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A note on ethical aspects of BCI

Pim Haselager^{a,*}, Rutger Vlek^{a,1}, Jeremy Hill^{b,2}, Femke Nijboer^{c,d,3}^a Donders Institute of Brain, Cognition and Behaviour, Centre for Cognition, Radboud University, Montessorilaan 3, 6525 HR Nijmegen, The Netherlands^b Max Planck Institute for Biological Cybernetics, Dept. Schölkopf, Spemannstraße 38, 72076 Tübingen, Germany^c Institute for Medical Psychology and Behavioral Neurobiology, Gartenstraße 29, 72074 Tübingen, Germany^d Department of Neuroengineering, Fatronik – Tecnia, Paseo Mikeletegi 7, 20009, Donostia – San Sebastián, Spain

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ABSTRACT

This paper focuses on ethical aspects of BCI, as a research and a clinical tool, that are challenging for practitioners currently working in the field. Specifically, the difficulties involved in acquiring informed consent from locked-in patients are investigated, in combination with an analysis of the shared moral responsibility in BCI teams, and the complications encountered in establishing effective communication with media.

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1. Introduction

Brain-Computer Interfacing (BCI) is a challenging and fast growing field of research, holding great promise for fundamental research and the development of a variety of applications, ranging from neurofeedback and neurostimulation to neurocontrol of actuators (e.g. for the purpose of communication and movement). Like other new and promising developments in research areas like genetics, neuroscience and AI, BCI provides cause for considering its potential philosophical, ethical and societal consequences. Especially over the last few years, there has been an enormous growth in publications in the area of *neuroethics* (Farah, 2005, 2007; Fins & Shapiro, 2007; Freeman, 2007; Fukushi, Sakura, & Koizumi, 2007; Glannon, 2007; Greely, 2007; Illes, 2007, 2005; Roskies, 2007; Wolpe, 2007). Various definitions of neuroethics have been offered, one of the more straightforward ones being the following: “a discipline that aligns the exploration and discovery of neurobiological knowledge with human value systems” (Illes, 2007, p. 537). For BCI, the ‘alignment’ mentioned in the definition specifically concerns the practical application of

neurobiological knowledge, with a focus on the development of technologies that mediate (facilitate, enhance) that application. Within neuroethics, many different topics could potentially be relevant to BCI: mind-reading and privacy; mind-control and the suppression/stimulation of (un)wanted impulses; personhood and the ownership of mind; elective enhancement and social stratification, to name but a few. Undoubtedly this list could be expanded. However, in this paper we will not try to give a comprehensive review of these major topics of neuroethics, but restrict ourselves to a domain that we think is of particular relevance to practitioners currently working in the field of BCI: the process of acquiring informed consent from locked-in patients. We will also discuss two problems that are not often mentioned but that nonetheless can have substantial impact on acquiring informed consent: sharing moral responsibility in BCI teams, and maintaining effective communication with the media. Adequately shared responsibility in interdisciplinary BCI teams is a prerequisite for good communication with patients and the presentation of BCI research within the public media is an important factor in the creation of reasonable expectations about the possibilities and limits of BCI.

Earlier this year Clausen observed that BCIs “pose ethical challenges, but these are conceptually similar to those that bioethicists have addressed for other realms of therapy.” (e.g. liability, side effect, ‘policy of normalizing’, risks) (Clausen, 2009). Moreover he suggested that bioethics is well-prepared to deal with the issues that arise with BCI technologies. We agree, and therefore, throughout this paper, we will attempt to extract valuable insights from bioethical discussions of issues encountered in clinical research in general, as well as from practical experiences of medical teams such as Intensive Care Units.

* Corresponding author. Tel.: +31 0 24 3616148; fax: +31 0 24 3616066.

E-mail addresses: w.haselager@donders.ru.nl (P. Haselager),r.vlek@donders.ru.nl (R. Vlek), jez@tuebingen.mpg.de (J. Hill),fnijboer@fatronik.com (F. Nijboer).¹ Tel.: +31 0 24 3615458; fax: +31 0 24 3616066.² Tel.: +49 7071 601 547; fax: +49 7071 601 552.³ Tel.: +34 943 005500; fax: +34 943 005511

2. BCIs for locked-in patients

The locked-in syndrome is often ill-defined in BCI research and, between varieties of the locked-in syndrome, different ethical issues regarding informed consent may be present. The classical locked-in syndrome (LIS) can be defined as lack of voluntary motor control except for vertical eye movements and blinking, combined with preserved consciousness, whereas if any other remnants of voluntary motion other than those mentioned are present, one should consider the condition as an *incomplete* LIS (Bauer, Gerstenbrand, & Rumpl, 1979). A total lack of voluntary motor control, including all eye movements with intact cognition and sensory processing, is referred to as *total or complete* LIS. (Bauer et al., 1979; Kübler & Birbaumer, 2008).

