_brain_injury.html</p>	<p>The effects of a traumatic brain injury are largely dependant on which area of the brain has been injured. Paralysis, difficulty moving body parts, weakness and poor coordination are some possible results, and in severe cases can cause 'Locked-In syndrome' – see above for details. http://www.biausa.org/Pages/types_of_brain_injury.html</p>
<p>Repetitive strain injury</p>	<p>'Occupational overuse syndrome', 'work-related upper limb injury', and 'isometric contraction myopathy', are all phrases used to describe what is more commonly known as RSI. Overuse of the muscles of the hands, wrists, arms or shoulders on a repeated, and usually, daily basis, causes injury to these muscles. This results in inflammation that is never really given a chance to recover, since these everyday activities invariably continue. http://www.bbc.co.uk/health/healthy_living/health_at_work/physical_rsi.shtml</p>	<p>Although not a group particularly focused on within the project, eye control has obvious potential benefits for anybody who needs to rest injured muscles and joints, or find an alternative method of controlling a computer or machine.</p>

Table 4. Description of the condition and characteristics of the different target groups according to there specific diagnoses

Appendix C: Target groups, progression

Target group	Progression / Stable (and speed of progression)
MND / ALS	The effect of MND varies enormously in respect of initial symptoms, rate and pattern of progression, and survival time after diagnosis. http://www.mnd.asn.au/whatis.html . MND is generally a steadily progressive disease, but the rate of progression varies greatly from one person to another. http://www.mndassociation.org/full-site/what/index.htm
Multiple sclerosis (MS)	It is generally very difficult to predict the course of MS. The disorder varies greatly in each individual but most people with MS can expect to live 95% of the normal life expectancy.
Cerebral palsy (CP)	At this time, cerebral palsy cannot be cured, but due to medical research, many patients can enjoy near-normal lives if their neurological problems are properly managed. Appear in the first few years of life and generally do not worsen over time. http://www.ninds.nih.gov/disorders/cerebral_palsy/cerebral_palsy.htm
Spinal muscular atrophy	Unlike types I, II and III, which aren't usually progressive, adult-onset SMA tends to progress very slowly, although it's not usually life-threatening. Symptoms are variable and depend on the muscles affected. Fatigue may be a problem, but the muscles used for swallowing and respiratory function are rarely affected. http://www.bbc.co.uk/health/conditions/spinalmuscularatrophy1.shtml
Werdnig-Hoffman syndrome	See above (Type I Spinal Muscular Atrophy)
Rett syndrome	Despite the difficulties with symptoms, most individuals with Rett syndrome continue to live well into middle age and beyond. Because the disorder is rare, very little is known about long-term prognosis and life expectancy. While it is estimated that there are many middle-aged women (in their 40s and 50s) with the disorder, not enough women have been studied to make reliable estimates about life expectancy beyond age 40.
Muscular dystrophy	The prognosis of MD varies according to the type of MD and the progression of the disorder. Some cases may be mild and progress very slowly over a normal lifespan, while other cases may have more marked progression of muscle weakness, functional disability, and loss of the ability to walk. In Duchenne MD, death usually occurs in the early 20s. http://www.ninds.nih.gov/disorders/md/md.htm
Locked-in syndrome	The prognosis for those with locked-in syndrome is poor. The majority of individuals do not regain function. http://www.ninds.nih.gov/disorders/lockedinsyndrome/lockedinsyndrome.htm
Quadriplegia – spinal cord injury	There are two types of lesion, these are a complete injury and an incomplete injury. Someone with a complete injury will have complete loss of muscle control and sensation below their level of lesion. An incomplete injury is where maybe only the muscles have been paralyzed, or where there is impaired sensation. Many incomplete injury's may regain some functionality with time. http://www.apparelyzed.com/paralysis.html
Brainstem stroke	Specific effects of a stroke may worsen (i.e. if unable to eat, digestive problems may arise) but rehabilitation and medical treatment can help a person recover from the direct effects of a stroke. http://www.4woman.gov/faq/stroke.htm#4
Traumatic brain injury	These impairments may be either temporary or permanent, depending on the severity of the injury. http://www.biausa.org/Pages/types_of_brain_injury.html
Repetitive strain injury	If untreated, symptoms and pain worsen. Could benefit from being able to choose to use eye control to alleviate pain or rest a muscle/joint in the operation of a computer/machine.

