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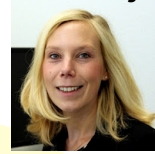
ELSI of neurotechnology



Radboud University Nijmegen



Femke Nijboer



Jason Farquhar



Pim Haselager

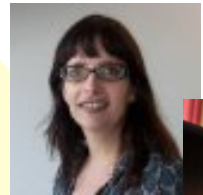


WP7.1:
Internal
communication

WP 7.2
Education

WP 7.8
Ethical legal
societal aspects

Susanna Bicknell



Project 7
Dissemination

WP 7.3
Academics

WP 7.7
Bonus



Peter Veltink

Femke Nijboer



WP 7.4:
Industry

WP 7.6:
Society

WP 7.5
Patients &
other
users



Marc Grootjen



Susanna Bicknell



Ton Tempels



Marie-Louise Wauters

Aims of today

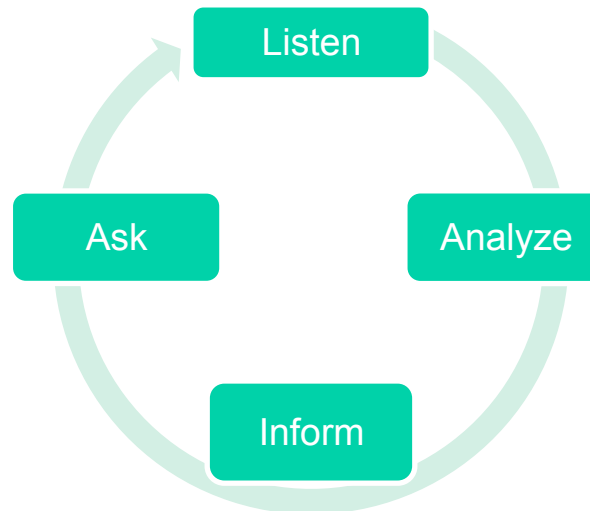
- Introduce you to Ethical, Legal & Societal Implications of BCI
 - General ELSI intro
 - BCI & sense of agency
- Not:
 - To tell you ‘how it is’
 - To tell you ‘to be good’
- Instead:
 - Show you some issues to think about
 - Help you think about (some of) them
 - Stimulate you to talk about (some of) them
 - Increase your awareness
- Consider this talk as a kind of guided museum tour
 - Showing you some issues worthy of attention
 - Not telling you what is good or bad

Neuroethics & ELSI

- “a discipline that aligns the exploration and discovery of neurobiological knowledge with human value systems”. (Illes, 2007, p.537)
- Henry Greely:
 - “Personally, I find ‘neuroethics’ less than ideal as a description for this field. It focuses entirely on ‘ethics’ and ignores the legal and social issues that may be quite important.” (Minn. Journal for Science & Technology, 2006, 7(2), p.602)
- Investigation of the Ethical, Legal and Social Implications that may arise from neuroscientific research and its applications
 - Sometimes Societal instead of Social
 - Sometimes Issues instead of Implications

ELSI' s outlook

- Constructively alert
 - Not just raising problems and worries
 - Use ELSI to communicate with (potential) stakeholders about the possible, desirable, avoidable
 - Use ELSI to possibly improve (potential applications of) neurotechnology
- Listen, Analyze, Inform, Ask





Discussing ELSI



 Wetenschappelijk Onderzoek- en Documentatiecentrum
Ministerie van Veiligheid en Justitie

Research Publications Organization

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Organization

Aim and role

The WODC aims to make a professional contribution to development and evaluation of justice policy set by the Netherlands Ministry of Security and Justice.

WODC (the Dutch abbreviation for Wetenschappelijk Onderzoek- en Documentatiecentrum, in English: Research and Documentation Centre) can best be characterised as an international criminal justice knowledge centre. "Excellence" and "customer-orientation" are the organisation's guiding principles. Its major output is knowledge for the benefit of policy development.