Several studies have shown that incomplete LIS and classical LIS patients can use a BCI based on the electroencephalogram (EEG) for communication (Birbaumer et al., 1999; Kübler et al., 2001, 2005; Neuper, Müller, Kübler, Birbaumer, & Pfurtscheller, 2003; Nijboer et al., 2008; Sellers & Donchin, 2006; Vaughan et al., 2006). However, only two patients were able to use the BCI independently for the purpose of private communication without BCI experts being present at their home (Kübler, Nijboer, & Birbaumer, 2007; Vaughan et al., 2006). In addition, as long as reliable muscular functions such as eye movements or a minimal thumb movement are available, muscular based communication systems (e.g. with an infrared eye movement sensor) are probably more efficient than BCIs at their current level (Neumann & Kübler, 2003).

Furthermore, to this date no complete locked-in patient has been able to use a BCI (Kübler & Birbaumer, 2008). Possible reasons for this are published in Birbaumer (2006), Hill et al. (2006) and Kübler and Muller (2007). Invasive Brain-Computer interfaces, which measure brain signals directly from the surface of the brain or from within the brain may provide better signal quality and dimensionality, in contrast to the above mentioned non-invasive EEG-based BCIs (Huggins, Levine, Graimann, Young Chun, & Fessler, 2007; Kübler & Muller, 2007; Leuthardt, Schalk, Wolpaw, Ojemann, & Moran, 2004). The electrocorticogram (ECoG) is recorded by placing an array of millimetre-scale electrodes epidurally or subdurally on the surface of the cortex inside the skull, whereas intracortical electrodes penetrate the grey matter and measure spike or field potentials from small numbers (tens, hundreds) of cells. ECoG-based BCIs can provide accurate control over a computer cursor in as little as 21 min in healthy subjects (Leuthardt et al., 2004). However, a complete LIS patient, who had been implanted with an array of ECoG electrodes did not achieve BCI control (Hill et al., 2006). Encouraging results come from the studies performed by Cyberkinetics Inc. with Brown University, in which tetraplegic patients are shown to be able to operate simplified computer interfaces via neural spiking recorded by intracranial electrodes (Hochberg et al., 2006; Kim, Simeral, Hochberg, Donoghue, & Black, 2008). Significantly, this included one incompletely locked-in patient with amyotrophic lateral sclerosis (Kim et al., 2008). Despite these and other promising results, there is no current out-of-the-box BCI application that might be offered to LIS patients. It is clear, however, that as soon as a BCI application effectively helps an individual who participated in a BCI study, one can speak of the BCI as not only a research tool, but also as a therapeutic intervention to maintain health and quality-of-life.

Regarding clinical research in general, the 35 articles of the Declaration of Helsinki (World Medical Association, 1964/2008), constitute a widely-accepted set of ethical rules governing work with human subjects. Emanuel, Wandler, and Grady (2000) have grouped the ethical requirements of clinical research under the following diverse headings: social and scientific value, scientific validity, fair subject selection, favourable risk-benefit ratio,

independent review, informed consent, and respect for subjects. Naturally one can expect to encounter BCI-specific issues in many if not all of these categories (in addition to some of the issues unique to BCI, as mentioned above). In the next section, we will focus specifically on the process of acquiring informed consent.

3. Informed consent

In medicine, informed consent to an intervention is the process, dialog and invitation for the fully informed patient to participate in choices about his/her healthcare (Liesegang, 2007). Faden and Beauchamp defined informed consent as the autonomous act by a patient or research subject to expressly permit a professional person to perform a medical action on a patient or to include a person in a research project (Faden & Beauchamp, 1986). It implies that a discussion has to take place about basic elements, including the nature of the decision procedure; reasonable alternatives to the proposed intervention; the relevant risks, benefits and uncertainties related to each alternative; assessment of the understanding of the patient; and the acceptance of the intervention by the patient (Chenau, Merlani, & Ricou, 2007; Liesegang, 2007). For participation in research, the basic elements of informed consent are required. In addition, the patient should be informed about the purpose of the research, the expected duration of the subject's participation, a description of the procedures to be followed and an identification of all the procedures which are considered experimental. Moreover, the patient should receive a statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained.

For consent to be considered informed, patients and their relatives must have a realistic picture of the procedure being offered. During initial patient contact, expectations of the BCI should be clarified and misunderstandings carefully resolved: for example, do the patient and family erroneously believe that BCI is a *treatment* for a disease, or for the locked-in state itself (Neumann & Kübler, 2003)? Do they understand the difference between the pathology of cases they may have heard about in the media, and their own? A stroke patient should have rather different expectations of BCI than a spinal-cord-injury patient whose cortex is essentially intact, for example. Do the patients realize the extent of media exaggeration and gloss, or are they under the mistaken impression that BCI has already allowed communication by people who cannot otherwise communicate at all? Researchers should take all necessary steps to verify the patients' understanding of the issues discussed, perhaps by asking "comprehension" questions if appropriate, or by having patients give their assessment of risks and probable benefits. If the risks of the procedure under consideration are high, then to what extent is a patient's decision based on reason, and to what extent on desperation, given that no known treatment offers hope? The latter mode of thinking can only weaken the ethical basis of consent. Is it possible to establish what level of pain or risk the patient would *not* accept?