Table 5. Description of the progression in the diseases

Appendix D: Number of person with different diagnosis in Europe

Country	Population	ALS	MS	CP	SMA	Rett syndrome	SCI	Stroke	TBI	Total / country
Austria*	8 100 000	486	2 430	16 848	97	810	324	10 935	16 200	48 130
Belgium*	10 400 000	624	3 120	21 632	125	1 040	416	14 040	20 800	61 797
Denmark*	5 400 000	324	1 620	11 232	65	540	216	7 290	10 800	32 087
Finland*	5 200 000	312	1 560	10 816	62	520	208	7 020	10 400	30 898
France*	59 600 000	3 576	17 880	123 968	715	5 960	2 384	80 460	119 200	354 143
Germany*	82 500 000	4 950	24 750	171 600	990	8 250	3 300	111 375	165 000	490 215
Greece*	11 000 000	660	3 300	22 880	132	1 100	440	14 850	22 000	65 362
Ireland*	4 000 000	240	1 200	8 320	48	400	160	5 400	8 000	23 768
Italy*	57 300 000	3 438	17 190	119 184	688	5 730	2 292	77 355	114 600	340 477
Luxembourg*	400 000	24	120	832	5	40	16	540	800	2 377
Netherlands*	16 200 000	972	4 860	33 696	194	1 620	648	21 870	32 400	96 260
Portugal*	10 400 000	624	3 120	21 632	125	1 040	416	14 040	20 800	61 797
Spain*	40 700 000	2 442	12 210	84 656	488	4 070	1 628	54 945	81 400	241 839
Sweden*	8 900 000	534	2 670	18 512	107	890	356	12 015	17 800	52 884
UK*	59 300 000	3 558	17 790	123 344	712	5 930	2 372	80 055	118 600	352 361
Cyprus**	600 702	36	180	1 249	7	60	24	811	1 201	3 569
Czech Republic**	10 241 138	614	3 072	21 302	123	1 024	410	13 826	20 482	60 853
Estonia**	1 332 893	80	400	2 772	16	133	53	1 799	2 666	7 920
Hungary**	10 006 835	600	3 002	20 814	120	1 001	400	13 509	20 014	59 461
Lithuania**	3 596 617	216	1 079	7 481	43	360	144	4 855	7 193	21 371
Latvia**	2 290 237	137	687	4 764	27	229	92	3 092	4 580	13 609
Malta**	398 534	24	120	829	5	40	16	538	797	2 368
Poland**	38 635 144	2 318	11 591	80 361	464	3 864	1 545	52 157	77 270	229 570
Slovakia**	5 431 363	326	1 629	11 297	65	543	217	7 332	10 863	32 273
Slovenia**	2 011 070	121	603	4 183	24	201	80	2 715	4 022	11 950
Total	453 944 533	27 237	136 183	944 205	5 447	45 394	18 158	612 825	907 889	2 697 338

Table 6. Number of persons with different diagnosis in Europe (diagnosis numbers calculated using the prevalence numbers from Table 1).

* Numbers from http://europa.eu.int/abc/keyfigures/sizeandpopulation/wholives/index_accessible_en.htm

** Numbers from <http://www.cia.gov/cia/publications/factbook/>

Appendix E: Number of disabled in Europe

It has been estimated, that 10-15% of the total European population is disabled (in 1992). The total population in EU is about 380 million. There is variation in the estimates of each country due to different criteria in defining disabilities and in collecting the data. Only Spain and UK use the International Classification of Impairments, Disabilities and Handicaps (ICIDH) recommended by WHO to record their data at the international level. (Besson, R. 1995, 21) About 70 % of all disabled people can also be defined as elderly. However, majority of elderly people are not disabled.¹¹

Country	Population	Number of disabled in percentage
EU-15	379,5	10- 15
Austria (A)	8,1	
Belgium (B)	10,4	11,1
Denmark (DK)	5,4	12,0
Finland (FIN)	5,2	8,3
France (F)	59,6	10,2
Germany (D)	82,5	13,1
Greece (EL)	11,0	9,0
Ireland (IRL)	4,0	11,6
Italy (I)	57,3	12,1
Luxembourg (L)	0,4	
Netherlands (NL)	16,2	11,9
Portugal (P)	10,4	11,4
Spain (E)	40,7	14,9
Sweden (S)	8,9	12,0
United Kingdom (UK)	59,3	11,6

Table 7. Population on 1 January 2003, measured in millions of people.

