COGAIN



# Eye Tracking Impact on Quality-of-Life The case of ALS Patients in Torino

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#### **Outline**



- Objective
- Methodology
- Experimental settings
- Case studies
- Quantitative results
- Conclusions



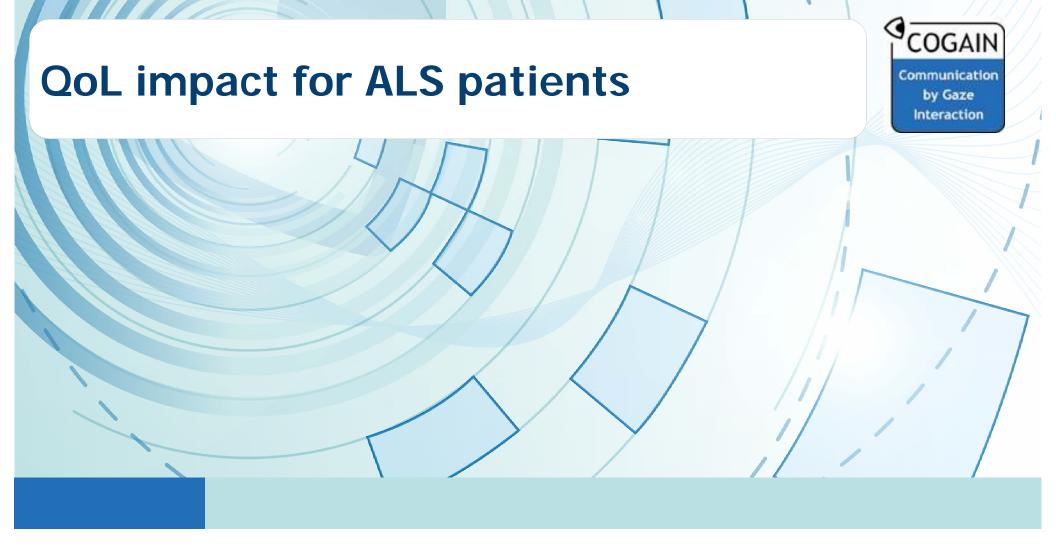
# Objective

# **Objective**



- To evaluate if and when eye tracking technologies have a positive impact on ALS patients' lives
  - Adopting Quality of Life assessment scales
  - Experimenting with off-the-shelf devices
  - Involving a large user base





# Methodology

# Methodology (1/2)



- Each patient uses an eye tracking system
  - For several consecutive days
  - In his/her own domestic environment
- Multi-disciplinary team
  - Neurologist
  - Psychologist
  - Speech therapist
  - Engineer

# Methodology (2/2)



- Three contacts during the lending period
  - Initial contact, training and evaluation
  - Mid-period check
  - Final evaluation



#### **Patients**



- Recruitment criteria
  - Unable to speech intelligibly
  - Able to understand the aim of the study
  - Able to give an informed consent
  - Basic to good level of computer literacy
- Various degrees of hand function impairment

#### Support team



- Neurologist
  - Selects patients
- Psychologist
  - Evaluates quality of life throughout the experimentation
- Speech therapist
  - Trains patients in eye tracking usage and related applications
- Engineer
  - Provides technical support and troubleshooting

# Initial meeting (1/2)



- Assessment questionnaires
  - Quality of life, using the Mc Gill Scale



SWLS, Satisfaction With Life Scale



Depression, with the Zung Depression Scale



Perception to represent a burden, with the Self-Perceived Burden Scale





# Initial meeting (2/2)



- Initial training to patient and caregiver on
  - Calibration and usage of the eye tracking system
  - Applications used in eye tracking mode
    - Writing
    - Communication
    - Internet
    - Windows
    - ... according to user's needs and interests





### **During the period**



- Hotline support with psycologist, speech therapist and engineer
  - Usability issues
  - Technical problems
- Mid-period call to check about progress or problems