Then, there is the question to what extent the patient is *able* to signal their consent. Some locked-in patients may not be able to express consent adequately without the help of others to serve as interlocutors and may be declared *incompetent*. Incompetence is a legal term and refers to a juridical declaration that a person cannot manage his or her affairs (Terry, 2007). In this case, a legal representative of the patient is appointed, and informed consent must be obtained from this person (World Medical Association, 1964/2008, article 27). In addition, a patient may still be able to give *assent* (the ethically necessary, but not sufficient, expression of a legally "incompetent" person's agreement to participate). Where this is possible, even if it is only by signalling "yes" via eye-blinks, researchers must seek that assent in addition to the consent of the legal representative, and dissent should be respected (World

Medical Association, 1964/2008, article 28). Terry (2007) points out that obtaining informed consent and/or assent is a process, rather than just a signature on a piece of paper. Clearly it is desirable to begin this process as early as possible if the patient's competence is decreasing over time, and to make every reasonable effort to interpret whatever signals may remain.

The weakness or unreliability of the patient's signals leads to challenges in obtaining consent or assent: one must also establish to what extent a patient's consent, needs, or requests for information have been correctly *interpreted* by researchers and physicians. As Neumann and Kübler (2003) point out, a patient's idiosyncratic signs for 'yes' and 'no' may require some study before they can be recognized reliably. Furthermore, does a weak or ambiguous signal indicate physical inability to respond clearly, or does it reflect ambivalence, confusion or indecision in the mind of the patient? Or the reluctance to give a yes/no answer to a question whose nuances the patient is not equipped to go into? Researchers have a duty to make communication with patients as clear as possible. Yet, faced with ambiguous or infrequent responses, it is common to observe how those attempting to communicate with a patient will compensate by projecting their own expectations selectively onto the patient's movements and it can be difficult, even for a researcher or practitioner who is aware of this, to avoid asking "leading questions" unless a rigid protocol has been put in place. At the simplest level this involves ensuring that questions be formulated unequivocally and be issued one at a time, leaving enough time for the patient to consider and respond. Basic principles of experimental design must then assert themselves in order to avoid bias: questions must not be unfairly weighted with regard to the time allotted to them, and the criteria for judging whether a response has been made must be consistent across questions. If the patient does not have a "yes" and "no" modality available to him or her, but only a unary "yes" in contrast to remaining inactive, adequate steps have to be taken to distinguish a voluntary from an involuntary lack of response. In such a case, questions must be asked in positive/negative pairs, sometimes with the positive half presented first, and sometimes second, as would befit a well-designed trial-based experiment. Responses should be objectively verified, perhaps by using EMG traces, or by having colleagues score a video of the communication attempt while blind to the questions being asked. From these measures, can we quantify our certainty of the interpretations we make of a patient's response, using the appropriate statistical methods? Finally, might an impartial, untrained observer entertain any doubt that the patient can hear and understand the questions, that the patient is cognitively capable of reaching the correct answer, or even that the patient is conscious, at any given moment? If so, as in any experimental procedure, a control is required: "stupid questions", to which patient and researcher both know the obvious answers, should be mixed into the design, and must occur in sufficient numbers to provide the required statistical power. The purpose of such questions must of course be made clear, diplomatically, to the patient.

Video and audio records of such conversations between researchers and patients are very important, particularly when it comes to asking consent. Consent must also be asked repeatedly at intervals during an ongoing study, since patients may, and have the right to, change their mind during the study, yet they may be unable or be hesitant to report this (Chenaid et al., 2007). Patients must also be well informed in advance of what is expected of them in a study—in particular, how long a study will last (Liesegang, 2007). Neumann and Kübler (2003) suggest that patients should be told that a first test training of 4–6 weeks will be conducted, in which multiple approaches to BCI will be tested, after which a decision will be made on the continuation of the training. Although the data of a patient should always be kept confidential, it is wise to

anticipate that researchers will want to use videos and pictures of the patient in conference presentations and publications. It should be a policy in BCI research to ask patients, early on, to what extent information about them may be used for publications, conferences or press releases.

