

# Chapter 10

## The Users' Perspective

Various Authors

### 10.1 Introduction

Research subjects in the sciences are usually people who are spoken about and not asked to speak themselves. Their personal views are not part of their role within a study. From the scientific and technological point of view this might be reasonable. However, research subjects are often the first contact laboratory matter has with everyday life and the reality outside the lab. As average citizens these prime users of new technologies can display in advance the impressions, feelings, and ideas new gadgets will cause in a population. And in the case of projects working with a special selection of people, research subjects' opinions might be seen as insights into the opinions of their peer group and allow information to be gained regarding the overall acceptance, demand, and usability of a technology. The following statements are extractions from interviews held in 2011 in Switzerland, Italy, and Germany. They originate from people who have been involved in brain-computer interface (BCI) research and have had the opportunity to use and to try out BCI-based devices of different sorts. Some of them are stroke patients who worked with assistive technology designed to help them regain lost motor functionalities. Others are motor-impaired people who went through a BCI training program. Those who successfully trained were given the opportunity to test several BCI applications, among them a telepresence robot, writing software, and entertainment software. Participation was not a success for all of the participants: Not everybody from the first group noticed a therapeutic effect, and not everybody from the second group achieved control over the interface. However, all of them had personal experiences with BCI technology and have their stories about it. This chapter will give them a voice and let them tell their stories. Their answers and comments to a range of questions are reported as they were given, and not modified and not included in a theoretical frame. The only editorial adaptation we necessarily had

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Some anonymized information about the authors can be found at the end of the chapter; the editors contributed the introduction and compiled the answers.

to make is the selection of interesting statements and where necessary the anonymization thereof. We present the material in the order of the questions we used to make the participants talk. The answers are chosen to display the spectrum of answers on each topic. We like to say thank you to all the participants in our interviews and to all our colleagues who held these interviews in the different countries and languages.

## 10.2 Questions and Answers

### **What did you know about BCI technology before?**

Absolutely nothing. (13)

Before the experiment, nothing. (5)

I did not know about it, but I could imagine you can find devices that make life easier for people with disabilities. This did not seem impossible. (1)

I watched a TV show that was talking a little bit about this. (3)

Not that much, not that much. I knew that. . . I saw some documentary with some people who had an electrode in their brain to make a special device work. I never heard about non-invasive technology. (19)

What I know is enough, because I saw a lot of TV shows where they sometimes show how they move the brain through the scanner etc. So I was interested, I saw a lot, so I knew enough, but this thing I did, I'd never seen or tried. The study that was done here I had never done before. (4)

### **How well informed did you feel when you started participation in the BCI trials?**

I made sure I knew everything. (15)

Very well informed. (14)

My doctor informed me about everything, and every day I had a lot of questions for the EEG technician. (11)

I was well informed, but it was difficult to bring it into practice and also to truly understand the explanations. They were not easy for me to understand. (3)

Not really. I expected something more global and more oriented towards real life – and I practiced only moving left, right, and ahead. (1)

### **What did you expect from this technology?**

That it improves the life of anyone who is not independent. (19)

It may be good for people like me who have a disability and can no longer use their hands. (2)

I expected that it could help me in everyday life or help others. It is not fully developed at the moment, but I hope that it works to make things in life more quick and easy, of course. (7)

At first, I think, it was just the curiosity for the technology: to see what it looks like and what it is. (6)

For me, it was mainly to participate in a test and in something that could be useful for tetraplegics in general. Personally, as I have some mobility in the arms and a little in the hands, it was not directly useful for me, I think. (8)

My aim concerning this technology was that at the end I can by myself take a glass of water and drink from it, i.e. grasp the glass, bring it to my mouth, and put it down again. (18)

Well, not too much! I expected help, something that could add to the rehabilitation I already did. (17)

Well, I'm a guitar player. I'd like to play my guitar like before the stroke! I know it's so difficult but maybe this training can help in some way. (14)

I was hoping to bring things forward a bit and to provide help to those who might be in need of it. (9)

I expected this technology to succeed fully, and unfortunately this was apparently not the case. (4)

I expected a lot more but this was because I didn't know much about neural functioning! (12)

**After you were asked to participate in the studies, which were your motivations to agree? Why did you become a participant in the BCI study?**

