Multimedia **A**uthoring and **M**anagement using your **E**yes and **M**ind

H2020-ICT-2014 - 644780

D6.2
Definition of pilot trials with the participation of patients

Dissemination level:	Public (PU)
Contractual date of delivery:	Month 7, 30/11/2015
Actual date of delivery:	Month 7, 30/11/2015
Workpackage:	WP6 Clinical requirements analysis and pilot trials with patients
Task:	T6.2 Definition of pilot trials with the participation of patients
Type:	Report
Approval Status:	Final
Version:	V0.5
Number of pages:	166
Filename:	D6.2_ClinicalRequirements_PilotTrialsDefinition_Final.docx

Abstract: This report provides a detailed description of the methods that will be necessary for conducting the pilot studies, which have been elicited with the participation of patients. In particular, analysis of the questionnaires from the three groups of patients and their caregivers are included describing patients' disabilities in computer operation, their desired goals for improvements and their willingness to perform multimedia related tasks using MAMEM. The report also contains three case scenarios for the use of MAMEM platform by the three groups of patients, as well as a preliminary and indicative set of interface adjustments that will be necessary for using MAMEM platform.

co-funded by the European Union

Copyright

History

Version	Date	Reason	Revised by
V0.1 (alpha)		Table of contents to be checked and revised by the consortium and coordinator	Dr. Sevasti Bostantjopoulou Dr. Sevasti Katsarou Dr. Spiros Nikolopoulos
V0.2	Novemeber 13th 2015	Refinements across all sections	Dr. Meir Plotnik Mr. Amihai Gottlieb Dr. Gabi Zeilig Dr. Rachel Kizony Dr. Zoe Katsarou Dr. Sevasti Bostantzopoulou Ms. Ariana Nichogiannopoulou Ms. Sissy Chlomissiou
V0.3 (beta)	November 17th 2015	Address comments from internal reviewers	Dr. Meir Plotnik Mr. Amihai Gottlieb Dr. Gabi Zeilig Dr. Rachel Kizony Dr. Zoe Katsarou Dr. Sevasti Bostantzopoulou Ms. Ariana Nichogiannopoulou Ms. Sissy Chlomissiou Dr. Chandan Kumar Dr. Spiros Nikolopoulos
V0.4 (pre-final)	November 27th 2015	Addressed the remarks of the internal reviewers' and finalized the document.	Dr. Meir Plotnik Mr. Amihai Gottlieb Dr. Gabi Zeilig Dr. Zoe Katsarou Dr. Sevasti Bostantzopoulou Ms. Ariana Nichogiannopoulou Ms. Sissy Chlomissiou
V0.5 (final)	November 30th 2015	Proof reading and minor editing.	Dr. Sevasti Bostantzopoulou Dr. Zoe Katsarou Dr. Spiros Nikolopoulos

Author list

Organization	Name	Contact Information
SHEBA	Dr. Meir Plotnik	Meir.PlotnikPeleg@sheba.health.gov.il
SHEBA	Mr. Amihai Gottlieb	Amihai.gottlieb@gmail.com
SHEBA	Dr. Gabi Zeilig	Gabi.Zeilig@ sheba.health.gov.il
SHEBA	Dr. Racheli Kitzony	Racheli.kizony@gmail.com
AUTH	Dr. Zoe Katsarou, MD	katsarouzoe@gmail.com
AUTH	Dr. Sevasti Bostantjopoulou, MD	bostkamb@otenet.gr
MDA Hellas	Ms. Ariana Nichogiannopoulou	ArianaNichogiannopoulou@mdahella.gr
MDA Hellas	Mr. Sissy Chlomissiou	sissychlomisiou@mdahellas.gr
UNI KO-LD	Chandan Kumar	kumar@uni-koblenz.de
CERTH	Spiros Nikolopoulos	nikoopo@iti.gr

Executive Summary

The rationale behind this deliverable is to provide an outline of the definition of the clinical trials. In addition, to provide the technology developing partners information concerning the difficulties of Spinal Cord Injury (SCI), Parkinson's Disease (PD) and Neuromuscular Disorders (NMD) patients in using the computer, as well as their needs and demands for improvement in order to determine the nature of MAMEM's novel interaction paradigm. Furthermore, motivated by these requirements the goal of this deliverable has been also to provide three detailed case scenarios that could be implemented based on a set of novel interaction elements.

More specifically, the three clinical partners worked in parallel, along the following axes:

a) Definition of clinical trials: we defined the procedure and the outcome measures for the trials that will be conducted in order to demonstrate the ability of the MAMEM platform to become operational through the users' eyes and mind, **b) Analysis of questionnaires:** we analyzed the computer use habits, difficulties and needs through a set of questionnaires answered by the patient and caregivers groups, **c)** we described three **detailed usage scenarios** with patients searching on the Web, navigating and posting on Facebook and undertaking a slides generation process using multimedia content.

In D6.2 we outline a two staged clinical trials: (1) a pilot phase in which we will test feasibility and usability of the MAMEM platform; and (2) short efficacy phase during which we will test whether social engagement, as reflected by web based multimedia authoring, is improved among users (Section 2).

An important outcome of D6.2 is extracting clinical requirements for the MAMEM platform, based on interviews with patients and care givers (Section 3). Thus, D6.2 complements the analysis done in D6.1 [1], where such requirements were derived from literature reviews and focus groups. The main product of this deliverable appears in section 3.6 in a table of the requirements which were derived from the questionnaires results, similar to the one appearing in D6.1.

Finally, Section 4, provides elaborations to the user scenarios that were depicted in D6.1. In particular we describe here in more detail the foreseen user interaction with the MAMEM platform.

Abbreviations and Acronyms

AD	Assistive Devices
DBS	Deep Brain Stimulation
EEG	Electroencephalography
NMD	Neuromuscular Diseases
PD	Parkinson's Disease
SCI	Spinal Cord Injury
SUS	Standard User Satisfaction questionnaire
ADL	Activities of daily living
SMA	Spinal Muscular Atrophy

Table of Contents

List of Figures

1 INTRODUCTION

Individuals with motor disabilities due to loss of voluntary muscular control are marginalized from mainstream society. Due to the inability to gain employment and have recreational activities, difficulty of travel and access to rehabilitation services, people with such disabilities have a restricted social life that revolves around their family, with little opportunity for social inclusion. This, in turn, creates the condition known as social isolation. Using a computer connected to the world via the Internet, they have a high degree of independence and communication. They can read the news, research areas of interest, purchase supplies and have access the world. So MAMEM's goal is to integrate these people back to the society by increasing their potential for communication. MAMEM will deliver technology to enable interface channels that can be controlled through eye-movements and mental commands. Three groups of patients with disabilities (Parkinson's disease, tetraplegia and neuromuscular diseases) will test MAMEM's applications dealing with multimedia authoring and management.

In order to define the clinical requirements derived from the specific needs from each patient group we adopted the following approach: a) we outline the procedure for the clinical trials (phases of the trials, number of participants, methods of testing in the different phases and outcome measures for the multimedia authoring), b) we report the results and requirements derived from the analysis of questionnaires dealing with the computer use habits, difficulties and needs of patients. The methodology followed consists in handing over the questionnaires, collecting answers from a number of patients and caregivers that answered the questionnaires in the three groups, considering the clinical characteristics of patients, describing the statistical analysis of the questionnaires' answers; and c) we give a detailed description of cases (usage scenarios) with patients searching on the web, navigating and posting on Facebook and undertaking a multimedia authoring task using a web-based tool.

In section 2, we report about the analysis results of the questionnaires that were developed as part of D6.1 [1]. The purpose of the questionnaires (see Appendices) is to assess the computer use habits, difficulties and needs of subjects with spinal cord injury (SCI), subjects with Parkinson's diseases (PD) and subjects with neuromuscular disorders (NMD).

The main results of this deliverable are a set of requirements for designing the MAMEM platform derived from the answers of the questionnaires and a description of the procedure that will be followed for the clinical trials. This set appears in chapter 3.6.

The document is divided into three main Sections. The first section defines the two phases of the pilot trials and the outcome measures. The second section contains the results and the statistical analysis of the computer use habits, difficulties and needs questionnaires. Finally, the third section describes the three indicative usage scenarios for MAMEM platform, as well as a set of indicative and preliminary elements of human-computer interaction using your eyes and mind.

2 DEFINITION OF PILOT TRIAL WITH THE PARTICIPATION OF PATIENTS

Rational: The rational of the clinical trials stage is to demonstrate the ability of the MAMEM platform to become operational through the users' eyes and mind. In order to do this, in each clinical site, we will define an experimental protocol. More specifically, the trials will be divided in two phases. The first phase is designed to test the platform in a controlled environment to address feasibility and usability. The second phase is designed to assess the impact of the platform on the core target variable which is the multimedia authoring of the participants in less controlled settings, i.e. the patient's homes. In total, there will be 21 participants (6 healthy + 5 patients + 10 patients) in each of the clinical site (SHEBA, AUTH, MDA Hellas), summing up to 18 healthy participants and 45 patients.

2.1 Outline of the clinical trials

2.1.1 Phase I

The first phase will consist of testing 6 healthy participants and 5 patients from the local clinical cohort of each site. The trials will be held at the institute of the local investigators and will take approximately a half day visit. All travel expenses of the participants will be reimbursed and the participants will be paid for their time. The MAMEM platform will be tested in a dedicated room.

Since the study's population includes patients of clinical cohorts that may find it difficult to withstand the studies procedure, every part of the study will consist of several sessions with breaks and if needed, the subject will be invited for a second visit to complete the protocol.

a) Participants

Each site will be in charge of recruiting 11 participants. This number will include 6 healthy participants and 5 patients from the local clinical cohort. The inclusion/exclusion criteria of the patients will be specific to the characteristics of the local clinical cohort and will be specified as part of the experimental protocol. The healthy participants will be age and gender matched to the patient as much as possible.

Phase I inclusion/exclusion criteria for SCI patients (SHEBA):

Inclusion criteria:

- Men and women aged 18-80
- Suffering from a complete or incomplete spinal cord injury from C5 [3] and above

Exclusion criteria:

- Involuntary eye movements
- Implanted devices that may interfere with the brain electrical activity recorded by the EEG sensor
- Medical conditions that may induce seizures

- Brain conditions such as brain trauma, brain surgery, stroke that may interfere with the brain electrical activity recorded by the EEG sensor
- Any psychiatric (e.g., major depression) or cognitive conditions that may interfere with understanding the instructions or with participant cooperation
- Drugs or alcohol abuse

Phase I inclusion/exclusion criteria for PD patients (AUTH)

Inclusion criteria:

- Men and women aged 50-75 years
- Suffering from idiopathic Parkinson's disease

Exclusion criteria:

- Patients with dementia
- Any psychiatric or cognitive conditions that may interfere with understanding the instructions
- Implanted deep brain stimulator (DBS) or other electrical medical device
- Involuntary eye movements (nystagmus)
- Very severe body involuntary movements/dyskinesias
- Diminished visual acuity
- Prominent EEG abnormalities e.g. continuous slowing, epileptiform discharges

Phase I inclusion/exclusion criteria for neuromuscular diseases patients (MDA)

Inclusion criteria:

- Men aged 18-35 years
- Suffering from Duchenne disease or Spinal Muscular (SMA) Atrophy

Exclusion criteria:

- Involuntary eye movements and twitches
- Implanted devices (pacemaker) that may interfere with the absorption of EEG signals
- Medical conditions that can cause seizures, such as epilepsy
- Brain conditions that may affect EEG signals
- Any psychiatric or cognitive conditions that may interfere with understanding the instructions or with cooperation

b) Apparatus

The apparatus of this phase will include the MAMEM platform and desktop computer. The MAMEM platform will be set-up by an investigator or a research assistant who will be trained to operate the platform.

c) Procedure

The test day will be divided as well into two parts. The first part will be 1-2 hours of setup and training. This will include the introduction to the platform, putting it on the participants and training them using a learning curve. Learning curves are useful learning performance measures, and enable us to understand if the subject exhausted his/her capacity to learn. For example, if the more skilled a person is in performing an action, the lower will be the execution time, and the lower will be the error rate while completing the trial. If it is noticed that execution time does not reduce any more from trial to trial, or the error rate does not improve, one can conclude that the subjects reached a 'plateau' in his/her capacity to improve the performance. The training will include training with the EEG element, training with the gaze element and training with both elements (including also the GSR element). Designated software will be used to train the participants that will be specified and implemented as part of deliverable D5.2 – "Initial design and implementation of the prototype interface applications". The training will continue until a predefined threshold is passed, which will indicate the subject operates in a satisfactory level (e.g., minimal errors when writing a sentence, sufficient low values of execution time).

Once reaching a satisfactory level, the second part will begin. In this part, the feasibility and usability of the MAMEM platform will be tested using dictated tasks. These will include: (1) basic computer operations such as: moving the mouse cursor, opening windows and saving files and (2) advanced usage scenarios for managing, authoring and sharing multimedia content.

The dictated tasks will be introduced by a designated software program. The following are suggested indicative tasks for some of the computer operations that will be considered during the clinical trials. The exact list of these tasks will be specified and implemented as part of deliverable D5.2 – "Initial design and implementation of the prototype interface applications".

Cursor – basic

- Click the left button
- Click the right button
- Double click the left button
- Move the cursor around the edges of the screen
- Click and drag an icon around edges of the screen

Cursor – advanced

- Open a window, move it, resize it and close it.
- Scroll bar- scroll down and up, change pages

- Menu – select text , open category and select “copy”
- Typing
- Press the four cornered letter keys on the keyboard (q,p,m,z)
- Press and hold the shift key, then press the ‘ key
- Write all letters of the alphabet, with no space.
- Write a series of words
- Write two sentences in two different lines

The following are suggested tasks for advanced usage scenarios for multimedia management, authoring and sharing:

Multimedia management and authoring – Part I

- Open webcam software
- Use webcam to take picture and save it
- Open an image editing software and resize picture, save it
- Open internet browser
- Open MAMEM Facebook page
- Post picture on wall with caption (only after obtaining the consent of the subject)
- Comment on picture

Multimedia management and authoring – Part II

- Open webcam software
- Use webcam to take several pictures and make a video. Save the video.
- Open power point and create a slideshow.

2.1.2 Phase II

In the second phase, the participants will go over the same protocol as in the first phase, but this time in their home environment (and using the lightweight installation). The platform will be given to them for a fixed period in which they will be encouraged to use it. Since there are a limited number of platforms to be distributed, the devices will be given in a rotational process that will accommodate the time restrictions of the project. Designated software will monitor the online activities of the patients. This software will be installed few months prior to the trial to obtain baseline data. To allow privacy, the participants will be able to turn off the monitoring software.

a) Participants

Each site will be in charge of recruiting 10 patients from its local clinical cohort. The inclusion\exclusion criteria of the patients during this stage will be almost identical to the previous phase, with the necessary modifications regarding the procedure, and will also be specific to the characteristics of the local clinical cohort.

Efforts will be made that the 5 patients who participated in Phase I will also participate in Phase II. This will enable to assess the platform's learning effect over time, by offering a baseline to which these patients performance will be compared.

Two months before receiving the platform to their homes, the subject's online social multimedia authoring activities will be assessed using software designed for this purpose. This software will be specified and developed as part of WP7-Monitoring Social Integration and will be either installed on the patients' computer (if they own and use one), or monitor their activity externally by following their social accounts.

All the data collected in this way will be stored anonymously (i.e. initials of the participants) and will comply with the legal and ethical regulations. Using this data, the impact on the social multimedia authoring activities of the participants could be later assessed during this phase of the clinical trials. Not owning or using a computer will not be an exclusion criteria since some patients find it too difficult for them to use one and thus redundant to own one.

b) Apparatus

The apparatus of this phase will include the MAMEM platform and a computer used by the patient. The MAMEM platform will be set-up by an investigator or a research assistant who will be trained to install the platform. The patient will be trained to operate it during the half day visit. Technical support will arrive to the patient's homes if needed.

c) Procedure

The phase II procedure will include a half day visit to the patient's house for setup and training (same as phase I) and leaving the MAMEM platform for a fixed period (i.e. one week) in which the activities of the participants will be monitored. The half day visit will demand bringing all the necessary equipment and setting it up by an investigator or a research assistant trained to do so. In case the patient has a computer, the platform will be connected to it (for ecological reasons) unless there will be technical issues. In this case, or If the patient has no computer, a laptop will be provided for the patient for the fixed period. During this period, if needed, technical support will arrive to the patient's homes. In case some participants will have difficulties using the computer with the platform for experience reasons, technical support will assist them as much as possible. If these participants will have too many difficulties, they will be removed from the study.

The procedure during the half day visit will be identical to the procedure during Phase I.

2.2 Outcome measures of the clinical trials

2.2.1 Phase I

a) Outcome measures

The outcome measures during this phase will be measured by a software program. The software will automatically grade the actions undertaken by the subject: as a Success (S) or; a success with mistake (SM) or; a partial success (PS) ; or a failure (F). In addition, the time to finish (seconds) and the Number of mistakes will be measured. The advantage of this type of measuring is that we have statistics regarding some of the above tasks done by healthy participants using a mouse and keyboard, and patients using different assistive devices.

Later we will be able to compare our participants performances to this data. Below, we provide some examples for these outcome measures:

Primary outcome: The time needed to type without mistakes a 100 character (including spaces) sentence

Secondary outcomes:
Number of mistakes and the time it takes when preforming:

- movement of cursor to a target
- typing
- open windows
- perform a search
- learning curves

In addition patient and caregiver user satisfaction will be measured using standard user satisfaction (SUS) questionnaires. Examples of questions, include:

- Did it feel comfortable?
- How easy it was using the device?
- Do you believe you could use the device by yourself?
- Would you purchase the device?
- Any suggestions or comments?

b) Statistical analysis

Success rates, response errors and reaction times will be analysed. Learning curves based on success rates, response errors and reaction times will be created according to the data. User and care givers satisfaction will be assessed according to the questionnaires.

To assess the general feasibility and usability of the MAMEM platform, the outcome measures of the healthy participants will be compared to known operation measures of assistive devices in similar tasks. Non-significant outcomes will suggest that the platform can be considered as a satisfactory assistive device to be tested by the clinical cohorts. In order to assess the MAMEM platform's feasibility and usability by the clinical cohorts, the outcome measures of the patients will be compared to the outcome measures of the healthy participants. Non-significant result would suggest that the clinical cohorts could use the platform at a satisfactory level without the need for modifications. Significant results would warrant additional modification to the platform during the interim assessment stage between the two clinical trials phases.

In addition to the feasibility and usability analysis, success rates, time to finish rates and number of mistakes will be compared across the different patient cohorts and the healthy participants groups.

2.2.2 Phase II

a) Outcome measures

During the fixed period, designated software will measure the subject's online social activity, supported by multimedia authoring capabilities. The outcome measures during this phase will consist of the online authoring activities of the patients. Examples of such activities are:

surfing, posting, commenting on Facebook, YouTube, twitter etc. in addition, any activity that can be considered as social communication will be assessed as well, such as emails, skype conversations etc.

After the fixed period, patients and caregiver/family members will be asked to fill out standard user satisfaction (SUS) questionnaires. Examples for potential outcomes, include:

Primary outcome:

- The time spend per day in social media

Secondary outcomes:

- The time spent per day on the computer
- Technical features like above, and more

b) Statistical analysis

The number of online social multimedia authoring activities will be compared to these activities before the fixed period (if any). User satisfaction will also be compared across cohorts, patients and caregivers.

3 QUESTIONNAIRES REGARDING COMPUTER USE HABITS, DIFFICULTIES AND NEEDS

3.1 Methodology

Formulating the questionnaires: questionnaires for the assessment of computer habits, difficulties and needs of patients with spinal cord injuries (SCI), Parkinson's disease (PD) and neuromuscular disorders (NMD) designated for patients and caregivers have been formulated as part of deliverable D6.1 [1]. The patient questionnaire has 3 sections. The first section contains demographic and clinical data. The second section assesses the computer habits, working environment and difficulties of the patients. The third section collects data about the needs, missing functions and demands of improvement that the patients have from the current computer and/or assistive device they are using. An almost identical questionnaire has been formulated for the caregivers of the patients. Some differences exists between the questionnaires of the three target groups, especially in the field of clinical information and clinical symptomatology. The questionnaires designated for both patients and caregivers appear in Appendix A.

Collection of answers: The subjects enrolled to the study signed an informed consent (see Appendix B) for participation. Then a research assistant interviewed the patients (or the caregiver) and filled the questionnaire. The research assistant had a set of instructions throughout the questionnaire in order to address questions that might rise with the subjects.

Questionnaire data analysis: At first level all data were expressed as percentages for each group of patients. These data are presented below as tables or graphs. Then differences between patient groups were explored by chi square analysis [2], [3] for every pertinent questionnaire item (non-parametric data). In case that chi square analysis showed that there was a significant difference between groups, the adjusted residual (ad. res.) calculation was employed for post hoc identification of the group with the highest impact on this difference. An ad.res. above 1,96 was regarded as statistically significant above the 0.05 level [3]. For parametric data such as age, time spent with computer, years of computer experience, ANOVA [2] testing was performed.

Adjusted residual = (observed – expected) / √[expected x (1 + row total proportion) x (1-column total proportion)]

Paired comparisons between patients and caregivers were performed by means of the Wilcoxon signed ranks test [2] for nominal data and the McNemar test [2] for dichotomous data. Null hypothesis was rejected when $p < 0.05$ (exact significance). However in cases where there was exceptional incongruity in percentages of observed answers, Cohen's kappa [2] was also calculated. Statistical analysis was performed by means of the SPSS software package, version 21.0

3.2 Demographic and clinical data (Questionnaire – Chapter I)

3.2.1 SCI patients and caregivers

Demographics of SCI patients:

Fifteen patients with high spinal cord injury answered the questionnaire. There were 9 men (60%) and 6 women (40%). Their mean age was 46.3 ± 15.7 years (min=22, max=73 years). Nine (60%) were married, five (33,3%) were single and one (6,7%) was a widower. They had from 0 to 4 children (mean number 1.0 ± 1.4) with a mean age of 20.8 ±19.6 years. Their mean educational level was 14.4 ± 4.2 (min=10, max=24 years). Their occupation is presented in Table 1.

Table 1: Occupation of SCI patients (N=15)

	Frequency	Percent
Accountant	1	6,7
Army - currently in rehab	1	6,7
artist	1	6,7
Beautician	1	6,7
Brinks driver in the past	1	6,7
Business	1	6,7
Carpenter - consulting	1	6,7
Computer programmer	1	6,7
Cook in the past	1	6,7
Student	2	13,3
Text editor/student	1	6,7
Unemployed	3	20,0

Currently only six patients were employed, working full time, approximately 35.83 ± 15.72 hours per week (min=5, max=60 hours).They had financial support from a) IDF/ministry of defence (8 pts; 53.33% and from social security 7 pts; 46,7%).

Clinical information of SCI patients:

Clinical information about level and etiology of SCI are presented in Table 2 & Table 3. SCI had happened 18.33 ± 12.47 years before (min =1, max=39 years).

Table 2: Level of SCI injury (N=15)

Level	Frequency	Percent
C2	1	6,7
C3	4	26,7
C4	5	33,3
C5	5	33,3

Table 3: Etiology of SCI (N=15)

Etiology	Frequency	Percent

Battle	2	13,3
Fall	1	6,7
Military training accident	1	6,7
Non-traumatic- transverse myelitis	1	6,7
Transport	10	66,7

Currently 12 (80%) SCI patients were moving using a motorized wheel chair and 3 (20%) did not. They spent 10.9±3.64 hours in bed (min=5, max=16 hours). All SCI patients have spent some time in a rehabilitation ward. Their mean time of care in rehabilitation ward was 13.20±5.93 months (min=6, max=24 months). SCI patients self-assessed the level of immobility of various body parts and the results are presented in Table 4. The fact that the SCI interviewees had relatively high level of spinal injury (C5 and above) is transpired by the high prevalence of partial or incomplete wrists and fingers immobility. It can also be seen that the higher the body part in question, the less immobility is seen, that is due to the bigger distance of the neuronal sites that activate this organ, from the actual injury point.

Table 4: SCI patients immobility self-assessment (N=15)

	None		Partial		Complete	
Immobility	Freq	%	Freq	%	Freq	%
Tongue	14	93,3	1	6,7	0	0
Jaw	14	93,3	1	6,7	0	0
Neck	11	73,3	2	13,3	2	13,3
Shoulders	7	46,7	6	40,0	2	13,3
Arms	2	13,3	9	60,0	4	26,7
Elbows	1	6,7	8	53,3	6	40,0
Wrists	0	0	8	53,3	7	46,7
Fingers	0	0	7	46,7	8	53,3

Demographics of SCI patients' caregivers:

Fifteen caregivers answered the questionnaires. There were 9 men (60%) and 6 women (40%). Their mean age was 41.7±10.08 years (min=27, max=59 years). Their mean educational level was 13.8±2.4 years (min=10, max=20 years). Concerning their relation to the patient eight (53.3%) were professional caregivers and 7 (46.7%) were relatives.

3.2.2 PD patients and caregivers

Demographics of PD patients:

Nineteen PD patients were included in the statistical analysis. There were 14 (73.7%) men and 5 (26.3%) women with a mean age of 59.6 ± 15.7 years (median=60 years, min=45,

max=80 years). All patients were married and lived with spouse. They had from 0 to 3 children (mean number 1.7±0.8) with a mean age of 28.7±9.3 years (min=7, max= 41 years). Their educational level was 14.6 ± 1.8 years (min=12, max=17 years). Their occupational level is presented in

Table **5**. Currently 10 were employed, working full time with approximately 42.4 ±17.5 hours per week (min=25, max=84 hours per week). Patients' source of financial income is presented in Table 6.

Table 5: Occupation of PD patients (N=19)

	Frequency	Percent
businessman	1	5,3
civil servant	2	10,5
economist	2	10,5
nurse	1	5,3
pensioner	9	47,4
professor	1	5,3
shopkeeper	1	5,3
teacher	2	10,5

Table 6: PD patients' source of financial income (N=19)

	Frequency	Percent
Business revenue	1	5,3
Pension	9	47,4
Salary	8	42,1
Shop revenue	1	5,3

Clinical information of PD patients:

Clinical information about age at disease onset, disease duration and severity of the disease according to the Hoehn and Yahr scale [6] are presented in Table 7.

Table 7: Clinical characteristics of PD patients (N=19)

	Mean	Median	Min	Max	SD
Age at diagnosis (yrs)	50,37	52,00	36,00	67,00	8,48
Disease duration (yrs)	9,58	9,00	3,00	18,00	4,51
PD stage(H&Y)	2.05	2,00	2,00	3,00	0,22

None of the patients was using a wheelchair or was bedridden. Furthermore none of the patients had been in rehabilitation ward. Moreover, PD patients self-assessed the level of akinesia/bradykinesia (slowness of movement) of various body parts and the results are presented in Table 8.

Table 8: PD patients' self-assessment of immobility/akinesia (N=19)

	None		Partial		Complete	
Immobility (akinesia)	Freq	%	Freq	%	Freq	%
Tongue	18	94,7	1	5,3	0	0
Jaw	18	94,7	1	5,3	0	0
Neck	16	84,2	3	15,8	0	0
Shoulders	14	77,8	4	22,2	0	0
Arms	14	73,7	4	21,1	1	5,3
Elbows	11	57,9	6	31,6	2	10,5
Wrists	5	26,3	12	63,2	2	10,5
Hands	2	10,5	15	78,9	2	10,5
Fingers	2	10,5	11	57,9	6	31,6

Hands, wrists and fingers were most affected by mild to moderate akinesia. As well as tremor was more prominent in the hands and fingers (see Table 9). Concerning the presence of dyskinesias (involuntary movements due to drug treatment-levodopa) hands and fingers are mostly involved (see Table 10). Eleven patients (61.1%) were able to take pictures or short videos with their computer workspace.

Table 9: PD patient's self-assessment of tremor (N=19)

	None		Mild/mod.		severe	
Tremor	Freq	%	Freq	%	Freq	%
Tongue	19	100	0	0	0	0
Jaw	17	89,5	1	5,3	1	5,3
Neck	18	94,7	0	0	0	0
Shoulders	18	94,7	0	0	0	0
Arms	18	94,7	0	0	0	0
Elbows	16	84,2	0	0	0	0
Wrists	11	57,9	2	10,5	2	10,5
Hands	2	10,5	4	21,0	4	21,0

Fingers	3	15,8	5	26,3	5	26,3

Table 10: PD patients' self-assessment of dyskinesia (N=19)

	None		Mild/mod.		Severe	
Dyskinesia	Freq	%	Freq	%	Freq	%
Tongue	17	89,5	2	10,5	0	0
Jaw	16	84,2	3	15,8	0	0
Neck	15	78,9	4	21,1	0	0
Shoulders	17	89,5	2	10,5	0	0
Arms	17	89,5	2	10,5	0	0
Elbows	16	84,2	3	15,8	0	0
Wrists	15	78,9	3	15,8	1	5,3
Hands	12	63,2	6	31,6	1	5,3
Fingers	13	68,4	5	26,3	1	5,3

Demographics of PD patients caregivers:

Nineteen caregivers answered the questionnaires. There were 5 men (26.3%) and 14 women (73.7%). Their mean age was 58.6±8.77 years (min=45, max=74 years). Their mean educational level was 14.8±2.7 years (min=12, max=21 years). Concerning their relation to the patient, they were all relatives.

3.2.3 NMD patients and caregivers

Demographics of NMD patients:

Nineteen NMD patients answered the questionnaire. There were 15 (78.9%) men and 4 (21.1%) women with a mean age of 27.2 ± 6.8 years (median=27 years, min=13, max=42 years). Only one was married, the rest of them were single. They do not have any children. Their educational level was 15.5 ± 3.8 years (min=6, max=24 years). Their occupational level is presented in Table 11. Currently 9 were employed, 4 working full time and 5 partial time. Mean hours employed per week were 23.4 ±15.7 (min=2, max=50). All of the patients had social security financial support.

Table 11: Occupation of NMD patients (N=18)

	Frequency	Percent
Archaeologist	1	5,56
Art Conservator	1	5,56
Athlete - Paralympic	1	5,56

Author / Translator	1	5,56
Business administrator	1	5,56
Economics	1	5,56
Graphic Designer	1	5,56
Informatics - Telecom	1	5,56
Journalist	2	11,12
Networks & Informatics	1	5,56
Psychiatrist	1	5,56
Psychologist	1	5,56
Public Servant	1	5,56
student history	1	5,56
Student photography	1	5,56
Teacher	1	5,56
Web designer / Logistics	1	5,56

Clinical information of NMD patients

Patients suffered from different neuromuscular diseases that are presented in Table 12. The diagnosis of their disease was made approximately 23.4±7.3 years ago. Seven patients had undergone spine surgery. Seventeen patients (89.5%) were in wheel chairs while two (10.55) were bedridden. None of the patients had been in rehabilitation ward.