It is vital, but in practice very complicated, to carefully explain the risks, disadvantages and benefits of the BCI to the patient. Risks of an EEG-based BCI system consist of the possibility of skin infections after applying the electrodes. Invasive methods carry a higher risk, since craniotomy is required to implant the electrode grid, and subjects are put under general or local anaesthesia, depending on whether interaction with the subject is required to position the electrode grid correctly. Implants can cause tissue damage and the surgery itself can lead to infections, although ECoG electrodes, particularly those placed epidurally, run this risk to a lesser extent (Schalk et al., 2008). Infections may be a long-term risk since the technology currently available for human use requires cables to be lead out of the body at some exit point that is kept permanently open—ideally, wireless transmission would be used in order to maintain full integrity of the skin. The long-term benefits of the electrodes may be difficult to predict, since immune-system reactions, and restoration of neurons' myelin encapsulation, might conceivably change the signal properties over time, something which is only beginning to be quantified in human subjects (Kim et al., 2008). Functional disadvantages of the BCI may be the time-consuming nature of the training, and the frustration that patients might experience when training does not go well (Neumann & Kübler, 2003). BCI researchers should warn patients that 'bad training' days will inevitably occur and reassure them that this does not mean the end of the world and it is very common in healthy subjects as well. A further (dis)advantage constitutes the many visits of BCI researchers to the house of the patient. Although this is often rated by the patients as a pleasant side-effect of entering in a BCI study, it may also inflict a further restriction to the privacy of the household, which is already crowded due to always present caregivers and visiting doctors, ergotherapists and physiotherapists. Lastly, it should be explained to locked-in patients for whom muscular-dependent communication is still possible, that BCI cannot be guaranteed to perform better than these.

A major problem regarding communication on this topic is that the often mentioned or implicitly used method of risk-benefit calculation is not easily applicable, if at all. Hildt (Hildt, 2006, 2008, p. 135) suggested that "Only those uses in which considerable benefit can reasonably be expected and in which the expected benefits clearly outweigh the risks can be considered acceptable." However, the scientific community has not yet established a reasonable expectancy of a considerable benefit of BCIs. Moreover, for people who are (on the verge of being) completely locked-in, the potential benefit of a BCI, lacking alternatives, means the difference between communicating and not communicating at all. Complete locked-in patients or patients who are on the verge of this state could well (and reasonably?) be inclined to accept any disadvantage or any risk associated with non-invasive or invasive BCI use to regain communication. Despite these difficulties with the risk-benefit method, it is difficult to formulate an alternative decision principle that does not involve an attempt to weigh risks and potential benefits and that would not be troubled by the problems indicated above.

A further issue is that, as Liesegang (2007) points out, alternatives should be mentioned to the patient (although for complete-LIS patients no alternatives currently exist). A final complicating factor in making a balanced decision is that expectations from patients and caregivers are almost always (too) high, mainly because science fiction stories are told in the media, sometimes partly induced by overly enthusiastic BCI

researchers (we will return to this point below). Clearly, no straightforward ethical procedure can be recommended here, but repeated and careful conversations with patients should guarantee their maximal understanding of the BCI system and its limits and possibilities.

4. Team responsibility

A full understanding of the limits and possibilities of BCI systems may not only be a difficult thing to achieve for the patient, but also not completely straightforward for the researchers working in the interdisciplinary research projects on BCI. The source of the problem of team responsibility is that teams that include a wide variety of experts (in BCI from mathematicians, electrical engineers and computer scientists to psychologists, neuroscientists, surgeons and physicians) have to deal with a fragmentation in the understanding of the overall picture. This is of course aggravated by the fact that the technology is developing fast, as is the knowledge about what the technology applies to (i.e. the brain). Furthermore, very different perspectives can be preferred by scientists from different disciplines. A pragmatic and, in itself, respectable viewpoint from an engineering perspective might be that we do not need to understand how the brain works as long as we can measure relative differences between mental tasks to drive the BCI, whereas for a neuroscientist the understanding of brain functioning is essential. Finally, it is not just knowledge about, or perspectives on, but also responsibility for the effects of BCI that can become unclear due to teamwork. As Alexander Hamilton, Jay, and Madison (1961, nr. 70) once stated succinctly: “plurality in the Executive (...) tends to conceal faults and destroy responsibility.” The influence of group dynamics on decision making is vividly illustrated by the Abilene Paradox (Harvey, 1974), where a family ends up having a bad dinner in a lousy restaurant in Abilene, Texas. Each member believes the others want to go and never questions this. It is vital to organize intra-group communication in a way that such suboptimal outcomes can be prevented.