First of all, I was curious about this study. And I wanted to see if I was able – if my brain was able – to give a command to a machine. (19)

To me it was very interesting and I wanted to discover the potentiality of my brain. (20)

The interaction between thought and technology has always interested me and I was very motivated for this reason. (7)

I wanted to discover whether I can think of something without making the movement. (2)

Out of curiosity, just to do something more, try to develop things. (9)

Because I was interested in seeing how you can make your brain work without the body being in movement. (10)

Well, my motivation for this study was... I'm actually an open person and have a good attitude and want to learn new things. (18)

Because I am interested in anything that is a little science, electronics, and other. I wanted to know exactly what is happening, what would happen, etc. (4)

Well, because I think it is interesting technology and it was fun to see what it is. Also later, well, there were exercises and it was nice and the atmosphere was very pleasant. So, this was the motivation. (6)

The training is quite boring, but I did it for science. (11)

I believe in the value of research and I think it is important to do something for it. (12)

I believe because I thought that it was important for me, for my hand, and for research too. (13)

I was hoping to be able to increase the use of my hand or otherwise to improve the movement in order to be as independent as possible. (15)

[...] in order to rehabilitate my hand, and I was happy to make my little contribution to science! (16)

The reason is also my health. I still have myotonic dystrophy and myopathy, and I have a problem in the muscles and, as I told myself, since I had problems with muscles, maybe one day it will be convenient for me to use it to move my legs or my arms or to move an object or the like, like vacuum cleaners that are remotely controlled now. (4)

All I wanted was to rehabilitate my left hand and given that BCI has no contraindications, I decided to participate. (17)

### **Can you describe what it is like to use a BCI-based device?**

They put a cap on our head, apply gel to make the contacts work well, and then you sit in front of a computer to control the system. In principle, that's it. (8)

They put a cap with electrodes on the head and then there is a small box that linked us to the laptop and then there are two laptops – one is connected to the [university] and the other we are working on. No, it's good it's clear it's weird to be at a computer with a cap on your head. (2)

It's a simple way to imagine, I can't explain better. (14)

It is just...imagination! (17)

It is a very strong stimulus! (15)

Funny! It's funny and helpful. (19)

Yes, it's a little science fiction, a little supernatural, a little magic indeed. (9)

It is really complicated to control a device via a brain-computer interface. I found it really demanding because one has to concentrate so much. (18)

### **How did you experience the whole procedure of using a BCI device with all its necessary preparations and efforts?**

Pretty good overall. (5)

Without problems. (10)

Very serene, therapists were very nice. Nothing bothered me in itself. (1)

Well, the stress is tolerable, actually it is not really stress, because I absolutely like to do it and I see it very positively. I'm totally motivated and it's really fun. (18)

I would not do it for all my life, but it was cool. (19)

Rewarding! But I expected it to be a little bit easier, because it is aimed at people with disabilities. (12)

Quite happily, even if it has been a little tiring for me. (15)

Some general discomforts but I overcame those discomforts: I'm talking about some little logistic discomforts like the transportation [...], washing hair after the session; the biggest discomfort was going out to do it. (20)

From the beginning, it is clear that it takes very, very long to install the system in the participants and there were some problems with the computers. It was not all good. (2)

[...] it was tiring: the cap, the electrodes, washing the hair each time...it was difficult for me. The training itself was relaxing! (17)

The cap was constricting. The gel was not very comfortable. The rest of the study needed a high level of concentration. It's not clear how to manage it. Besides this it was interesting like a new experience. (8)

Very annoying! I think it could be better if you can reduce it in some way. (11)

**Did you experience the technology as helpful and useful? If yes: How did you benefit from BCI use? If no: What kinds of problems did you face?**

Yes, after a few days I had a greater perception of my left hand, and I can use it in a more spontaneous way! (12)

Yes! The "illusion" of the movement of my own hand made me feel stimulated to continue the training. (13)

I appreciate the technology. I felt it to be useful for motor recovery. (15)

I had no visible physical improvements, so I don't know... (16)

It can, I think, provide assistance to people who are immobile in bed, who cannot move their arms, nothing at all. I think at this point it can be very useful. (5)