Table 12: Patients neuromuscular diseases (N=19)

	Frequency	Percent
Arthrogryposis	1	5,3
Duchenne	5	26,3
Duchenne/ Becker	2	10,5
Muscular Dystrophy	1	5,3

SMA	1	5,3
SMA II	6	31,6
Tunisian	2	10,5
Ulrich	1	5,3

NMD patients SCI patients self-assessed the level of immobility of various body parts and the results are presented in table 13.

Table 13: NMD patients' self-assessment immobility (N=19)

	None		Complete		Partial	
Paralysis	Freq	%	Freq	%	Freq	%
Tongue	16	84,2	0	0	3	15,8
Jaw	14	73,7	0	0	5	26,3
Neck	11	57,9	1	5,3	7	36,8
Shoulders	5	26,3	4	21,1	10	52,6
Arms	4	21,1	6	31,6	9	47,4
Elbows	2	10,5	7	36,8	10	52,6
Wrists	4	21,1	4	21,1	11	57,9
Hands	4	21,1	4	21,1	11	57,9
Fingers	7	36,8	1	5,3	11	57,9

Demographics of NMD patients caregivers:

Seventeen caregivers, 4 men (23.5%) and 13 women (76.5%) answered the questionnaire. Their mean age was 52.2±12.3 years (min-25, max=69 years). They had 11.3±5.02 year of education. Only 1 was a professional caregiver while the rest of them were relatives.

3.2.4 Demographic comparisons between groups

Patient group: There was a significant difference between groups regarding age, with PD patients being the oldest and NMD patients the youngest ($F_{2, 50} = 42.24$, $p<0.001$).There was no difference regarding gender of patients.

Caregiver group: There were the same findings regarding age of caregivers ($F_{2, 44} = 3.56$, $p=0.037$). There were no differences in gender.

3.3 Patients results

3.3.1 Computer habits, working environment and difficulties (Questionnaire – Chapter II)

The following results describe the computer habits, working environment and difficulties of SCI, PD and NMD patients. The same information which was gathered from the caregivers of these patients appears in chapter 3.4.

a) Computer use habits

The following sections was designed to assess the social life, hobbies, mobility, computer use rate, computer use importance and computer use habits of the patients.

Question a1: *"How is your social life affected by your disability?"*

Q a1.TABLE. Disability impact on SCI patients' social life (N=15)

Impact	Frequency	Percent
My social life is normal	6	**40,0**
There is no significant effect on my social life apart from limiting energetic aspects, such as dancing	4	26,7
My social life is restricted and I do not go out as often	3	20,0
My social life is restricted to my home	0	0
I have no social life and feel lonely	2	13,3

Q a1.TABLE. Disability impact on PD patients' social life (N=19)

	Frequency	Percent
My social life is normal	7	**36,8**
There is no significant effect on my social life apart from limiting energetic aspects, such as dancing	7	**36,8**
My social life is restricted and I do not go out as often	1	5,3
My social life is restricted to my home	4	21,1
I have no social life and feel lonely	0	0

Q a1.TABLE. Disability impact on NMD patients' social life(N=19)

	Frequency	Percent
My social life is normal	1	5,3
There is no significant effect on my social life apart from limiting energetic aspects, such as dancing	14	**73,7**
My social life is restricted and I do not go out as often	2	10,5
My social life is restricted to my home	1	5,3
I have no social life and feel lonely	1	5,3

Most patients indicate that their social life is normal or little affected.

Question a2 and Question a3: *"Have you any kind of hobby or recreational activity? Yes /No. If yes, please specify:*"

The following tables specify the hobbies or recreational activities that were mentioned only if the patient had answered yes in Question a2.

Question a3. TABLE .Hobbies and recreational activities of SCI patients (N=10)

Hobby/recreational activity	Frequency	Percent
Bbeing outside	1	10,0
Bbeing with the children	1	10,0
Eexercise, ceramics	1	10,0
Hiking	1	10,0
Music, reading, writing	1	10,0
Nintentdo wii	1	10,0
RC cars	1	10,0
Reading	2	20,0
TV	1	10,0

Question a3. TABLE. Hobbies and recreational activities of PD patients (N=9)

	Frequency	Percent
Amateur Actor	1	7,69
Artistic Creativity	2	15,38
Backgammon	1	7,69
Cooking	1	7,69
Fishing	1	7.69
Fishing, Painting, Internet	1	7,69
Gardening	1	7,69
Jogging	1	7,69

Question a3. TABLE. Hobbies and recreational activities of NMD patients (N=17)

Hobby or recreational activity	Frequency	Percent
Cinema, Theater	1	5,9
Computer	1	5,9
Movies, Boccia	1	5,9
Movies, Music, Going out on a walk	1	5,9
Movies, Music, Sports	1	5,9

Music, Football, Reading	1	5,9
Music, Movies	1	5,9
Music, Sport, Computer	1	5,9
Painting, Going out on a walk	1	5,9
Photography, Boccia	1	5,9
Play Music, Computer	1	5,9
Play station, Night Clubs	1	5,9
Sport, Computer, Games	1	5,9
Sport, Reading, Movies, Music	1	5,9
Theater, Painting	1	5,9
Travel	1	5,9
Volunteering	1	5,9

Question a4: *"How is your mobility outdoors affected by your disability*?**"**

Question a4. TABLE. Impact of disability on SCI patients mobility outdoors (N=14)

Impact on mobility	Frequency	Percent
I travel frequently for needs / pleasure	10	**71,4**
I travel sometimes	2	14,3
I travel very rarely and only when there is an absolute need	2	14,3
I cannot travel and must stay home	0	0

Question a4 TABLE. Impact of disability on PD patients mobility outdoors (N=19)

	Frequency	Percent
I travel frequently for needs / pleasure	10	**52,6**
I travel sometimes	5	26,3
I travel very rarely and only when there is an absolute need	3	15,8
I cannot travel and must stay home	1	5,3

Question a4 TABLE. Impact of disability on NMD patients mobility outdoors (N=19)

Mobility outdoors	Frequency	Percent
I travel frequently for needs / pleasure	7	**36,8**
I travel sometimes	7	**36,8**
I travel very rarely and only when there is an absolute need	4	21,1
I cannot travel and must stay home	1	5,3

According to these results, most of the patients indicate that their mobility outdoors is not affected or little affected by their disability.

Question a5: *"Of the following systems, which do you own?"*

Question a5 .Table. Type of computer system owned by SCI patients (N=15)

	Frequency	Percent
Desktop computer	6	40,0
.aptop computer	11	**73,3**
Tablet	9	60,0
Smartphone	10	66,7

Question a5. Table. Type of computer system owned by PD patients (N=19)

	Frequency	Percent
Desktop computer	15	**78,9**
.aptop computer	11	57,9
Tablet	7	36,8
Smartphone	6	31,6

Question a5 .Table. Type of computer system owned by NMD patients (N=19)

	Frequency	Percent
Desktop computer	12	63,2
.aptop computer	15	**78,9**
Tablet	7	36,8
Smartphone	12	63,2

According to these results, it seems that most of the patients own a desktop or a laptop computer.

Question a6. *"If you own more than one, which one do you use the most?"*
Computer types used by patients more frequently are shown in the following graph. There is a statistically significant difference between the three groups regarding preferred type of the computer system they use. SCI patients use smartphones, PD patients desktops and NMD patients laptops (chi square=35,127/DF=6; $p<0.001$)

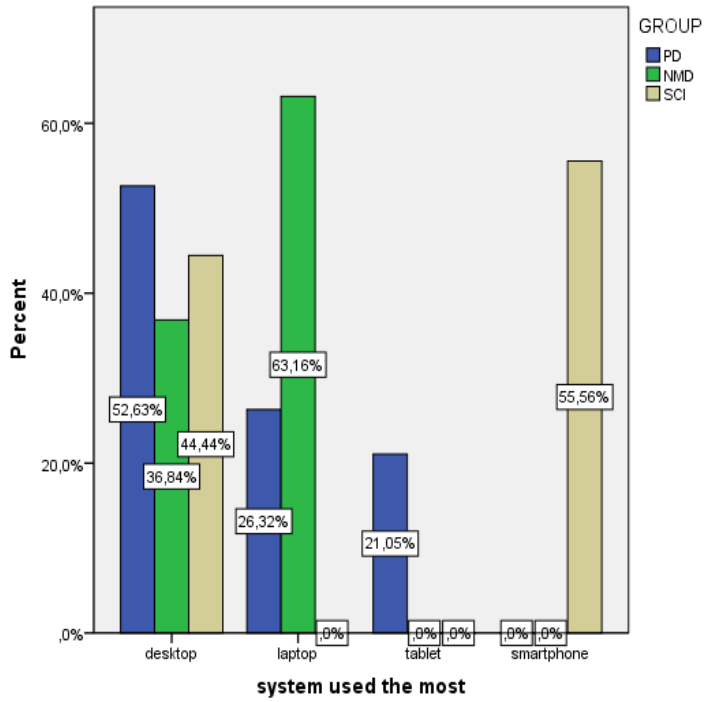


Figure 1: Computer system that is more frequently used by the different patients groups.

Although SCI patients report using smartphone the most, this outcome is very close to the desktop computer choice. In general – most of the patients report using computers the most.

Question a8: "*If so, how many hours (approximately) a day do you use it?***"**

Qa8. TABLE .Time of computer use every day*

Computer use (hours)	N	Mean	St. deviation
SCI patients	11	5,4	3,13
PD patients	19	4,34	2,88
NMD patients	19	6,05	2,99

*$F_{2,\ 46}$=1,458, p=0.275 (no significant difference)

All patients use the computer similarly, and for a considerable amount of time every day.

Question a9: *"How many years of experience do you have using a computer?"*

Q a9 .TABLE .Years of computer experience*

Computer experience (years)	N	Mean	St. deviation
SCI patients	11	19,09	8,31
PD patients	19	13,31	9,50
NMD patients	19	14,05	5,49

*$F_{2,\ 46}$ =2,04, p=0.151(no significant difference).

All patient groups have a similar and considerable experience in using a computer

Question a10: "*Please indicate your main uses of your computer system and the three most important ones*"

Qa10.TABLE. Main uses of computer system by SCI patients (N=15)

	Frequency	Percent
Social participation (Facebook, forums, etc.)	6	54,5
Productive activities (writing, editing, etc.)	8	**72,7**
Study (on-line courses, articles, etc.)	7	63,6
Games	1	9,1
Recreation (movies, music, crossword puzzles, blogs, etc.)	9	**81,8**
Communication (email, Skype, etc.)	8	**72,7**
Activities of daily living (purchases, payments, bank, etc.)	6	54,5
Information (Wikipedia, governmental sites, news, maps, etc.)	7	63,6
Other*	1	6,7

*=job searching

Qa10 .TABLE. Main uses of computer system by PD patients (N=19)

	Frequency	Percent
Social participation (Facebook, forums, etc.)	11	57,9
Productive activities (writing, editing, etc.)	10	52,6
Study (on-line courses, articles, etc.)	9	47,4
Games	6	31,6
Recreation (movies, music, crossword puzzles, blogs, etc.)	8	42,1
Communication (email, Skype, etc.)	15	**78,9**
Activities of daily living (purchases, payments, bank, etc.)	11	57,9
Information (Wikipedia, governmental sites, news, maps, etc.)	13	**68,4**
Other	0	0

Qa10 .TABLE . Main uses of computer system by NMD patients (N=19)

	Frequency	Percent
Social participation (Facebook, forums, etc.)	18	**94,7**
Productive activities (writing, editing, etc.)	14	73,7
Study (on-line courses, articles, etc.)	16	84,2

Games	10	52,6
Recreation (movies, music, crossword puzzles, blogs, etc.)	19	**100,0**
Communication (email, Skype, etc.)	19	**100,0**
Activities of daily living (purchases, payments, bank, etc.)	12	63,2
Information (Wikipedia, governmental sites, news, maps, etc.)	17	89,5
Other	0	0

SCI patients reported that their main uses of computer (in descending order) were: Recreation (movies, music, crossword puzzles, blogs, etc.), productive activities (writing, editing, etc.) and communication (email, Skype, etc.). PD patients selected: communication and Information (Wikipedia, governmental sites, news, maps, etc.). NMD patients chose Recreation, communication and Social participation (Facebook, forums, etc.). The highest frequencies altogether were observed in recreation, communication and social participation.

The following tables present the three most important uses of the computer by each patient group. This was done in order to obligate the participants to choose the most important uses in case they mark more than three uses.

Qa10. Table .The <u>three</u> most important uses of SCI patients' computer system

	N	Frequency	Percent
Social participation (Facebook, forums, etc.)	11	4	36,4
Productive activities (writing, editing, etc.)	11	5	**45,5**
Study (on-line courses, articles, etc.)	11	4	36,4
Games	11	1	9,1
Recreation (movies, music, crossword puzzles, blogs, etc.)	11	4	36,4
Communication (email, Skype, etc.)	11	5	**45,5**
Activities of daily living (purchases, payments, bank, etc.)	11	2	18,2
Information (Wikipedia, governmental sites, news, maps, etc.)	11	4	36,4
Other	15	1	6,7

Qa10. Table .The <u>three</u> most important uses of PD patients' computer system

	N	Frequency	Percent
Social participation (Facebook, forums, etc.)	19	7	36,8
Productive activities (writing, editing, etc.)	19	4	21,1
Study (on-line courses, articles, etc.)	19	7	36,8
Games	19	2	10,5
Recreation (movies, music, crossword puzzles, blogs, etc.)	19	1	5,3

Communication (email, Skype, etc.)	19	14	**73,7**
Activities of daily living (purchases, payments, bank, etc.)	19	7	36,8
Information (Wikipedia, governmental sites, news, maps, etc.)	19	12	**63,2**
Other	19	0	0

Qa10. Table .The <u>three</u> most important uses of NMD patients' computer system

	N	Frequency	Percent
Social participation (Facebook, forums, etc.)	19	16	**84,2**
Productive activities (writing, editing, etc.)	19	3	15,8
Study (on-line courses, articles, etc.)	19	7	36,8
Games	19	2	10,5
Recreation (movies, music, crossword puzzles, blogs, etc.)	19	8	**42,1**
Communication (email, Skype, etc.)	19	14	**73,7**
Activities of daily living (purchases, payments, bank, etc.)	19	2	10,5
Information (Wikipedia, governmental sites, news, maps, etc.)	19	5	26,3
Other	19	0	0

Regarding the three most important computer uses, SCI patients chose: productive activities and communication. PD patients' choices were communication and information. NMD patients selected social participation, communication and recreation as their three most important computer uses. Therefore, Communication represents the only important computer use beyond the various groups. Based on the above, between groups significant differences regarding the three most important computer uses were observed in: i) participation with the NMD patients reporting higher frequencies (chi square= 10.63/DF=2; p=0,005, ad.res. =3,3) while for PD patients this was the least important (ad.res.=2.0) and ii) the same applied to recreation [(chi square=7,39/DF=2;p=0,021),ad.res.=2,00 & 2.7 respectively].

Question a11A: "*Please indicate the main applications you use and the three most important ones:***"**

Q a11A. TABLE. SCI patients' Most important computer applications (N=15)

	Frequency	Percent
Internet browser	7	**46,7**
Email client	3	20,00
Word processor	7	**46,7**
Audio/video/image applications	5	**33,33**
Spreadsheets (e.g. Excel)	3	20,00

Computer games	2	13,33
Presentation software	4	26,67
Programming/database	2	13,33
Media editing applications	1	6,66
Other*	1	6,66

***= Solid works.**

Details of applications used: [SCI patients]

NOTE: *SCI patients were the only patient group that gave details about various computer applications*

Internet browser	Frequency	Percent
Chrome	2	28,6
Explorer	2	28,6
Firefox	2	28,6
Safari	1	14,3
Total	7	100,0

Email client	Frequency	Percent
Mail	1	33,3
Outlook	2	66,7
Total	3	100,0

Word processor	Frequency	Percent
Pages	1	14,3
Word	6	85,7
Total	7	100,0

Audio/video/image applications	Frequency	Percent
Media center	1	20,0
Paint	1	20,0
VLC	2	40,0
Youtube app	1	20,0
Total	5	100,0

Spreadsheets (e.g. Excel)	Frequency	Percent
Excell	3	100,0
Total	3	100,0

Computer games	Frequency	Percent
FIFA	1	50,0
Luxor	1	50,0
Total	2	100,0

Presentation software	Frequency	Percent
Keynote	1	25,0
Powerpoint	3	75,0
Total	4	100,0

Programming/database	Frequency	Percent
Delphi	1	50,0
Matlab	1	50,0
Total	2	100,0

Media editing applications	Frequency	Percent
Photoshop	1	100,0
Total	1	100,0

Other	Frequency	Percent
Solidworks	1	100,0
Total	1	100,0

TABLE Q a11A . PD patients' most important computer applications (N=19)

	Frequency	Percent
Internet browser	18	**94,7**
Email client	15	**78,9**
Word processor	9	**47,4**
Audio/video/image applications	8	42,1
Spreadsheets (e.g. Excel)	6	31,6
Computer games	3	15,8
Presentation software	4	21,1
Programming/database	3	15,8
Media editing applications	2	10,5
Other	1	5,3

TABLE Q a11A. NMD patients' most important computer applications (N=19)

main applications	Frequency	Percent
Internet browser	19	**100,0**
Email client	19	**100,0**
Word processor	17	**89,5**
Audio/video/image applications	17	**89,5**
Spreadsheets (e.g. Excel)	5	26,3
Computer games	10	52,6
Presentation software	11	57,9
Programming/database	8	42,1
Media editing applications	10	52,6
Other	1	5,3

SCI patients indicated as main applications the following (in descending order): internet browser, Word processor and Audio/video/image applications. PD patients reported internet browser, e-mail and Word processor. NMD patients selected internet browser, e-mail and Word processor.

The following tables present the three most important applications by each patient group. This was done in order to obligate the participants to choose the most important applications in case they mark more than three.

TABLE Q a11B.The three most important applications SCI patients use

	N	Frequency	Percent
Internet browser	10	10	**100,0**
Email client	10	2	20,0
Word processor	10	3	**30,0**
Audio/video/image applications	10	3	**30,0**
Spreadsheets (e.g. Excel)	10	0	0
Computer games	10	1	10,0
Presentation software	10	1	10,0
Programming/database	10	1	10,0
Media editing applications	10	1	10,0

Other	15	1	6,7

TABLE Q a11B.The three most important applications PD patients use

	N	Frequency	Percent
Internet browser	19	17	**89,5**
Email client	19	14	**73,7**
Word processor	19	7	**36,8**
Audio/video/image applications	19	5	26,3
Spreadsheets (e.g. Excel)	19	5	26,3
Computer games	19	3	15,8
Presentation software	19	2	10,5
Programming/database	19	1	5,3
Media editing applications	19	1	5,3
Other	19	0	0

TABLE Q a11B.The three most important applications NMD patients use

3 MOST IMPORTANT	N	Frequency	Percent
Internet browser	19	19	**100,0**
Email client	19	16	**84,2**
Word processor	19	9	**47,4**
Audio/video/image applications	19	7	36,8
Spreadsheets (e.g. Excel)	19	1	5,3
Computer games	19	5	26,3
Presentation software	19	1	5,3
Programming/database	19	3	15,8
Media editing applications	19	1	5,3
Other	19	0	0

The three most important applications were consistent to the same applications that were marked as the most used by the participant groups. Patients use browsers, email clients and word processors the most.

Group comparisons: Between groups significant differences regarding the three most important computer applications were observed in e-mail being important mainly for the

NMD group [(chi square=12,85/DF=2;p=0.002), ad.res.2,1]. E-mail was the least important for SCI patients (ad.res 3,7).

Question a12: Which operating systems do you work with?

The majority of patients, as shown in the graph of

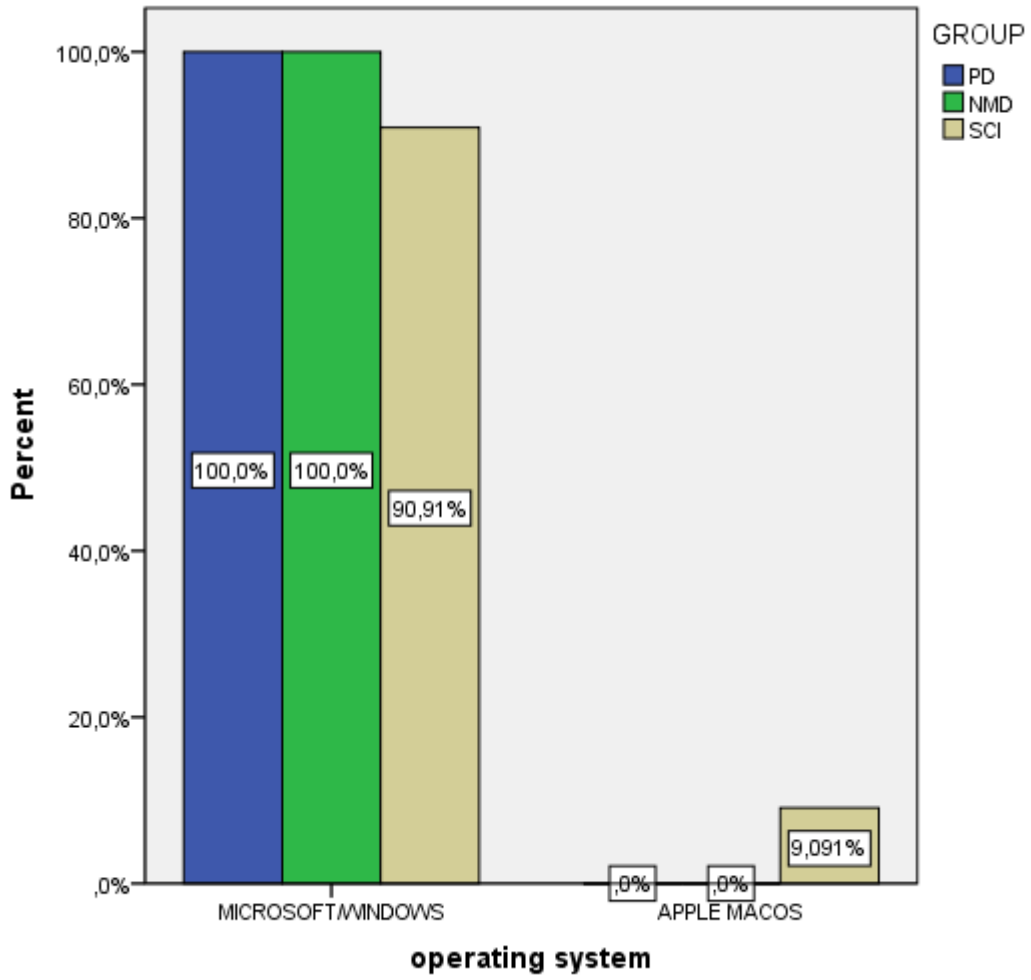


Figure 2 , use Microsoft Windows. This is a rather expected outcome given that Microsoft Windows is the most popular operating system and is in alignment with the technical decision described in deliverable D4.1 [2].

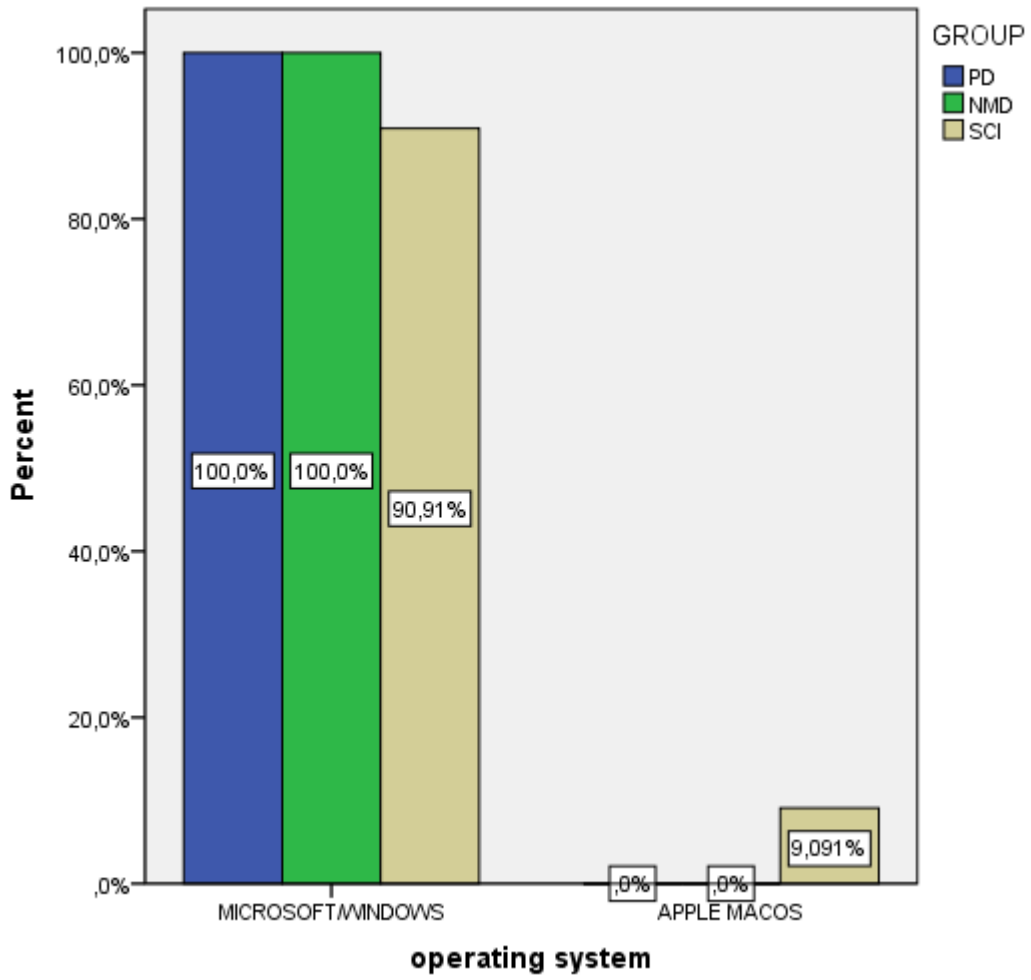


Figure 2: Operating system that is most frequently used by the patients groups.

Question a13. All patients were asked to evaluate the various aspects of computer contributions to their life using a scale from 1-5 (1- not important at all, 5- very important). Their evaluation is presented in the following 3 tables.

Q a13A. TABLE. SCI patients evaluation of computer contribution (N=11)

Computer contribution	Mean	Median	Min	Max	SD
Interpersonal interactions and relationships	3,09	3,00	1,00	5,00	1,70
Close, intimate relationships	2,00	1,00	1,00	4,00	1,26
Educational attainment	**4,18**	5,00	1,00	5,00	1,33
Work and employment status/potential	**4,00**	4,00	2,00	5,00	,89
Participation in desired community, social and civic activities	1,91	1,00	1,00	5,00	1,38
Autonomy and self-determination (making decisions)	**3,36**	4,00	1,00	5,00	1,50
Fitting in, belonging, feeling connected	2,73	3,00	1,00	5,00	1,79

Emotional well-being	2,36	2,00	1,00	5,00	1,63
Overall health	-	-	-	-	-

Q a13A. TABLE. PD patients evaluation of computer contribution (N=19)

	Mean	Median	Min	Max	SD
Interpersonal interactions and relationships	**3,26**	3,00	1,00	5,00	1,37
Close, intimate relationships	2,21	2,00	1,00	5,00	1,18
Educational attainment	**3,21**	3,00	1,00	5,00	1,40
Work and employment status/potential	**3,42**	3,00	1,00	5,00	1,43
Participation in desired community, social and civic activities	2,16	2,00	1,00	4,00	1,17
Autonomy and self-determination (making decisions)	2,58	3,00	1,00	5,00	1,39
Fitting in, belonging, feeling connected	3,00	3,00	1,00	5,00	1,25
Emotional well-being	2,89	3,00	1,00	5,00	1,59
Overall health	2,00	2,00	1,00	4,00	1,11

Qa13A. TABLE. NMD patients evaluation of computer contribution (N=19)

	Mean	Median	Min	Max	SD
Interpersonal interactions and relationships	**4,16**	4,00	1,00	5,00	,96
Close, intimate relationships	3,47	4,00	1,00	5,00	1,12
Educational attainment	**3,95**	4,00	1,00	5,00	1,13
Work and employment status/potential	3,68	4,00	1,00	5,00	1,38
Participation in desired community, social and civic activities	3,53	3,00	2,00	5,00	,90
Autonomy and self-determination (making decisions)	3,63	4,00	1,00	5,00	1,12
Fitting in, belonging, feeling connected	**4,00**	4,00	3,00	5,00	,75
Emotional well-being	3,21	3,00	1,00	5,00	1,32
Overall health	3,33	3,50	1,00	5,00	1,08

SCI patients gave the highest scores to the following aspects (in descending order): Educational attainment, work and employment status/potential, autonomy/self-determination (making decisions). PD patients gave the highest scores to the following aspects: Educational attainment, work and employment status/potential, autonomy and

self-determination (making decisions). NMD patients gave the highest scores to Interpersonal interactions and relationships, Educational attainment and Fitting in, belonging, feeling connected. Therefore, it seems that the most important aspects of computer use for all patient groups are Interpersonal interactions and relationships, Educational attainment and Work and employment status/potential.

Comparisons between groups showed a statistically significance difference in high scores (meaning very important) in: i) interpersonal interactions and relationships for NMD patients (chi square=19,97/DF=8; p=0,007, ad.res.3.6); ii) close, intimate relationships for NMD patients (chi square= :16,87/DF=8; p=0,026, ad.res.2.3); iii) participation for NMD patients (chi square =19,92/DF=8; p=0,008, ad.res.1.96); iv) significant differences between groups were also observed for fitting in, belonging, feeling connected (chi square=15,90/DF=8; p=0,03) and overall health (chi square =11,16/DF=4; p=0,017), but ad.res. were low and could not differentiate groups.

Question a13B. Patients were also asked to choose the three most important aspects of computer contributions to their life .Their answers are shown in the following three tables.

Q a13B. TABLE. SCI patients' three most important aspects of computer contribution (N=11)

Computer contribution	Frequency	Percent
Interpersonal interactions and relationships	6	**54,5**
Close, intimate relationships	1	9,1
Educational attainment	8	**72,7**
Work and employment status/potential	6	**54,5**
Participation in desired community, social and civic activities	0	0
Autonomy and self-determination (making decisions)	3	27,3
Fitting in, belonging, feeling connected	4	36,4
Emotional well-being	1	9,1
Overall health	0	0

Q a13B. TABLE. PD patients' three most important aspects of computer contribution (N=19)

	Frequency	Percent
Interpersonal interactions and relationships	8	**42,1**
Close, intimate relationships	2	10,5
Educational attainment	10	**52,(**

Emotional well-being	10	**52,6**
Fitting in, belonging, feeling connected	3	15,8
Autonomy and self-determination (making decisions)	5	26,3
Overall health	1	5,3
Participation in desired community, social and civic activities	7	36,8
Work and employment status/potential	0	0

Q a13B. TABLE. PD patients' three most important aspects of computer contribution (N=19)

	Frequency	Percent
Interpersonal interactions and relationships	14	**73,7**
Close, intimate relationships	4	21,1
Educational attainment	11	**57,9**
Work and employment status/potential	8	**42,1**
Participation in desired community, social and civic activities	2	10,5
Autonomy and self-determination (making decisions)	4	21,1
Fitting in, belonging, feeling connected	7	36,8
Emotional well-being	4	21,1
Overall health	3	15,8

The three most important aspects were not very similar to the ones who got the highest scores. SCI patients chose Educational attainment, interpersonal interactions and relationships, as well as work and employment status/potential. PD patients chose: Interpersonal interactions & relationships, educational attainment and emotional well-being. Finally, NMD patients chose: Interpersonal interactions & relationships, educational attainment and work and employment status/potential. Therefore, after obligating the patients to choose the most important aspect of computer use, the most important aspects for all patient groups were Interpersonal interactions & relationships and Educational attainment.

b) Difficulties in computer operations

The following sections was designed to assess the difficulties in computer operations of the patients.