for Brain, Cognition and Behaviour



Radboud University Nijmegen



Workshops

Team 9: Urgent issues

Dear team members,

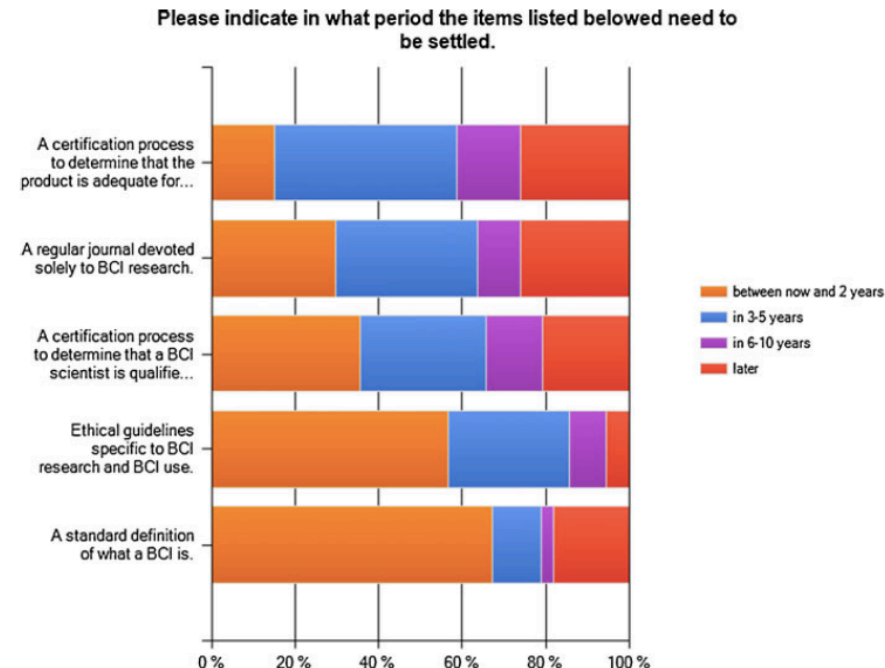
We would like you to work toward the following 'product':

1. Consider Figure 4 (from Nijboer et al. 2011). Which of these issues need to be settled in the field of brain-computer interfacing within the given timeframe?
2. Which issues should be added to the list and why?
3. Who should address these issues?
4. How can we implement this?

One team member should present your findings in the 2 minutes. Thank you!

The Asilomar Survey: Stakeholders' Opinions on Ethics and BCI

Fig. 4 An overview of when respondents think certain BCI issues should be settled. From top to bottom bar: 'a certification process to determine that the product is adequate for a BCI', 'a regular journal devoted solely to BCI research', 'a certification process to determine that a BCI scientist is qualified to work with patients', 'ethical guidelines specific to BCI research and BCI use' and 'a standard definition of what a BCI is'



Workshops

Team 10: Personal experience in (applied) neuroscience

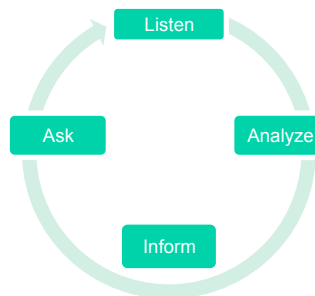
Dear team members,

Maybe we have given you one of the most difficult assignments: introspection.

We would like you to work toward the following 'product':

1. Can you recall experiencing (or being close to) ethically or legally difficult situations in your own research or work?
2. Can you as a group, without identifying names or institutes, give some examples?
3. Can you indicate how the difficulties were dealt with?
4. Can you indicate how, in your view, the difficulties should have been dealt with?

One team member should present your findings in the 2 minutes. Thank you!



Challenges for neurotechnology

- Clinical issues
 - (1) obtaining **informed consent**
 - (2) **risk/benefit** analysis
 - (3) shared responsibility of **teams**
 - (4) the consequences for **quality of life** (patient, family)
 - (5) **side-effects**
 - (6) **therapeutic** applications & their limits
- Responsibility and privacy
 - (7) personal **responsibility** and **liability** (intention and agency)
 - (8) issues concerning **personality** and personhood
 - (9) mind-reading, **privacy** and data protection
 - (10) **mind-control**
- Societal acceptance
 - (11) questions of **research ethics**
 - (12) selective **enhancement** and social stratification
 - (13) communication to the **media**.