Especially in relation to clinical aspects of BCI applications, much can be learned from interdisciplinary teams working in similarly demanding situations, such as intensive care units (ICU), teams concerned with severe mentally disordered patients (Lieberman, Hilty, Drake, & Tsang, 2001), or chronic or progressively ill patients facing end-of-life care decisions. A critical element in this type of interdisciplinary teamwork is that the different areas of expertise must be integrated into a practical “service delivery” for the patient, while at the same time “mechanisms for accountability” must be assured (Lieberman et al., 2001, p. 1334). It is noticeable that disagreements arise easily in such situations. In one ICU study (Breen, Abernethy, Abbott, & Tulskey, 2001) conflicts were observed to occur among staff in 48% of cases (equal to the percentage of conflicts between staff and family), whereas only 24% of conflicts among family members were reported. In medical teams, conflict between medical and nursing staff is often “frequent and bitter” (Tchudin, 2001, p. 465). The character of these conflicts is mainly determined by the different viewpoints from the different types of experts, each having contact with the patient. It is pressured even more by difference in social hierarchy (educational level). Similar to medical teams, a BCI team usually has a hierarchical structure, potentially pressuring the influence of experts lower in rank in favour of their authorities. However, whereas nurses have an intensive patient contact, many of the co-working experts in the BCI team do not. This difference can potentially decrease the feeling of moral responsibility in those co-working experts, while their unique point of view may actually be crucial for the evaluation of a specific moral consideration.

Among several recommendations to improve team functioning, many of which are reasonably obvious (e.g. regular team meetings, ensuring good lines of communication), two are worth mentioning in relation to acquiring informed consent. First, ensure that appropriate members of the team are asked whether they should be present at a decision making meeting with patient and family. Second, have a ‘preconference’ of team members to develop team consensus and facilitate discussion of issues or conflicts that may occur within the team (Shanawani, Wenrich, Tonelli, & Curtis, 2008, p. 780). Current ethical guidelines, such as formulated in the Declaration of Helsinki (World Medical Association, 1964/2008), focus on a single scientifically/medically competent individual who carries the responsibility for the human subject. However, it is precisely this individualized type of responsibility that becomes problematic in a multidisciplinary research environment. It may well be possible that the scientist with the most encompassing perspective may not be the one actually communicating with the patient or family.

In all, it is important that, within BCI projects, considerable attention is given to four general ethical issues regarding teamwork (Frey, 2007): how teams achieve *justice* in the distribution of work and the credits thereby attainable, assign *responsibility* for decisions that are made, especially those that may have far-reaching consequences for participants or patients, ensure *reasonableness* in allowing participation, resolution of conflicts and reaching consensus, and maintain *honesty* in communication and reporting results. It requires continuous effort and attention from the entire multidisciplinary BCI team to provide one or more well-informed, multidisciplinary competent individuals as contact persons for the patient, capable of translating the multidisciplinary scientific content into understandable indications of risks and benefits for the subject.

5. Communication with the media

The difficulties involved in communicating about BCI deserve specific attention. Publicity about the possibilities and impossibilities of BCI will have implications for the expectations of patients, thereby influencing the process of acquiring informed consent. As Illes et al. (2005, p. 981) say: “A risk of public engagement is that of creating false hopes and expectations”. There are two major aspects of communicating with the press about BCI that are directly relevant to the topic of informed consent.

First, there is the general issue of the (un)certainly of scientific knowledge. Researchers are thoroughly familiar with the vagaries of science, especially when it comes to recent developments and the process of acquiring new insights. For the general public, however, a ‘scientific finding’ is taken as a fact, as equivalent to ‘100% accuracy’ (Garrett & Bird, 2000). Explaining that certain statements for the moment do not go beyond being conjectures or hypotheses under investigation can be a long and arduous process. As every teacher knows, most students take years to go from a ‘tell me how it is’ attitude to the cautious questioning approach towards scientific findings that is characteristic of professional researchers. Even worse, uncertainty is generally not what the larger public seeks or appreciates about science (Bird, 2003). Although it is hardly possible to communicate effectively about the nature of science in general while announcing one’s recent research findings, this difference in perception of scientific certainty helps to emphasize that it is “extraordinarily important that scientists avoid over-hyping the significance of their findings”. (Garrett & Bird, 2000, p.439). Rather, the accent should be put on the qualifications and limitations concerning the results reported. In other words, it is important to actively resist the temptation to go along with the public’s desire for certainty.

The second problem in communicating with the media that is challenging in its own right, but that may also affect the process of acquiring informed consent arises due to the, at times large, gap between currently feasible and potentially possible applications in the medium or long term. Specifically the topic of mindreading (in connection to all kinds of spectacular applications) is bound to attract attention from the media. It is not hard to find headlines in media like BBC news and Science Daily such as ‘Paralysed man’s mind is ‘read’ (BBCNews, 2007; ScienceDaily, 2008), ‘Brain fingerprints under scrutiny’ (McCall, 2004), ‘Towards zero training for BCI’ (ScienceDaily, 2008), and ‘Brain sensor for market research’ (Greene, 2007). Such reports mostly deal with future possibilities. This focus on what might be achievable with BCI is not objectionable in itself. If no one would expect important progress within a reasonable amount of time, BCI would not be the fast growing field it is now. Also, in relation to BCI’s ethical implications, potentially problematic developments need to be identified before they arise, so that they may be dealt with properly. Therefore it is logical that future expectations do play a role in ethical analyses and in communication between scientists and journalists. The big question, of course, is what constitute *reasonable* expectations concerning *which point* (nearby, distant) in the future. It is precisely regarding these aspects that self-restraint and clarity are called for. When talking to the press about BCI it, therefore, would be advisable to be extremely reluctant to engage in speculations concerning anything beyond the near future (3–5 years or so) or depending on breakthroughs that, at present, are not foreseeable.