I think it will become very useful, maybe not directly for me. The cap is quite restrictive and not very practical, not very pleasant to use. But for people who have absolutely no arm mobility it is very useful. I think it should be further improved, but it is something really useful. (8)

I discovered myself to be clever. The stroke didn't slow me down. Problem: prolonged concentration. (20)

Yes, I think that this technology provides support and even though I was not able to make it work, I think it will help others. (7)

I think that the experience in general was helpful and useful to understand what is possible to do with a brain, with a brain at an interface. (19)

I found that it was a good exercise in concentration. Yes, in that sense it helped me. I was a little frustrated because I could not do it well. (10)

[...] it's all about concentration, it required a lot of concentration, but it is not really a problem for everyone. (9)

No, I had no problem, but at the same time I had no improvement. (11)

The problem I faced was that it was not adapted to my disability. Yes, it allowed me to discover that thinking of something could move an arrow on the screen. (2)

It is indeed very important that it works well, because without that the utility I could gain for myself, I do not see. [...] it should work, in my opinion, much better than it works here, every time I came here was a failure. (4)

**Have you been generally satisfied with your experiences or did you experience disappointments? Please specify how far your expectations were met or frustrated**

I'm completely satisfied. (15)

Ok, well, fully satisfied because I saw something interesting. (6)

Satisfaction: to be able to control it despite the stroke. (20)

As I had no expectations beforehand, and under no circumstances did I involve myself personally in the success or failure of the study, I had no feeling for or against this approach. I did it with good faith and according to what I can do. (1)

Yes, I am satisfied. I thought it was very interesting to develop that system, to achieve control over something only by thought, this was very interesting.

Again, the cap could be improved. One might find another system that is less restrictive. But for the other things, no, I think it is a really useful technology. (8)

I enjoyed seeing that I could participate a little, but I could have done differently, perhaps if I could have practiced more at the beginning of the experiment. (3)

I feel no frustration or disappointment; it has been fun to participate even if sometimes it has been a little boring! (11)

I felt no disappointment because my expectations were not that high. (16)

Satisfied, I could measure if I could do it, I am . . . I had a good impression. The negative is that because of my illness I could not continue to the end. (2)

Disappointed, yes, because I would have liked to contribute something, as I said before. But not personally, not for myself, not really. Rather concerning the advancement of the project, yes. Otherwise no. It was a good experience. (9)

Well I'm a little disappointed because I had no visible improvement. . .but I already knew that would not be easy. (13)

At first I was happy because it worked good, there were some interesting aspects.

And later I was disappointed. Generally, now after all these sessions, I'm a little disappointed and I do not know if I'll come back, because that's up to you. (4)

**Was there a specific act that you were able to do that surprised or astonished you?**

No, no. (1)

No, it does not surprise me, there are opportunities with new technologies. (3)

A little, yes, I was surprised to be able to follow through. (5)

To imagine the movement while holding the movement itself, I never thought of being able to do it. (12)

Yes, I was surprised and amazed. I'm a little on another planet when with you. (10)

Yes, my own performance, I did not think I would be that good. (13)

I was surprised by the success of the training, I was so good. (15)

It's already amazing just to see that the mind can control a computer. (7)

Yes, I didn't expect to open and close my hand with my brain, just by using my imagination. (17)

What astonished me was the level of sensation I had when I imagined a movement, for example standing up or standing on tiptoes, because the movement is a movement which I did not know at all but which seemed to work well in my case. (6)

**Did you experience a difference between using the BCI device and using more common tools or devices? If yes, how did you experience the difference?**

I have not yet experienced any difference between the use of the BCI and the use of usual devices. (18)

Traditional is easier. [If so, how did you experience the difference?] Philosophically. (5)

The others don't need electrodes. The BCI cannot be used outside. (20)

Yes, it's a big difference, especially in terms of speed. And I think it's an additional option, it would be very useful for some things that are not possible with other tools. (7)

Yes, I see the BCI system requires a high level of concentration. If there were only such things . . . functional keys, it would be easier for me. (8)

**How did you experience the role of your brain while using a BCI-based device?**

It was the star of the project! (11)

Protagonist! (12)

I did everything with my brain. (17)

My brain was very stimulated by BCI. So it plays an important role, the brain is the core of the study. (15)

In any case, I challenged my brain and the machine did not bother me. And the fact that it did not really work did not cause any inconvenience. I trust in my brain. (1)

It was the first time I was using my brain in that way, it was very interesting. (3)

I was a little disappointed by my brain as it couldn't do what I expected it to do. (4)

Well, I think it went well. I think my brain did not explode, so it's ok. (6)

I think it made my brain work and I have experienced this role well. (7)

One has to try not to have negative thoughts, not to think only to control the system.