Typical ELSI questions

- What is possible?
 - What is currently possible (applications)
 - What will be possible in the near future (current research with applications in next 5-10 years)
 - What could 'ultimately' become possible (long term prospects)
- What is desirable?
 - Clinical applications
 - Healthy users
- What should be avoided
 - Clinical applications
 - Healthy users
- What should be regulated, by whom and how?
 - Policy makers (governmental)
 - Legal institutions
 - Scientific experts/organizations (selfregulation)
 - Nongovernmental organizations
 - Patient groups
 - General public
 - Other stakeholders?

right
wrong
honesty
Ethical
you CAS actions
compassion
decisions justice integrity
fairness



ORIGINAL PAPER

The Asilomar Survey: Stakeholders' Opinions on Ethical Issues Related to Brain-Computer Interfacing

Femke Nijboer • Jens Clausen •
Brendan Z. Allison • Pim Haselager



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- Survey among 145 BCI researchers in 2010
- Terminology, expected marketability, informed consent, risk-benefit, team responsibility, quality of life, liability, personal identity, media communication



A simple question?

Fig. 2 The percentage of people who did (*orange*) or did not (*blue*) consider the listed example as a BCI or who did not know (*purple bar*)

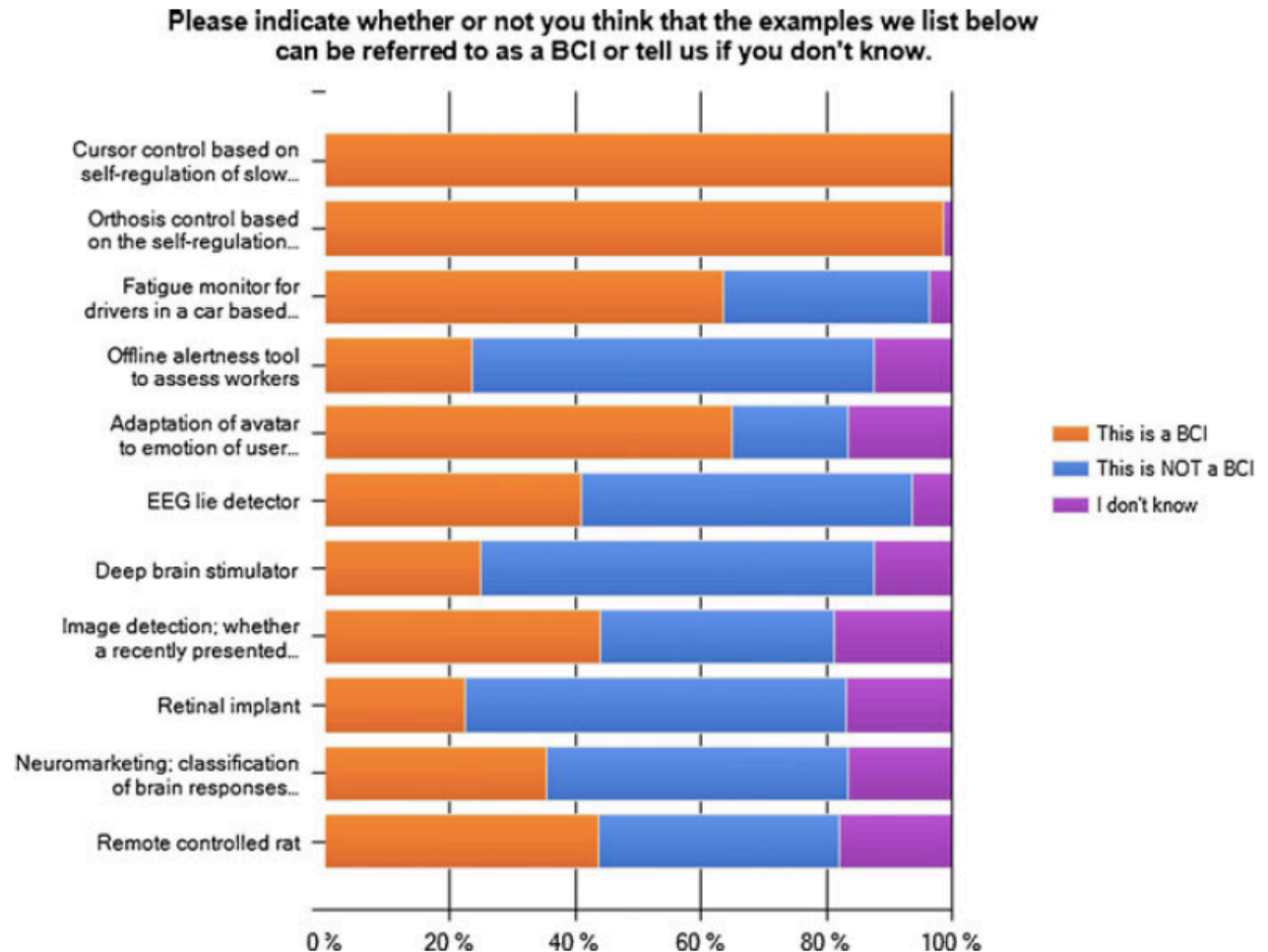
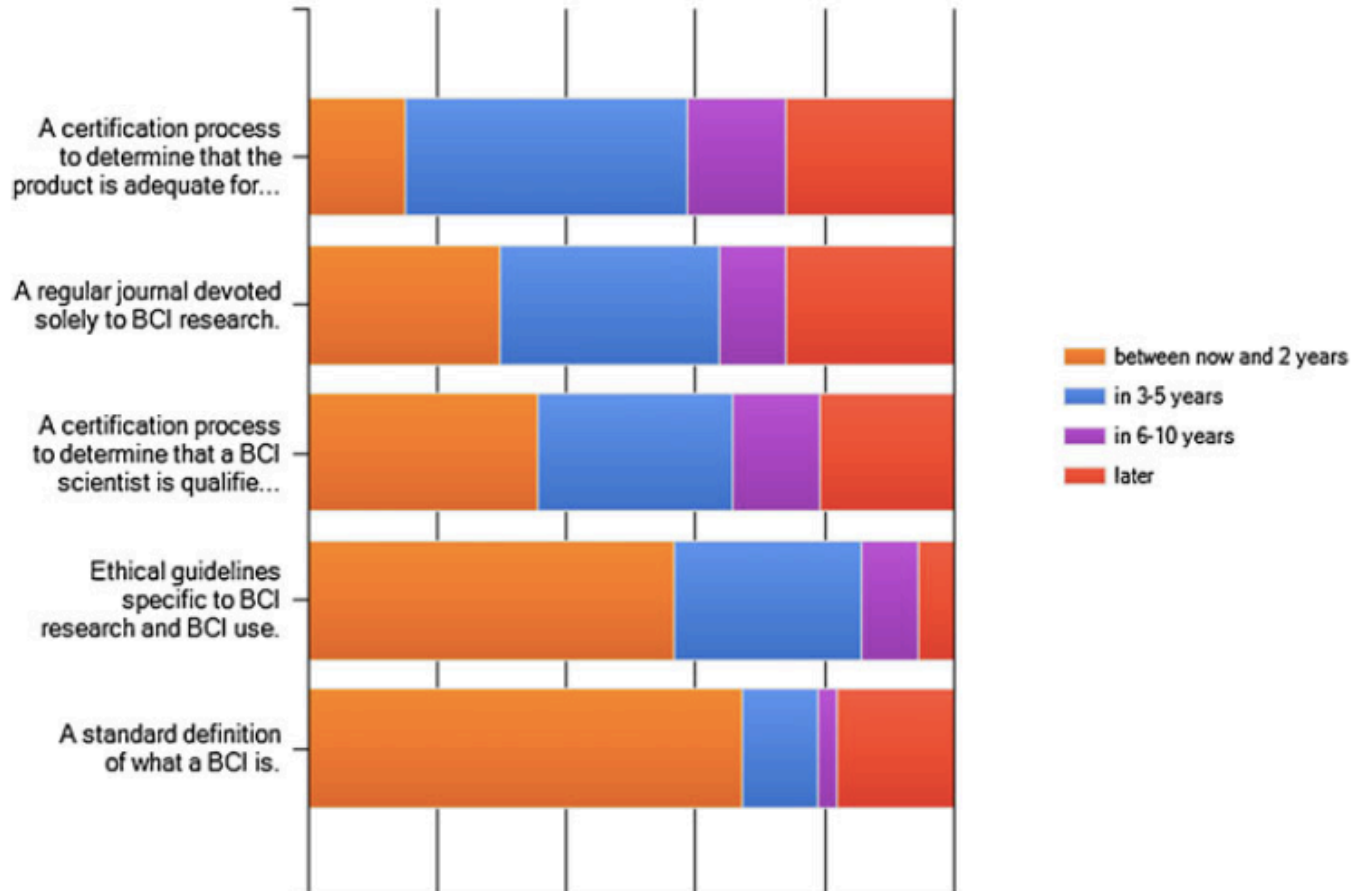


Fig. 4 An overview of when respondents think certain BCI issues should be settled. From top to bottom bar: ‘a certification process to determine that the product is adequate for a BCI’, ‘a regular journal devoted solely to BCI research’, ‘a certification process to determine that a BCI scientist is qualified to work with patients’, ‘ethical guidelines specific to BCI research and BCI use’ and ‘a standard definition of what a BCI is’

Please indicate in what period the items listed below need to be settled.