The two problems indicated above are aggravated by the potential occurrence of misunderstandings or inadequate renderings in the media of a scientist’s statements. As most people who have been involved with media will know, it is not unusual that journalists come with a specific story in mind that they would like to tell their audience. Even if this is not the case, public media are generally more interested in what may be possible than in reporting scientists’ scepticism and reservations. It can be quite difficult to avoid seeing one’s words appear as part of an overall message that is not the scientist’s own. Avoiding this danger is, to a significant extent, the scientist’s responsibility, as Dennett (2003, p. 17) has suggested: “We need to recognize that our words might be misunderstood, and that we are, to some degree just as responsible for likely misunderstandings of what we say as we are for the “proper” effects of our words. (...) Sometimes the likelihood of misunderstanding (or other misuse) of one’s true statements, and the anticipatable harm such misunderstanding could propagate, will be so great that one had better shut up.”

However, such radical non-cooperation with the press can be undesirable for many different reasons, ranging from a sincerely felt general duty to inform the public to creating well-timed publicity for research project proposals that need funding. As Rose (2003, p. 310) formulates it: “Researchers depend on grants for their work, and the higher the public visibility, the more likely one feels that one’s work is going to be noticed and the grant money flow in (...) It is no good announcing anything less than a major breakthrough”. Still, a responsible media strategy may consist in being as explicit as possible concerning the limitations of scientific ‘certainty’ in general and the current boundaries of BCI in particular. Restricting discussions of topics and illustrative cases to a short term future cannot guarantee against misinterpretations or exaggerated headlines, but it may help in taming the more extravagant claims or expectations of the media. For similar reasons, a certain amount of self-restraint concerning catchy but too promising titles of publications in scientific journals (or statements in them) is called for.

6. Conclusion

To conclude, many practical ethical issues surround BCI in relation to both research and intervention. Acquiring an ethically sound informed consent from a locked-in patient may be challenging due to the high expectations of the patient, the difficulty in communicating and the lack of alternatives. However, more attention to strict and standardized policies like the ones suggested above could help to maximise the chance that patients get adequate information, have maximal comprehension and voluntarily enter the study. Similarly, a focus on the ethical issues regarding teamwork may help to achieve responsible functioning of everyone involved in BCI research. Prudence in what researchers communicate to the public media and watchfulness concerning how what has been said gets represented, would help to reduce unrealistic expectations. Research into BCI, as well as its applications in clinical settings, involves the exploration of a relatively new terrain, and is likely to become more important in the near future. A growing attention for the practical ethical challenges faced by scientists, clinicians, participants and patients is clearly called for.

