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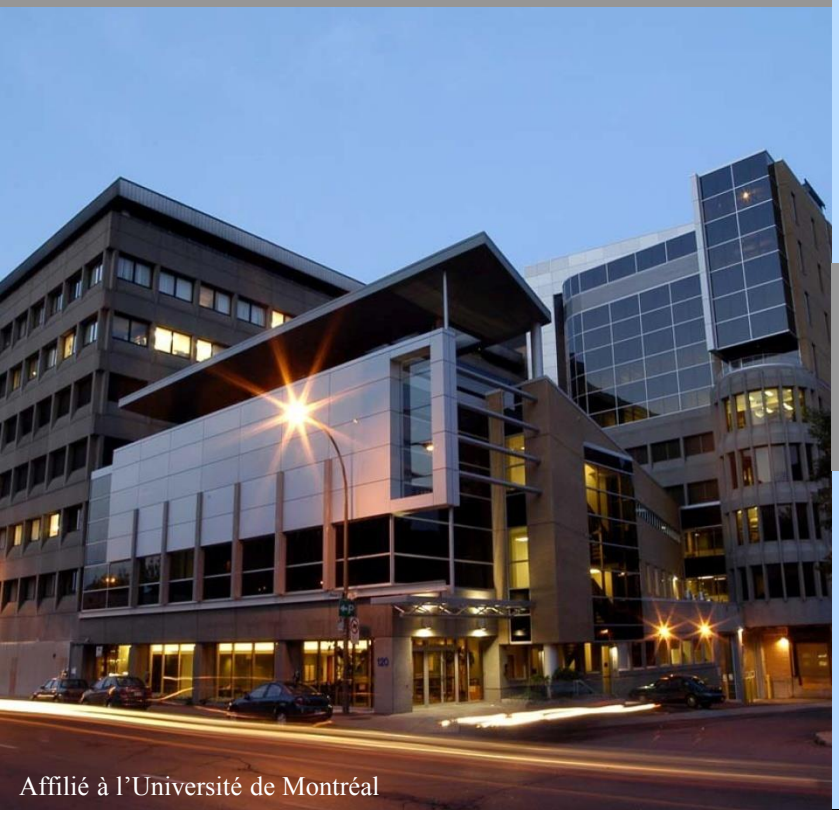

Neuroscientists and the public

Perspectives and questions from neuroethics

Presidential Commission for the Study of Bioethical Issues

Washington, DC
Feb 10th, 2014

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BACKGROUND QUESTIONS

- **Does public communication and public understanding of neuroscience matter from an ethics standpoint? Why?**
- **What are some potentially problematic aspects of public communication/understanding?**
- **Are there solutions or paths to explore?**

OUTLINE

- **Does public communication and public understanding of neuroscience matter from an ethics standpoint? Why?**
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Does public communication and public understanding of neuroscience matter from an ethics standpoint? Why?

No (descriptive and normative):

- Outside the purview of neuroscientists and their research
- Neuroscientists not equipped to tackle relevant issues
- Not enough evidence of an existing problem
- Nothing impactful could be done to remediate the situation
- Neuroscience is no different than other fields of biological research – no specific impact of neuroscience…

Does public communication and public understanding of neuroscience matter from an ethics standpoint? Why?

Yes (descriptive):

- Knowledge transfer is now part of research
- Public expects return on investment and wants to know
- Could be some significant public impact of neuroscience
- Some evidence (even if suboptimal) of significant challenges…

Does public communication and public understanding of neuroscience matter from an ethics standpoint? Why?

Yes (normative):

- Communication is an act like other acts, which can be the object of ethical analysis (virtue-, principle-, or consequence-based)
- Interdisciplinary models can be developed
- Solutions can involved multiple stakeholders beyond single neuroscientist
- Science can contribute to enlightened public/democratic dialogue…

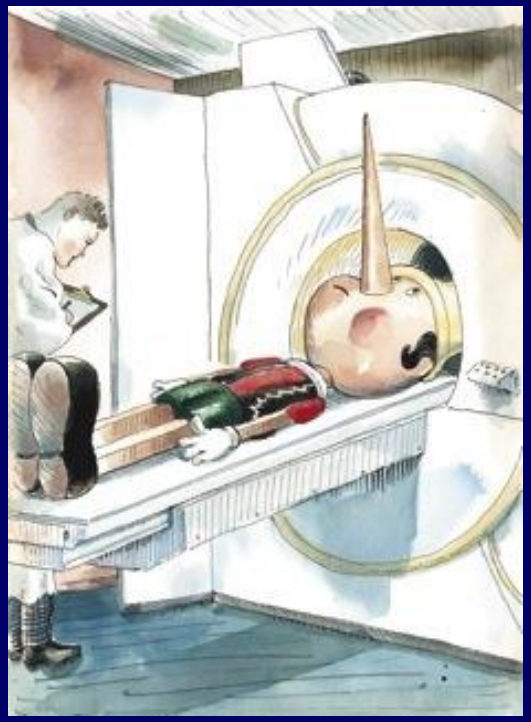
Manifest image of the world

The common view of humans. The way we see ourselves in ordinary life based on common sense assumptions about human nature.