Question b1 . All patients selected, from a list of various computer functions, those who found difficult to perform. Their answers are shown in the following three tables.

Qb1. TABLE. SCI patients' Difficulties performing on the computer (N=10)

Action	Frequency	Percent
Identifying the cursor on the screen	0	0
Moving the cursor on the screen	3	30,0
"Clicking" with the cursor	2	20,0
"Double clicking" with the cursor	2	20,0
Selecting and dragging, resizing windows	4	40,0
Zooming / Panning	5	**50,0**
Using the keyboard	3	30,0
Identifying the letters on the keyboard	0	0
Typing with the keyboard	6	**60,0**
Using two keys at the same time	7	**70,0**
Reading the words on the screen	0	0
Understanding how to use the assistive device software	0	0
Opening a file on the computer	1	10,0
Picking an item from a list or menu	1	10,0
Navigating the directory structure	0	0
Perform a search on the computer or on the Web	1	10,0
Browsing/Navigating the internet	1	10,0
Other	3	20,0

Qb1. TABLE. PD patients' Difficulties performing on the computer (N=19)

PD/ ACTION	Frequency	Percent
Identifying the cursor on the screen	7	**36,8**
Moving the cursor on the screen	12	**63,2**
"Clicking" with the cursor	6	31,6
"Double clicking" with the cursor	12	**63,2**
Selecting and dragging, resizing windows	5	26,3
Zooming / Panning	1	5,3
Using the keyboard	5	26,3
Identifying the letters on the keyboard	1	5,3

Typing with the keyboard	5	26,3
Using two keys at the same time	7	**36,8**
Reading the words on the screen	1	5,3
Understanding how to use the assistive device software	0	0
Opening a file on the computer	1	5,3
Picking an item from a list or menu	0	0
Navigating the directory structure	0	0
Perform a search on the computer or on the Web	0	0
Browsing/Navigating the internet	1	5,3
Other	1	5,3

Q b1. TABLE. NMD patients' Difficulties performing on the computer (N=19)

NMD /ACTION	Frequency	Percent
Identifying the cursor on the screen	0	0
Moving the cursor on the screen	4	21,1
"Clicking" with the cursor	4	21,1
"Double clicking" with the cursor	4	21,1
Selecting and dragging, resizing windows	7	36,8
Zooming / Panning	5	26,3
Using the keyboard	11	**57,9**
Identifying the letters on the keyboard	11	**57,9**
Typing with the keyboard	1	5,3
Using two keys at the same time	10	**52,6**
Reading the words on the screen	0	0
Understanding how to use the assistive device software	0	0
Opening a file on the computer	1	5,3
Picking an item from a list or menu	2	10,5
Navigating the directory structure	2	10,5
Perform a search on the computer or on the Web	2	10,5
Browsing/Navigating the internet	2	10,5

Other	3	15,8

The most difficult computer tasks as reported by SCI patients according to frequency were: “using two keys at the same time”, “typing with the keyboard “and “zooming / panning”. PD Patients reported major difficulties in: “Moving the cursor on the screen”, "double clicking with the cursor”, “using two keys at the same time” and” identifying the letters on the keyboard”. Finally, NMD patients have difficulties in: “Using the keyboard”, “identifying the letters on the keyboard” and “using two keys at the same time”. It seems that the most common difficulties to all patient groups are: using two keys on the keyboard at the same time, identifying the letters on the keyboard and using the keyboard to type.

Group Comparison: Significant differences between groups were observed in the following items: i) identifying cursor, PD patients expressed most frequent difficulty compared to the other two groups [(chi square=11,51,/DF=2; p=0.004) ad.res.=3.5); ii) moving cursor, PD patients expressed most frequent difficulty [(chi square=7,53/DF=2; p=0.028), ad.res.=3.0) and NMD patients the least (ad.res.2.1); iii) double clicking, PD patients expressed more frequent difficulty [(chi square=8,84/DF=2; p=0.014) ad.res.=2.7); iv) zooming/panning, SCI patients had more frequent difficulty [(chi square=7.36/DF=2; p=0.016), ad.res.=2.3] and PD patients less (ad.res.=2.4); v) identifying letters, was most difficult for NMD patients [(chi square=18,25/DF=2; p=0.000), ad.res=4.3] and least for PD patients; vi) typing with keyboard was most difficult for SCI patients [(chi square=10,5/DF=2;p=0.005, ad.res=2.9)] and least for NMS pts (ad.res.=2.7).

Question b2. Part A_1: "*How do you create text in the computer and how easy it is?* "

Since the patients could mention more than one way that use to create text, cumulative percent can reach more than 100%.

Qb2 A_1. TABLE. SCI patients’ ways to create a text on the computer (n=14)

	Frequency	Percent
Keyboard	6	**42,8**
By vocal dictating (a machine or a person)	2	14,2
By touch	0	0
Pointer and virtual keyboard	2	14,2
Other	6	**42,8***

* typing stick (6)

Qb2 A_1. TABLE. PD patients’ ways to create a text on the computer (N=19)

	Frequency	Percent

Keyboard	17	**89,5**
By vocal dictating (a machine or a person)	1	5,3
By touch	3	15,8
Pointer and virtual keyboard	1	5,3
Other	0	0

Qb2 A_1. TABLE. NMD patients' ways to create a text on the computer (N=19)

	Frequency	Percent
Keyboard	9	**47,4**
By vocal dictating (a machine or a person)	2	10,5
By touch	0	0
Pointer and virtual keyboard	10	**52,6**
Other	0	0

Most SCI Patients create text on the computer by the keyboard or by using a typing stick. PD patients create text mostly by keyboard and a few by touch. The majority of NMD patients prefer a pointer and virtual keyboard for text creation, but a significant percentage also uses the keyboard.

PD patients are the most frequent keyboard users for text creation [(chi square=8,16/DF=2; p= 0.02) ad.res.2,8]and NMD patients the least frequent (ad.res.2,1); ii) virtual keyboard is mostly used by NMD patients [(chi square=13,35/DF=2; p=0.001) ad. res.3,6] and less frequent by PD patients (ad.res.2,5).

Question b2 Part A_2: Self- assessment of difficulty in text creation is presented in the following three tables**.**

Qb2 A_2 . TABLE. SCI patients' Evaluation of creating text difficulty (1- very difficult, 5- very easy)

	Mean	Median	Min	Max	SD
Keyboard	**2,62**	2,50	1,00	5,00	1,47
By vocal dictating (a machine or a person)	1,00	1,00	1,00	1,00	.
By touch	-	-	-	-	-
Pointer and virtual keyboard	2,00	2,00	2,00	2,00	.
Other	**2,67**	2,50	1	5	2,06

Qb2 A_2. TABLE. PD patients' creating text difficulty (1- very difficult, 5- very easy)

	Mean	Median	Min	Max	SD
Keyboard	**3,76**	4,00	1,00	5,00	1,15
By vocal dictating (a machine or a person)	3,00	3,00	3,00	3,00	.
By touch	**4,33**	5,00	3,00	5,00	1,15
Pointer and virtual keyboard	3,00	3,00	3,00	3,00	.
Other	-	-	-	-	-

Qb2 A_2 .TABLE. NMD patients' creating text difficulty (1- very difficult, 5- very easy)

	Mean	Median	Min	Max	SD
Keyboard	3,56	4,00	1,00	5,00	1,59
By vocal dictating (a machine or a person)	**4,50**	4,50	4,00	5,00	,71
By touch	-	-	-	-	-
Pointer and virtual keyboard	**3,80**	3,50	3,00	5,00	,92
Other	-	-	-	-	-

For SCI patients, the easiest way to create text is by using the assistive device, for PD patients it is by using touch and NMD patients report they find it the easiest to use vocal dictating.
SCI patients reported more difficulty in creating text compared to the two other patient groups but this was not statistically significant.

Q b2 Part B_1 ***: "How do you point on the screen?"***

Since the patients could mention more than one way that use to create text, cumulative percent can reach more than 100%.

Q b2 B_1: Table. Patients ways to point on the computer (N=14)

	SCI (N=14)	PD (N=19)	NMD (N=19)

	Frequency	Percent	Frequency	Percent	Frequency	Percent
Mouse	3	21,4	17	**89,5**	14	**73,7**
Keyboard	0	0	3	15,8	1	5,6
By touch	2	14,2	6	**31,6**	3	**16,7**
Assistive device	7*	**50,0**	0	0	1	5,6
Other	1**	7,1	0	0	1***	5,3

*track ball (2); smartnav (2); upside mouse (2); mouthstick+touchpad (1)
** Other person moving the mouse
*** By vocal dictation to person

Most SCI patients point on the computer screen using an Assistive device. Most PD patients point by mouse or touch. NMD patients point mainly by mouse.
Comparisons between groups showed that PD patients are the most frequent mouse users for pointing [(chi square=20,83,/DF=2; p=0,000, ad.res.=2.8)], while SCI patients were the least frequent users of the mouse (ad.res.=4.4).

QUESTION b2 Part B_2: Patients were asked to evaluate their level of difficulty for screen pointing. Their answers are presented in the following three tables.

Qb2 B_2 TABLE. SCI patients' Pointing on the screen difficulty (1- very difficult, 5- very easy)

	Mean	Median	Min	Max	SD
Mouse	5,00	5,00	5,00	5,00	.
Keyboard	-	-	-	-	-
By touch	3,00	3,00	1,00	5,00	2,00
Assistive device	2,00	1,50	1,00	4,00	1,26
Other	-	-	-	-	-

Qb2 B_2 TABLE. PD patients' Pointing on the screen difficulty (1- very difficult, 5- very easy)

	Mean	Median	Min	Max	SD
Mouse	3,06	3,00	1,00	5,00	1,56
Keyboard	4,33	4,00	4,00	5,00	,58
By touch	4,17	4,50	3,00	5,00	,98
Assistive device	-	-	-	-	-
Other	-	-	-	-	-

Qb2 B_2 TABLE. NMD patients' Pointing on the screen difficulty (1- very difficult, 5- very easy)

	Mean	Median	Min	Max	SD
Mouse	4,36	4,50	3,00	5,00	,74
Keyboard	1,00	1,00	1,00	1,00	.
By touch	4,67	5,00	4,00	5,00	,58
Assistive device	5,00	5,00	5,00	5,00	.
Other	5,00	5,00	5,00	5,00	.

For SCI patients, those who report to be able to use a mouse to point expressed no difficulty. Yet, those who report using an assistive device seem to have significant difficulty. PD patients expressed some difficulty using the mouse and NMD patients little difficulty using the keyboard. However, differences in scores did not reach statistical significance.

c) Current working environment

The next set of questions was targeted to assess the working environment of patients using a computer and its effect on the using experience.

Question c1: The diagram presented in Figure 3 shows the percentage of patients using a stationary computer or a portable computer across the different patients groups.

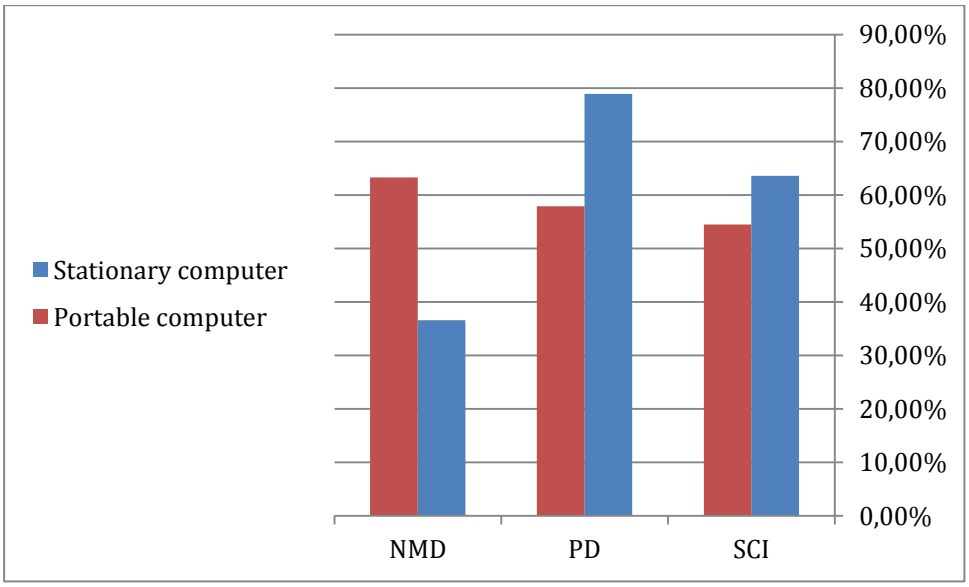


Figure 3: Percentage of users using a stationary and a portable computer across the patients groups

Since the participants could mark more than one answer, cumulative percent may be more than 100%. It seems that SCI patients use stationary and portable computer equally, while PD patients tend to use stationary computers and NMD patients tend to use laptops.

Questions c2 & c3: The goal of these questions was to identify the location of the computer and the positioning of the user when in use.

SCI patients: Computer is located mostly on a desk (63,6%) or rarely on a side table. They sit usually on a motorized wheel chair while they operate the computer (72,7%).

PD patients: Computer is located mostly on a desk (94,7%) or on a special tray or table. All patients sit usually on an arm chair while they operate the computer (100%).

NMD patients: Computer is located mostly on a desk (68,4%) or rarely mounted on an arm (1 person). Two patients have reported having the computer on bed and one on his legs. They sit usually on either a motorized wheel chair or a wheelchair while they operate the computer [(57,9%) and (26,3%) respectively].

For all patient groups, the most common computer location while operating them is on a desk. While the most common positioning for SCI and NMD patients is sitting in a motorized or a regular wheelchair, all PD patients seem to use armchairs.

Question c4. Common operating location/s: The goal of this question was to identify the common operating locations. Participants could mark more than on answer so cumulative percent may be more than 100%.

Qc4. TABLE. SCI patients' common operating location/s (N=14)

	SCI (N=14)		PD (N=19)		NMD (N=19)	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
Home	9	**81,8**	14	**73,7**	18	**94,7**
Work	2	18,2	8	**42,1**	2	10,5
Coffee shops	0	0	1	5,3	1	5,3
Other	7	**46,7**	2	10,5	2	10,5

The most common operating place for all patient groups was at home, while a substantial number of SCI patients operate computer at other locations such as university or at friends and a substantial number of PD patients operate computer at work.

Question c5: All patients were asked to evaluate how the working environment and their physical condition affect certain computer use aspects. Their evaluation is presented in the following three tables.

Qc5.TABLE. Evaluation of SCI patients' physical condition impact on various computer use aspects (1- No effect, 5- Completely)

	N	Mean	Median	Min	Max	SD
Comfort	11	3,18	3,00	1,00	5,00	1,60
Independence	10	3,30	4,50	1,00	5,00	2,00
Satisfaction	11	2,91	2,00	1,00	5,00	1,76
Pain	11	2,64	3,00	1,00	5,00	1,43
Speed of operation	11	3,18	4,00	1,00	5,00	1,78
Fatigue	11	**3,36**	4,00	1,00	5,00	1,43
Accuracy of operation	11	2,73	2,00	1,00	5,00	1,68
Endurance	11	**3,55**	4,00	1,00	5,00	1,52
Effectiveness	11	**3,45**	4,00	1,00	5,00	1,57
Ease of use	11	3,09	4,00	1,00	5,00	1,70
Enabling privacy	11	2,82	4,00	1,00	5,00	1,78

Q c5.TABLE.Evaluation of PD patients' physical condition impact on various computer use aspects (1- No effect, 5- Completely)

	N	Mean	Median	Min	Max	SD
Comfort	19	2,32	2,00	1,00	5,00	1,38
Independence	19	2,00	1,00	1,00	5,00	1,29
Satisfaction	19	2,16	2,00	1,00	4,00	1,17
Pain	19	1,42	1,00	1,00	4,00	,90
Speed of operation	19	**3,00**	3,00	1,00	5,00	1,25
Fatigue	19	2,47	2,00	1,00	5,00	1,47
Accuracy of operation	19	**2,68**	3,00	1,00	5,00	1,25
Endurance	19	2,21	2,00	1,00	5,00	1,36
Effectiveness	19	**2,63**	3,00	1,00	4,00	1,12
Ease of use	19	2,58	2,00	1,00	5,00	1,39
Enabling privacy	18	1,56	1,00	1,00	5,00	1,20

Qc5.TABLE.Evaluation of NMD patients' physical condition impact on various computer use aspects (1- No effect, 5- Completely) (N=19)

	Mean	Median	Min	Max	SD
Comfort	**2,11**	2,00	1,00	4,00	1,05
Independence	2,00	1,00	1,00	5,00	1,33
Satisfaction	**2,05**	2,00	1,00	5,00	1,27
Pain	1,42	1,00	1,00	4,00	,84
Speed of operation	1,95	2,00	1,00	5,00	1,08
Fatigue	**2,16**	2,00	1,00	4,00	1,07
Accuracy of operation	2,00	2,00	1,00	5,00	1,15
Endurance	1,68	1,00	1,00	4,00	1,00
Effectiveness	1,58	1,00	1,00	4,00	1,02
Ease of use	2,00	1,00	1,00	5,00	1,29
Enabling privacy	1,61	1,00	1,00	5,00	1,04

SCI patients reported the highest impact of the working environment and their physical condition on the following computer aspects: fatigue, endurance, and effectiveness. PD patients reported the highest impact on speed of operation, accuracy of operation and effectiveness. NMD patients reported the highest impact on comfort, satisfaction and fatigue.

In general, SCI patients reported on higher effects of the working environment and their physical condition on the various computer aspects than PD or NMD patients. The most mentioned aspects by all patient groups to be affected were fatigue and effectiveness.

Between group comparisons showed that there were significant differences in the following aspect of computer use in relation to current physical condition: SCI patients were significantly different (yielding higher scores), from the two other groups in the following aspects: i) independence (chi square=15,73/DF=8; p=0,039, ad,res.=3,3); ii) pain (chi square=14,73/DF=8; p=0.040, ad.res.=2.4); iii) speed of operation (chi square=16,67/DF=8; p=0,030, ad.res.=2.4); iv) endurance (chi square=17,42/DF=8; p=0,021, ad.res.=3.3); v) effectiveness (chi square=26,35/DF=8; p=0,000, ad.res.=3.9), and vi) enabling privacy (chi square=17,85/DF=8; p=0,013, ad.res.=3.2).

3.3.2 Description and evaluation of assistive device/s

Since only SCI Patients reported in using assistive devices, in this section cumulative data are presented for SCI patients only.

Question d1 -Question d6. Questions d1-d6 asked the patients whether they used an AD to operate the computer, if so, what type, for how long, where was it fitted, and whether they used a different one in the past.

Most SCI patients (87,8%) reported using an assistive device (AD) for computer operation. In the following table, various types of ADs used are presented. Most popular AD is the typing stick (87,5%). Patients could mention more than one AD so cumulative percent may be more than 100%. ADs have been used for a mean time of 182, 25±116,16 months. In 62,55% the AD device was fitted for the patient at a rehabilitation center, in 12,5% at a vocational/assistive-device counseling center and in 37,5% the AD was fitted by a private/commercial company. The patients did not report having used another AD in the past.

Qd1-d6: TABLE. Types of ADs used by SCI patients

	Frequency	Percent
Typing Stick	7	**87,5**
Mouthstick	4	50,0
Chin joystick	0	0
Mouth joystick	0	0
Gaze tracker	0	0
Head tracker	1	12,5
Speech recognition	0	0
Mounting system (arms and support)	0	0
Other	4	26,7

Question d7. Question q7 asked the participants to mention which body parts they used to operate the AD and how much pain and /or fatigue it caused them.

SCI patients used their neck (75%), shoulders (62,5%) and arms or elbows (50%) to operate the Ads (table **Q d7A**).Mean values of their self-assessment of pain and fatigue caused by AD operation are presented in tables **Q d7B & Q d7C** .However their experience from the Ads is neither painless nor comfortable because their mean reported levels of pain and fatigue are significant.

Q d7A.TABLE. Body parts used by SCI patients to operate the assistive device

	N	Frequency	Percent
Tongue	8	0	0
Eyes	8	1	12,5
Jaw	8	3	37,5

Neck	8	6	**75,0**
Shoulders	8	5	**62,5**
Arm	8	4	**50,0**
Elbows	8	4	**50,0**
Wrists	7	3	42,9
Fingers	8	1	12,5

Q d7 B.TABLE. Assessment of the pain caused by AD after prolong use (1 – no pain at all, 5 – extreme pain)

	N	Mean	Median	Min	Max	SD
Eyes	1	5,00	5,00	5,00	5,00	.
Jaw	3	1,67	1,00	1,00	3,00	1,15
Neck	6	2,67	3,00	1,00	4,00	1,03
Shoulders	5	3,60	4,00	3,00	4,00	,55
Arm	4	**3,75**	3,50	3,00	5,00	,96
Elbows	4	3,50	3,00	3,00	5,00	1,00
Wrists	4	**3,75**	4,00	3,00	4,00	,50
Fingers	1	1,00	1,00	1,00	1,00	.

Q d7C. TABLE. Assessment of fatigue caused by AD (1 – no fatigue at all, 5 – extreme fatigue)

	N	Mean	Median	Min	Max	SD
Tongue	0	-	-	-	-	-
Eyes	1	5,00	5,00	5,00	5,00	.
Jaw	3	2,33	2,00	1,00	4,00	1,53
Neck	6	2,83	2,50	1,00	5,00	1,47
Shoulders	5	3,60	4,00	2,00	5,00	1,14
Arm	4	**3,75**	3,50	3,00	5,00	,96
Elbows	4	3,50	3,00	3,00	5,00	1,00
Wrists	4	**4,00**	4,00	3,00	5,00	,82
Fingers	1	5,00	5,00	5,00	5,00	.

The most common body parts used to operate the ADs are neck, shoulders, arms and elbows. The most pain and fatigue caused after prolonged use was to the arms and wrists.

Questions Q.d8 to Q.d10 referred to various AD characteristics and patients' assessment of them. These questions are derived from the *Quebec User Evaluation of Satisfaction with assistive Technology QUEST (Version 2.0*) questionnaire [7].

Qd8.TABLE 1. Satisfaction level with AD (1 – 5)

Satisfaction level	N	Mean	Median	Min	Max	SD
The dimensions (size, height, length, width) of your assistive device?	5	**3,60**	4,00	1,00	5,00	1,67
The weight of your assistive device?	4	**3,25**	3,50	1,00	5,00	1,71
The ease in adjusting (fixing, fastening) the parts of your assistive device?	5	4,60	5,00	4,00	5,00	,55
How safe and secure your assistive device is?	5	4,60	5,00	4,00	5,00	,55
The durability (endurance, resistance to wear) of your assistive device?	5	**3,80**	4,00	1,00	5,00	1,64
How easy it is to use your assistive device?	5	4,00	4,00	3,00	5,00	1,00
How comfortable your assistive device is?	5	4,00	4,00	3,00	5,00	1,00
How effective your assistive device is (the degree to which your device meets your needs)?	5	4,20	4,00	3,00	5,00	,84

SCI patients evaluated various aspects of their AD in general and they concluded that they are more than average satisfied with the AD (Qd8.TABLE 1). However, the lowest scores were observed in aspects of dimension, weight and durability.

Qd8 TABLE 2. Level of satisfaction with AD service (1 – 5) (N=4)

	Mean	Median	Min	Max	SD
The service delivery program (procedures, length of time) in which you obtained your assistive device?	3,50	4,00	1,00	5,00	1,91
The repairs and servicing (maintenance) provided for your assistive device?	3,50	4,00	1,00	5,00	1,91
The quality of the professional services (information, attention) you received for using your assistive device?	3,50	4,00	1,00	5,00	1,91
The follow-up services (continuing support services) received for your assistive device?	3,25	3,50	1,00	5,00	2,06

SCI patients' level of satisfaction with AD service was above average (Q.d8 TABLE 2).

Qd8 TABLE 3. The <u>three</u> most important items related to AD for SCI patients (N=5)

	Frequency	Percent

Dimensions	1	20,0
Comfort	4	**80,0**
Weight	0	0
Effectiveness	3	**60,0**
Adjustments	0	0
Service delivery	0	0
Safety	0	0
Repairs/servicing	0	0
Durability	4	**80,0**
Professional service	0	0
Easy to use	3	**60,0**
Follow-up services	0	0

When SCI patients were asked to select the **three** most important items related to ADs they chose comfort (80%), durability (80%), effectiveness (60%) or "easy to use" (60%), (Qd8 TABLE 3).

QUESTION d9. SCI patients evaluated the importance of various attributes of ADs.

Qd9. TABLE. Important attributes of the AD for SCI patients (1- not important at all, 5 - very important) (N=7)

	Mean	Median	Min	Max	SD
Noninvasiveness	4,43	5,00	2,00	5,00	1,13
Setup time	3,57	4,00	1,00	5,00	1,62
Independent operation	**5,00**	5,00	5,00	5,00	,00
Training time	4,43	5,00	3,00	5,00	,98
Cost	2,71	2,00	1,00	5,00	1,89
Number of functions provided	4,71	5,00	3,00	5,00	,76
Response time	**5,00**	5,00	5,00	5,00	,00
Productivity	4,71	5,00	4,00	5,00	,49
Ease of use	**5,00**	5,00	5,00	5,00	,00
Aesthetics	4,00	4,00	3,00	5,00	,82
Enabling privacy	4,86	5,00	4,00	5,00	,38

Results show that Independent operation, Response and time ease of use received the highest scores in average.

Qd9. TABLE. The three most important attributes of the AD for SCI patients (N=7)

	Frequency	Percent
Noninvasiveness	4	**57,1**
Setup time	0	0
Independent operation	6	**85,7**
Training time	0	0
Cost	0	0
Number of functions provided	0	0
Response time	1	14,3
Productivity	4	**57,1**
Ease of use	5	**71,4**
Aesthetics	0	0
Enabling privacy	1	14,3

For SCI patients, the three most important attributes are: Independent operation, ease of use, non- invasiveness and productivity.

Question d10. SCI patients' assessment of level of comfort of the assistive device is presented in the following table.

Qd10. TABLE. Assessment of Comfort of the AD (1- Extremely Uncomfortable, 7- very Comfortable) (N=6)

	Mean	Median	Min	Max	SD
Force required for actuation	5,50	6,00	2,00	7,00	1,87
Smoothness during operation	**6,00**	6,50	3,00	7,00	1,55
Effort required for operation	5,17	6,00	2,00	7,00	2,14
Accuracy	**5,83**	6,50	3,00	7,00	1,60
Operation speed	**5,83**	6,50	3,00	7,00	1,60
General comfort	5,17	6,00	2,00	7,00	2,14
Overall operation of input device	5,33	6,00	3,00	7,00	1,86

Mean scores show that SCI patients are satisfied with their device yielding satisfaction scores over average.

NOTES ON ASSISTIVE DEVICES USED BY OTHER PATIENT GROUPS

a. One PD patient reported that he had started using a voice recognition system for computer operation recently, but his experience was limited and he could not make a thorough evaluation.
b. One NMD patient reported using an AD (*Tracker Pro & Magic Cursor*) for 134 months and that this device was fitted for him at home. The patient reported he is not satisfied with size, weight, adjustability, safety, durability, easiness to use, comfort or effectiveness of AD. However he is satisfied with maintenance and follow-up service.

3.3.3 Needs, missing functions and demands of improvement (Questionnaire – Chapter III)

Question1 : "*Why don't you use a computer?"*

Some SCI patients reported that they do not use a computer. The following table shows the various reasons for not doing so. All patients from other groups reported the use of a computer

Q1.TABLE. Reasons for not using a computer (SCI patients) (N=4)

	Frequency	Percent
I cannot find a good assistive device	2	50%
I don't like computers	1	25&
I don't have a computer	3	**75%**
I don't need to use a computer	3	**75%**
It is too difficult in my condition	1	25&
Other*	1	25&

*I have a head mouse but it's hard for me to use it

Of the SCI patients who don't use a computer, most of them do not own a computer and say they don't need one, although mentioning some difficulties in operating them and finding good assistive devices.

Question 2*:"If you could design your own assisted device (AD) for computer use or improve an existing one, what it would look like?"*

Q2.TABLE. SCI patients' Design or improve an AD /summary of individual answers (N=15)

	Frequency	Percent
AD operated by voice	4	**26,66**
AD involving thought	2	13.33
Improvement of currently used device	5	**33,33**

AD using gaze	1	6,66
Satisfied with current AD	1	6,66
Do not know/not relevant	2	13,33

PD patients: Most patients could not answer this question. One patient proposed a better dictation application in Greek and a supportive device for his hand and another one a special key board adapted to his disability.

Q2.TABLE. NMD patients' Design or improve an AD /summary of individual answers (N=19)

	Frequency	Percent
AD operated by voice	3	15,7
AD involving thought	3	15,79
Improvement of currently used device	2	10,53
AD using gaze	2	10,53
Miscellaneous	3	15,79
Do not know/not relevant	6	**31,57**

When asked to design or improve as AD, Most of the patients chose to add voice operation.

Question 3*:"What operation of the computer you used to do prior to the disease, that you can't do now, you miss the most, if any?"*

Ten **SCI** patients did not answer this question. Of the remaining five, two reported they miss games and the three missing computer functions related to keyboard and mouse use.

Q3.TABLE. PD patients' Missing computer functions /summary of individual answers (N=19)

	Frequency	Percent
Never used PC before PD	8	**42,10**
No missing function/doing less	4	21,05
None	4	21,05
Better keyboard, writing text	3	15,79

Q3.TABLE. NMD patients' Missing computer functions /summary of individual answers (N=19)

	Frequency	Percent
No answer	8	**42,10**

Typing	7	**36,84**
Moving cursor easily	2	10,52
Miscellaneous	2	10,52

Most of the patient do not miss any computer functions they could do prior to their disease or the did not use a pc before.

Question 4: *"What computer applications were you using prior to your disease that you now can't operate (or find very hard to operate) and miss the most, if any?"*

SCI patients. Only two SCI patients answered this question reporting that they miss games.