What's in a name?

- BCI dilution
 - “The rapidly developing tendency to expand the conventional definition of BCI to include that group’s interests”
 - e.g. include passive monitoring systems, or relying on facial muscle signals
 - “The term BCI runs the risk of being diluted into meaninglessness.”
- BCI exaggeration
 - “The tendency to make unrealistic claims about what BCIs can do, or could do with a few years of funding”
 - B. Allison (2011) Trends in BCI research: Progress today, backlash tomorrow? ACM Crossroads 18(1): 18-22.

Asilomar survey

- Half or more than half of the respondents identified 4 elements as crucial (in order of importance);

A BCI

1) must detect brain activity directly (without using signals from peripheral nerves or muscles) (83.8% of the respondents).

2) provides feedback in realtime, or neartime (71.1% of the respondents).

3) must classify brain activity (60.6% of the respondents).

4) provides feedback to the user that reflects whether s/he successfully attained a goal (50.0% of the respondents).

What is **BCI *USE***?

1. BCIs for healthy users
2. BCIs as assistive technology, which provides compensation for loss of motor function (e.g. BCI-controlled communication program or wheelchair)
3. BCI-controlled prostheses, which restore motor function by replacing a paralyzed limb by a prosthesis (e.g. a BCI-controlled robotic arm or leg)
4. BCIs as therapy tools, which help people with psychological/neurological disorders to directly use feedback of their brain activity for training/recovery purposes (e.g. neurofeedback of sensorimotor rhythms may promote brain recovery after stroke, neurofeedback of slow cortical potentials may help improve attention).



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A note on ethical aspects of BCI

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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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- Locked-in patients, informed consent, team responsibility & communication with the media

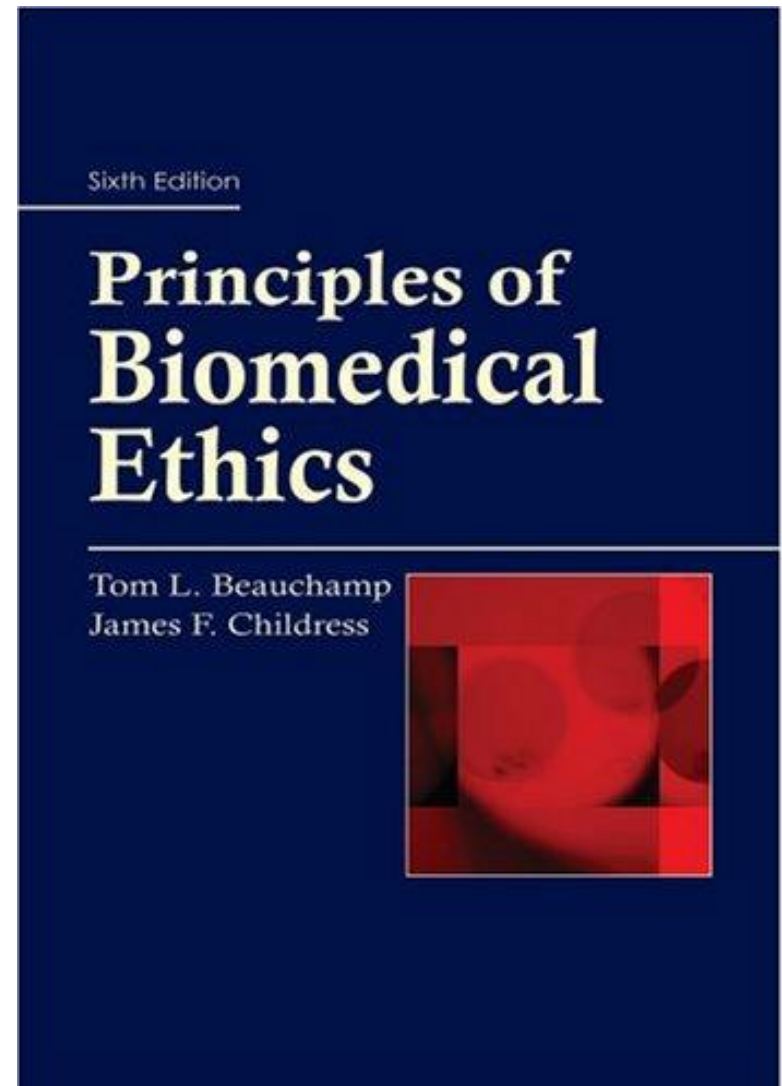


Locked-in syndrome (LIS)