References

- Bauer, G., Gerstenbrand, F., & Rimpl, E. (1979). Variables of the locked-in syndrome. *Journal of Neurology*, 221, 77–91.
- BBCNews, (2007). Paralysed man’s mind is ‘read’. Retrieved June 23, 2008, from <http://news.bbc.co.uk/2/hi/health/7094526.stm>.
- Birbaumer, N. (2006). Brain–computer–interface research: Coming of age. *Clinical Neurophysiology*, 117(3), 479–483.
- Birbaumer, N., Ghanayim, N., Hinterberger, T., Iversen, I., Kotchoubey, B., Kubler, A., et al. (1999). A spelling device for the paralysed. *Nature*, 398(6725), 297–298.
- Bird, S. J. (2003). Communicating scientific advice to the public. *The IPTS Report* Retrieved June 2, 2009, from <http://ipts.jrc.ec.europa.eu/home/report/english/articles/vol72/SCI3E726.htm>.
- Breen, C., Abernethy, A., Abbott, K., & Tulskey, J. (2001). Conflict associated with decisions to limit life-sustaining treatment in intensive care units. *Journal of General Internal Medicine*, 16(5), 339–341.
- Chenau, C., Merlani, P., & Ricou, B. (2007). Research in critically ill patients: standards of informed consent. *Critical Care*, 11(1), 110.
- Clausen, J. (2009). Man, machine and in between. *Nature*, 457(26), 1080–1081.
- Dennett, D. C. (2003). *Freedom evolves*. New York: Viking.
- Emanuel, E., Wendler, D., & Grady, C. (2000). What makes clinical research ethical? *Journal of the American Medical Association*, 283, 2701–2711.
- Faden, R., & Beauchamp, T. (1986). *A history and theory of informed consent*. New York, NY: Oxford University Press.
- Farah, M. J. (2005). Neuroethics: The practical and the philosophical. *Trends in Cognitive Sciences*, 9(1), 34–40.
- Farah, M. J. (2007). Social, legal, and ethical implications of cognitive neuroscience: “Neuroethics” for short. *Journal of Cognitive Neuroscience*, 19(3), 363–364.
- Fins, J. J., & Shapiro, Z. E. (2007). Neuroimaging and neuroethics: Clinical and policy considerations. *Current Opinion in Neurology*, 20(6), 650–654.
- Freeman, A. (2007). Neuroethics: Defining the issues in theory, practice, and policy. *Journal of Consciousness Studies*, 14(3), 118–121.
- Frey, W. (2007). Ethics of team work. Retrieved October 25, 2008, from <http://cnx.org/content/m13760/1.7/>.
- Fukushi, T., Sakura, O., & Koizumi, H. (2007). Ethical considerations of neuroscience research: The perspectives on neuroethics in Japan. *Neuroscience Research*, 57(1), 10–16.
- Garrett, J. M., & Bird, S. J. (2000). Ethical issues in communicating science. *Science and Engineering Ethics*, 6, 435–442.
- Glannon, W. (Ed.). (2007). *Defining right and wrong in brain science*. Washington, DC: Dana Press.
- Greely, H. (2007). On neuroethics. *Science*, 318(5850), 533–533.
- Greene, K. (2007). Brain Sensor for Market Research: A startup claims to read people’s minds while they view ads. Retrieved September 27, 2008, from <http://www.technologyreview.com/Biztech/19833/>.
- Hamilton, A., Jay, J., & Madison, J. (1961). *The federalist papers*. New York: New American Library.
- Harvey, J. B. (1974). The Abilene paradox and other meditations on management. *Organizational Dynamics*, 3(1), 63.
- Hildt, E. (2006). Electrodes in the brain: Some anthropological and ethical aspects of deep brain stimulation. *International Review of Information Ethics*, 5(9), 33–39.
- Hildt, E. (2008). Theoretical and ethical issues on brain–computer interfaces. IN *Paper presented at the 4th international brain–computer interface workshop and training course*.
- Hill, N. J., Lal, T. N., Schroder, M., Hinterberger, T., Wilhelm, B., Nijboer, F., et al. (2006). Classifying EEG and ECoG signals without subject training for fast BCI implementation: Comparison of nonparalyzed and completely paralyzed subjects. *IEEE Transactions on Neural Systems and Rehabilitation Engineering*, 14(2), 183–186.