# Final meeting

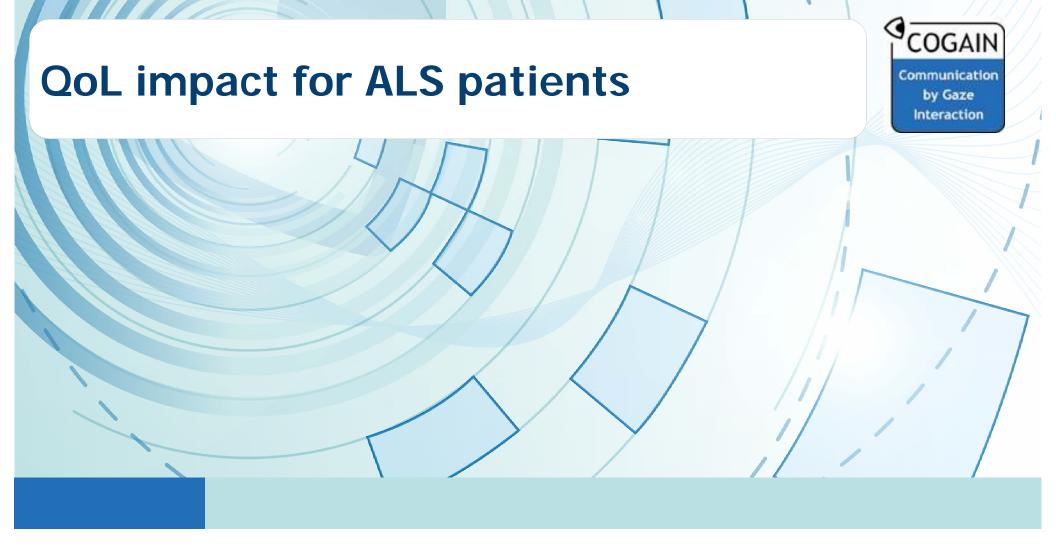


- Second round of assessment questionnaires
  - The same 4 scales as the initial meeting
  - The standard COGAIN questionnaire



A specific questionnaire focusing on qualitative aspects and feelings





# Experimental settings

# **Equipment**



- Eye Response Technologies' ERICA Standard System
- Assistive and Communication software
  - ERICA keyboard and mouse emulators
  - Sensory Software's The Grid
- Standard Windows and Internet applications
- Personalized software



# Study population (1/2)



- 16 patients
  - 12 men, 4 women
  - Age: 32 to 78 (average 45)
  - 7 patients are tracheotomized
  - 8 patients have PEG
  - 6 patients are anarthric and 7 have a severe disarthria

# Study population (2/2)



- All patients showed a strong interest in eye-tracking systems
  - Most of them had already looked for information about this technology

# **Experimentation period**



- Experiments from April 2006 to August 2007, still ongoing
- Each patient received the eye tracker for a one-week period



Example usage during the week



#### Case studies

#### Case number 1: Marco (1/2)



- Marco is 47 and lives in his house with his family
- Before the disease he was a traveling salesman
- Currently he uses a communication system with a computer and a foot switch



#### Case number 1: Marco (2/2)



- When he tried the Erica system he was very excited; he used a screen keyboard for communication and for sending emails quickly and easily
- Now he has a lot of problems with his current system because he has less and less movement on his feet
- He wants this system but he hasn't enough money; the Piemonte Regional Government denied him a grant

#### Case number 2: Paolo (1/2)



- Paolo is 52 years and lives with his wife
- He was and still is a web designer
- He currently uses two mouse devices, one for moving the cursor and the other for clicking



#### Case number 2: Paolo (2/2)



- He needs the eye tracker for his work, only, because he successfully uses labial movements for communication
- He uses many programs for his work, and tried them on the Erica system. The results were positive and he wants to buy the software and camera add-on to his computer
- In the past he tried the MyTobii system but he didn't like it because «it doesn't work well with web design programs»