PD patients. Two PD patients answered that they miss text writing; eight PD patients reported that they started using the computer after their illness was diagnosed, so they do not know what they are missing. Three PD patients reported that they do not miss functions in particular, but they have to work less on the computer. No missing application was reported by six patients.

NMD patients. Five NMD patients reported missing computer games (with or without use of joy stick), one patient reported missing internet, newspapers, and magazines. Two report no missing applications and 11 gave no answer.

Of the patients who miss computer application they used prior to their disease, most of them miss playing games.

Question 5: "*Would you use an assistive device system based on mental commands?"*

Most patients responded positively to this question. There were no significant differences between groups (chi square=2,7/DF=2; p=0.316). Patients' responses are presented in the graph of **Error! Reference source not found.**.

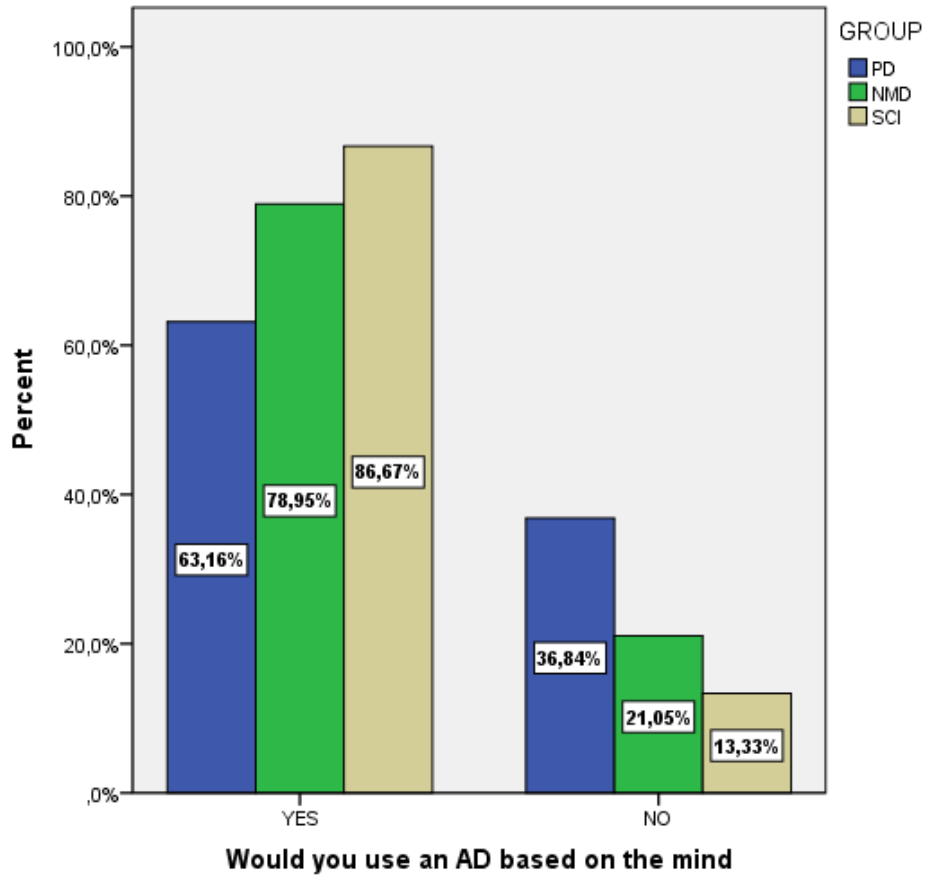


Figure 4: Percentage of user that would be willing to use an assistive device

Most of the patients are positive toward using an AD based on mental commands.

CH.III Q5: *(DETAIL)"would you use an assistive device system based on mental commands?"*

SCI patients: Twelve SCI patients did not give a detailed answer to this question about an AD based on mind commands. One patient said "If it is aesthetic, not invasive and self-operated", another expressed doubts and a third thought "it sounds less tiring".

Q5. TABLE. Summary of PD patients' individual answers to Q5 (N=19)

	Frequency	Percent
Yes, if it was easy and had training	10	**52,63**
Could operate computer better	2	10,52
Do not like it/incomprehensible/not practical	7	36,84

NMD patients: Twelve NMD patients gave no answer. Five gave a positive, but conditional answer (if the AD was easy, if it is needed or functions properly and two answered negatively ("do not need it", "fear for mind influencing").

Of the patients who were positive toward using an AD based on mental commands, most of them stated they preferred it to be easy and with a training program.

CH.III Q6: **"***What type of computer interaction do you think you could perform with an interface based on mental commands?"*

Q6. Table. Summary of SCI patients' individual answers for interactions based on mind commands (N=14)

	Frequency	Percent
Surfing the web/educational activity	6	**42,86**
Moving cursor/using keyboard	4	28,57
Everything need for computer operation	2	14,28
Communication /entertainment	1	7,14
Turn computer on/off	1	7,14

CH.III.Q6 Summary of PD patients' individual answers for interactions based on mind commands (N=19)

	Frequency	Percent
Communication/games/internet	9	**47,36**
text writing /operate PC effectively	2	10,52
No answer/do not know	8	12,42

CH.III.Q6 . Summary of NMD patients' individual answers for interactions based on mind commands (N=19)

	Frequency	Percent
All kinds of operations	4	**21,05**
Typing/drag &click	4	**21,05**
Facebook/audio-visual applications	1	5,26
Miscellaneous	2	10,52
Missing answers	8	42,10

The patients believe that a mental command based AD could enable them to better move the cursor and/or use the keyboard and to preform various computer activities.

CH.III Q7: *"Would you use an assistive device system based on eye movements? "*

Most patients responded positively. There were no statistically significant differences between groups (chi square=1,54/DF=2; p=0.472). Patients' responses are presented in the following graph.

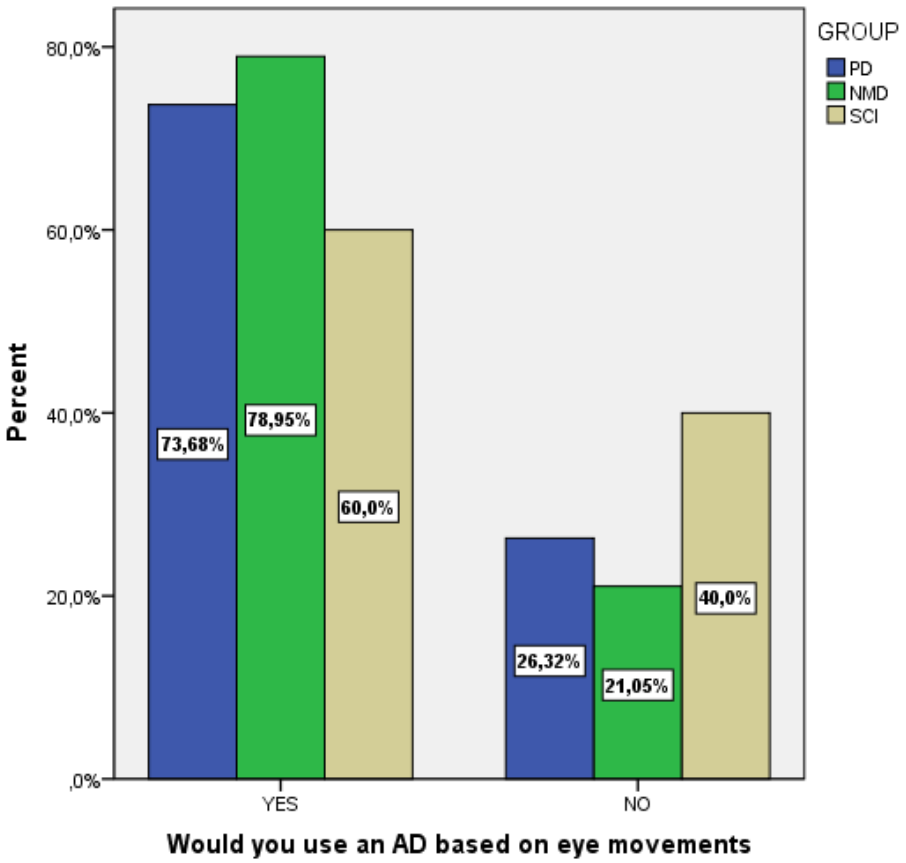


Figure 5: Percentage of users that would use an Assistive Device based on eye movements

Most of the patients are positive toward using an AD based on eye movements.

CH.III Q7: *(DETAIL) "Would you use an AD based on eye movements?"*

SCI patients: Nine patients did not gave details to the question about an AD based on eye movements .Of the six responses 5 were negative comments and one positive, but conditional.

CH.III.Q7. Summary of PD patients' interactions with an AD based on eye movements (N=19)

	Frequency	Percent
Yes ,but conditional, need to try first	6	31,58
Do not like/do not know	6	31,58
Improve computer operation	1	5,26

Missing answers	6	31,58

NMD patients: There were only three answers and all negative (one "no need" and two reported problems with focus).

Of the patients who were detailed about using an AD based on eye movements, most of them were cautious and conditioned their use of it with trying it first.

CH.III QUESTION 8: "*What type of computer interaction do you think you could perform with an interface based on eye-tracking? "*

Ch.III Q 8.TABLE .Summary of SCI patients' interactions based on eye tracking AD (N=14)

	Frequency	Percent
Web actions	4	**28,57**
moving cursor etc	2	10,52
Multiple computer functions	2	10,52
Negative view	1	5,26
No answer	5	26,31

PD patients: Only four PD patients responded to this question. Two answered that they will have more easy access to internet and the PD Association site, two that they will operate the computer more easily.

NMD patients: Eleven NMD patients did not respond to this question. From the eight responders, three answered that it will help them with all computer functions , three for typing or moving the cursor ,one for hacking and one for playing music**.**

The patients believe that an eye tracking based AD could enable them to preform various computer activities.

CH.III. Question 9: *"Would you wear on your head an EEG recording device to facilitate controlling the computer with your thinking*?"

Patients' responses are presented in the graph of **Error! Reference source not found.**. There were no statistically significant differences between groups (chi square=2,62/DF=2; p=0.302).

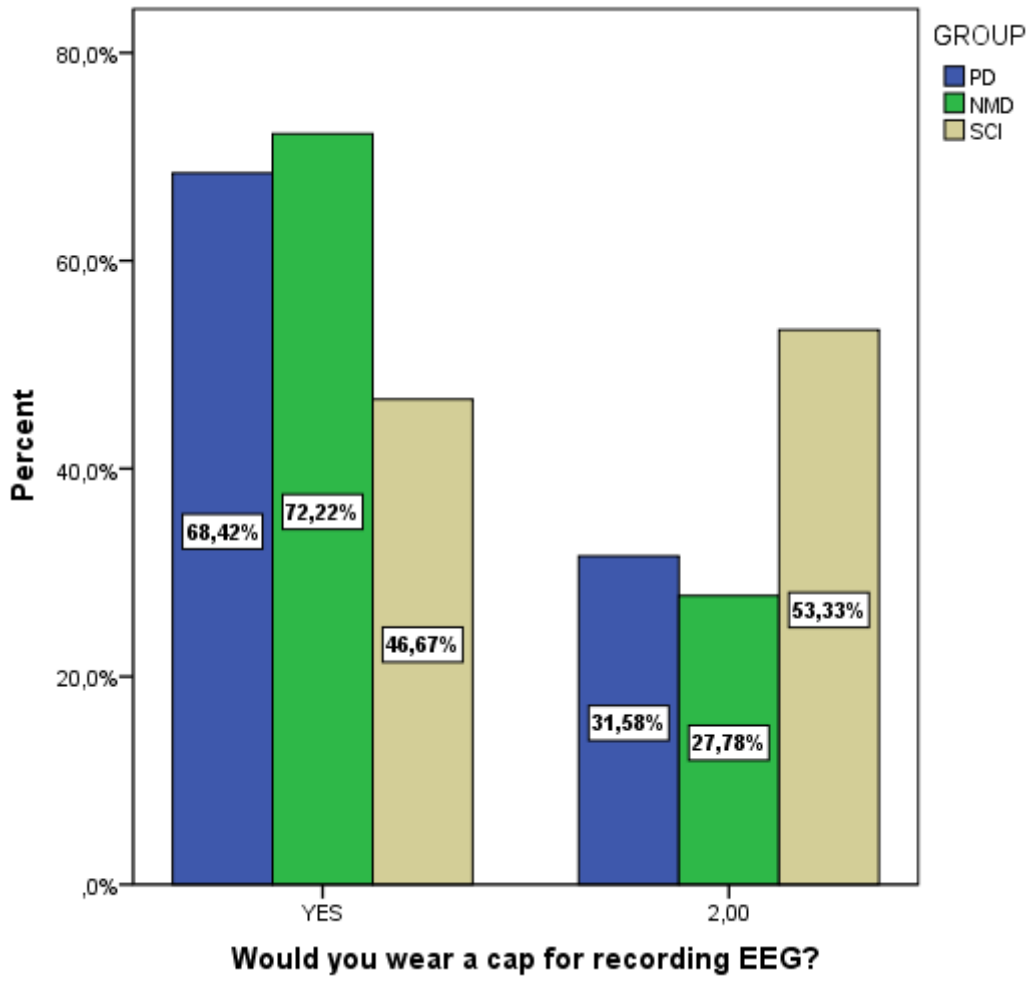


Figure 6: Percentage of users that would be willing to wear a cup for EEG recording

CH.III Question 9. *(DETAIL) "Would you wear on your head an EEG recording device to facilitate controlling the computer with your thinking*?"

CH.III Q. 9.TABLE .Summary of SCI patients' responses to question:" Would you wear a cap for recording EEG" (N=15)

	N	Frequency	Percent
Negative views	15	7	**46,66**
Positive	15	2	13.33
Optional	15	4	26,66
No answer	15	2	13,33

PD patients: Only three PD patients gave details to this question. Two patients commented that the AD would be difficult to handle and one that it could help him to operate the computer more easily.

NMD patients: Nine NMD patients gave no answer to this question. Five gave a positive but conditional answer (if the device was needed or comfortable/easy to use).One patient was positive but expressed concern about pressure on the head by the AD Negative answers included fear of radiation (1 Pt.) and sensitivity to touch on the head (1 Pt.).

The patients were generally positive towards using an EEG recording device. Although, when asked to detail, most of them were skeptical, expressed concerns and conditioned their use.

CH III Question 10: "*Would you wear on your head special glasses designed to facilitate controlling the computer with your eyes*? "

Most patients were willing to use special; glasses in order to facilitate computer control. There were not significant differences between groups (chi square=2,62/DF=2; p=0.302). Their response frequencies are presented in the following graph.

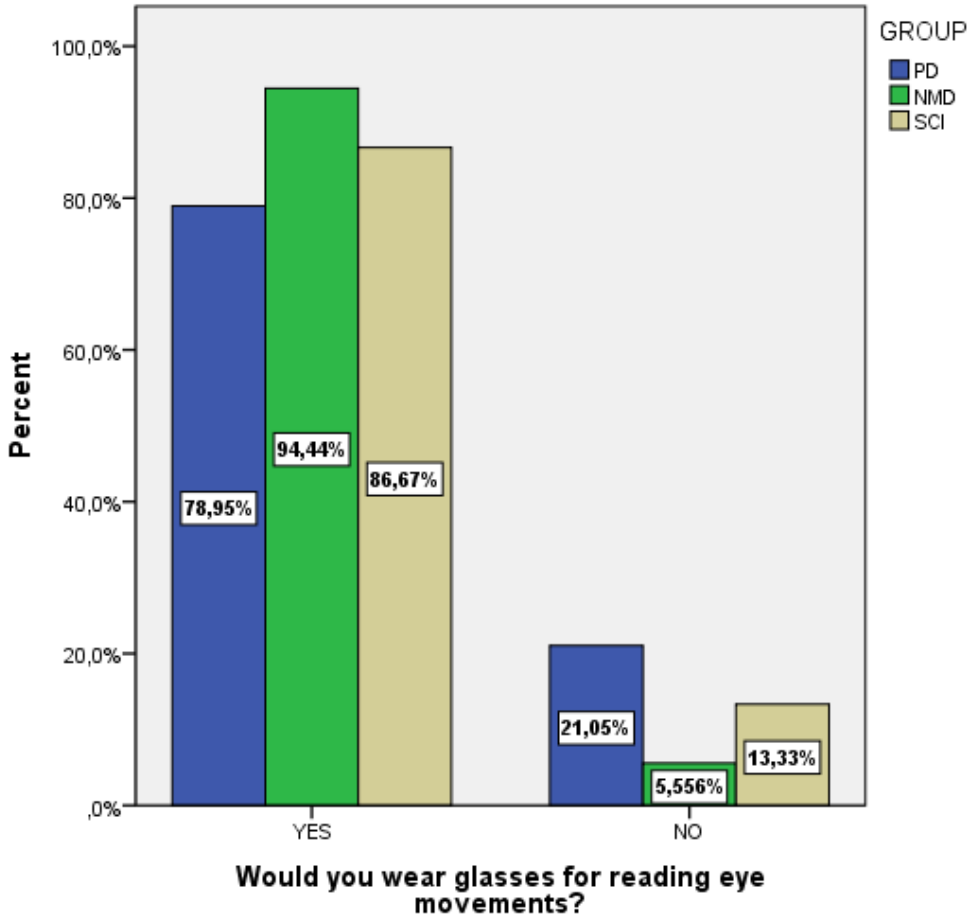


Figure 7: Percentage of users that would be willing

CH.III Q 10 (detail):"*Would you wear glasses for reading eye movements?*

SCI patients: Only five patients gave details to this question. One remark was positive, two were conditional and two were negative.

PD patients: Only four PD patients responded. Two replied that the device would be difficult to handle , one that it will help him to operate the computer more easily and another that he would use it only if this AD could improve quality of life**.**

NMD patients: Eleven NMD patients did not answer this question. From the eight responders there were five positive, but conditional answers (if needed, if comfortable and easy to operate). One patient expressed sensitivity to pressure on head ,one had issues with focus and third with the respirator.

The patients were generally positive towards using the special head glasses for computer operation. When asked to detail, the patients mainly conditioned their use with ease of use and comfort.

3.3.4 Summary of patients results

a) Computer use habits

Patients reported that they owned the following types of computer: a) SCI patients: laptop and smartphone; b) PD patients: desktop and laptop; and c) NMD patients: laptop, smartphone & desktop. In addition, they used mostly the following three types; smart phones for SCI patients, desktop for PD patients and laptop for NMD patients.

The three most important computer uses were: a) SCI patients: productive activities and recreation (first rank), social participation, study, recreation and information (second & third rank); b) PD patients' first choice was communication, second choice information and in third rank social participation and ADL grouped together; c) NMD patients selected social participation, communication and recreation as their three most important computer uses.

The three most important computer applications were: a) SCI patients: internet browser, Word processor and Audio/video/image applications; b) PD patients: internet browser, e-mail, Word processor; c) NMD patients: the same as for PD patients.

In the question "Which operating systems do you work with": a) 91% of SCI patients reported using Microsoft Windows as their computer operating system and the rest of them preferred Apple Mac OS; b) All PD patients used Microsoft Windows; and c) all NMD patient used Microsoft Windows.

The three most important aspects of computer contribution in a patients' life are the following (in descending order): a) SCI patients: Educational attainment, interpersonal interactions and relationships, as well as work and employment status/potential; b) PD patients: Interpersonal interactions & relationships, educational attainment and emotional well-being; and c) NMD patients: Interpersonal interactions & relationships, educational attainment and work and employment status/potential were the three most important choices.

Discussion: According to Chapter I, we consider the following conclusions: (1) despite their disabilities, most of the patients do use computers, extensively (i.e., few hours a day) in their daily life, reflecting, in fact normal modern daily life habits among the general population;

(2) They prefer either stationary or laptop computers over the tablet/smartphone platforms – seeming a fact that reflects their disabilities, as smartphones and tablets require more refined motor skills; (3) They mainly use windows operating system; (4) Computer use is important for the patients in several aspects. We may therefore state that every improvement that will facilitate computer use among these patients populations, will immensely improve their quality of life.

b) Difficulties in computer operations

All patients selected, from a list of various computer functions, those who found difficult to perform:

Difficulties performing on the computer as reported by SCI patients according to frequency (over 35%) were: “using two keys at the same time” (70%), “typing with the keyboard “(60%), “zooming/panning” (50%), “selecting and dragging, resizing windows’’ (40%). “Moving the cursor on the screen” (30%) and ”using the keyboard” (30%).

PD Patients reported difficulties in: “Moving the cursor on the screen” (63,2%) , "double clicking" with the cursor (63,2%), “using two keys at the same time” (36,8%) and "clicking" with the cursor “(31,6%).

NMD patients had difficulties in: “Identifying the cursor on the screen” (100%), “using the keyboard” (57,9%), ”identifying the letters on the keyboard” (57,9%), “using two keys at the same time” (52, 6%) and “selecting and dragging, resizing windows” (36,8%).

Answering the question “How do you create text”, the following answers were obtained:

Most SCI Patients create text on the computer by the keyboard (54,5%) or by using a typing stick.

PD patients create text mostly by keyboard (89,5%) and a few by touch.

The majority of NMD patients prefers a pointer and virtual keyboard (52.6%) for text creation, but a significant percentage uses the key board (47,4%).

Evaluating difficulty on a scale from 1 (very difficult) to 5 (very easy) only SCI patients reported considerable difficulty in creating text, compared to the two other patient groups. Describing how they point on the screen they answered the following:

SCI patients point on the computer screen mostly with an assistive device (54,5%). However some of them can point by touch (27,3%).

Most PD patients point with a mouse (89,5%) and/or touch (31,6%). No one is using an assistive device.

NMD patients point mainly with a mouse (73,7%) and a small number by touch (16,7%).

Evaluating difficulty on a scale from 1(very difficult) to 5 (very easy) , SCI patients reported significant difficulty pointing to the computer screen with an AD, PD patients had more difficulty with the mouse and NMD patients with the keyboard.

Discussion: Apparently there are differences between the groups in terms of mouse and keyboard usage, and in the level of difficulties they report about using them. This could possibly reflect the clinical differences. While PD and NMD subjects usually suffer from progressive neural degeneration, the SCI subjects (except from one) suffered acute sever in their upper spinal cord, which led them immediately to rely on assistive devices for computer use, as relying on assistive devices become as part of their lives (e.g., wheel chair use). We anticipate that both PD and NMD will recognize the advantages of using assistive devices for computer use such as the MAMEM platform, even before the disease progresses and 'force' them to leave behind the old habits.

c) Current working environment

The findings in the section summarize the patients' view about their working environment and the functionalities that they are able to perform within it.

In terms of the computer type that they tend to use more frequently: a) A Stationary computer is used by 63.6% of SCI patients and a portable one by 54,5%; b) A Stationary computer is used by 78.9% of PD patients and a portable one by 57,9%; c) A Stationary computer is used by 36.6% of NMD patients and a portable one by 63,3%.

With respect to the computer location and positioning: a) SCI patients: Computer is located mostly on a desk (63,6 %) or rarely on a side table. They sit usually on a motorized wheel chair while they operate the computer (72,7%); b) PD patients: Computer is located mostly on a desk (94,7%) or on a special tray or table. All patients sit usually on an arm chair while they operate the computer (100%); c) MND patients: Computer is located mostly on a desk (68,4%) or rarely mounted on an arm (1 person). Two patients have reported having the computer on bed and one on his legs. They sit usually on either a motorized wheel chair or a wheelchair while they operate the computer (57,9% and 26,3%, respectively). Usually patients operate the computer at their home (SCI:81,8%), (PD:73,7%). (NMD:94,7%).

A self-evaluation physical condition impact on various computer use aspects (1- No effect, 5-Completely), showed the following:

SCI patients reported considerable impact (median value 3 or higher) of their physical condition on the following computer aspects: independence, speed of operation, fatigue, endurance, effectiveness, ease of use, enabling privacy, comfort and independence.

PD patients reported a moderate effect of their physical condition on speed of operation, accuracy of operation and effectiveness

Most of NMD patients did not report a significant effect of their physical condition on the above mentioned aspects of computer operation.

Discussion: Group differences in the subjectively perceived impact of physical condition on various computer use aspects can be explained by the general immobility experienced by SCI patients as compared to only limited immobility from which NMD and PD subjects suffer. Interestingly the younger NMD subjects (mean age = 27) tend to prefer portable computer, as compared to the older PD and SCI subjects (e.g., mean age of PD subjects = 59), similar to the trends seen in the general populations.

d) Description and evaluation of assistive devices (ADs)

NOTE: *In this section cumulative data are presented for SCI patients only.*

Most SCI patients (87,8%) reported using an assistive device (AD) for computer operation. Most popular AD is the typing stick (87,5%). ADs have been used for a mean time of 182, 25±116,16 months. In 62,55% the AD device was fitted for the patient at a rehabilitation centre, in 12,5% at a vocational/assistive-device counselling centre and in 37,5% the AD was fitted by a private/commercial company. The patients did not reported having used another AD in the past.

SCI patients used their neck (75%), shoulders (62,5%) and arms or elbows (50%) to operate the Ads (Table Qd7A). However their experience from the ADs is neither painless nor comfortable because their mean reported levels of pain and fatigue are significant.

SCI patients evaluated various aspects of their AD in general and they concluded that they are more than average satisfied with the AD. However, the lowest scores were observed in aspects of dimension, weight and durability. Their level of satisfaction with AD service was above average. When SCI patients were asked to select the three most important items related to ADs. they chose comfort (80%), durability (80%),effectiveness (60%) or “easy to use” (60%).

SCI patients evaluated the importance of various attributes of their AD and their scores were above average level. Selecting the three most important attributes they chose: independent operation (85,7%), ease of use (71,4%), non-invasiveness (57,1%) or productivity (57,1%). Regarding satisfaction with AD, SCI patients reported that they are satisfied with their device.

Discussion: It seems that so far SCI mostly use assistive device. As noted before, this is probably due to lack of exposure of PD and NMD subjects to the possibilities that ADs can provide them with, and make their computer use more easy.

e) Needs, missing functions and demands for improvement

Of the SCI patients who don’t use a computer, most of them do not own a computer and say they don’t need one, although mentioning some difficulties in operating them and in finding good assistive devices. Most of the patient do not miss any computer functions they could do prior to their disease or the did not use a PC before. Of the patients who miss computer application they used prior to their disease, most of them miss playing games. Most of the

patients are positive toward using an AD based on mental commands. Of the patients who were positive toward using an AD based on mental commands, most of them stated they preferred it to be easy and with a training program. The patients believe that a mental command based AD could enable them to better move the cursor and/or use the keyboard and to perform various computer activities. The patients were generally positive towards using the special head glasses for computer operation. When asked to detail, the patients mainly conditioned their use with ease of use and comfort ability. Most of the patients are positive toward using an AD based on eye movements. Of the patients who detailed about using an AD based on eye movements, most of them were cautious and conditioned their use of it with trying it first. The patients believe that an eye tracking based AD could enable them to perform various computer activities. The patients were generally positive towards using an EEG recording device. Although, when asked to detail, most of them were sceptical, expressed concerns and conditioned their use.

Discussion: From the 'open questions' section of the questionnaires emerges that across all populations there is openness and even expectations towards the use of AD based on eye tracing and EEG reading.

Summary: In agreement with the MAMEM assumptions, the questionnaires results, also supported by the literature review and the focus group discussions (c.f., D6.1 [1]), suggest that there is a need by the examined patients' cohorts for computer operating assistive device that is based on eye tracking and reading EEG. Since device combining the two features does not commercially exist, we could not surface the question about such a device in the interviews. However, according to the responses of the focus groups of health professionals, the merits of such combination is clearly apparent [1]. For example, it was noted that operating system based on eye tracking alone can cause fatigue. Complementary use of EEG may address this problem. As noted in the short discussion sections above, we assert that even though substantial part of PD and NMD subjects do not use presently ADs for computer operation, they will most likely resort to such options as the disease progresses and as they will become acquainted with the advantages.

The main MAMEM goal to create a vehicle that will re-engage the disabled users into social media, was strongly supported by the response of patients across the cohorts, as many of them cited the importance of educational attainment, interpersonal interactions and relationships, as well as work and employment status/potential, as the most important aspects of computer use.

3.4 Care-givers results

The following results describe the computer habits, working environment and difficulties of the caregivers. The same information which was gathered from the patients appears in chapter 3.3.

3.4.1 Computer habits, working environment and difficulties (Questionnaire – Chapter II)

a) Computer use habits

The following section was designed to assess the social life, hobbies, mobility, computer use rate, computer use importance and computer use habits of the patients.

Question a1: *"How is your patient social life affected by his/her disability?"*

Q.a1A. TABLE . Disability impact on SCI patients' social life

SCI CGs	Frequency	Percent
Social life is normal	3	20,0
There is no significant effect on social life apart from limiting energetic aspects, such as dancing	5	**33,3**
Social life is restricted and he/she does not go out as often	3	20,0
Social life is restricted to the home	2	13,3
He/she has no social life and he/she feels lonely	2	13,3

Q.a1B.TABLE . Disability impact on PD patients' social life

PD CGs	Frequency	Percent
Social life is normal	6	31,6
There is no significant effect on social life apart from limiting energetic aspects, such as dancing	8	**42,1**
Social life is restricted and he/she does not go out as often	4	21,1
Social life is restricted to the home	0	0
He/she has no social life and he/she feels lonely	1	5,3

Q a1C. TABLE . Disability impact on NMD patients' social life

NMD CGs	Frequency	Percent
Social life is normal	0	0
There is no significant effect on social life apart from limiting energetic aspects, such as dancing	13	**76,5**
Social life is restricted and he/she does not go out as often	2	11,8

Social life is restricted to the home	0	0
He/she has no social life and he/she feels lonely	2	11,8

Most CGs indicate that their patients' social life is normal or little affected.

Question a2 and Question a3: *"Have he/she any kind of hobby or recreational activity? Yes /No. If yes, please specify:"*

The following tables specify the hobbies or recreational activities that were mentioned only if the patient had answered yes in Question a2.