Once again, it requires a lot of effort of concentration. And from one day to the other it is not always easy. There are days that are better than others. (8)

I had the feeling of being schizophrenic sometimes because I was using my brain as a slave. (19)

I had the impression that it makes me a little tired. (10)

**Did you have the impression that you and the BCI-based device together form some kind of functional unit? Or, to put it in other words, did you experience the BCI device, the moment you used it, in any sense as part of you?**

Yes, when I saw the fake hand opening and closing I felt it like a natural movement of my real hand. (13)

Yes, I felt like one with the tool. (15)

I do have the impression that the device and I are a unit; and the control actually works very well. (18)

I felt we were one entity when I could visually see what was happening on the computer, advancing, retreating and trying to put the arrows where needed. (3)

I think it was a part of me, yes [pause] because my brain was involved in it . . . did you read something by Isaac Asimov? (19)

No I would not say it was like this, then. But of course, we should try to make it a whole. (7)

No, I never got to this because of the technology; the lack of cybernetic interfacing is a practical obstacle. (12)

No, I never felt one with the BCI, it was just a way to work on my affected hand. (14)

No, never. It was me, I learned to use a tool for rehabilitation; the tool was just a way to reach rehabilitation. (11)

No, it is a communication device, it is not me! (20)

Not at all. (5)

**While using the BCI device, could you directly concentrate yourself on the work you tried to do? In other words: Could you forget about the technology and the learned strategies of using it and just do what you wanted to do?**

Yes, after a lot of training. (19)

Generally yes. It was fine. Well, I think I was a little tired at the end of the sessions, so it was a bit more difficult. But in general I think I managed more or less well to focus on work and exercise – more than on the technology. (6)

At first it was difficult. And a little later, I managed to focus well enough but I could be bothered with things quite easily. But overall I managed to focus well. The longer it lasted the more I was able to focus. [. . .] the more time passed the less I was bothered by the technology, the less I thought about it. (7)

Yes there have been times when the technology and I were linked. (11)

Yes, yes, I think I got it. There maybe was one time or another when I had negative thoughts, but overall I succeeded. (8)

Yes, definitely because I managed to concentrate well. (3)

No, actually the tool has the central role in the training and its role is central until the end of the entire training. (15)

No, it's not so easy to forget the technology and just focus on the hand. For me it's impossible. (14)



**Imagine that the device you tested were to become a standard solution that is broadly used in everyday life. Could you imagine some specific problems that might result from such use?**

No, I do not see any. (5)

Good question! Maybe that you become dependent or feel frustrated because the device is not developed further. (19)

That a patient must have a cap on his head all the time? It seems to me very complicated to set it up. Perhaps with sensors implanted throughout the year?

I do not see much alternative. (1)

Yes, there are problems, bugs, and the computer program would have to be adapted to many disabilities. (2)

No, I don't. ...but you have to find a way to reduce the preparation time. (16)

I see the device as rather tedious for everyday use. (18)

The big problem I see is the use of the cap, which is not easy to apply. You have to have somebody for people with problems with their hands. I could not do it myself. Otherwise, for my personal use, I do not think it is really useful. (8)

Yes, having to wash the hair every time after the daily training! (12)

**Do you think there should be special formal regulations concerning the use of BCI technology in general or the device you used in particular?**

No, I do not see any reason. (7)

No. I use an electric chair in the street: It was difficult at first, but now I do not care. (1)

No, not of law but a brochure that clearly explains how to use it here. (2)

Yes, there must be mechanisms in place fitting with this new technology. (3)

Yes, I think that it is important to respect the patient [...]. (17)