#### Case number 3: Domenico



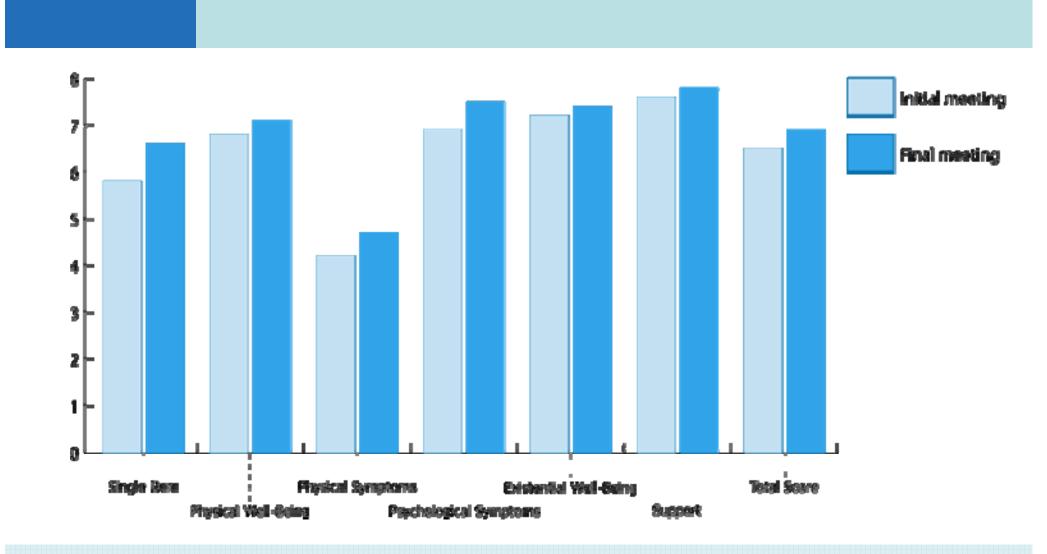
- Domenico is a young man, he lives with his wife
- He wants to try the ERICA system to speak with his 2-years old nephew
- ... and also to express his feelings with bad words
- When he tried ERICA finally he could speak with his nephew who could listen for the first time his "voice"