Q a3 A.TABLE. Hobbies and recreational activities of your SCI patients

Hobby/recreational activity	Frequency	Percent
Being with friends	1	11,1
Cars	1	11,1
Ceramics	1	11,1
Music, writing	1	11,1
Off road	1	11,1
Painting	1	11,1
Reading, dogs	1	11,1
Reading, movies	1	11,1
TV	1	11,1

Q a3B.TABLE.Hobbies and recreational activities of your PD patients

Hobby/recreational activity	Frequency	Percent
Amateur actor	1	6,67
Art	2	**13,33**
Backgammon	1	6,67
Facebook	1	6,67
Fishing	1	6,67
Fishing, Painting	1	6,67
Fishing ,Jogging	1	6,67
Gardening, PC	1	6,67
Jogging	1	6,67
Music	1	6,67
Painting	2	**13,33**
Repairs machines	1	6,67
Swimming	1	6,67

Q a3 C.TABLE. Hobbies and recreational activities of NMD patients

NMD CG	Frequency	Percent
Computer	1	5,9

Computer games	1	5,9
Movies, travels, friends	1	5,9
Music	2	**11,8**
Music, movies	1	5,9
Music, museums, clubs, exhibitions	1	5,9
Painting	1	5,9
PlayStation, Greek night clubs	1	5,9
Reading, games sports	1	5,9
Sport s, music, movies	2	**11,8**
Sports, reading	1	5,9
Sports, soccer, travels, music	1	5,9
Theater, dance, travel, computer	1	5,9
Travels	1	5,9
Writing, music	1	5,9

Question a4: *How is your patient's mobility outdoors affected by his/her disability?*

Question a4A.TABLE.Impact of disability on SCI patients' mobility outdoors

Impact on mobility	Frequency	Percent
My patient can travel frequently for needs / pleasure	8	**57,1**
My patient can travel sometimes	2	14,3
My patient can travel very rarely and only when there is an absolute need	4	28,6
My patient cannot travel and must stay home	0	0

Q. a 4B.TABLE. Impact of disability on PD patients' mobility outdoors

Impact on mobility	Frequency	Percent
My patient can travel frequently for needs / pleasure	12	**63,2**
My patient can travel sometimes	4	21,1
My patient can travel very rarely and only when there is an absolute need	3	15,8
My patient cannot travel and must stay home	0	0

Q a4.C.TABLE.Impact of disability on NMD patients' mobility outdoors

Impact on mobility	Frequency	Percent
My patient can travel frequently for needs / pleasure	2	11,8
My patient can travel sometimes	10	**58,8**
My patient can travel very rarely and only when there is an absolute need	3	17,6
My patient cannot travel and must stay home	2	11,8

Most of the patients indicate that their mobility outdoors is not affected or little affected by their disability

Questions a5: "*Of the following systems, which do your patient own?* **"**

Q a5A .Table. Type of computer system owned by SCI patients (N=15)

	Frequency	Percent
Desktop computer	7	46,7
.aptop computer	12	**80,0**
Tablet	7	46,7
Smartphone	10	66,7

Q a5B.Table.Type of computer system owned by PD patients (N=19)

	Frequency	Percent
Desktop computer	14	**73,7**
.aptop computer	11	57,9
Tablet	8	42,1
Smartphone	6	31,6

Q a5 C. Table. Type of computer system owned by NMD patients (N=17)

	Frequency	Percent
Desktop computer	10	58,8
.aptop computer	14	**82,4**
Tablet	8	47,1
Smartphone	8	47,1

Question a6. "*If you own more than one, which one do you use the most?"*

Q a6.A TABLE .Type of computer used most by SCI patients

MOST USED (SCI CG)	Frequency	Percent
Desktop computer	3	30,0
Laptop computer	0	0
Tablet	1	10,0
Smartphone	6	**60,0**
None	0	0

Q a6.B. TABLE .Type of computer used most by PD patients

PD	Frequency	Percent
Desktop computer	8	**42,1**

Laptop computer	7	36,8
Tablet	4	21,1
Smartphone	0	0
None	0	0

Q a6.C. TABLE .Type of computer used most by NMD patients

NMD	Frequency	Percent
Desktop computer	6	35,3
Laptop computer	10	**58,8**
Tablet	1	5,9
Smartphone	0	0
None	0	0

Questions a 7-a 9: *"Patients owning and using a computer, hours spent per day and year of experiments."*

A.SCI CGs reported that 73,7% of their patients use a computer. They use it for 5,73±3,95 hours/day and they have 15,8 ±11,03 years of experience.

B.PD CGs reported that all of their patients use a computer. They use it for 4,56 ±2,33 hours/day and they have 13,7 ±9,38 years of experience.

C.NMD CGs reported also that all of their patients use a computer. They use it for 5,24 ±2,7 hours/day and they have 13,56 ±2,79 years of experience.

Question a 10: *"Please indicate your patient's main uses of his/her computer system (i) and the three most important ones (ii):"*

(i)/Q a10A. TABLE. Main uses of computer system by SCI patients (N=11)

SCI CGs	Frequency	Percent
Social participation (Facebook, forums, etc.)	7	63,6
Productive activities (writing, editing, etc.)	4	36,4
Study (on-line courses, articles, etc.)	3	27,3
Games	5	45,5
Recreation (movies, music, crossword puzzles, blogs, etc.)	9	**81,8**
Communication (email, Skype, etc.)	5	45,5
Activities of daily living (purchases, payments, bank, etc.)	3	27,3
Information (Wikipedia, governmental sites, news, maps, etc.)	6	54,5
Other	2	18,2

(i)/Q a10B. TABLE. Main uses of computer system by PD patients (N=19)

PD CG	Frequency	Percent
Social participation (Facebook, forums, etc.)	11	57,9
Productive activities (writing, editing, etc.)	4	21,1

Study (on-line courses, articles, etc.)	7	36,8
Games	4	21,1
Recreation (movies, music, crossword puzzles, blogs, etc.)	6	31,6
Communication (email, Skype, etc.)	14	73,7
Activities of daily living (purchases, payments, bank, etc.)	7	36,8
Information (Wikipedia, governmental sites, news, maps, etc.)	14	**77,8**
Other	2	10,6

(i)/Q a10C. TABLE. Main uses of computer system by NMD patients (N=17)

NMD CG	Frequency	Percent
Social participation (Facebook, forums, etc.)	15	**88,2**
Productive activities (writing, editing, etc.)	9	52,9
Study (on-line courses, articles, etc.)	10	58,8
Games	9	52,9
Recreation (movies, music, crossword puzzles, blogs, etc.)	12	70,6
Communication (email, Skype, etc.)	14	82,4
Activities of daily living (purchases, payments, bank, etc.)	7	41,2
Information (Wikipedia, governmental sites, news, maps, etc.)	14	82,4
Other	0	0

(ii)/Qa 10A Table .The three most important uses of SCI patients' computer system (N=9)

SCI CGs/ THREE MOST IMPORTANT PC USES	Frequency	Percent
Social participation (Facebook, forums, etc.)	5	**55,6**
Productive activities (writing, editing, etc.)	2	22,2
Study (on-line courses, articles, etc.)	2	22,2
Games	3	33,3
Recreation (movies, music, crossword puzzles, blogs, etc.)	5	**55,6**
Communication (email, Skype, etc.)	3	33,3
Activities of daily living (purchases, payments, bank, etc.)	1	11,1
Information (Wikipedia, governmental sites, news, maps, etc.)	2	22,2
Other	1	11,1

(ii)/Qa 10B Table .The three most important uses of PD patients' computer system (N=19)

PD CGs /THREE MOST IMPORTANT PC USES	Frequency	Percent
Social participation (Facebook, forums, etc.)	9	47,4
Productive activities (writing, editing, etc.)	3	15,8
Study (on-line courses, articles, etc.)	5	26,3
Games	3	15,8
Recreation (movies, music, crossword puzzles, blogs, etc.)	4	21,1
Communication (email, Skype, etc.)	13	**68,4**
Activities of daily living (purchases, payments, bank, etc.)	7	36,8
Information (Wikipedia, governmental sites, news, maps, etc.)	11	57,9

Other	2	10,6

(ii)Qa 10AC Table .The <u>three</u> most important uses of NMD patients' computer system (N=17)

NMD CG/ THREE MOST IMPORTANT PC USES	Frequency	Percent
Social participation (Facebook, forums, etc.)	12	**70,6**
Productive activities (writing, editing, etc.)	2	11,8
Study (on-line courses, articles, etc.)	6	35,3
Games	2	11,8
Recreation (movies, music, crossword puzzles, blogs, etc.)	5	29,4
Communication (email, Skype, etc.)	7	41,2
Activities of daily living (purchases, payments, bank, etc.)	2	11,8
Information (Wikipedia, governmental sites, news, maps, etc.)	10	58,8
Other	2	11,8

COMMENT ON QUESTION a10:."Please indicate your main uses of your computer system and the three most important ones": (for the first part of the question, only answers with a frequency over 50% are included in comment).

(i) The CGs reported the following about the use of computers:

a) **SCI CGs** reported that their patient' main uses of computer (in descending order) were : Recreation (movies, music, crossword puzzles, blogs, etc.), Social participation (Facebook, forums, etc.) ,Information (Wikipedia, governmental sites, news, maps, etc.).
b) **PD CGs** answered that their patients used the computer mainly for: Information (Wikipedia, governmental sites, news, maps, etc.), Communication (email, Skype, etc.), Social participation (Facebook, forums, etc.)
c) **NMD CGs** reported that NMD patients' main uses of computer are: Social participation (Facebook, forums, etc.), Communication (email, Skype, etc.), Information (Wikipedia, governmental sites, news, maps, etc.), Recreation (movies, music, crossword puzzles, blogs, etc), Study (on-line courses, articles, etc.), Productive activities (writing, editing, etc.) and games.

(ii) The three most important computer uses according to CGs were:

a) SCI patients: Social participation (Facebook, forums, etc.), recreation (movies, music, crossword puzzles, blogs, etc.),games and communication (email, Skype, etc.) grouped together in third rank.
b) PD patients: Communication (email, Skype, etc.) Information (Wikipedia, governmental sites, news, maps, etc.) and Social participation (Facebook, forums, etc.).
c) NMD patients: Social participation (Facebook, forums, etc.), Information (Wikipedia, governmental sites, news, maps, etc.), Communication (email, Skype, etc.).

<u>Question a11:</u> *"Please indicate the main applications your patient uses and the three most important ones*:"

i/A.SCI CGs: Only one SCI CG answered this question reporting that the patient's main application is internet browser.

(i)TABLE Q a11.A Main computer applications [PD CGs] (N=19)

PD CGs/MAIN APPLICATIONS	Frequency	Percent
Internet browser	19	**100,0**
Email client	15	78,9
Word processor	8	42,1
Audio/video/image applications	7	36,8
Spreadsheets	4	21,1
Computer games	4	21,1
Presentation software	3	15,8
Programming/database	3	15,8
Media editing applications	1	5,3
Other	2	10,6

(i)TABLE Q a11B.Main computer applications [NMD pts] (N=17)

NMD CGs/MAIN APPLICATIONS	Frequency	Percent
Internet browser	14	82,4
Email client	15	**88,2**
Word processor	11	64,7
Audio/video/image applications	10	58,8
Spreadsheets	2	11,8
Computer games	9	52,9
Presentation software	4	23,5
Programming/database	3	17,6
Media editing applications	6	35,3
Other	0	0

(ii)/Q.a11A. The three most important applications [SCI CGs] (N=9)

SCI CGs/ THREE MOST IMPORTANT APPLICATIONS	Frequency	Percent
Internet browser	8	**88,9**
Email client	3	42,9
Word processor	0	0
Audio/video/image applications	3	42,9
Spreadsheets (e.g. Excel)	0	0
Computer games	2	28,6
Presentation software	0	0
Programming/database	0	0

Media editing applications	0	0
Other	0	0

(ii)/Q.a11B.Please indicate the three most important applications your patient uses [PD CGs] (N=19)

PD CGs /THREE MOST IMPORTANT APPs	Frequency	Percent
Internet browser	19	**100,0**
Email client	15	78,9
Word processor	2	10,5
Audio/video/image applications	5	26,3
Spreadsheets (e.g. Excel)	3	15,8
Computer games	3	15,8
Presentation software	1	5,3
Programming/database	1	5,3
Media editing applications	0	0
Other	2	10,6

(ii)/Q.a11C.Please indicate the three most important applications your patient use (NMD CGs) (N=17)

NMD CGs/THREE MOST IMPORTANT APPs	Frequency	Percent
Internet browser	14	**82,4**
Email client	14	**82,4**
Word processor	3	17,6
Audio/video/image applications	5	29,4
Spreadsheets (e.g. Excel)	0	0
Computer games	5	29,4
Presentation software	0	0
Programming/database	3	17,6
Media editing applications	0	0
Other	0	0

COMMENT ON QUESTION a 11 *:"Please indicate the main applications you use and the three most important ones"* (for the first part of the question, only answers with a frequency over 30% are included in comment).

(i) On the use of computers the following were reported:

a) PD CGs: internet browsing, e-mail, Word processor, audio-visual;
b) NMD CGs: e-mail, Internet browser, Word processor, audio- visual and games.

(ii).The **three most important** applications according to CGs were:

a) for SCI patients: Internet browser, email, audio-visual apps;
b) for PD patients: the same as in SCI patients;
c) for NMD patients: Internet browser, e-mail, audio-visual and games grouped together in third rank.

Question a12: "*Which operating systems do you work with?"*

A. SCI CGs reported that ninety per cent of their patients were using Microsoft Windows as their computer operating system and the rest of them preferred Apple mac os. B. PG CGs & NMD CGs reported that all PD and NMD patients were using Microsoft Windows.

Question a13. "*How does computer use contribute to you in the following aspects?"*

All CGs were asked (**i**) to evaluate the various aspects of computer contributions to their patient's life using a scale from 1-5 (*1- not important at all, 5- very important*) and (**ii**) to indicate the three most important ones .Their evaluation is presented in the following tables.

(i)/Q a13A . TABLE. Evaluation of computer contribution to patient's life [SCI CGs] (N=11)

SCI CG/ COMPUTER USE CONTRIBUTION	Mean	Median	Min	Max	SD
Interpersonal interactions and relationships	3,27	4,00	1,00	5,00	1,62
Close, intimate relationships	2,70	2,50	1,00	5,00	1,49
Educational attainment	**3,60**	4,00	1,00	5,00	1,43
Work and employment status/potential	**3,70**	4,00	2,00	5,00	1,16
Participation in desired community, social and civic activities	2,30	2,00	1,00	4,00	1,34
Autonomy and self-determination (making decisions)	3,40	4,00	1,00	5,00	1,56
Fitting in, belonging, feeling connected	3,40	4,00	1,00	5,00	1,58
Emotional well-being	**3,82**	4,00	1,00	5,00	1,33
Overall health	-	-	-	-	-

(i)/Q a13B . TABLE. Evaluation of computer contribution to patient's life[PD CGs] (N=19)

PD CGs /COMPUTER CONTRIBUTTION	Mean	Median	Min	Max	SD
Interpersonal interactions and relationships	**3,00**	**3,00**	1,00	5,00	1,45
Close, intimate relationships	1,53	1,00	1,00	5,00	1,31
Educational attainment	**3,00**	**3,00**	1,00	5,00	1,56
Work and employment status/potential	2,95	**3,00**	1,00	5,00	1,90
Participation in desired community, social and civic activities	2,16	2,00	1,00	5,00	1,12
Autonomy and self-determination (making decisions)	2,37	2,00	1,00	5,00	1,46
Fitting in, belonging, feeling connected	2,21	2,00	1,00	5,00	1,23
Emotional well-being	2,95	**3,00**	1,00	5,00	1,35
Overall health	2,21	1,00	1,00	5,00	1,55

(i)/Q a13C . TABLE. Evaluation of computer contribution to patient's life[NMD CGs] (N=16)

NMD	Mean	Median	Min	Max	SD
Interpersonal interactions and relationships	3,94	5,00	1,00	5,00	1,48
Close, intimate relationships	3,38	3,50	1,00	5,00	1,50
Educational attainment	3,94	5,00	1,00	5,00	1,48
Work and employment status/potential	3,63	4,50	1,00	5,00	1,71
Participation in desired community, social and civic activities	3,75	4,00	1,00	5,00	1,39
Autonomy and self-determination (making decisions)	4,06	5,00	1,00	5,00	1,39
Fitting in, belonging, feeling connected	**4,19**	5,00	1,00	5,00	1,17
Emotional well-being	**4,19**	4,00	2,00	5,00	,91
Overall health	3,88	4,00	1,00	5,00	1,02

COMMENT ON Q. a13 PART (i). Note: Median scores of 3 and higher, for every aspect, were regarded as an indication of importance.

a) SCI CGs gave high scores for the following important aspects of computer contributions :Educational attainment, work and employment status/potential, autonomy / self-determination (making decisions),interpersonal interactions and relationships, fitting in, belonging, feeling connected.
b) PD CGs gave medium high scores for the following important aspects of computer contributions: Educational attainment ,work and employment status/potential, autonomy and self-determination (making decisions), fitting in/ belonging/feeling connected, and emotional well-being.
c) NMD CGs gave high scores to all aspects of computer contributions.

Question a13 part (ii). *"CGs were also asked to choose the three most important aspects of computer contributions to their patient's life."* Their answers are shown in the following three tables.

(ii) /Q a13A. TABLE. The three most important aspects of computer contribution [SCI CGs] (N=10)

SCI CG/PC CONTRIBUTION -3 MOST IMPORTANT	Frequency	Percent
Interpersonal interactions and relationships	6	**60,0**
Close, intimate relationships	3	30,0
Educational attainment	3	30,0
Work and employment status/potential	3	30,0
Participation in desired community, social and civic activities	1	10,0
Autonomy and self-determination (making decisions)	3	30,0
Fitting in, belonging, feeling connected	4	40,0
Emotional well-being	2	20,0
Overall health	0	0

(ii) / Q a13B. TABLE.The three most important aspects of computer contribution [PD CGs] (N=19)

PD CG /COMPUTER CONTRIBUTIONS-3 MOST IMPORTANT	Frequency	Percent
Interpersonal interactions and relationships	8	42,1
Close, intimate relationships	1	5,3
Educational attainment	7	36,8
Work and employment status/potential	11	**57,9**
Participation in desired community, social and civic activities	3	15,8
Autonomy and self-determination (making decisions)	5	26,3
Fitting in, belonging, feeling connected	7	36,8
Emotional well-being	8	42,1
Overall health	3	15,8

(ii) /Q a13C. TABLE.The three most important aspects of computer contribution [NMD CGs] (N=17)

NMD CGs -THREE MOST IMPORTANT	Frequency	Percent
Interpersonal interactions and relationships	11	**64,7**
Close, intimate relationships	2	11,8
Educational attainment	5	29,4
Work and employment status/potential	5	29,4
Participation in desired community, social and civic activities	4	23,5
Autonomy and self-determination (making decisions)	6	35,3
Fitting in, belonging, feeling connected	6	35,3
Emotional well-being	3	17,6
Overall health	3	17,6

COMMENT ON Question a13, PART (ii):The three most important aspects of computer contribution in a patients' life according to CGs are the following (in descending order):

a) For SCI patients: Interpersonal interactions and relationships (first rank),fitting in, belonging, feeling connected (second rank) and in third rank group together :close, intimate relationships, educational attainment, work and employment status/ potential, autonomy and self-determination (making decisions).
b) For PD patients: Work and employment status/potential ,Interpersonal interactions and relationships and emotional well-being.
c) For NMD patients Interpersonal interactions and relationships, autonomy and self-determination (making decisions) and fitting in, belonging, feeling connected.

b) Difficulties in computer operations

Question.b1. *"All CGs selected ,from a list of various computer functions, those who thought that their patients found difficult to perform."* Their answers are shown in the following three tables.

Q b 1.A TABLE. Difficulties performing on the computer [SCI pts] (N=9)

SCI CG DIFFICULTIES	Frequency	Percent
Identifying the cursor on the screen	2	22,2
Moving the cursor on the screen	7	77,8
"Clicking" with the cursor	5	55,6
"Double clicking" with the cursor	4	44,4
Selecting and dragging, resizing windows	7	77,8
Zooming / Panning	7	77,8
Using the keyboard	5	55,6
Identifying the letters on the keyboard	2	22,2
Typing with the keyboard	6	66,7
Using two keys at the same time	8	**88,9**
Reading the words on the screen	1	11,1
Understanding how to use the assistive device software	0	0
Opening a file on the computer	1	11,1
Picking an item from a list or menu	1	11,1
Navigating the directory structure	2	22,2
Perform a search on the computer or on the Web	1	11,1
Browsing/Navigating the internet	1	11,1
Other	1	11,1

Q. b 1.B TABLE. Difficulties performing on the computer [PD pts] (N=19)

PD CGs / DIFFICULTIES	Frequency	Percent
Identifying the cursor on the screen	4	21,1
Moving the cursor on the screen	8	**42,1**
"Clicking" with the cursor	5	26,3
"Double clicking" with the cursor	8	**42,1**
Selecting and dragging, resizing windows	5	26,3
Zooming / Panning	1	5,3
Using the keyboard	4	21,1
Identifying the letters on the keyboard	0	0
Typing with the keyboard	5	26,3
Using two keys at the same time	3	15,8
Reading the words on the screen	0	0
Understanding how to use the assistive device software	0	0
Opening a file on the computer	1	5,3
Picking an item from a list or menu	0	0
Navigating the directory structure	0	0
Perform a search on the computer or on the Web	1	5,3

Browsing/Navigating the internet	1	5,3
Other	0	0

Q. b 1C. TABLE. Difficulties performing on the computer [NMD pts] (N=17)

NMS CGs /ACTION	Frequency	Percent
Identifying the cursor on the screen	3	17,6
Moving the cursor on the screen	2	11,8
"Clicking" with the cursor	3	17,6
"Double clicking" with the cursor	3	17,6
Selecting and dragging, resizing windows	4	23,5
Zooming / Panning	4	23,5
Using the keyboard	9	**52,9**
Identifying the letters on the keyboard	3	17,6
Typing with the keyboard	9	52,9
Using two keys at the same time	11	**64,7**
Reading the words on the screen	2	11,8
Understanding how to use the assistive device software	0	0
Opening a file on the computer	3	17,6
Picking an item from a list or menu	2	11,8
Navigating the directory structure	3	17,6
Perform a search on the computer or on the Web	2	11,8
Browsing/Navigating the internet	2	11,8
Other	0	0

COMMENT ON Question. b1 :

a) Difficulties performing on the computer as reported by CGs according to frequency (over 35 %) were: Using two keys at the same time, selecting and dragging/ resizing windows, zooming / panning, moving the cursor on the screen, typing with the keyboard, "clicking" with the cursor, using the keyboard, "double clicking" with the cursor.
b) PD Patients reported difficulties in: Moving the cursor on the screen, "Double clicking" with the cursor.
c) NMD patients had difficulties in: Using two keys at the same time ,using the keyboard, typing with the keyboard.

Question b2: *"How does your patient create text in the computer (Part A1) and how easy it is* (Part A_2)*?"* All CGs answers are presented in the next three tables.

Q b2 A1.TABLE A. How the SCI patient create a text on the computer (N=10)

SCI CGS/ How does your patient create a text on the computer?	Frequency	Percent
Keyboard	4	**40,0**
By dictating (a machine or a person)	2	20,0
By touch	2	20,0
Pointer and virtual keyboard	1	10,0

Other*	5	33,3

*=touchpad(1);assistive device (1);typing stick (2);another person (1)

Q b2 A1.TABLE B. How the PD patient create a text on the computer (N=19)

PD CGs/TEXT CREATION	Frequency	Percent
Keyboard	17	**89,5**
By dictating (a machine or a person)	1	5,3
By touch	2	10,5
Pointer and virtual keyboard	0	0
Other	0	0

Q b2 A1.TABLE C. How does your patient create a text on the computer?[NMD CG] (N=17)

NMD CG /TEXT CREATION	Frequency	Percent
Keyboard	10	**58,8**
By dictating (a machine or a person)	2	11,8
By touch	1	5,9
Pointer and virtual keyboard	6	**35,3**
Other	1	5,9

COMMENT on Question. b2 (Part A_1):

a) SCI CGs report that their patients create text on the computer by the keyboard (40%)
b) PD patients CGs answered that PD patients create text mostly by keyboard (89,5%).
c) According to CGs the majority of NMD patients prefers a key board for text creation (58,8%), but a significant percentage uses a pointer and virtual keyboard.

Question. b2 (Part A_2): "*How do your patient create text in the computer and how easy it is?* **"**

Q. b2 A2 .TABLE A. Evaluation of creating text difficulty (1- very difficult, 5- very easy)/ [SCI CGs] (N=4)

SCI CGs /DIFFICULTY CREATING TEXT	Mean	Median	Min	Max	SD
Keyboard	**4,00**	4,50	2,00	3,00	1,41
By dictating (a machine or a person)	3,00	3,00	2,00	2,00	1,41
By touch	**4,00**	4,00	3,00	2,00	1,41
Pointer and virtual keyboard	1,00	1,00	1,00	,00	.
Other	3,50	3,50	2,00	3,00	1,29

Q. b2 A2 .TABLE B. Evaluation of creating text difficulty (1- very difficult, 5- very easy)/[PD pts] (N=17)

PDCG /DTEXT CREATION DIFFICULTY	Mean	Median	Min	Max	SD
Keyboard	**3,53**	4,00	1,00	5,00	1,23
By dictating (a machine or a person)	3,00	**3,00**	3,00	3,00	.
By touch	3,00	**3,00**	3,00	3,00	.

Pointer and virtual keyboard	-	-	-	-	-
Other	-	-	-	-	-

Q. b2 A2 .TABLE C. Evaluation of creating text difficulty (1- very difficult, 5- very easy)/[NMD CGs] (N=17)

NMD CG/TEXT DIFFICULTY	Mean	Median	Min	Max	SD
Keyboard	1,82	**1,00**	,00	5,00	2,04
By dictating (a machine or a person)	3,00	**3,00**	1,00	5,00	2,83
By touch	4,00	4,00	4,00	4,00	.
Pointer and virtual keyboard	3,67	**3,50**	2,00	5,00	1,21
Other	-	-	-	-	-

COMMENT ON Question b2 A $_2$:

a) SCI CGs reported that their patients had considerable difficulty creating text by pointer and virtual keyboard.
b) PD CGs reported moderate difficulty for text creation by dictation (a machine or a person) or by touch.
c) NMD CGs reported that their patients had significant difficulty creating text using the keyboard. NMD patients had moderate difficulty creating text by dictation and pointer & virtual key.

Question .b2 (Part B$_1$): *"How does your patient point on the screen?"*. All CGs answers are presented in the following three tables

Q .b2 B1: A.Table. How does your patient point on the screen? [SCI CGs] (N=10)

SCI point	Frequency	Percent
Mouse	2	20,0
Keyboard	1	10,0
By touch	2	20,0
Assistive device*	3	**30,0**
Other**	3	20,0

*=trackball(1); upsidedown mouse (1)
**=special touch gadget(1); another person (2)

Q .b2 B1:B.Table. How does your patient point on the screen? [PD CGs] (N=19)

PD CG/POINTING	Frequency	Percent
Mouse	18	**100,0**
Keyboard	2	10,5
By touch	2	10,5
Assistive device	0	0
Other	0	0

Q .b2 B1: Table. How does your patient point on the screen? [NMD CGs] (N=17)

NMD CG//POINTING	Frequency	Percent
Mouse	11	64,7
Keyboard	1	5,9
By touch	5	29,4
Assistive device	0	0
Other	0	0

COMMENT ON Question.b2 B_1 :

a) SCI CGs replied that their patients point on the computer screen mostly by an Assistive device (AD) (30%).However some of them can point by touch (20%)
b) PD CGs reported that most PD patients point by mouse .No one is using an assistive device.
c) NMD patients point mainly by mouse and by touch.

QUESTION b2 Part B_2: "*CGs were asked to evaluate their patients level of difficulty for screen pointing*". Their answers are presented in the following three tables.

Q .b2 B2 TABLE. Pointing on the screen difficulty (1- very difficult, 5- very easy) /[SCI CGs]

SCI CG/ POINTING DIFFICULTY	Mean	Median	Min	Max	SD
Mouse	3,00	3,00	2,00	2,00	1,41
Keyboard	**4,00**	4,00	4,00	,00	.
By touch	3,50	3,50	3,00	1,00	,71
Assistive device	2,33	2,00	1,00	3,00	1,53
Other	**5,00**	5,00	5,00	,00	.

Q .b2 B2 TABLE. Pointing on the screen difficulty (1- very difficult, 5- very easy) /[PD CGs]

PD CG POINTING DIFFICULTY	Mean	Median	Min	Max	SD
Mouse	3,11	**3,00**	1,00	5,00	1,18
Keyboard	**4,00**	4,00	4,00	4,00	,00
By touch	**4,00**	4,00	4,00	4,00	,00
Assistive device	-	-	-	-	-
Other	-	-	-	-	-

Q .b2 B2 TABLE. Pointing on the screen difficulty (1- very difficult, 5- very easy) /[NMD CGs]

NMD CG/ POINTING DIFFICULTY	Mean	Median	Min	Max	SD
Mouse	3,75	4,00	2,00	5,00	1,29
Keyboard	1,00	1,00	1,00	1,00	.
By touch	3,75	3,50	3,00	5,00	,96
Assistive device	-	-	-	-	-
Other	-	-	-	-	-

COMMENT ON QUESTION b2 Part B_2 :

a) SCI CGs think that their patients have significant difficulty pointing to the computer screen by an AD, while pointing by mouse and touch was easier.
b) PD GCs reported that their patients had more difficulty with the mouse and NMD patients with the keyboard.

c) Current working environment

The next set of questions was targeted to assess the working environment of patients using a computer and its effect on the using experience

Question c1: "*(Computer type)".*

Caregivers reported that:

a) A Stationary computer is used by 70% of SCI patients and a portable one by 50%.
b) A Stationary computer is used by 89.5% of PD patients and a portable one by 57,9%.
c) A Stationary computer is used by 35.3% of NMD patients and a portable one by 64,7%.

Questions c2 & c3: *"The goal of these questions was to identify the location of the computer and the positioning of the user when in use."*

SCI patients: reported that patients' computer is located mostly on a desk (80 %) or may be on a wheel chair tray (20%) or mounted on an arm (10%) They sit usually on a motorized wheel chair or a wheel chair while they operate the computer[(70 %) and (20%) respectively or lay in bed 20%). Positioning details are presented in the following table.

PD patients : reported that PD patients ' computer location is a desk (100%). All patients sit usually on an arm chair while they operate the computer (100%).Some of them can also operate the computer standing.

NMD patients: Computer is located mostly on a desk(76,5 %)or rarely mounted on an arm or wheel chair tray (2 persons).Two patients have reported having the computer on bed and one on his lap. They sit usually on either a motorized wheel chair or a wheelchair while they operate the computer[(58,9%) and (17,6%) respectively] or laying in bed (18,8).One patient uses a stander.

Question c4. *"Common operating location/s"*

Usually SCI patients operate the computer at their home (100%). Other options are presented in the following table. According to CG's report SCI patients usually operate the computer at their home (100%). Other options are presented in the following table.

TABLE. Common operating location/s [SCI CGs] (N=10)

SCI CGs	Frequency	Percent
Home	10	**100,0**
Work	0	0
Coffee shops	0	0
Other*	2	13,3

*=studies (1),rehabilitation (1)

PD patients also operate their computers at home (78,9%).Other locations are presented in the following table **(N=19)**

TABLE. Common operating location/s [PD CGs] (N=10)

PD CGS LOCATION	Frequency	Percent
Home	15	**78,9**
Work	7	36,8
Coffee shops	0	0
Other	0	0

NMD patients operate the computer at home (94,7%).All other locations are presented in the following table.

TABLE. Common operating location/s [NMD CGs] (N=17)

	Frequency	Percent
Home	17	**100,0**
Work	0	0
Coffee shops	1	5,9
Other	1	5,9

Question c5. *"All CGs were asked to evaluate how their physical condition is related to the certain computer use aspects".* Their evaluation is presented in the following three tables.