- Hochberg, L. R., Serruya, M. D., Friehs, G. M., Mukand, J. A., Saleh, M., Caplan, A. H., et al. (2006). Neuronal ensemble control of prosthetic devices by a human with tetraplegia. *Nature*, 442(7099), 164–171.
- Huggins, J. E., Levine, S. P., Graimann, B., Young Chun, S., & Fessler, J. A. (2007). Electrooculogram as Brain–computer interface signal source. In G. Dornhege, R. Millan Jdel, T. Hinterberger, D. McFarland, & K.-R. Müller (Eds.), *Toward brain–computer interfacing* (pp. 129–145). Cambridge, Massachusetts, USA: The MIT Press.
- Illes, J. (2007). Empirical neuroethics – Can brain imaging visualize human thought? Why is neuroethics interested in such a possibility? *Embo Reports*, 8, S57–S60.
- Illes, J. (Ed.). (2005). *Neuroethics: Defining the issues in theory, practice and policy*. Oxford: Oxford University Press.
- Illes, J., Blakemore, C., Hansson, M. G., Hensch, T. K., Leshner, A., Maestre, G., et al. (2005). International perspectives on engaging the public in neuroethics. *Nature Reviews Neuroscience*, 6(12), 977–982.
- Kim, S., Simeral, J., Hochberg, L., Donoghue, J., & Black, M. (2008). Neural control of computer cursor velocity by decoding motor cortical spiking activity in humans with tetraplegia. *Journal of Neural Engineering*, 5(4), 455–476.
- Kübler, A., & Birbaumer, N. (2008). Brain–computer interfaces and communication in paralysis: Extinction of goal directed thinking in completely paralysed patients?. *Clinical Neurophysiology*, 119, 2658–2666.
- Kübler, A., & Muller, G. R. (2007). An introduction to Brain–Computer Interfacing. In G. Dornhege, R. Millan Jdel, T. Hinterberger, D. McFarland, & K.-R. Müller (Eds.), *Toward brain–computer interfacing* (pp. 1–25). Cambridge, MA, USA: The MIT Press.
- Kübler, A., Neumann, N., Kaiser, J., Kotchoubey, B., Hinterberger, T., & Birbaumer, N. P. (2001). Brain–computer communication: Self-regulation of slow cortical potentials for verbal communication. *Archives of Physical Medicine and Rehabilitation*, 82(11), 1533–1539.
- Kübler, A., Nijboer, F., & Birbaumer, N. (2007). Brain–computer interfaces for communication and motor control - perspectives on clinical applications. In G. Dornhege, R. Millan Jdel, T. Hinterberger, D. McFarland, & K.-R. Müller (Eds.), *Toward brain–computer interfacing* (pp. 373–392). Cambridge, Massachusetts, USA: The MIT Press.
- Kübler, A., Nijboer, F., Mellinger, J., Vaughan, T. M., Pawelzik, H., Schalk, G., et al. (2005). Patients with ALS can use sensorimotor rhythms to operate a brain–computer interface. *Neurology*, 64(10), 1775–1777.
- Leuthardt, E., Schalk, G., Wolpaw, J. R., Ojemann, J. G., & Moran, D. W. (2004). Brain–computer interface using electrocorticographic signals in humans. *Journal of Neural Engineering*, 1, 63–71.
- Liberman, R. P., Hilty, D. M., Drake, R. E., & Tsang, H. W. H. (2001). *Requirements for Multidisciplinary teamwork in psychiatric rehabilitation* (pp. 1331–1342). Vol. 52.
- Liesegang, T. J. (2007). The meaning and need for informed consent in research. *Indian Journal of Ophthalmology*, 55(1), 1–3.
- McCall, B. (2004). Brain fingerprints under scrutiny. Retrieved May 25, 2006, from <http://news.bbc.co.uk/2/hi/science/nature/3495433.stm>.
- Neumann, N., & Kübler, A. (2003). Training locked-in patients: A challenge for the use of brain–computer interfaces. *IEEE Transactions on Neural Systems and Rehabilitation Engineering*, 11(2), 169–172.
- Neuper, C., Müller, G. R., Kübler, A., Birbaumer, N., & Pfurtscheller, G. (2003). Clinical application of an EEG-based brain–computer interface: A case study in a patient with severe motor impairment. *Clinical Neurophysiology*, 114(3), 399–409.
- Nijboer, F., Sellers, E. W., Mellinger, J., Jordan, M. A., Matuz, T., Furdea, A., et al. (2008). A P300-based brain–computer interface for people with amyotrophic lateral sclerosis. *Clinical Neurophysiology*, 119(8), 1909–1916.
- Rose, S. P. R. (2003). How to (or not to) communicate science. *Biochemical Society Transactions*, 31(2), 307–312.
- Roskies, A. L. (2007). Neuroethics beyond genetics: Despite the overlap between the ethics of neuroscience and genetics, there are important areas where the two diverge. *Embo Reports*, 8, S52–S56.
- Schalk, G., Miller, K. J., Anderson, N. R., Wilson, J. A., Smyth, M. D., Ojemann, J. G., et al. (2008). Two-dimensional movement control using electrocorticographic signals in humans. *J. Neural Eng.*, 5, 75–84.
- ScienceDaily, (2008). Towards zero training for Brain–computer Interfacing. Retrieved September 30, 2008, from <http://www.sciencedaily.com/releases/2008/08/080812213820.htm>.
- Sellers, E. W., & Donchin, E. (2006). A P300-based brain–computer interface: Initial tests by ALS patients. *Clinical Neurophysiology*.
- Shanawani, H., Wenrich, M. D., Tonelli, M. R., & Curtis, J. R. (2008). Meeting Physicians Responsibilities in Providing End-of-Life Care. *CHEST*, 133(3), 775–786.
- Tchudin, V. (2001). Special issues facing nurses. In H. Kuhse, & P. Singer (Eds.), *A companion to bioethics* (pp. 463–471). Oxford: Blackwell Publishing.
- Terry, P. B. (2007). Informed consent in clinical medicine. *Chest*, 131(2), 563–568.
- Vaughan, T. M., McFarland, D. J., Schalk, G., Sarnacki, W. A., Krusienski, D. J., Sellers, E. W., et al. (2006). The Wadsworth BCI research and development program: At home with BCI. *IEEE Transactions on Neural Systems and Rehabilitation Engineering*, 14(2), 229–233.
- Wolpe, P. R. (2007). Virtual mentor. *American Medical Association Journal of Ethics*, 9(2), 128–131.
- World Medical Association, (1964/2008), World medical association declaration Of Helsinki: Ethical principles for medical research involving human subjects. 6th revision. Retrieved June 24, 2009, from <http://www.wma.net/e/policy/pdf/17c.pdf>.