# Quantitative results

# Quality of Life (Mc Gill scale)

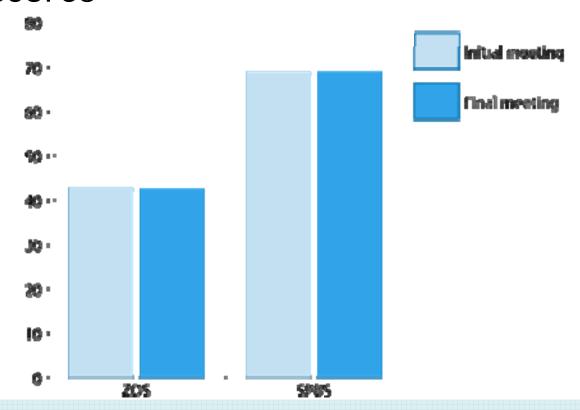




### Depression and self-estimated burden

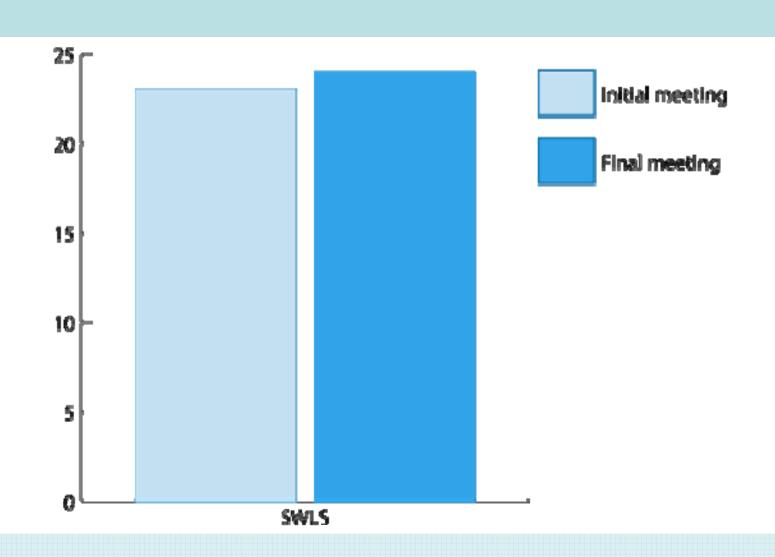


There were no significant modifications on depression and burden scores



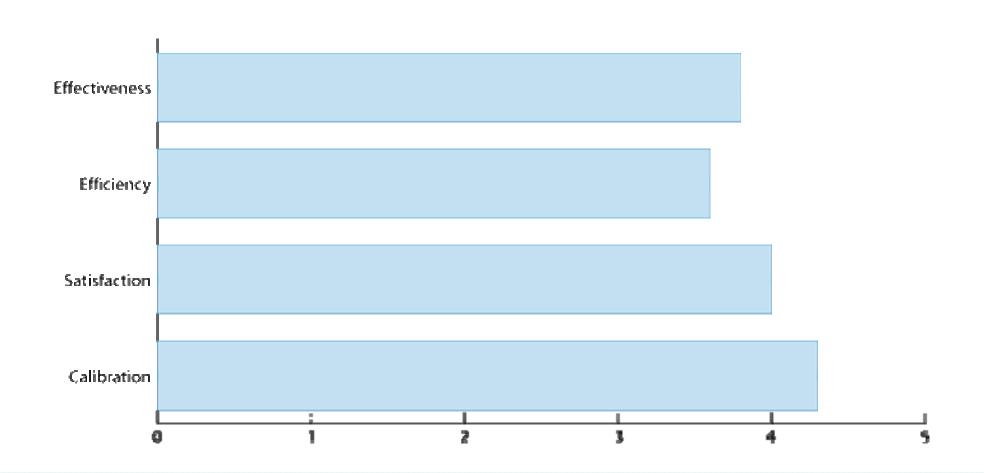
# **SWLS** (satisfaction with life scale)





# **COGAIN** questionnaire





# Patients feelings from the COGAIN questionnaire (1/2)



- Efficient and effective system, allows more complex communication, beyond the primary needs
- After calibration the user is independent in using applications (compared with Plexiglas tables)
- Users appreciated the dictionary for faster communication and the vocal synthesis

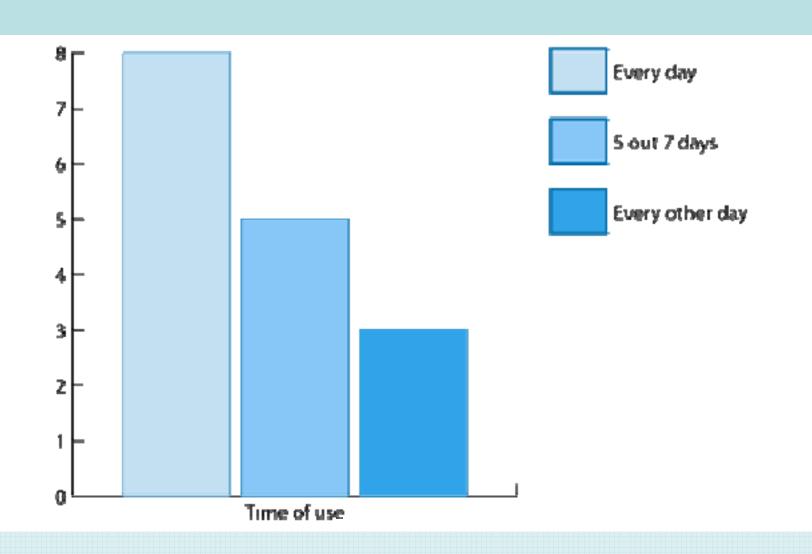
# Patients feelings from the COGAIN questionnaire (2/2)



- Difficulties in the calibration procedure, and this caused weariness and frustration before using the system
- Suggestions expressed by the patients
  - A device for maintaining the head in the correct position
  - Software for phone communication

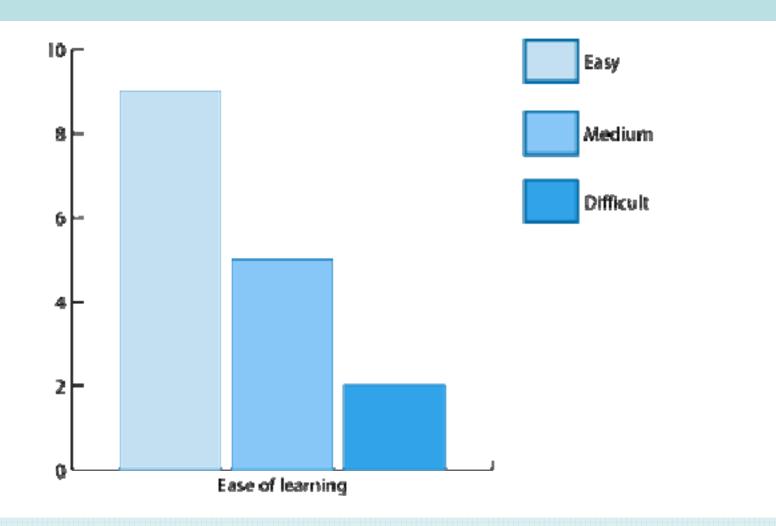
# Patients feelings: the Torino ALS center questionnaire (1/4)