Q c5.TABLE.Evaluation of SCI patients' physical condition impact on various computer use aspects by CGs (1- No effect, 5- Completely,) (N=8)

SCI CGs	Mean	Median	Min	Max	SD
Comfort	2,71	3,00	1,00	4,00	1,50
Independence	**3,25**	4,00	1,00	4,00	1,91
Satisfaction	2,63	2,50	1,00	4,00	1,60
Pain	2,63	2,50	1,00	3,00	1,30
Speed of operation	2,50	2,50	1,00	4,00	1,51
Fatigue	2,88	3,00	1,00	4,00	1,46
Accuracy of operation	2,57	3,00	1,00	4,00	1,62

Endurance	2,63	2,50	1,00	4,00	1,60
Effectiveness	2,50	2,50	1,00	4,00	1,51
Ease of use	2,63	2,50	1,00	4,00	1,60
Enabling privacy	2,00	1,50	1,00	4,00	1,41

Q c5.TABLE.Evaluation of PD patients' physical condition impact on various computer use aspects by CGs (*1- No effect, 5- Completely,*) (N=19)

PD CGs	Mean	Median	Min	Max	SD
Comfort	**2,68**	3,00	1,00	5,00	1,42
Independence	**2,68**	3,00	1,00	5,00	1,29
Satisfaction	2,56	2,50	1,00	5,00	1,20
Pain	1,22	1,00	1,00	3,00	,55
Speed of operation	2,58	3,00	1,00	4,00	1,12
Fatigue	2,11	2,00	1,00	4,00	1,20
Accuracy of operation	2,63	3,00	1,00	4,00	1,01
Endurance	2,22	2,50	1,00	4,00	1,11
Effectiveness	2,53	3,00	1,00	5,00	1,22
Ease of use	**2,84**	3,00	1,00	5,00	1,17
Enabling privacy	1,47	1,00	1,00	4,00	1,02

Q c5.TABLE.Evaluation of NMD patients' physical condition impact on various computer use aspects by CGs (1- No effect, 5- Completely,) (N=16)

NMD CG	Mean	Median	Min	Max	SD
Comfort	1,75	2,00	1,00	3,00	,77
Independence	1,38	1,00	1,00	3,00	,62
Satisfaction	2,00	1,50	1,00	5,00	1,41
Pain	1,69	1,00	1,00	5,00	1,08
Speed of operation	**2,38**	2,00	1,00	5,00	1,41
Fatigue	**2,38**	2,00	1,00	4,00	1,15
Accuracy of operation	1,69	1,50	1,00	4,00	,87
Endurance	1,88	1,00	1,00	4,00	1,20
Effectiveness	1,50	1,00	1,00	4,00	,89
Ease of use	1,88	1,00	1,00	4,00	1,26
Enabling privacy	1,50	1,00	1,00	5,00	1,09

Comment on question c5.

a) SCI patients reported considerable impact(median value 3 or higher) of their physical condition on the following computer aspects: Independence, fatigue, accuracy of operation endurance, and comfort .

b) CGs of PD patients reported a moderate effect of their physical condition on computer speed of operation, accuracy of operation, comfort, effectiveness, independence and ease of use.
c) CGs of NMD patients did not report a significant effect of their physical condition on the above mentioned aspects of computer operation.

3.4.2 Description and evaluation of assistive device/s

In this Section cumulative data are presented for SCI patients only.

Question d1 - Question d6. Questions d1-d6 asked the patients' CGs whether they used an AD to operate the computer, if so, what type, for how long, where was it fitted, and whether they used a different one in the past.

Half CGs of SCI patients (87,8%) reported that their patients use an assistive device (AD) for computer operation. In the following table, various types of ADs used are presented. Most popular AD is the typing stick (87,5%). ADs have been used for a mean time of 149, 25±162,71months. In 80% the AD device was fitted for the patient at a rehabilitation center, in 20% at vocational/assistive-device counseling. The CGs did not report their patients having used another AD in the past

TABLE. Types of Ads used by SCI patients (N=6)

SCI CGI	Frequency	Percent
Typing Stick	3	**50,0**
Mouthstick	1	16,7
Chin joystick	0	0
Mouth joystick	0	0
Gaze tracker	0	0
Head tracker	1	16,7
Speech recognition	0	0
Mounting system (arms and support)	0	0
Other*	2	13,3

***=trackball (1);upsidedown mouse (1)**

Question d7. CGs reported that SCI patients used mostly their neck (83,3%), jaw(50%), and wrists (50%) to operate the Ads (table **Q d7A**).Mean values of their self- assessment of pain and fatigue caused by AD operation are presented in tables Q d7B & Q d7C.However their experience from the Ads is neither painless nor comfortable because their mean reported levels of pain and fatigue are significant.

TABLE Q d7A.Body parts used by SCI patients to operate the assistive device (N=6)

SCI CGs	Frequency	Percent
Tongue	1	16,7
Eyes	1	16,7
Jaw	3	50,0

Neck	5	**83,3**
Shoulders	2	33,3
Arm	2	33,3
Elbows	2	33,3
Wrists	3	50,0
Fingers	2	33,3

Table Q d7 B. Assessment of the pain caused by AD after prolong use (1 – no pain at all, 5 – extreme pain)

SCI CGs	Mean	Median	Min	Max	SD
Tongue	1,00	1,00	1,00	,00	.
Eyes	1,00	1,00	1,00	,00	.
Jaw	2,00	2,00	1,00	2,00	1,00
Neck	2,60	3,00	1,00	3,00	1,14
Shoulders	**4,00**	4,00	4,00	,00	,00
Arm	**4,00**	4,00	4,00	,00	,00
Elbows	3,50	3,50	3,00	1,00	,71
Wrists	**4,33**	4,00	4,00	1,00	,58
Fingers	3,00	3,00	2,00	2,00	1,41

Table Q d7C.Assessment of fatigue caused by AD (1 – no fatigue at all, 5 – extreme fatigue)

SCI CGs	Mean	Median	Min	Max	SD
Tongue	1,00	1,00	1,00	,00	.
Eyes	1,00	1,00	1,00	,00	.
Jaw	2,67	2,00	1,00	4,00	2,08
Neck	2,80	3,00	1,00	4,00	1,48
Shoulders	**3,50**	3,50	3,00	1,00	,71
Arm	**3,50**	3,50	3,00	1,00	,71
Elbows	3,00	3,00	3,00	,00	,00
Wrists	**3,67**	4,00	3,00	1,00	,58
Fingers	3,00	3,00	2,00	2,00	1,41

Questions Q. d8 to Q.d10 are referring to various AD characteristics and CGs assessment of them. These questions are derived from the *Quebec User Evaluation of Satisfaction with assistive Technology QUEST (Version 2.0*) questionnaire.

ASSISTIVE DEVICE

Qd8.TABLE 1. Satisfaction level with AD (scoring:1 – 5) (N=3)

SCI	Mean	Median	Min	Max	SD
The dimensions (size, height, length, width) of the assistive device?	4,33	5,00	3,00	2,00	1,15
The weight of the assistive device?	4,67	5,00	4,00	1,00	,58

The ease in adjusting (fixing, fastening) the parts of the assistive device?	4,33	5,00	3,00	2,00	1,15
How safe and secure the assistive device is?	4,33	5,00	3,00	2,00	1,15
The durability (endurance, resistance to wear) of the assistive device?	3,67	4,00	2,00	3,00	1,53
How easy it is to use the assistive device?	4,33	5,00	3,00	2,00	1,15
How comfortable the assistive device is?	3,67	4,00	2,00	3,00	1,53
How effective the assistive device is (the degree to which the device meets the patient's needs)?	4,33	5,00	3,00	2,00	1,15

SERVICES

Q.d8 TABLE 2 .Level of satisfaction with AD service (scoring:1 – 5) (N=3)

SCI CG	Mean	Median	Min	Max	SD
The service delivery program (procedures, length of time) in which your patient obtained the assistive device?	**4,33**	5,00	3,00	2,00	1,15
The repairs and servicing (maintenance) provided for the assistive device?	3,67	4,00	2,00	3,00	1,53
The quality of the professional services (information, attention) your patient received for using the assistive device?	4,00	5,00	2,00	3,00	1,73
The follow-up services (continuing support services) received for the assistive device?	4,00	5,00	2,00	3,00	1,73

□

Q d8 TABLE 3. The <u>three</u> most important items related to AD for SCI patients (N=3)

SCI CG	Frequency	Percent
Dimensions	0	0
Comfort	3	**100,0**
Weight	1	33,3
Effectiveness	1	33,3
Adjustments	1	33,3
Service delivery	0	0
Safety	0	0
Repairs/servicing	0	0
Durability	1	33,3
Professional service	0	0
Easy to use	2	66,7
Follow-up services	0	0

TABLE. Important attributes of the AD for SCI patients (1- not important at all, 5 - very important (N=4)

SCI CG	Mean	Median	Min	Max	SD
Noninvasiveness	3,50	4,00	1,00	4,00	1,73
Setup time	3,25	3,50	1,00	4,00	1,71
Independent operation	**4,75**	5,00	4,00	1,00	,50
Training time	3,75	4,50	1,00	4,00	1,89
Cost	3,25	3,50	1,00	4,00	2,06
Number of functions provided	3,50	4,00	1,00	4,00	1,91
Response time	4,00	5,00	1,00	4,00	2,00
Productivity	4,50	4,50	4,00	1,00	,58
Ease of use	**4,75**	5,00	4,00	1,00	,50
Aesthetics	3,50	3,50	3,00	1,00	,58
Enabling privacy	3,25	3,50	1,00	4,00	2,06

TABLE. The three most important attributes of the AD for SCI patients (N=4)

SCI CG	Frequency	Percent
Noninvasiveness	0	0
Setup time	0	0
Independent operation	3	75,0
Training time	0	0
Cost	1	25,0
Number of functions provided	1	25,0
Response time	1	25,0
Productivity	2	50,0
Ease of use	4	**100,0**
Aesthetics	0	0
Enabling privacy	0	0

Qd10 TABLE .Assessment of Comfort of the AD (1- Extremely Uncomfortable, 7- very Comfortable) (N=4)

SCI CAREGIVER	Mean	Median	Min	Max	SD
Force required for actuation	5,50	6,50	2,00	5,00	2,38
Smoothness during operation	**5,75**	6,50	3,00	4,00	1,89
Effort required for operation	4,75	5,00	2,00	5,00	2,22
Accuracy	5,50	6,00	3,00	4,00	1,73
Operation speed	5,50	6,00	3,00	4,00	1,73
General comfort	5,00	5,50	2,00	5,00	2,16
Overall operation of input device	5,00	6,00	1,00	6,00	2,71

3.4.3 Needs, missing functions and demands of improvement (Questionnaire – Chapter III)

CHAPTER.III, Question1. A. Some SCI patients reported that they do not use a computer .The following table shows the various reasons for not doing so.

CH III.Q.1TABLE.Reasons for not using a computer (SCI CGs)

SCI	Frequency	Percent
He/she doesn't need to use a computer + He/she doesn't know how to use a computer + It is too difficult in my patient condition + He/she doesn't like computers	1	25,0
He/she doesn't know how to use a computer + No patience	1	25,0
He/she cannot find a good assistive device + It is too difficult in my patient condition	1	25,0
It is too difficult in my patient condition	1	25,0

All patients from other groups used a computer.

NOTE: Some of the following questions require a detailed descriptive response from the patient. Results are presented as a list of individual answers and as summaries (when possible).

CH.III, Question 2. *:"If you could design your own assisted device (AD) for computer use or improve an existing one, what it would look like?"*

SCI CGs. Individual answers to this question are presented in the following table, while a summary of all answers is presented in CH.III, Q2 table for SCI pts.

CH.III Q2 TABLE. Design or improve an AD, SCI CGs perspective [summary] (N=15)

	Frequency	Percent
Improve current AD	7	**46,66**
Use gaze and/or thought	3	20
No answer/don't know	4	26,66
No need	1	6,66

PD CGs. No answer.
NMD CGs:No answer.

CH.III, Question 3*:"***What operation of the computer your patient used to do prior to the disease, that he/she can't do now, he/she misses the most, if any?"**

SCI CGs. There was only one answer: " games, editing programs".

PD CGs. No answer.

NMD CGs. There were five answers: joystick games; keyboard/ track pad; keyboard/ mouse; easiness in handling the laptop lid; difficulty with everything.

CH.III Question 4: "*What computer applications your patient was using prior to his/her disease that he/she now can't operate (or find very hard to operate) and miss the most, if any?"*

SCI patients CGs: two answers :"games" (1); "e-mails" (1)
PD patients. CGs: No answers.
NMD patients. CGs: Games (3 CGs),None missing app.(1 GC).

CH.III. Question 5: *"Would your patient use an assistive device system based on mental commands?"*

SCI patients CGs: The majority of SCI CGs answered "Yes" .

CH.III Q.5 TABLE . Willingness to use an AD based on mental commands (SCI CGs)

SCI CG MENTAL CONTROL	Frequency	Percent
Yes	9	**69,2**
No	4	30,8

PD CGs. most responded :"do not know".
NMD CGs . Most SCI CGs answered "Yes" .

CH.III Q.5 TABLE . Willingness to use an AD based on mental commands (NMD CGs)

NMD CG MENTAL CONTROL	Frequency	Percent
Yes	10	**62,5**
No	6	37,5

CH.III Q.5: "*Would your patient use an AD based on the mind? Please detail:"*

SCI patients CGs: Four responses. One positive "moving the cursor, opening and closing applications"; three negative :"does not need it.
PD patients. CGs: Three responses:[possibly (1);the patient must decide (1);"do not know"(1)].
NMD patients. CGs: five responses. Three positive but conditional ("if it is quick"; "if it is necessary") and two negative.

CH.III Question 6. "What type of computer interaction do you think your patient could perform with an interface based on mental commands?"

SCI patients CGs: Three responses: "turning on and off, surfing the web" (1); "surf the internet, play games" (1); "everything that involves controlling the computer" (1).

PD patients CGs: Three responses:[possibly (2);the patient must decide (1)].
NMD patients CGs: Four responses: three 'full functionality", one "reading".

CH.III Question 7. *"Would your patient use an assistive device system based on eye movements? "*

SCI patients CGs: Most SCI CGs responded positively to this question.

CH.III Q7 Table. Willingness to use an AD based on eye movements (SCI CG)

SCI CG EYE CONTROL	Frequency	Percent
Yes	9	**69,2**
No	4	30,8

PD patients CGs: One negative answer. All others replied that they do not know.

CH.III Q7 Table. NMD patients: All CGS were positive

NMD CGs EYE CONTROL	Frequency	Percent
Yes	17	**100,0**
No	0	0

b. CH.III Q7 (Detail). *"Would your patient use an AD based on eye movements. Please detail":*

SCI patients CGs: Four answers: three negative "no need", one optional : " only if more useful than what he tried before**"**
PD patients CGs: No response
NMD patients CGs: Two answers. One positive ("reading"),one expressing concern about eyesight.

CH.III Question 8: *"What type of computer interaction do you think you could perform with an interface based on eye-tracking? "*

SCI patients CGs: Three responses: "surf the internet, play games" (2); "games" (1)
PD patients CGs: No response.
NMD patients CGs: Four responses. Three "everything", one "download songs".

CH.III. Question 9 : *"Would your patient wear on his/her head an EEG recording device to facilitate controlling the computer with his/her thinking?"*

SCI patients CGs: The majority of CGs gave a negative answer.

CH.III. Question 9.Would SCI patients wear EEG device

SCI CGs /WEAR EEG CAP	Frequency	Percent
Yes	5	41,7

No	7	**58,3**

PD patients CGs: No response.

NMD patients CGs: Most responses were positive.

CH.III. Question 9.Would a NMD patient wear EEG device

NMD CGs /WEAR EEG CAP	Frequency	Percent
Yes	11	**64,7**
No	6	35,3

CH.III Question 9. *(DETAIL)"Would your patient wear on his/her head EEG a recording device to facilitate controlling the computer with his/her thinking*?" .

SCI patients CGs: There were four negative responses ('not needed" ,"two complicated", "too bulky");two positive ,but conditional ("only for 3 hours", "depends on the weight, comfort and effectiveness").

PD patients CGs: No response.

NMD patients CGs: There were eight responses as shown in next table.

CH III Question 10 : *"Would your patient wear on his/her head special glasses designed to facilitate controlling the computer with his/her eyes?* **"**

SCI patients CGs: The majority of CGs responded positively

CH III Question 10. TABLE. "Would patient wear special glasses" (SCI CG)

SCI CG/WEAR SPECIAL GLASSES	Frequency	Percent
Yes	7	**58,3**
No	5	41,7

PD patients CGs: On CG replied "possibly" and the rest that they do not know.

NMD patients CGs: Most CGs responded positively

CH III Question 10. TABLE. "Would patient wear special glasses" (NMD CG)

NMDCG/WEAR SPECIAL GLASSES	Frequency	Percent
Yes	14	**82,4**
No	3	17,6
Total	17	100,0

CH III Q. 10. "*Would your patient wear glasses for reading eye movements? "(detail)*

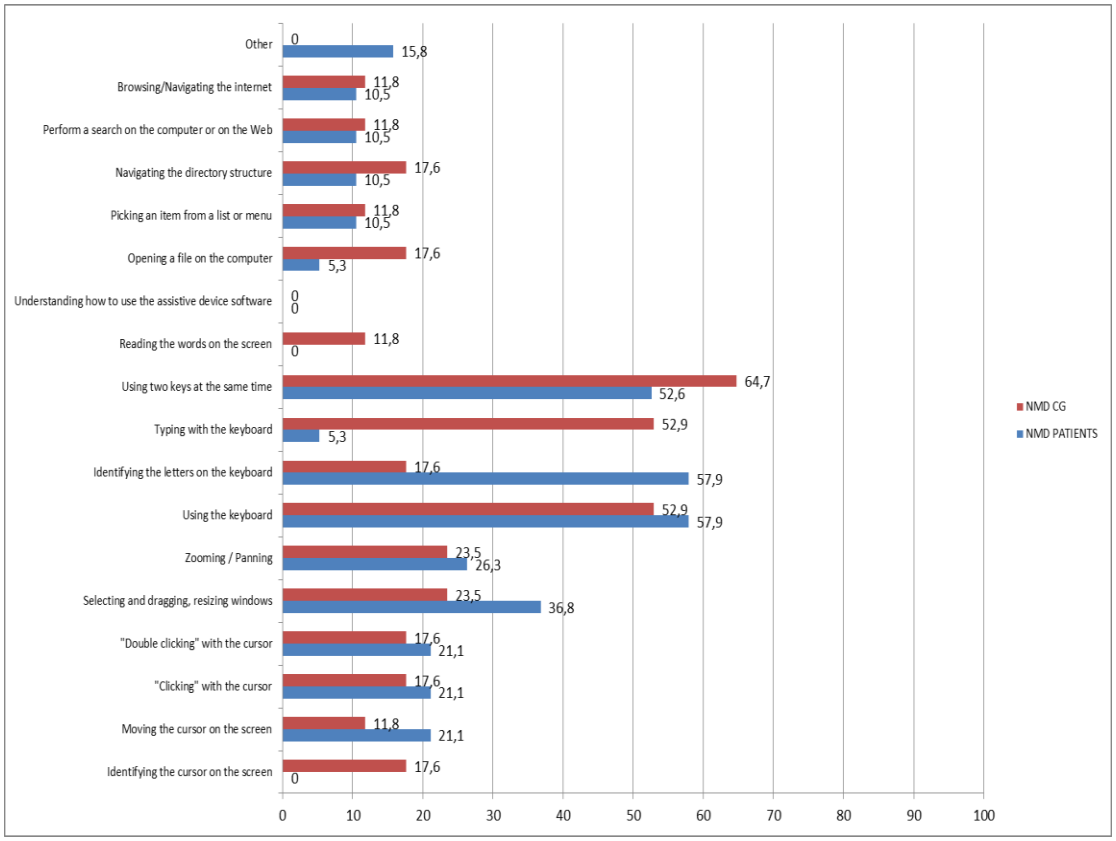
SCI CGs. There were five responses. Four were negative [“no need”(3),”wears regular glasses “(1)],one positive, but conditional (“it has to be practical and accurate”).

PD CGs. No response.

NMD CGs. There were four positive, but conditional answers (“only if comfortable”; “only if this would be his only choice and depending on the pressure on the head”; ‘how would she look”; “ needs his finger exercise”).

3.5 Comparison between patients and caregivers responses

Patients' responses on Chapters II and III of the questionnaire were compared to those of their caregivers. A striking disagreement in percentages of positive answers between NMD patients and their caregivers was found only in Question b1 *(Do you have difficulties performing the following on the computer system which you are using?)* concerning the item typing with the keyboard (see Graph below). According to the majority of CGs, NMD patients had difficulty in typing with the keyboard but patients strongly disagreed.



Qb1 . *(Do you have difficulties performing the following on the computer system which you are using?)*

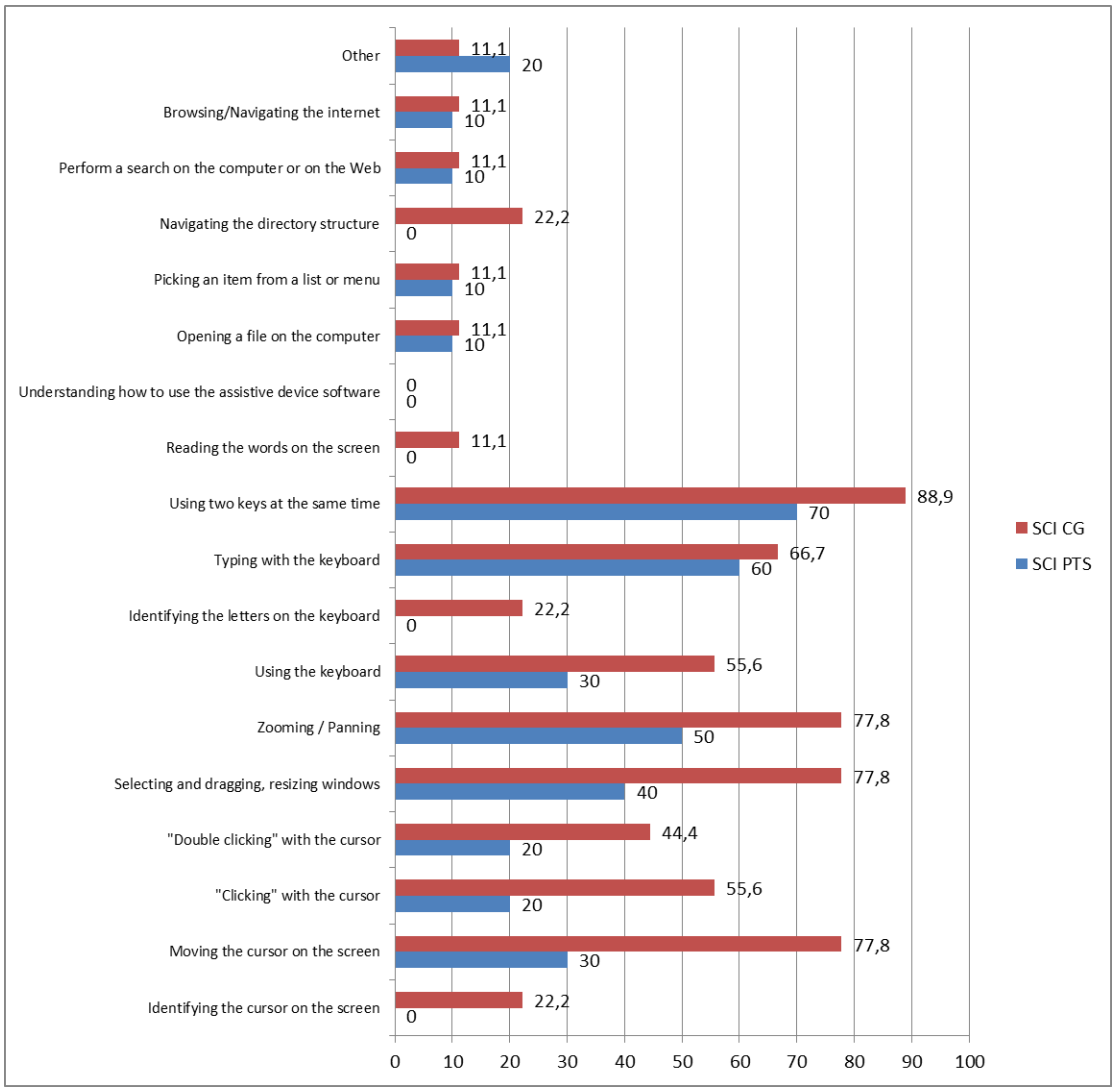
NMD pts vs CGs. GRAPH . Percentages of positive answers concerning difficulties ,between patients and their CGs. Statistically significant difference was observed in typing with the key board (Mc Nemar test exact significance, p=0.004).

In all other questions although there were some striking disagreements in percentages of positive answers between patients and their caregivers they did not reach statistical significance.

We present four graphs concerning questions (Chapter II Qb1, Chapter III question 5 and 7) showing the abovementioned disagreements in responses which however did not reach statistical significance.

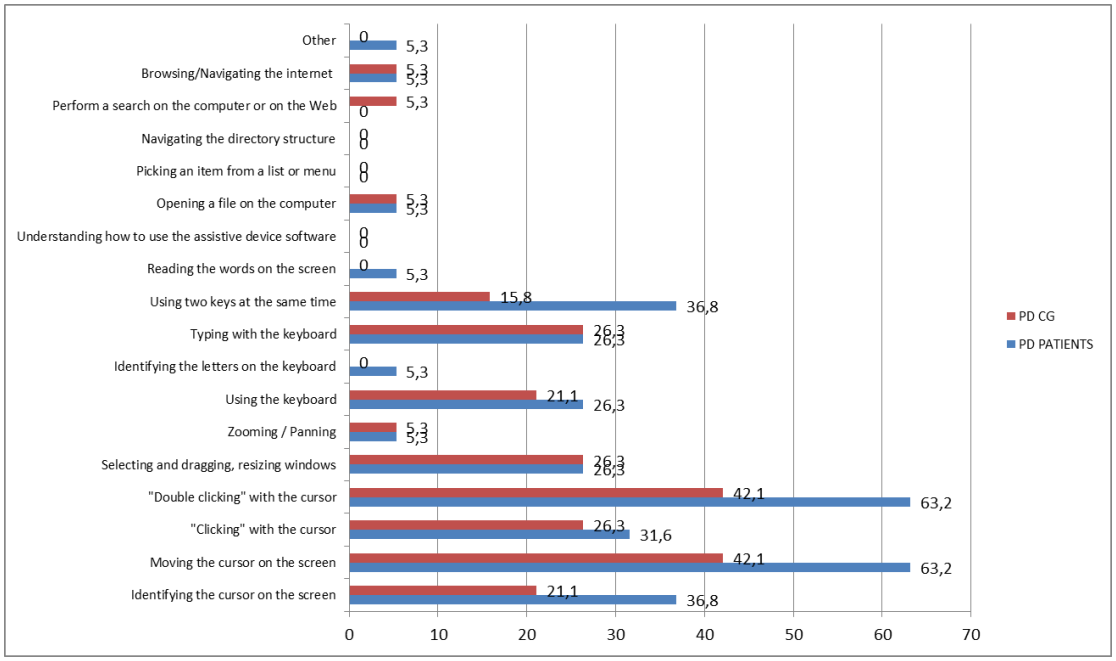
Qb1 . ***(Do you have difficulties performing the following on the computer system which you are using?)*** Comparisons between **SCI patients and caregivers** concerning difficulties on the computer system.

There is striking disagreement in percentages of positive answers concerning difficulties, between patients and CGs in the following items: moving cursor on the screen [Cohen's κ =0.207; exact significance=1.0] Selecting & dragging [κ =0.077; exact significance= 1.0]; zooming & panning [κ= =0.077; exact significance= 1.0] & zooming and panning [κ =0.087; exact significance=1.0], but these differences did not reach statistical significance



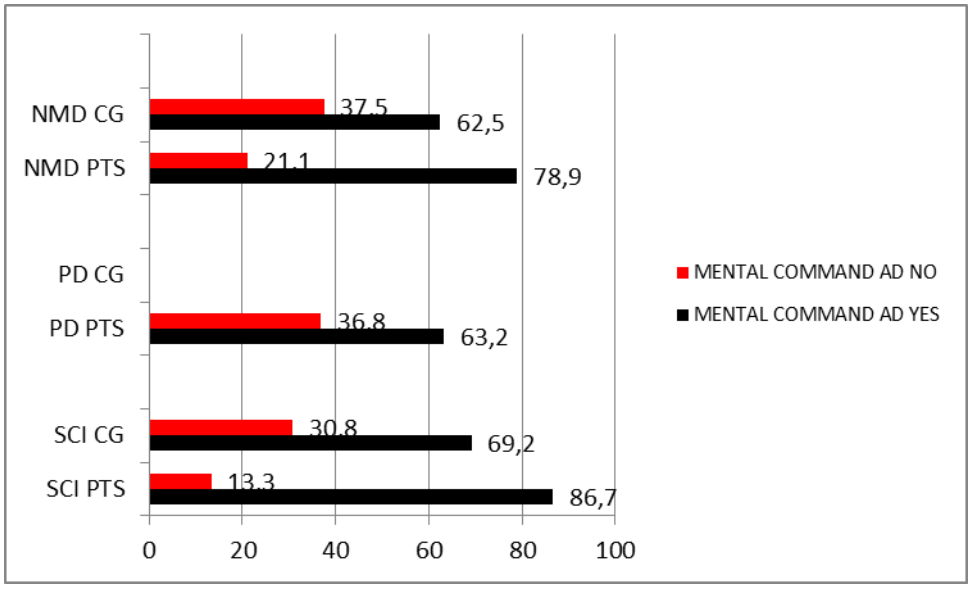
Qb1 . ***(Do you have difficulties performing the following on the computer system which you are using?)*** Comparisons between **PD patients and caregivers** concerning difficulties on the computer system.

There is striking disagreement in percentages of positive answers concerning difficulties between patients and CGs in the following items: Moving cursor on the screen [κ=.394, exact sign.=0.147]; double click at the same time [κ=0.394, exact sign.=0.147]; using two keys at the same time [κ=0.230, exact sign.=0.523]. Differences were not statistically significant.