Now if we talk about other technologies in addition, like the lie detector or whatever, then I'm sure there must be laws. But for what I did here, there are no safeguards necessary because it does not influence the brain. It is we who need to influence the machine. I do not see, as long as it is not more like maybe some stuff like brainwashing or other [...]. (4)

Since I'm a techie, I tend to say: we go and see how it works! It's cool. Eventually it's true that we can perhaps imagine some trouble that could happen. I don't know enough about how it works but I guess the data transmitted to the computer can probably be interpreted. I don't know but it's something that could potentially be possible in the future [...]. (6)

Perhaps it is necessary to secure the system like wireless LAN in order to prevent hacking. We have to await further development to see whether this is really possible. (9)

**Now, when the studies are over, do you feel relieved? Or do you regret that the studies are over?**

I'm sorry that it is completed. (7)

I'm sorry that they are, I'm a little disappointed. I may have preferred to continue.

But, hey, I'm not going to kill myself if I don't go on. I have other occupations and I can focus on them, but I'm disappointed. (4)

I already regret that the studies are over because I'm always expecting that I can discover something new. (19)

I enjoyed participating in the study and I'm not relieved that they are finished. (18)

Well, yeah, it was, it was cool, it's not a relief that I finished. When I finished it was clear that I wished, I would still do it, have fun with it. Because it was really nice.

So when it was over I was a little disappointed but only a little, I'd say, because it was cool. (6)

I'm happy to have participated, and I hope my contribution will help someone else. (16)

Given the time I have, I am relieved not to go on with the study because I'm a very busy man. (1)

I would say that I was a little relieved to get to the end; it's a question of time and fatigue. (5)

Well, yes I feel relieved but I'm glad to have participated. (17)

I'm relieved because I'm going home. (11)

I think I will feel relieved! Sorry for you but I have to go home. (14)

I'm untouched. (12)

**If you look back to your participation, which are your personal conclusions or comments?**

I think the simple ways on the table were not adequate. I repeat that I have found that the magnitude of the study was not according to what I expected. (1)

I would advise you to do it for all patients and adapt this special technology to the needs of each one. (11)

I would have liked to do more exercises in the beginning to see if I could pass on to the computer the feelings of the brain. I stayed a little bit stuck. (3)

I think there might have been more explanations and especially more training sessions. But since this is not the case, overall I'm glad I participated and I hope others will succeed and will make this project succeed. (7)

As for the comments with the helmet and the pads: I hope in the future development we will not be obliged to carry the whole system in order to make it work. This is my personal conclusion. (5)

I liked it because I wanted to see where I stood. For it is not easy to interact with the computer by thought. (2)

I think this is a very interesting system, which still requires some principle improvements: again, I refer to the cap. But for complete tetraplegic patients who have no movement in the arms, I think it is a technology that is very useful. (8)

It was interesting. If there was other stuff like this, I would probably also be a candidate to participate. (4)

It was a good experience! From a human and technological point of view! (20)

## Authors

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2. male, age 29, spinocerebellar ataxia with polyneuropathy, cervical dystonia, rubral tremor, and anemia, BCI training only
3. female, age 61, Landouzy-Dejerine myopathy, BCI training only
4. male, age 50, Steinert myopathy, BCI training only
5. male, age 59, C5 lesion, tetraplegia, BCI training and prototype testing
6. male, age 29, spinal amyotrophy type II, BCI training and prototype testing
7. male, age 52, C5 lesion, tetraplegia, BCI training only
8. male, age 41, C6 lesion, complete tetraplegia, BCI training and prototype testing
9. male, age 32, incomplete AIS B, tetraplegia, BCI training only
10. female, age 70, shoulder-hand syndrome (complex regional atrophy) following fracture of the left wrist, BCI training only
11. male, age 59, subacute stroke patient
12. male, age 40, subacute stroke patient
13. female, age 71, subacute stroke patient
14. male, age 54, subacute stroke patient
15. male, age 67, subacute stroke patient
16. male, age 59, subacute stroke patient
17. female, age 67, subacute stroke patient
18. male, age 40, C4/C5 lesion, tetraplegia, BCI training and prosthesis control
19. male, age 43, C5/C6 lesion, incomplete tetraplegia, BCI training and prototype testing
20. female, age 47, major impairment (ischemic stroke, right hand movement residual), BCI training and prototype testing