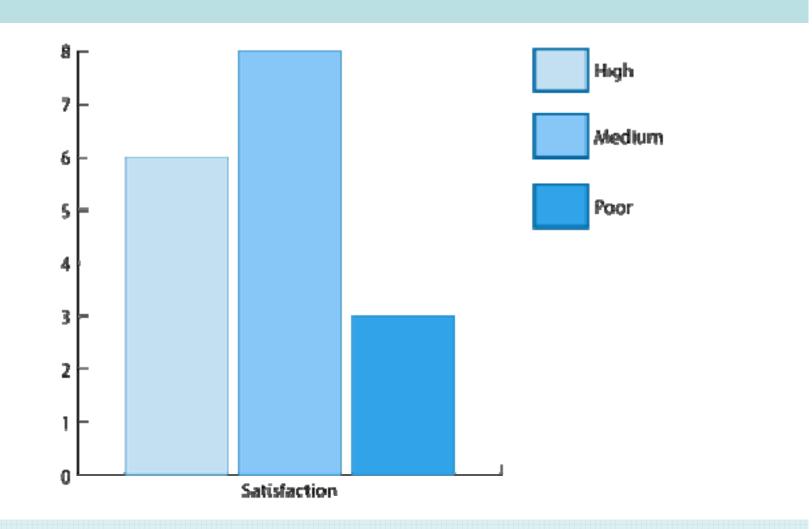
# Patients feelings: the Torino ALS center questionnaire (2/4)





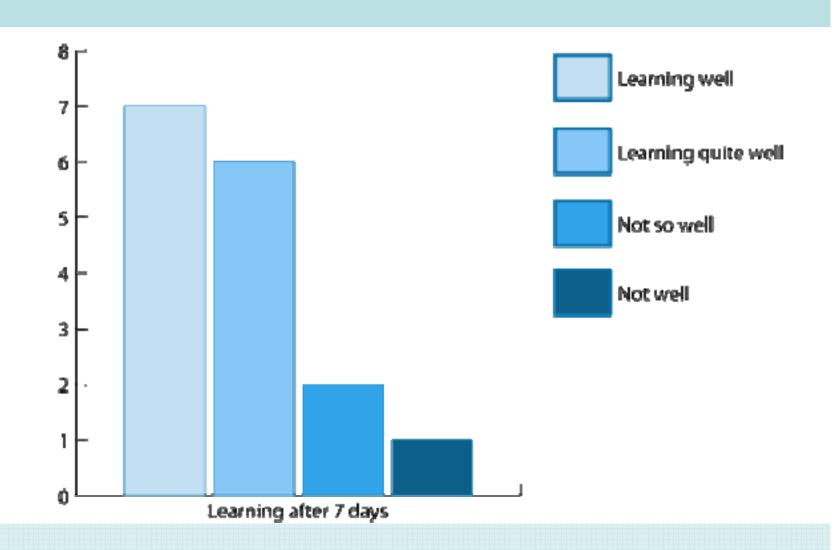
# Patients feelings: the Torino ALS center questionnaire (3/4)





# Patients feelings: the Torino ALS center questionnaire (4/4)







#### Conclusions

#### **Conclusions**



- The Erica system was generally well accepted and considered easy enough to be used by ALS patients with severe disability
  - No correlation with caregiver's motivations or patient's motivations
- Better acceptance from patients with worse clinical conditions
  - Eye tracking benefits are lower for patients with residual arm mobility

# Interesting findings



- Tracheomized patients had stronger motivation
- Due to two reasons
  - Anarthria represents the first motivation for communicating
  - Tracheotomized patients have better ventilation, therefore higher brain oxygenation, than patients with dispnea



### Local impact



Many patients tried to ask Piemonte Regional Government for a grant to buy eye-tracking systems but they had a negative answer

At least three patients found some associations that

helped them raising money

Now, these three patients regularly use an eye-tracking system for communication

#### **Future perspectives**



- Continuation of the experimental quality of life studies
- Analysis of work opportunities for ALS patients and spreading of the findings through associations and authorities
- Actions towards Piemonte Regional Government for political decisions concerning grants for eye tracking equipment

# **COGAIN Eye Control Hints and Tips**



- This presentation is part of the COGAIN Eye Control Hints and Tips packet
- For more information, visit
- www.cogain.org