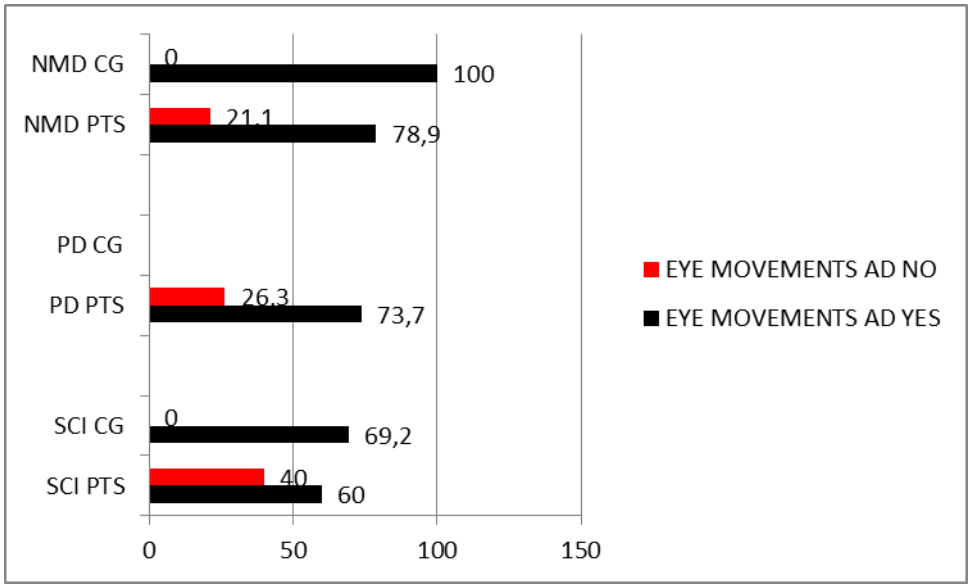
1.CH.III. Question 5. (*Would you use an assistive device system based on mental commands?)*

Comparisons between patients and caregivers concerning patients' attitude towards a computer AD based on mental commands. Both positive and negative views are presented. There were no statistically significant differences between patients and caregivers.



2.CH.III. Question 7. *(Would you use an assistive device system based on eye movements?)*

Comparisons between patients and caregivers concerning patients' attitude towards a computer AD based on eye movements. Both positive and negative views are presented. There were no statistically significant differences between patients and caregivers. (Mc Nemar test exact significance p>0.05)



Note: Regarding detailed answers concerning questions of Chapter III (possible use of computer ADs based on mind or eye control), PD caregivers did not respond to most questions at all. A number of SCI and NMD expressed their opinion about this devices. Usually negative answers focused on safety issues and positive answer expressed the need for devices that would be easy to use and comfortable for the patient.

IMPORTANT CONCLUSION. In many items CG and patient responses do not match, but they deviate over 25 %. However these differences did not reach a statistically significant level so as to reject the null hypothesis .Therefore we should assume that there is no significant differences between CGs and patients responses.

3.6 Clinical requirements according to the answers of the questionnaires

Before discussing the clinical requirements derived from the questionnaires there are some major issues that we must pay attention to. The target population is not homogenous, but it is formed by three groups of patients with different age (PD being older and NMD being younger), different type and severity of disability and different needs and priorities in their lives.

The following table presents the requirements for the MAMEM platform which were derived from the questionnaires results:

Clinically driven requirements for the MAMEM platform from the questionnaires results		
#	Insight/Rational	Requirement
1	It seems that most of the patients own a desktop or a laptop computer.	The platform should be targeted to work with a regular desktop or laptop computer running windows OS.
2	Although SCI patients report using smartphone the most, this outcome is very close to the desktop computer choice. In general – most of the patients report using computers the most.	
3	The vast majority of patients use Microsoft Windows	
4	All patients use the computer similarly, and for a considerable amount of time every day.	Since all patient groups have considerable experience using computer, the platform can be designed to be operated by experienced computer operating audiences.
5	All patient groups have a similar and considerable experience in using a computer	
6	The highest frequencies of computer uses were observed in recreation, communication and social participation	The platform should be mainly targeted to improve computer communication use aspects
7	Communication represents the only important computer use aspect beyond the various groups.	
8	Patients use browsers, email clients and word processors the most.	The platform should be mainly targeted to be able to operate internet browsers, email clients and word processors
9	It seems that the most important aspects of computer use for all patient groups are Interpersonal interactions and relationships, Educational attainment and Work and employment status/potential.	The platform should be mainly targeted to be able to enable better Interpersonal interactions & relationships and Educational attainment.
10	After obligating the patients to choose the	

	most important aspect of computer use, the most important aspects for all patient groups were Interpersonal interactions & relationships and Educational attainment.	
11	It seems that the most common difficulties to all patient groups are: using two keys on the keyboard at the same time, identifying the letters on the keyboard and using the keyboard to type.	The platform should be designed to overcome these difficulties by enabling the users to easily type, identify the letters on the keyboard and using two keys at the same time.
12	PD patients mostly use the keyboard to create text, while SCI patients also prefer to use assistive devices and NMD patients tend to use a pointer and a virtual keyboard.	The platform should provide an easier way to create text and move the pointer than a regular keyboard a regular mouse for PD and NMD patients and an easier way than various assistive devices for SCI patients.
13	For SCI patients, the easiest way to create text is by using the assistive device, for PD patients it is by using touch and NMD patients report they find it the easiest to use vocal dictating.	
14	Most SCI patients point on the computer screen using an Assistive device. Most PD patients point by mouse or touch. NMD patients point mainly by mouse.	
15	For SCI patients, those who report to be able to use a mouse to point expressed no difficulty. Yet, those who report using an assistive device seem to have significant difficulty. PD patients expressed some difficulty using the mouse and NMD patients little difficulty using the keyboard.	
16	It seems that SCI patients use stationary and portable computer equally, while PD patients tend to use stationary computers and NMD patients tend to use laptops.	The platform should work equally on stationary and portable computers to answer all patients' needs.
17	For all patient groups, the most common computer location is on a desk. While the most common positioning while operating for SCI and NMD patients is sitting in a motorized or a regular wheelchair, all PD patients seem to use armchairs.	The platform should be designed to be operated while the computer is on a desk, and while the patients are sitting in a regular or a motorized wheelchair or an armchair in order to answer most of the patients' needs.
18	The most common operating place for all patient groups was at home, while a substantial number of SCI patients operate	The optimal solution would be an easy portable platform to answer all of the patients' needs, yet the second best

	computer at other locations such as university or at friends and a substantial number of PD patients operate computer at work.	solution would be a platform for home use.
19	In general, SCI patients reported on higher effects of the working environment and their physical condition on the various computer aspects than PD or NMD patients. The most mentioned aspects by all patient groups to be affected were fatigue and effectiveness.	The greatest effect on the patients' computer usage will be reducing fatigue and increasing effectiveness caused by operating the computer.
20	Among SCI patients, the most popular AD is the typing stick.	The platform should be able provide a better solution to the current AD by reducing the pain and the fatigue to the arms and wrist while enabling same or better usage of computers.
21	Among SCI patients, the most common body parts used to operate the ADs are neck, shoulders, arms and elbows. The most pain and fatigue caused after prolonged use was to the arms and wrists.	
22	Current users of AD are most unsatisfied with its dimension, weight and durability.	These attributed should be in the attention of the platform's designers since they were reported as creating dissatisfaction by assistive device users.
23	The most important aspects of ADs among SCI patients are comfort , durability, effectiveness and easy to use.	These attributed should get the most attention from the platform's designers since they were reported as the most important by assistive device users.
24	For SCI patients, the three most important attributes are: Independent operation, ease of use, non- invasiveness and productivity.	
25	Of the SCI patients who don't use a computer, most of them do not own a computer and say they don't need one, although mentioning some difficulties in operating them and in finding good assistive devices.	In case the platform could ease computer operation, some patients who do not use computers at all would be able to start using them.
26	Most of the patient do not miss any computer functions they could do prior to their disease or the did not use a PC before.	According to this, there is no need to replace old functions and patient may be open to learn new things.
27	Of the patients who miss computer application they used prior to their disease, most of them miss playing games.	A nice addition to the platform would be The ability to play games.
28	Most of the patients are positive toward using an AD based on mental commands.	The platform should be easy to use the have a training program.
29	Of the patients who were positive toward using an AD based on mental commands,	

	most of them stated they preferred it to be easy and with a training program.	
30	The patients believe that a mental command based AD could enable them to better move the cursor and/or use the keyboard and to preform various computer activities.	
31	The patients were generally positive towards using the special head glasses for computer operation. When asked to detail, the patients mainly conditioned their use with ease of use and comfortability.	The platform should be easy to use and comfortable

In addition to the above table, the following are a few important points to be considered: (1) Most patients indicate the their social life is normal or little affected; (2) Most of the patients indicate that their mobility outdoors is not affected or little affected by their disability; (3) Most of the patients are positive toward using an AD based on eye movements; (4) Of the patients who detailed about using an AD based on eye movements, most of them were cautious and conditioned their use of it with trying it first; (5) The patients believe that an eye tracking based AD could enable them to perform various computer activities; (6) The patients were generally positive towards using an EEG recording device. Although, when asked to detail, most of them were skeptical, expressed concerns and conditioned their use.

4 CASE SCENARIOS AND USER INTERACTION DESCRIPTION

The goal of this Section is to provide a set of scenarios that entail the usage of the computer through eye-gaze and mental commands. The motivation behind these scenarios is to capture the actual needs of our end-users in undertaking a full computer task and serve as inspiration for the design and implementation of the prototype interface applications – to be developed under WP5. In this respect, the presented scenarios cover three frequent computer tasks that have been chosen to also facilitate MAMEM's overarching objective "to integrate people with disabilities back-into society by endowing them with the critical skill of authoring and sharing multimedia content". These tasks consists in: a) searching on the web, b) navigating and posting on facebook, and c) generating slides for a presentation using multimedia content. Finally, we conclude this section by presenting a set of elements for basic human-computer interaction using your eyes and mind, as inspired by the presented scenarios. These elements will be further extended at a later stage of the project, as part of WP3 and WP5.

4.1 Searching on the web

Mrs. Sharon Levi is 34 years old. She suffered from a spinal cord injury 16 years ago while serving in the military. The injury occurred during a jeep ride collision which caused the jeep to turn over. As a result, she was suffered for a complete injury in the c4 vertebra and lost all movement ability from the neck down. A few years after the injury she met her husband and today they live together in an adapted apartment they recently bought. She has a professional caregiver living with them, who takes care of her. She receives support from social security and from the ministry of defence. At the moment, Sharon is a student at the university. She goes there three times a week, her professional caregiver being her driver. During classes she sits in class on her motorized wheel chair with her laptop in front of her. In order to operate it, she has a typing stick, with a rubber end, she uses to move an upside down mouse and to push the keyboard. She had tried several assistive devices in the past but realized that the current method was the most useful one for her, although typing is very slow and after a while her neck and jaw hurts and she gets exhausted. To be able to learn for tests she tapes classes and hears the tapes again at home, yet with this method she cannot write personal notes for herself. Her studies are very important for her since before them she spend all her time at home and felt lonely and bored. Also, using the computer from home to create meaningful relationship using social networks, proved to be too hard and exhausting.

Sharon decides to search for scientific journal articles for a class project she is doing with two other partners. She asks her caregiver to position her near the computer, attach the electrodes and to put on the MAMEM cap and eye-tracker, and to turn on the computer. Once the PC is turned on and the operating system starts, the OS senses that the cap and eye-tracker are attached, and automatically opens the customized MAMEM overlay software for calibration. After a few minutes of calibration by asking the user to follow a specified position on screen for few seconds, the platform is ready for use. She uses the gaze tracker to open the Facebook messenger program and to contact her work group. Her work group members greet her and they all immediately start discussing what journals they must

find. Using the virtual keyboard and the enlarged character focus area, Sharon manages to move the cursor and create text much faster and easier than before. The group agrees to search simultaneously so Sharon opens the internet browser and uses the MAMEM platform to go to the journal articles search page. She enters the keywords of her search and the search page returns several articles. Using her gaze, she quickly scans the articles and finds a few that seem suitable. She downloads them and shares them with her team partners. They all read the articles together, discuss them using the messenger and decide to select two of them for the project. Her partners compliment Sharon since she was the one who found the suitable articles first. They set a virtual meeting later to continue working, so after conversation ends, Sharon starts reading and summarizing one of the article.

4.2 Navigating and posting on Facebook

Mr. Giannis V. is 28 years old. He has Duchenne and was diagnosed when he was 6. He lives with his widowed mother who is also his caregiver.

Giannis has attended the University in Athens and got his Economics degree. He is on a motorised wheelchair and requires round the clock care. He has very limited movement in his hands, wrists and fingers, and has had great difficulty operating his laptop until now. His hobbies which include movie watching, music and social media are almost exclusively dependent on computer use. As his condition progressed the use of a computer became increasingly difficult and he has never found an assistive device to meet his needs until he found MAMEM, a friend of his read about it on Facebook and told him.

He has just finished the MAMEM training and is very excited with its potential.

He wants to go online to see what the rest of the world is up to and feel a part of that world. He calls his mother who puts his MAMEM cap and eye-tracker on and makes sure that they sit comfortably, and turns the laptop on and leaves the room.

Windows 10 starts and immediately senses the MAMEM and opens the MAMEM software. Calibrating needs only a few minutes and Giannis is ready to go online. Using his mind to open Facebook and YouTube, he proceeds with his eye movements to scroll through the latest song videos, occasionally selecting some to listen to. Having found one song that he likes very much, he uses a combination of eye and mind steps he has been trained to do and copies the YouTube link, then goes to the Facebook tab, pastes the link, uploads it and shares it with his friends. It doesn't take long and the "likes" start to appear on the notifications. Every time this happens, Giannis uses the MAMEM to scroll back up and check on who liked his posts. This is the highlight of his day. He uses MAMEM to pick a smiley emoticon and post is as a comment under his song. More likes follow. He navigates back to the YouTube tab to find another song.

4.3 Presentation slides generation using multimedia content

Mr. John K. is a retired civil engineer suffering from Parkinson's disease (PD). He has severe tremor on both hands, with moderate bradykinesia and rigidity. He is not responding to treatment satisfactorily and for this reason he has significant difficulty in his activities of daily living. He has been using his PC for more than 15 years, but the last two years he has

serious problems with the key board and the mouse and he had depended on his son's help in in order to send e-mails or navigate the web or create PowerPoint presentations.

Mr. K is the vice president of the Parkinson's disease Association and tomorrow is going to present a talk for the public Awareness Day for Parkinson's disease at the City Hall. Mr. K wishes to make it as attractive and comprehensible as possible and for this he plans to include pictures and short videos in his slides. His son has helped him to choose four short videos from the PD Association archive showing members of the PD patient's Association in action and he has already transferred them to the video file of his PC. His personal pictures file contains many photographs showing PD patients in various stages of the disease and he wishes to include some of them in his slides in order to show to the public different aspects of a PD patient's life. Recently Mr. K has started using a special assistive system that helps him to overcome his difficulties with the computer using his eyes and mind. Using this assistive system Mr. K. can operate his computer again with considerable ease now.

He adjusts the MAMEM cap and eye-tracker with a little help from his wife and turns his computer on. Once turned on, the MAMEM software automatically starts and Mr. K is ready to build up his presentation. He uses gaze control to open the PowerPoint application.

The first slide is the title slide but he needs ten more so he clicks on the tool bar on "new slide" and selects a slide with title and multimedia options. He repeats the process until he has the desired number of slides. He needs to choose a certain theme for the background of his slides so he moves the cursor with his assistive device on the tool bar and using his gaze he clicks on "design". A number of background options appear and he clicks on the first one, which is his favorite and he has used it before. Now all his slides have a theme and he clicks on the title slide to insert a title for his presentation .He prefers to use "word art" font, so he moves the cursor to "insert " on the tool bar and clicks. He chooses "word art" and then using the virtual keyboard types "Parkinson's disease: Our Journey in life" .He thinks that a title in diagonal position would be more interesting and using mental command of imaginary left hand movement to rotate the text in the left direction until it reaches the diagonal position. Then he moves his cursor on the tool bar and clicks on "picture" in order to insert the logo of the Parkinson's disease Association. He clicks on the logo picture from his file then "insert" and the PD logo appears on his title slide. Then he proceeds to slide two .He types a title on his virtual keyboard using gaze command and he inserts a photograph from his archive as previously described .This photograph includes a fellow PD patient who does not want to appear in public. He clicks "crop" button to cut off the unwanted part of the picture. In the third slide he wishes to include a short video showing PD patients dancing at the annual Parkinson's disease. He clicks on the video icon on the screen and opens the video file. He uses gaze to select the desired file and clicks to insert video on slide. He uses the virtual keyboard to type with mental command a short title. In the same way he creates all his slides inserting photographs or videos .Finally he clicks using gaze command on "file"-"save as" and saves his presentation on his desktop.

4.4 User interaction with MAMEM application platform

The scenarios have described the limited ability of users due to severe SCI, PD, and NMD diseases. MAMEM platform would provide easy interaction capabilities to such users, so that they can operate various computer applications and accomplish their desired tasks. Eye

movements and cognitive thoughts would be the primary interaction mechanism between the user and the application platform.

The scenarios have discussed the usage of popular applications such as browsing, search, Facebook etc. by patients according to their needs. However, new interaction mechanism brings new challenges to operate these applications, e.g., touch-based interaction on smart phones and tablets have been successful phenomena due to its customized app design and functionality. Similarly, MAMEM would cater the novel formalism of Eye and Mind based interaction, i.e., to provide an optimized application interface so the patients could perform various operations more intuitively. To provide easy initial access, MAMEM platform present various applications icons on the desktop screen, and the movement of user eyes would primarily emulate the mouse pointer on computer screen. The operation to select and open a particular application is equivalent to click events of a conventional mouse, which the MAMEM user could perform via the gaze intensity/threshold. Figure 8, shows an example of three different states of user attention over an icon. At first, there is no user attention on the icon, in the second state user's gaze is on the icon coordinates for a very short duration, the third image (with completely filled icon surface) showcase that the user looked at the icon for a considerable period of time. This time threshold could be used as a click event, e.g., to open a messenger/browser application discussed in SCI scenario.

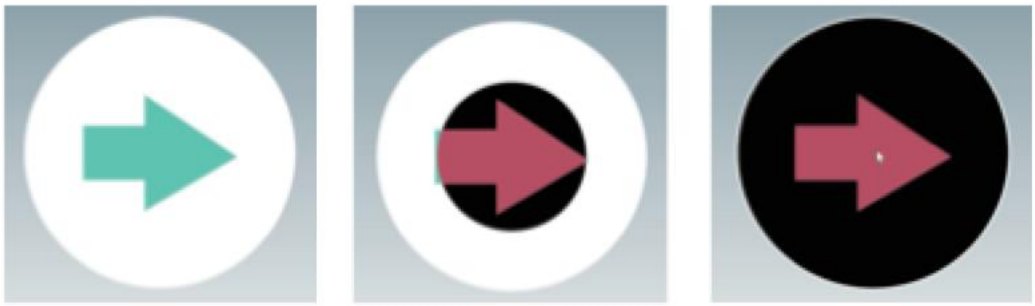


Figure 8: Gaze duration over an icon

Once the user has opened a particular application of interest, the customized interface helps them to perform various functions via eye/mind based interaction. Figure 9 shows the hypothetical example of browser application that would be effectively controlled via eye movements of the patients. Such an interface provide an overlay of self-explanatory buttons which goes beyond the conventional menu-based functionality to assist gaze based interactions to perform operations like select, click, zoom, scroll, etc. For example in Figure 9, user's current gaze attention is on the scroll down button (highlighted at the lower panel of the overlay interface), hence the duration of user's gaze could controls the scroll down event of the Web page.

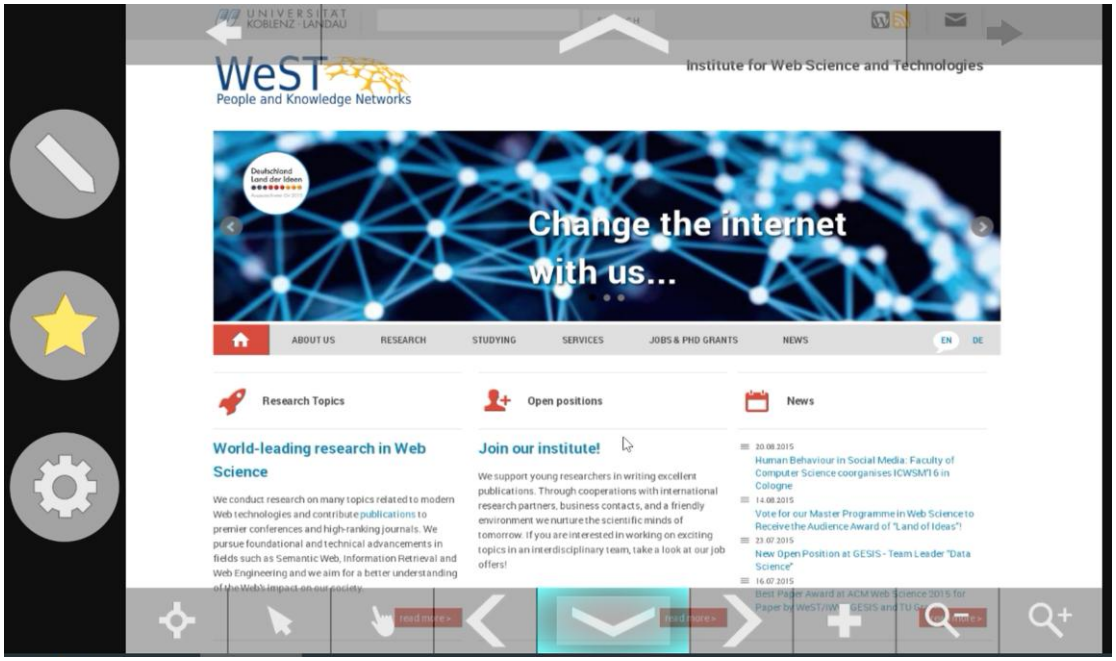


Figure 9: Customized MAMEM overlay on browser application

In addition to the functional overlay, MAMEM applies intelligent text input, and personalized representation techniques to provide easy access to the desired information. For example in Web search scenario when user intends to type a search keyword, a keyboard layout appears on the search query box, where the character focus area enlarges based on user attention for the easier selection of characters (Figure 10). Moreover the system helps autocompleting the keyword based on the language dictionary and personal keyword history (e.g., in case of SCI scenario, for the scientific keyword to find journal article). The presentation of search results is also adapted to provide more detailed information of the individual result snippets, additionally when the user attention is on a particular result; the other results fade away for quicker overview to relevant results.

Figure 10: Character selection

Similarly other applications such as Facebook, YouTube, PowerPoint (described in NMD and PD scenarios) implies the customized MAMEM layout and functionality for easy end user interaction. Moreover, MAMEM provide the multi-model interaction framework, i.e., to be able to switch to other modes of interaction, for example if the patient is tired to control the interface buttons via eye movements, he could activate mental commands to select specific buttons and functions (e.g., in the PD scenario when user wants to rotate the Title diagonally, he could use mental command of imaginary left hand movement to rotate the text in the left direction).

5 CONCLUSIONS

The main outcome of this document has been the elicitation of the requirements for MAMEM system that have been derived by interviewing a number of patients and care-givers through a set of questionnaires and by analysing the collected answers. This list of requirements (Section 3.6) complements the ones derived in D6.1 [1] and together they form the full list of requirements for the envisaged software.

Apart from the requirements, in this document we also present an outline of the pilot trials, as well as a set of measures for assessing their outcomes. In particular, we foresee splitting each trial in two phases, so as to allow the subjects to initially get acquainted with the use of the platform and then run the full trial measuring also the impact achieved on their status of social integration.

Finally, the last outcome of this document is a set of case scenarios that have been provided to illustrate the needs of our end-users in performing regular computer operation tasks. The motivation for these case scenarios is to serve as inspiration for the design and implementation of MAMEM's prototype interface applications. Finally, a pre-view on how to adjust some of the basic interface elements in order to facilitate human-computer interaction through eyes and mind, has been also included in this document.

6 REFERENCES

[1] D6.1 - Clinical requirements for the MAMEM platform for each of the patient cohort, MAMEM Consortium, August 2015. url: http://www.mamem.eu/wp-content/uploads/2015/09/D6.1_Clinical_requirements_Final.pdf

[2] Armitage, P., Berry, G., & Matthews, J. N. (2008). Statistical methods in medical research. John Wiley & Sons.

[3] Sheskin, D. J. (2003). Handbook of parametric and nonparametric statistical procedures. crc Press.

[4] D4.1 - Report on the middleware architecture and technical requirements, MAMEM Consortium, November 2015. url: http://www.mamem.eu/wp-content/uploads/2015/09/D4.1_Architecture_Final.pdf

[5] Paralysis Resource Centre, **http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453403/k.CDCA/Spinal_Cord_Injury.htm#**

[6] Hoehn, M. M., & Yahr, M. D. (1998). Parkinsonism: onset, progression, and mortality. Neurology, 50(2), 318-318.

[7] Demers, L., Ska, B., Giroux, F, & Weiss Lambrou, R. (1999). Stability and Reproducibility of the *Quebec User Evaluation of Satisfaction with assistive Technology* (QUEST). *Journal of ehabilitation Outcomes Measurement,* 3(4).

7 Appendix A - Questionnaires for patients and for care givers

7.1 SCI patients Questionnaire in English

Multimedia **A**uthoring and **M**anagement using your **E**yes and **M**ind

H2020-ICT-2014 - 644780

Computer use habits, difficulties and needs questionnaire

Table of content

Rational for questionnaire:

The purpose of this questionnaire is to assess the computer use habits, difficulties and needs of subjects with spinal cord injury (SCI) under the demand of the first milestones of the MAMEM project.

Another issue regarding the questionnaires is the need for open and closed questions. The closed questions are designed to collect data appropriate for quantification and statistical analysis and the open questions are designed not to limit the subjects with their answers.

Since an appropriate questionnaire design to answer the specific study questions does not exist in the literature, some parts of the questionnaire were obtained from existing questionnaires and some were created specifically for the MAMEM project objectives.

Questionnaire structure:

The questionnaire is based on three parts. First is the demographic & clinical information section. The second is designed to assess the computer related habits, environment and difficulties. The last part consists of open questions targeted to collect data regarding the needs, missing functions and demands of improvements that the subjects have from the current system and/or assistive device they are using.

Instructions for the interview:

The questionnaire should be filled by a research assistant interviewing the subject. All questions should be answered according to the order of their appearance. Some questions have specific instructions for the interviewer. These are italicized and appear in parenthesis below the question. When answering an open question, the interviewer should try to recap the subjects' remarks and summarize them in a few words.

IMORTANT – an interview can start only after an informed consent form has been signed by the interviewee.

Chapter I

Demographic and clinical information

a. Demographic information

Subject code: _____

(*Instructions to interviewer: create the code like this: SCI -#- XX.*

 # - according to participation order, XX – according to the first letters of the subject's first and last name. Make sure you match the subject's code to his/hers real name in a separate coding form. Subject's real name will be kept in the coded list together with the informed consent by the PI of each site according to privacy regulations)

Date:	Age:	Gender:
_____	_____	Male \ female
Single \ married \ Divorced \ widower	Number of children: _____	Ages of children: _____ _____
Educational years: _____	Occupation: _____	If employed: Full time \ partial
Hours employed per week: _____		

b. Clinical information

1. Diagnosis: (Neurological level of injury (NLI) & American Spinal Cord Injury association – (ASIA) impairment scale (AIS) (International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI).
   (Instructions to interviewer: consult with MD/medical records)

_____

2. Reason of SCI:
   Traumatic:

☐ Sport

_____

☐ Assault
☐ Transport
☐ Fall
☐ Other:_____

Non-traumatic:

☐ _____

3. Years with SCI: _____

4. Are you in a motorized wheelchair? Yes / No

5. How many hours per day (approximately) do you spend in bed?

6. For how long have you been in a rehabilitation ward / day care ward, if any?
   _____

7. Please specify the financial support (e.g. medical insurance) you are provided with, in order to address your disease).
   (Instructions to interviewer: only name the major sources of income)
   _____

8. In which of the following parts of the body do you present partial or complete immobility/numbness?

	Tongue	Jaw	Neck	Shoulders	Arms	Elbows	Wrists	Fingers
Complete								
Incomplete								

9. **If you own and use a PC, can we take pictures or short videos of your computer workspace while you are using it? (This will be shared only with the research team. In case the pictures or videos will be shared beyond the research team, your face will be blurred out.)** **Yes / No**

Chapter II

Computer habits, working environment and difficulties

a. Computer use habits

1. How is your social life affected by your disability?

☐ My social life is normal.
☐ There is no significant effect on my social life apart from limiting energetic aspects, such as dancing.
☐ My social life is restricted and I do not go out as often.
☐ My social life is restricted to my home.
☐ I have no social life and feel lonely.

2. Have you any kind of hobby or recreational activity? Yes /No

3. If yes, please specify: _____

4. How is your mobility outdoors affected by your disability?

☐ I travel frequently for needs / pleasure.
☐ I travel sometimes.
☐ I travel very rarely and only when there is an absolute need.
☐ I cannot travel and must stay home.

5. Of the following systems, which do you own?

☐ Desktop computer
☐ Laptop computer
☐ Tablet
☐ Smartphone

6. If you own more than one, which one do you use the most? _____

7. Do you use a PC? Yes / No
(Instructions to interviewer: if the subject does not use a PC – even if he/she owns one - go straight to chapter III.)

8. If so, how many hours (approximately) a day do you use it? _____

9. How many years of experience do you have using a computer?
_____

10. Please indicate your main uses of your computer system and the three most important ones:
Instructions to interviewer: can choose more than one; mark an x next to the important three uses)

Social participation (Facebook, forums, etc.)	