- Bauer, Gerstenbrand, & Rumpl (1979); Smith & Delargy, (2005) BMJ 330: 406-409
- Classical
 - lack of voluntary motor control except for vertical eye movements, combined with consciousness
- Incomplete
 - remnants of voluntary motion other than vertical eye movements
- Complete
 - a total lack of voluntary motor control, including all eye movements, with consciousness
 - invasive BCI's with better signal quality than non-invasive
Significantly higher risks involved

Medical Ethics

- **Autonomy**
 - The right for an individual to make his or her own choice.
- **Beneficence**
 - The principle of acting with the best interest of the other in mind.
- **Non-maleficence**
 - The principle of above all, do no harm.
- **Justice**
 - Ensure fairness and equality among individuals.





Team 1: Case scenario Jane

Dear team members,

We would like you to work toward the following ‘product’:

- 1) Please **identify the main ethical, legal or societal (ELSI) issues** that need to be discussed regarding the case scenario about Jane (taken from Vlek et al. 2012).
- 2) Keep in mind different perspectives, such as a) what information needs to be presented to the person and/or family and/or legal representative in order to make an informed consent decision, b) how would one communicate the possibilities and difficulties involved in such a case to the public media?
- 3) What information would you need additionally to form an opinion about this case? In other words, **what information is missing** in the scenario below?
- 4) What would you recommend in this case scenario? What are the **do’s, don’ts**?
- 5) What kind of **research project** is needed to address these ELSI issues?

Try to summarize the team’s major findings. One team member should present this plenary in 2 minutes. Thank you!

“Jane”

Jane is a 46-year-old housewife who has had the neurodegenerative disease ALS for 10 years. She lives at home and has a full-time staff of caregivers. Since the onset of locked-in syndrome 1 year ago, she has not been able to communicate in any way. She has a legal representative who enrolled her in tests with noninvasive brain-computer interfaces. The researchers using noninvasive BCI say they can see that Jane is making an effort but that they are unable to reliably decode Jane’s brain activity. Jane’s husband, who is eager to communicate with his wife again, has read about invasive BCIs in the media and would like to try this method. He asks the BCI team whether his wife could be considered for brain surgery.

Opinions on informed consent

Table 3 Overview of statements regarding the informed consent process. Columns 2 to 5 show the percentage of respondents (dis)agreeing (with the extent indicated in the column) to the different statements The last column (response count) indicates how many respondents scored the statement

Statement	Disagree completely	Mostly disagree	I don't know	Mostly agree	Agree completely	Response count
People who cannot communicate in any way should <i>*not*</i> be included in BCI studies even if their legal representative agrees with their participation	33.3	42.4	12.5	9.7	2.1	144
Obtaining an informed consent from a locked-in patient should be video-taped	4.2	9.0	31.9	34.7	20.1	144
A BCI expert is the suited person to inform the locked-in patients about the BCI studies, the risks and the benefits	4.9	18.8	13.2	49.3	13.9	144
A medical expert is the suited person to inform the locked-in patients about the BCI studies, the risks and the benefits	2.1	17.6	14.8	59.2	6.3	142
If a patient has no means to communicate but the legal representative of a patient asks for a BCI intervention then an attempt should be made to provide him or her with a BCI	0	8.4	17.5	53.8	20.3	143
If a patient has no means to communicate, and the legal representative does not agree to a BCI intervention, you should still attempt to provide a BCI	37.8	29.4	21	8.4	3.5	143

Informed consent

- In medicine
 - Assuring that fully informed patients are able to fully participate in decisions about their healthcare
- Involving
 - 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
 - certainty about the acceptance of the intervention by the patient
- Additional elements concerning research in clinical cases
 - purpose & duration of research
 - research procedures
 - confidentiality of records

Deciding on using BCI

- Hildt (2008, p. 135)
 - "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, risk-benefit calculation is not easily applicable
 - expectations may be (too) high, due to media exaggeration
 - the scientific community has not yet established a reasonable expectancy of a considerable benefit of BCIs
 - risks are multi-faceted (infections, cumbersome training, household privacy)
 - people who are (on the verge of) being completely locked-in may seem to have little choice