¹¹ http://europa.eu.int/abc/keyfigures/sizeandpopulation/wholives/index_accessible_en.htm
<http://www.csreurope.org/csrfinfo/csrfdisability/DisabilityFactsandfigures/>

Appendix F: Sources for Table 1, 2 and 6

¹ Estimated by leading doctor, Ole Gredal, Bispebjerg Hospital, Denmark, 26.05.2005. Similar numbers are found in International Alliance of ALS/MND Associations, <http://www.alsmndalliance.org/whatis.html>

² MS-Network, http://www.ms-network.com/intl/msnetwork/general/guide_understanding_ms/what_is_ms/who_gets_ms/who_gets_ms.jsp

³ The Cerebral Palsies – Epidemiology, Prevalence and Incidence, Thames Valley Children’s Centre, <http://www.tvcc.on.ca/gateway.php?id=167&cid=2>

⁴ Spinal Cord Injury Facts, The Healthy Gimp, <http://www.rexdonald.com/facts.htm>,

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Spinal Cord Injury Facts, Foundation for Spinal Cord Injury Prevention, Care & Cure, <http://www.fscip.org/facts.htm>

⁵ Emedicine, Spinal Muscle Atrophy, <http://www.emedicine.com/orthoped/byname/spinal-muscle-atrophy.htm>

Understanding Spinal Muscular Atrophy, Families of SMA, <http://www.curesma.org/booklet.shtml>

⁶ Rett Syndrome Europe (RSE), <http://www.rettssyndrome.com/>,

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⁷ Duchenne and Becker Muscular Dystrophy, Athena Diagnostics, <http://www.athenadiagnostics.com/DMD/index.asp>

⁸ Stroke, brain attack, <http://www.5mcc.com/Assets/SUMMARY/TP0175.html>

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⁹ Acquired Brain Injury, Early rehabilitation and long term outcome, B Pentland, British Society for Disability and Oral Health, http://www.bsdh.org.uk/reports/Brian_Pentland.ppt#293,4, Epidemiology of Head Injury

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(estimation from The Centres for Disease Control and Prevention (CDC)),

International Brain Injury Association, <http://www.internationalbrain.org/content.php?pages=facts>

¹⁰ The World Factbook, <http://www.cia.gov/cia/publications/factbook/geos/ee.html>

¹¹ The numbers are collected from some disability organizations in Denmark.

¹² Spanish Statistics National Institute, <http://www.ine.es>

¹³ Lihastautiliitto, Finland, <http://www.lihastautiliitto.fi/cgi-bin/iisi3.pl?cid=lihastautiliitto&mid=77&sid=170>

¹⁴ MS-liitto, Finland http://www.ms-liitto.fi/index.phtml?page_id=103&topmenu_id=6&menu_id=103&page_id=103&this_topmenu=6&lang=1

¹⁵ Source: STT news agency

http://www.kuntalehti.fi/uploaded/template/asp/kl_perustyyli_0.asp?version=46866&category=49

¹⁶ Estimation based on several articles:

Organisations with resources for rare diseases, <http://www.harvinaiset.org/diagnoosit/p8.html>

Lihastautiliitto, Finland, <http://www.lihastautiliitto.fi/cgi-bin/iisi3.pl?cid=lihastautiliitto&mid=77&sid=170>

¹⁷ Finnish Information Center on Mental Retardation, <http://www.saunalahti.fi/kup/syndroma/rett.htm>

¹⁸ Estimate by the leading treating doctor, Jukka Turkka, Käpylän kuntoutuskeskus, 29.6.2005



¹⁹ Estimate by the leading treating and researching doctor, Eija Ahoniemi, Käpylän kuntoutuskeskus 29.6.2005

²⁰ Aivovammaliitto, Finland, <http://www.aivovammaliitto.fi/>