Productive activities (writing, editing, etc.)	
Study (on-line courses, articles, etc.)	
Games	
Recreation (movies, music, crossword puzzles, blogs, etc.)	
Communication (email, Skype, etc.)	
Activities of daily living (purchases, payments, bank, etc.)	
Information (Wikipedia, governmental sites, news, maps, etc.)	
Other: _____ _____	

11. Please indicate the main applications you use and the three most important ones:
Instructions to interviewer: can choose more than one; if chosen, name the main application the subject use; mark an x next to the important three)

Internet browser: _____	
Email client:_____	
Word processor:_____	
Audio/video/image applications:_____	
Spreadsheets (e.g. excel):_____	
Computer games:_____	
Presentation software:_____	
Programming/database:_____	
Media editing applications:_____	
Other: _____ _____	

12. Which operating systems do you work with?

☐ Microsoft Windows
☐ Unix / Linux
☐ Apple MacOS

13. How does computer use contribute to you in the following aspects?

	1- not important at all, 5- very important)	Please indicate the three most important aspects (*mark an x next to the aspects*)
Interpersonal interactions and	1 2 3 4 5	

relationships		
Close, intimate relationships	1 2 3 4 5	
Educational attainment	1 2 3 4 5	
Work and employment status/potential	1 2 3 4 5	
Participation in desired community, social and civic activities	1 2 3 4 5	
Autonomy and self-determination (making decisions)	1 2 3 4 5	
Fitting in, belonging, feeling connected	1 2 3 4 5	
Emotional well-being	1 2 3 4 5	
Overall health	1 2 3 4 5	

b. Difficulties

1. Do you have difficulties performing the following on the computer system which you are using? (*Instructions for interviewer: If a category is chosen, ask the subject to briefly specify what kind of difficulties*):

☐ Identifying the cursor on the screen
_____

☐ Moving the cursor on the screen
_____

☐ "Clicking" with the cursor
_____

☐ "Double clicking" with the cursor
_____

☐ Selecting and dragging, resizing windows
_____

☐ Zooming / Panning
_____

☐ Using the keyboard _____

☐ Identifying the letters on the keyboard
_____

_____

☐ Typing with the keyboard
_____

☐ Using two keys at the same time
_____

☐ Reading the words on the screen
_____

☐ Understanding how to use the assistive device software
_____

☐ Opening a file on the computer
_____

☐ Picking an item from a list or menu
_____

☐ Navigating the directory structure
_____

☐ Perform a search on the computer or on the Web
_____

☐ Browsing/Navigating the internet
_____

☐ Other:
_____

2. Fill up the following table:

		How difficult is it for you? (1- very difficult, 5- very easy)
How do you create a text on the computer and how easy it is? (*More than one option can be chosen*).	Keyboard	1 2 3 4 5
	By vocal dictating (a machine or a person)	1 2 3 4 5
	By touch	1 2 3 4 5
	Pointer and virtual keyboard	1 2 3 4 5
	Other : _____	1 2 3 4 5
How do you point on the screen and how easy it is? (*More than one option can be chosen*).	Mouse	1 2 3 4 5
	Keyboard	1 2 3 4 5
	By touch	1 2 3 4 5
	Assistive device: _____	1 2 3 4 5

	Other _____	1 2 3 4 5

c. Description and evaluation of the current working environment:

1. Computer type:
☐ Stationary
☐ Portable

2. Computer location:
☐ On a desk
☐ Mounted on an arm
☐ Wheelchair tray
☐ Other: _____

3. Positioning while using the computer:
☐ Sitting on an armchair
☐ Sitting on special armchair
☐ Sitting on wheelchair
☐ Sitting on motorized wheelchair
☐ Standing
☐ Laying
☐ Other:_____

4. Common operating location/s:
☐ Home
☐ Work
☐ Coffee shops
☐ Other: _____

5. How does the current physical condition affect the following computer use aspects?
(*Instructions for interviewer: This question inspects the effect of the specific working environment in which the computer is operated, i.e. armchair/wheelchair/bed, desk, etc.)*:

	No effect	Mildly	Moderately	Substantially	Completely	Not relevant
Comfort	1	2	3	4	5	
Independence	1	2	3	4	5	

Satisfaction	1	2	3	4	5	
Pain	1	2	3	4	5	
Speed of operation	1	2	3	4	5	
Fatigue	1	2	3	4	5	
Accuracy of operation	1	2	3	4	5	
Endurance	1	2	3	4	5	
Effectiveness	1	2	3	4	5	
Ease of use	1	2	3	4	5	
Enabling privacy	1	2	3	4	5	

d. Description and evaluation of assistive device/s

1. Do you use any assistive device for computer access (apart or instead from a standard keyboard and mouse)? Yes / No
   (*Instructions for interviewer: if the subject does not use an assistive device, skip to chapter III*)

2. If so, what device/s?
   (*Instructions for interviewer: can choose more than one, please specify brand*)

☐ Typing Stick:_____
☐ Mouthstick:_____
☐ Chin joystick:_____
☐ Mouth joystick:_____
☐ Gaze tracker: _____
☐ Head tracker :_____
☐ Speech recognition:_____
☐ Mounting system (arms and support):_____
☐ Other:

_____
_____

3. How long have you been using this device/ these devices (*months/years*)?
   _____
   _____

4. Where was this assistive device fitted for you?

☐ During rehabilitation
☐ Vocational/assistive-device counseling center
☐ Private/commercial company
☐ Other:
_____

5. Have you used a different assistive device in the past? Yes / No

6. If so, what kind of assistive device and why did you stop using it?
_____
_____

7. Please indicate which body parts do you use to operate the assistive device, and try to assess the pain and/or fatigue it causes after prolong use, if any:
(*Instructions for interviewer: can choose more than one*)

	Pain level after prolonged use (1 – no pain at all, 5 – extreme pain)	fatigue level after prolonged use (1 – no fatigue at all, 5 – extreme fatigue)
Tongue	1 2 3 4 5	1 2 3 4 5
Eyes	1 2 3 4 5	1 2 3 4 5
Jaw	1 2 3 4 5	1 2 3 4 5
Neck	1 2 3 4 5	1 2 3 4 5
Shoulders	1 2 3 4 5	1 2 3 4 5
Arm	1 2 3 4 5	1 2 3 4 5
Elbows	1 2 3 4 5	1 2 3 4 5
Wrists	1 2 3 4 5	1 2 3 4 5
Fingers	1 2 3 4 5	1 2 3 4 5

Instructions for interviewer:

Sections 7, 8, 9 and 10 are 'borrowed' from widely used questionnaires and their structure was kept.

Please fill out the following questionnaires regarding the assistive device the subject uses.

If the subject uses more than one assistive device, the following questionnaires refer to all of them as one 'system' which is actually the combination of all of them.

However, in case some questions in the questionnaires are answered in regards to a specific assistive device, please add in writing which device, next to the answer.

8. Quebec User Evaluation of Satisfaction with assistive Technology

QUEST
(Version 2.0)

Technology device: _____

Date of assessment: _____

The purpose of the **QUEST** questionnaire is to evaluate how satisfied you are with your assistive device and the related services you experienced. The questionnaire consists of 12 satisfaction items.

• For each of the 12 items, rate your satisfaction with your assistive device and the related services you experienced by using the following scale of 1 to 5.

• Please circle or mark the **one number** that best describes your degree of satisfaction with each of the 12 items.

• D**o not** leave any question unanswered.

• For any item that you were not "very satisfied", please comment in the section ***comments***.

Thank you for completing the QUEST questionnaire.

ASSISTIVE DEVICE

How satisfied are you with,

1. The **dimensions** (size, height, length, width) of your assistive device?	1 2 3 4 5
2. The **weight** of your assistive device?	1 2 3 4 5
3. The **ease in adjusting** (fixing, fastening) the parts of your assistive device?	1 2 3 4 5
4. How **safe and secure** your assistive device is?	1 2 3 4 5
5. The **durability** (endurance, resistance to wear) of your assistive device?	1 2 3 4 5
6. How **easy** it is to use your assistive device?	1 2 3 4 5
7. How **comfortable** your assistive device is?	1 2 3 4 5
8. How **effective** your assistive device is (the degree to which your device meets your needs)?	1 2 3 4 5

SERVICES

How satisfied are you with,

9. The **service delivery** program (procedures, length of time) in which you obtained your assistive device?	1 2 3 4 5
10. The **repairs and servicing** (maintenance) provided for your assistive device?	1 2 3 4 5
11. The quality of the **professional services** (information, attention) you received for using your assistive device?	1 2 3 4 5
12. The **follow-up services** (continuing support services) received for your assistive device?	1 2 3 4 5

• Below is the list of the same 12 satisfaction items. PLEASE **SELECT THE THREE ITEMS** that you consider to be **the most important to you**. Please put an X in the **3 boxes** of your choice.

- ☐ Dimensions
- ☐ Comfort
- ☐ Weight
- ☐ Effectiveness
- ☐ Adjustments
- ☐ Service delivery
- ☐ Safety
- ☐ Repairs/servicing
- ☐ Durability
- ☐ Professional service
- ☐ Easy to use
- ☐ Follow-up services

9. How important are the following attributes of the assistive device for you?

	1- not important at all 5 - very important	Please indicate the three most important attributes (*mark an x next to the attribute*)
noninvasiveness	1 2 3 4 5	
setup time	1 2 3 4 5	
independent operation	1 2 3 4 5	
training time	1 2 3 4 5	
cost	1 2 3 4 5	
number of functions provided	1 2 3 4 5	
response time	1 2 3 4 5	
productivity	1 2 3 4 5	
Ease of use	1 2 3 4 5	
Aesthetics	1 2 3 4 5	
Enabling privacy	1 2 3 4 5	

10. Assessment of Comfort

	1- Extremely uncomfortable 7- very comfortable
Force required for actuation	1 2 3 4 5 6 7
Smoothness during operation	1 2 3 4 5 6 7
Effort required for operation	1 2 3 4 5 6 7

Accuracy	1 2 3 4 5 6 7
Operation speed	1 2 3 4 5 6 7
General comfort	1 2 3 4 5 6 7
Overall operation of input device	1 2 3 4 5 6 7

Chapter III

Needs, missing functions and demands of improvements

1. Why don't you use a computer?
   (*Instructions to interviewer: apply only to those who answered NO on question a.6 in chapter II*)

☐ I don't need to use a computer
☐ I don’t know how to use a computer
☐ I don't have a computer
☐ I cannot find a good assistive device
☐ It is too difficult in my condition
☐ I don’t like computers
☐ Other : _____

2. If you could design your own assistive device for computer use or improve an existing one, what would it look like? What features would it have? If you chose to improve an existing one – how would you improve it?

   Please detail:
   _____

   _____

   _____

3. What operation of the computer you used to do prior to the disease, that you can't do now, you miss the most, if any?
   (Instructions to interviewer: ask this question only those who still use a computer or stopped using the computer due to disease. examples of operations: using the mouse, the keyboard, etc.)

   Please detail:
   _____

   _____

   _____

4. What computer applications were you using prior to your disease that you now can't operate (or find very hard to operate) and miss the most, if any?
   (*Instructions to interviewer: ask this question only those who still use a computer or stopped using the computer due to disease. if the subject hesitates, explain what is an application, e.g., Facebook, Word etc.*).
   _____

Please detail:

_____

_____

_____

5. Would you use an assistive device system based on mental commands? Yes/ No
(*Instructions to interviewer: if the subject hesitates, explain how such a system could function*).

Please detail:

_____

_____

6. What type of computer interaction do you think you could perform with an interface based on mental commands?

Please detail:

_____

_____

7. Would you use an assistive device system based on eye movements? Yes/ No
(*Instructions to interviewer: if the subject hesitates, explain how such a system could function*).

Please detail:

_____

_____

8. What type of computer interaction do you think you could perform with an interface based on eye-tracking?

Please detail:

_____

_____

9. Would you wear on your head an EEG recording device to facilitate controlling the computer with your thinking/mind? Yes/ No
(*Instructions to interviewer: if the subject hesitates, explain what a wearable EEG recorder looks like, e.g. how light it is*).

_____

Please detail:

_____

_____

_____

10. Would you wear on your head special glasses designed to facilitate controlling the computer with your eyes? Yes/ No
(*Instructions to interviewer: if the subject hesitates, explain how these glasses would look and feel like*).

Please detail:

_____

_____

_____

7.2 SCI patients caregivers Questionnaire in English

Multimedia **A**uthoring and **M**anagement using your **E**yes and **M**ind

H2020-ICT-2014 - 644780

Computer use habits, difficulties and needs questionnaire

Table of content

Rational for questionnaire:

The purpose of this questionnaire is to assess the computer use habits, difficulties and needs of subjects with spinal cord injury (SCI) under the demand of the first milestones of the MAMEM project. Here, the information will be provided from interviews with caregivers of SCI subjects.

Another issue regarding the questionnaires is the need for open and closed questions. The closed questions are designed to collect data appropriate for quantification and statistical analysis and the open questions are designed not to limit the subjects with their answers.

Since an appropriate questionnaire design to answer the specific study questions does not exist in the literature, some parts of the questionnaire were obtained from existing questionnaires and some were created specifically for the MAMEM project objectives.

Questionnaire structure:

The questionnaire is based on three parts. First is the demographic & clinical information section. The second is designed to assess the computer related habits, environment and difficulties. The last part consists of open questions targeted to collect data regarding the needs, missing functions and demands of improvements that the subjects have from the current system and/or assistive device their patients are using.

Instructions for the interview:

The questionnaire should be filled by a research assistant interviewing the subject. All questions should be answered according to the order of their appearance. Some questions have specific instructions for the interviewer. These are italicized and appear in parenthesis below the question. When answering an open question, the interviewer should try to recap the subjects' remarks and summarize them in a few words.

IMPORTANT – an interview can start only after an informed consent has been signed by the interviewee.

Chapter I

Demographic and clinical information

a. Demographic information

(Please note that the demographics of the interviewed person and subject he/she cares for are recorded separately in the following pages).

Subject code: _____

(*Instructions to interviewer: create the code like this: SCICG -#- XX.*

 # - according to participation order, XX – according to the first letters of the subject's first and last name. Make sure you match the subject's code to his/hers real name in a separate coding form. Subject's real name will be kept in the coded list together with the informed consent by the PI of each side according to privacy regulations)

1. Subject's demographics:

Date:	Age:	Gender:
_____	_____	Male \ female
Single \ married \	Number of children:	
Divorced \ widower	_____	
Educational years:	Occupation:	If employed:
_____	_____	Full time \ partial

a. You are: (please check the box)

☐ Professional Caregiver (i.e. nurse)
☐ Family member of the SCI patient

b. In average, how many hours per day do you take care of your patient?

_____

c. For how long have you been taking care of your patient (months):

_____

d. Besides taking care of the patient, do you have another occupation? Yes / no

e. If so, what is it, and how many hours per week are you engaged with this activity?

_____

_____

2. Subject's patient demographics:
(Instructions for interviewer: (1) in case the patient taken care by this subject also participated in this study – insert his/her code instead of the initials of the patient; (2) in case the subject is not certain on a particular item please indicate this)

Initials of patient *(first letters of the subject's first and last name)* _____	Age of patient: _____	Patient's Gender: Male \ female
Single \ married \ Divorced \ widower	Number of children: _____	Ages of children: _____ _____
Educational years: _____	Occupation: _____	If employed: Full time \ partial
Hours employed per week: _____		

b. Clinical information of the patient

(Instructions for the interviewer: in case the subject is not certain on a particular item please indicate this; if unknown, indicate "unknown")

1. Diagnosis: (*Neurological level of injury (NLI) & American Spinal Cord Injury association – (ASIA*) impairment scale (AIS) (International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI):

_____

2. Reason of SCI:

Traumatic:

☐ Sport
☐ Assault
☐ Transport
☐ Fall
☐ Other:_____

Non-traumatic:

☐ _____

3. Years with SCI: _____

4. Is your patient in a motorized wheelchair? Yes / No

5. How many hours per day (approximately) does your patient spend in bed?

6. For how long was your patient in a rehabilitation ward / day care ward, if any?

_____

7. Please specify the financial support (e.g. medical insurance) your patient is provided with, in order to address his/her disease).

(Instructions to interviewer: only name the major sources of income)

_____

8. In which of the following parts of the body does your patient present partial or complete immobility/ numbness?

	Tongue	Jaw	Neck	Shoulders	Arms	Elbows	Wrists	Fingers
Complete								
Incomplete								

Chapter II

Computer habits, working environment and difficulties

e. Computer use habits

14. How your patient's social life is affected by his/her disability?

☐ Social life is normal.
☐ There is no significant effect on social life apart from limiting energetic aspects, such as dancing.
☐ Social life is restricted and he/she does not go out as often.
☐ Social life is restricted to the home.
☐ He/she has no social life and he/she feels lonely.

15. Does he/she have any kind of hobby or recreational activity? Yes /no

16. If yes, please specify: _____

17. How your patient's mobility outdoors is affected by his/her disability?
☐ My patient can travel frequently for needs / pleasure.
☐ My patient can travel sometimes.
☐ My patient can travel very rarely and only when there is an absolute need.
☐ My patient cannot travel and must stay home.

18. Of the following systems, which does your patient own?
☐ Desktop computer
☐ Laptop computer
☐ Tablet
☐ Smartphone

19. If he/she owns more than one, which one does he/she use the most?

_____

20. Does your patient use a PC? Yes / No
(Instruction to interviewer: if the subject's patient does not use a PC – even if he/she owns one - go straight to chapter III.)

21. If so, how many hours (approximately) a day does your patient use it?

_____

22. How many years of experience (approximately) does your patient have using a computer?

_____

23. Please indicate your patient's main uses of his/her computer system and the three most important ones:
(*Instruction to interviewer: can choose more than one, mark an x next to the important uses*)

_____

Social participation (Facebook, forums, etc.)	
Productive activities (writing, editing, etc.)	
Study (on-line courses, articles, etc.)	
Games	
Recreation (movies, music, crossword puzzles, blogs, etc.)	
Communication (email, Skype, etc.)	
Activities of daily living (purchases, payments, bank, etc.)	
Information (Wikipedia, governmental sites, news, maps, etc.)	
Other: _____ _____	

24. Please indicate the main applications your patient use and the three most important ones:
(Instruction to interviewer: can choose more than one, if chosen, name the main application the subject's patient uses, mark an x next to the important ones)

Internet browser: _____	
Email client:_____	
Word processor:_____	
Audio/video/image applications:_____	
Spreadsheets:_____	
Computer games:_____	
Presentation software:_____	
Programming/database:_____	
Media editing applications:_____	
Other: _____ _____	

25. Which operating systems does your patient work with?

☐ Microsoft Windows
☐ Unix / Linux
☐ Apple MacOS

26. How does computer use contribute to your patient in the following aspects?

	1- not important at all, 5- very important)	Please indicate the three most important aspects (*mark an x next to the aspects*)

Interpersonal interactions and relationships	1 2 3 4 5	
Close, intimate relationships	1 2 3 4 5	
Educational attainment	1 2 3 4 5	
Work and employment status/potential	1 2 3 4 5	
Participation in desired community, social and civic activities	1 2 3 4 5	
Autonomy and self-determination (making decisions)	1 2 3 4 5	
Fitting in, belonging, feeling connected	1 2 3 4 5	
Emotional well-being	1 2 3 4 5	
Overall health	1 2 3 4 5	

f. Difficulties

3. Does your patient have difficulties performing the following on the computer system which he/she is using?
(*Instruction for interviewer: If a category is chosen, ask the subject to briefly specify what kind of difficulties*):

☐ Identifying the cursor on the screen
_____

☐ Moving the cursor on the screen
_____

☐ "Clicking" with the cursor
_____

☐ "Double clicking" with the cursor
_____

☐ Selecting and dragging, resizing windows
_____

☐ Zooming / Panning
_____

☐ Using the keyboard _____

☐ Identifying the letters on the keyboard
_____
_____

☐ Typing with the keyboard
_____

☐ Using two keys at the same time
_____

☐ Reading the words on the screen
_____

☐ Understanding how to use the assistive device software
_____

☐ Opening a file on the computer
_____

☐ Picking an item from a list or menu
_____

☐ Navigating the directory structure
_____

☐ Perform a search on the computer or on the Web
_____

☐ Browsing/Navigating the internet
_____

☐ Other:
_____

4. Fill up the following table:

		How difficult is it for him/her? (1-very difficult, 5-very easy)
How does your patient create a text on the computer and how easy it is? (*More than one option can be chosen*).	Keyboard	1 2 3 4 5
	By dictating (a machine or a person)	1 2 3 4 5
	By touch	1 2 3 4 5
	Pointer and virtual keyboard	1 2 3 4 5
	Other : _____	1 2 3 4 5
How does your patient point on the screen and how easy it is? (*More than one option can be*	Mouse	1 2 3 4 5
	Keyboard	1 2 3 4 5
	By touch	1 2 3 4 5
	Assistive device:	1 2 3 4 5

chosen).	_____	
	Other _____	1 2 3 4 5

g. Description and evaluation of the current working environment:

6. Patient's computer type:
☐ Stationary
☐ Portable

7. Patient's computer location:
☐ On a desk
☐ Mounted on an arm
☐ Wheelchair tray
☐ Other: _____

8. Positioning of the patient while using the computer:
☐ Sitting on an armchair
☐ Sitting on special armchair
☐ Sitting on wheelchair
☐ Sitting on motorized wheelchair
☐ Standing
☐ Laying
☐ Other:_____

9. Common operating location/s:
☐ Home
☐ Work
☐ Coffee shops
☐ Other: _____

10. How does the current environment affect the patients' following computer use aspects?
(*Instruction for interviewer: Answer this part regarding the working environment in which the computer is operated, i.e. armchair/wheelchair/bed, desk, etc.)*:

	No effect	Mildly	Moderately	Substantially	Completely	Not relevant
Comfort	1	2	3	4	5	

Independence	1	2	3	4	5	
Satisfaction	1	2	3	4	5	
Pain	1	2	3	4	5	
Speed of operation	1	2	3	4	5	
Fatigue	1	2	3	4	5	
Accuracy of operation	1	2	3	4	5	
Endurance	1	2	3	4	5	
Effectiveness	1	2	3	4	5	
Ease of use	1	2	3	4	5	
Enabling privacy	1	2	3	4	5	

h. Description and evaluation of assistive device/s

11. Does your patient use any assistive device for computer access (apart or instead from a standard keyboard and mouse)? Yes / No
    (*Instructions for interviewer: if the subject's patient does not use an assistive device, skip to chapter III*)

12. If so, what device/s?
    (*Instructions for interviewer: can choose more than one, please specify brand*)

☐ Typing Stick:_____
☐ Mouthstick:_____
☐ Chin joystick:_____
☐ Mouth joystick:_____
☐ Gaze tracker: _____
☐ Head tracker :_____
☐ Speech recognition:_____
☐ Mounting system (arms and support):_____
☐ Other:

_____
_____

_____

13. How long has your patient been using this device/ these devices (*months/years*)?
_____

14. Where was this assistive device fitted for your patient?

☐ During rehabilitation
☐ Vocational/assistive-device counseling center
☐ Private/commercial company
☐ Other:
_____

15. Has your patient used a different assistive device in the past? Yes / No

16. If so, what kind of assistive device and why did he/she stop using it?
_____
_____

17. Please indicate which body parts does your patient use to operate the assistive device, and try to assess the pain and/or fatigue it causes him/her after prolong use, if any:
(*Instructions for interviewer: can choose more than one*)

	Pain level after prolonged use (1 – no pain at all, 5 – extreme pain)	fatigue level after prolonged use(1 – no fatigue at all, 5 – extreme fatigue)
Tongue	1 2 3 4 5	1 2 3 4 5
Eyes	1 2 3 4 5	1 2 3 4 5
Jaw	1 2 3 4 5	1 2 3 4 5
Neck	1 2 3 4 5	1 2 3 4 5
Shoulders	1 2 3 4 5	1 2 3 4 5
Arm	1 2 3 4 5	1 2 3 4 5
Elbows	1 2 3 4 5	1 2 3 4 5
Wrists	1 2 3 4 5	1 2 3 4 5
Fingers	1 2 3 4 5	1 2 3 4 5

Instructions for interviewer:

Questions 7, 8 and 9 are 'borrowed' from widely used questionnaires and their structure was kept.

Please fill out the following questionnaires regarding the assistive device the subject's patient uses.

If the subject's patient uses more than one assistive device, the following questionnaires refer to all of them as one 'system' which is actually the combination of all of them.

However, in case some questions in the questionnaires are answered in regards to a specific assistive device, please add in writing which device, next to the answer.

18. Quebec User Evaluation of Satisfaction with assistive Technology

QUEST
(Version 2.0)

Technology device: _____

Date of assessment: _____

The purpose of the **QUEST** questionnaire is to evaluate how satisfied you are with your assistive device and the related services you experienced. The questionnaire consists of 12 satisfaction items.

• For each of the 12 items, rate your satisfaction with your assistive device and the related services you experienced by using the following scale of 1 to 5.

• Please circle or mark the **one number** that best describes your degree of satisfaction with each of the 12 items.

• D**o not** leave any question unanswered.

• For any item that you were not "very satisfied", please comment in the section ***comments***.

Thank you for completing the QUEST questionnaire.

ASSISTIVE DEVICE

How satisfied is your patient with,

1. The **dimensions** (size, height, length, width) of the assistive device?	1 2 3 4 5
2. The **weight** of the assistive device?	1 2 3 4 5
3. The **ease in adjusting** (fixing, fastening) the parts of the assistive device?	1 2 3 4 5
4. How **safe and secure** the assistive device is?	1 2 3 4 5
5. The **durability** (endurance, resistance to wear) of the assistive device?	1 2 3 4 5
6. How **easy** it is to use the assistive device?	1 2 3 4 5
7. How **comfortable** the assistive device is?	1 2 3 4 5
8. How **effective** the assistive device is (the degree to which the device meets the patient's needs)?	1 2 3 4 5

SERVICES

How satisfied is your patient with,

9. The **service delivery** program (procedures, length of time) in which your patient obtained the assistive device?	1 2 3 4 5
10. The **repairs and servicing** (maintenance) provided for the assistive device?	1 2 3 4 5
11. The quality of the **professional services** (information, attention) your patient received for using the assistive device?	1 2 3 4 5
12. The **follow-up services** (continuing support services) received for the assistive device?	1 2 3 4 5

• Below is the list of the same 12 satisfaction items. Please **select the three items** that you consider to be **the most important to your patient**. Please put an X in the **3 boxes** of your choice.

- ☐ Dimensions
- ☐ Comfort
- ☐ Weight
- ☐ Effectiveness
- ☐ Adjustments
- ☐ Service delivery
- ☐ Safety
- ☐ Repairs/servicing
- ☐ Durability
- ☐ Professional service
- ☐ Easy to use
- ☐ Follow-up services

19. How important are the following attributes of the assistive device for your patient?

	1- not important at all 5 - very important	Please indicate the three most important attributes (*mark an x next to the attribute*)
noninvasiveness	1 2 3 4 5	

setup time	1 2 3 4 5	
independent operation	1 2 3 4 5	
training time	1 2 3 4 5	
cost	1 2 3 4 5	
number of functions provided	1 2 3 4 5	
response time	1 2 3 4 5	
productivity	1 2 3 4 5	
Ease of use	1 2 3 4 5	
Aesthetics	1 2 3 4 5	
Enabling privacy	1 2 3 4 5	

20. Assessment of Comfort

	1- Extremely uncomfortable 7- very comfortable
Force required for actuation	1 2 3 4 5 6 7
Smoothness during operation	1 2 3 4 5 6 7
Effort required for operation	1 2 3 4 5 6 7
Accuracy	1 2 3 4 5 6 7
Operation speed	1 2 3 4 5 6 7
General comfort	1 2 3 4 5 6 7
Overall operation of input device	1 2 3 4 5 6 7

Chapter III

Needs, missing functions and demands of improvements

1. Why doesn't your patient use a computer?
   (*Instruction to interviewer: apply only to those who answered NO on question a.6 in chapter II*)

☐ He/she doesn't need to use a computer
☐ He/she doesn't know how to use a computer
☐ He/she doesn't have a computer
☐ He/she cannot find a good assistive device
☐ It is too difficult in my patient condition
☐ He/she doesn't like computers
☐ Other : _____

2. If you could design your own assistive device for computer use or improve an existing one, what would it look like? What features would it have? If you chose to improve an existing one – how would you improve it?

   Please detail:
   _____

   _____

   _____

3. What operation of the computer did your patient use to do prior to his/her disease, that he/she can't do now, you believe he/she miss the most, if any?
   (Instruction to interviewer: apply only to those who still use a computer or stopped using the computer due to disease. examples of operations: using the mouse, the keyboard, etc.)

   Please detail:
   _____

   _____

   _____

4. What computer applications was your patient using prior to his/her disease that he/she now can't operate (or find very hard to operate) and miss the most, if any?
   (*Instruction to interviewer: apply only to those who still use a computer or stopped using the computer due to disease. if the subject hesitate, explain what is an application, e.g., Facebook, Word etc.*).

   Please detail:
   _____

   _____

   _____

   _____

5. Do you think your patient would use an assistive device system based on mental commands? Yes / No
(*Instructions to interviewer: if the subject hesitates, explain how such a system could function*).

Please detail:
_____

_____

6. What type of computer interaction do you think your patient could perform with an interface based on mental commands?

Please detail:
_____

_____

7. Do you think your patient would use an assistive device system based on eye movements? Yes / No
(*Instructions to interviewer: if the subject hesitates, explain how such a system could function*).

Please detail:
_____

_____

8. What type of computer interaction do you think your patient could perform with an interface based on eye-tracking?

Please detail:
_____

_____

9. Do you think your patient would wear on his/her head an EEG recording device to facilitate controlling the computer with his/her thinking/mind? Yes/ No
(*Instructions to interviewer: if the subject hesitates, explain what a wearable EEG recorder looks like, e.g. how light it is*).

Please detail:
_____

_____

_____

_____

10. Do you think your patient would wear on his/her head special glasses designed to facilitate controlling the computer with his/her eyes? Yes/ No
(*Instructions to interviewer: if the subject hesitates, explain how these glasses would look and feel like*).

Please detail:

_____

_____

_____

8 Appendix B - informed consent form for patients and for care givers

8.1 Informed consent form in English

Informed consent form

I, the undersigned:

1. Hereby declare that I agree to participate in a clinical trial, as set forth in this document.
2. hereby declare that I have been informed by:

2.1) that the principal investigator (physician name): _____ received from the medical institution, the rights to study, within the meaning of the Public Health Regulations (Clinical Trials on humans law -1980).

2.2) that the clinical trial is conducted on the subject: The rehabilitation of the participation in the management of multi-media computer interfaces by monitoring eye movements and brain waves - questionnaires to identify needs, problems and applications.

2.3) that I am free to choose not to participate in the clinical trial, and that I am free to discontinue participation at any time In the experiment, all without compromising the right to receive the standard treatment.

2.4) that in the case of questionnaire completion - I may not answer all the questions in the questionnaire or some of them.

2.5) that are guaranteed to have my personal identity be kept secret by all those involved in the study and will not be published in any advertising, including scientific publications.

3. Declare that I was delivered detailed information about the clinical trial, according to the following topics:
3.1) General Background and importance of research. In order to develop better solutions for people with spinal cord injury (SCI) for usage of computers and participation in social networks, we must first identify the needs, difficulties and usage patterns of this population. To do this, we aim to ask this population, their family members and their caregivers to fill questionnaires. After passing these questionnaires, we will analyze the results and by using this information in the future, it will be possible to develop better solutions for people with SCI.

3.2) The purpose of the study. The purpose of the study is to identify the needs, difficulties and Uses of computer interface's (PCs, laptops, etc.) of people with spinal cord injury.

3.3) required from the participant in the study. The participants are asked to fill a series of short questionnaires.

3.4) anticipated duration of participation in the study. Filling out the questionnaires should take about half an hour.

3.5) the expected benefits to the participant or to others, as a result of the study. Identifying the computer interface's (PCs, laptops, etc.) needs, difficulties and Uses of people with spinal cord injury could help develop better solutions for them in the future.

3.6) inconvenience that may be caused by participating in the study. Not relevant.
3.7) this study does not include gathering information from a database.
3.8) other relevant information (as provided by the initiator of the experiment). None

4) Hereby declare that the above agreement was given voluntarily that I understood all of the above. In addition, I received a copy of this informed consent form, subject and date, duly signed.

5) With my signature on this consent form, I will allow the initiator of the clinical trial, the institutional Ethics Committee, the medical institution auditor and the Health Ministry direct access to my medical records, for the purpose of verification of the clinical trial methods and clinical data. This access my medical information will be made while maintaining confidentiality, in accordance with the laws and regulations of confidentiality.