Team responsibility

- Interdisciplinarity of BCI teams (mathematicians, computer scientists, psychologists, neuroscientists, physicians, etc.)
- Teamwork can lead to fragmentation in the understanding of the overall picture
- Not just knowledge about, or perspectives on, but also responsibility for the effects of BCI can become unclear due to teamwork
- The scientist with the most encompassing perspective may not be the one actually communicating with the patient or family

Table 5 Overview of statements regarding team responsibility. Columns 2 to 5 show the percentage of respondents (dis)agreeing (with the extent indicated in the column) to the

different statements The last column (response count) indicates how many respondents scored the statement

Statement	Disagree completely	Mostly disagree	I don't know	Mostly agree	Agree completely	Response count
All BCI teams should have 1 common code with rules & regulations for team responsibility issues	0.7	14.8	12	45.1	27.5	142
It is okay when a patient hears about the difference of opinion of various team members considering the risks and the benefits of a BCI	12.7	31	15.5	29.6	11.3	142
BCI teams should stick to one risk/benefit analysis and tell this to the patient	4.2	14.1	21.8	43.0	16.9	142

Some comments

- *“It's very important to have one clear message. The last thing we want is the patient to become confused”*
- *“I do not believe that a single party can, in all situations, adequately inform the patient about all issues concerning a BCI study. In such cases, I believe it would be more appropriate for experts with complementary areas of expertise to inform the patient. This raises the issue of whether multiple perspectives are consistent. It is not clear to me how this can be resolved systematically”.*

Learn from other interdisciplinary teams

Intensive care units (ICU)

Breen et al. 2001: staff conflicts more often than among patient family

- General lessons
 - Different areas of expertise must be integrated into a practical “service delivery” for the patient
 - ensure appropriate team members are present at consent procedure
 - While at the same time “mechanisms for accountability” must be assured
 - have ‘preconference’ to develop team consensus
- Specific team issues to keep attentive to
 - 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
 - maintain *honesty* in communication and reporting results

Media communication

- Expectations from patients and caregivers are high, in part because of news in the media
 - Paralysed man's mind is 'read' (BBCNews, 2007; ScienceDaily, 2008)
 - Towards zero training for BCI (ScienceDaily, 2008)
- Future expectations
 - The gap between the currently feasible and the potentially possible
- The (un)certainty of science
 - Researchers are aware that what is known is dwarfed by what is unknown
 - This uncertainty is not what policy makers, nor the larger society understand, seek, or value about science
 - In general, non-scientists tend to overestimate the degree of certainty attached to scientific results

Table 8 Columns 2 to 5 show the percentage of respondents (dis)agreeing (with the extent indicated in the column) to the different statements The last column (response count) indicates how many respondents scored the statement

Statement	Disagree completely	Mostly disagree	I don't know	Mostly agree	Agree completely	Response count
It is the responsibility of scientists to check whether their separation from the facts and fiction is adequately represented by journalists	2.1	9.1	7.7	51.0	30.1	143
BCI scientists should moderate their enthusiasm when speaking to the media	1.4	12.6	9.8	37.8	38.5	143
Each BCI scientist should restrict him/herself to discussing current and near-future applications of BCI instead of speculating about long-term applications	3.5	31.9	9.7	36.8	18.1	144
BCI scientists should actively speak out against inaccurate statements in the media, regardless of the source	0.0	4.2	9.0	47.2	39.6	144

Creating realistic expectations

- Don't empathize with the public's desire for certainty
 - The risk of creating false hopes and expectations
- Be aware of / feel responsible for potential misinterpretations
 - “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.” (Dennett, 2003, p. 17)
- Be explicit concerning the current limitations of BCI
 - Specify what constitute *reasonable* expectations concerning *which* (preferably nearby) point in the future
 - Refuse to engage in (or qualify explicitly as) speculations concerning anything beyond the near future or depending on breakthroughs that currently are not foreseeable

Conclusions/Suggestions

- What is a BCI exactly?
- Ethically sound informed consent from a locked-in patient requires the development of standardized procedures
- Awareness of the ethical issues regarding teamwork may help to achieve responsible team functioning
- Prudent communication with public media and watchfulness concerning how statements get represented could help to reduce unrealistic expectations
- A growing attention for the practical ethical challenges faced by scientists, clinicians, participants and patients is called for