?

Scientific image of the world

The scientific view of humans. The way we see humans given scientific knowledge. Questions and challenges the manifest image and beliefs underlying it.



Margaret Talbot. Duped. Can brain scans uncover lies? *The New Yorker*, July 2, 2007

Credit: Emma Zimmerman, Neuroethics Research Unit, IRCM

"Social Neuroscience is , above all else, the construction of a metaphysical mirror that will allow us to see ourselves for what we are and, perhaps, change our ways for the better." (Greene 2006)

OUTLINE

- **Does public communication and public understanding of neuroscience matter from an ethics standpoint? Why?**
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Research on media coverage of neuroscience innovation (neuroimaging, DBS)

fMRI in the public eye. *Nature Reviews Neuroscience* 2005; 6(2): 159-164.

Hyped biomedical science or uncritical reporting? Press coverage of genomics (1992-2001) in Quebec. *Social Science & Medicine* 2006; 62(5): 1278-1290.

Brain imaging: A decade of press coverage, *Science Communication* 2006; 28(1):122-143.

Currents of hope: Neurostimulation techniques in US and UK print media. *Cambridge Quarterly of Healthcare Ethics* 2007; 16(3): 314-318.

Internet marketing of neuroproducts: New practices and healthcare policy challenges. *Cambridge Quarterly of Healthcare Ethics* 2007; 16(2): 180-193.

Ethical issues in performance enhancing technologies: From bench to headline. *Technology* 2007; 11: 37-54.

Contemporary neuroscience in the media. *Social Science and Medicine* 2010; 71: 725-733

Research on media coverage and public understanding of "neurocognitive enhancers"

Ethical issues in performance enhancing technologies: From bench to headline. *Technology* 2007; 11: 37-54.

Disagreements with implications: Diverging discourses on the ethics of non-medical use of methylphenidate for performance enhancement, *BMC Medical Ethics* 2009; 10(9).

Autonomy and coercion in academic "cognitive enhancement" using methylphenidate: Perspectives of key stakeholders. *Neuroethics* 2009; 2(3): 163-177.f

Stakeholder perspectives and reactions to "academic" cognitive enhancement: Unsuspected meaning of ambivalence and analogies, *Public Understanding of Science* 2010

Cognitive enhancement, lifestyle choice or misuse of prescription drugs? Ethics blind spots in current debates. *Neuroethics* 2010; 3(1): 1-4.

Research on media coverage of neurological conditions (and end-of-life)

Media coverage of the persistent vegetative state and end-of-life decision-making: A case analysis of Terri Schiavo. *Neurology* 2008; 71: 1027-1032.

Depictions of "brain death" in the media: Implications for organ donation and public debate, *Journal of Medical Ethics* (in press)

How the public responded to the Schiavo controversy: Evidence from letters to editors, *Journal of Medical Ethics* 2010; **36**: 571-573.

Alzheimer's disease diet*ary supplements i*n websites, *HEC Forum* (in press)

Perspectives and experience of healthcare professionals on diagnosis, prognosis, and end-of-life decision making in patients with disorders of consciousness, *Neuroethics* 2013; 6: 25-36.

Research on the intersection of "formal" research ethics with concerns of researchers or clinicians

Perspectives of Canadian Researchers on Ethics Review of Neuroimaging Research**,** *Journal of Empirical Research on Human Research Ethics* 2010; 5(1): 49-66.

Ethical issues in psychiatric applications of deep brain stimulation: Learning from Canadian healthcare providers, *Journal of Ethics in Mental Health 2011;6:1-10.*

Hope and patient expectation in deep brain stimulation: Healthcare provider perspectives and approaches, *Journal of Clinical Ethics* 2010; 21(2): 113-125.

Ethical Issues in the Translation of Social Neuroscience: A Policy Analysis of Current Guidelines for Public Dialogue in Human Research, *Accountability in Research* 2012; 19: 27-46.

Theoretial and normative models for tackling the interface between ethics, public communication and neuroscience

Discourse ethics as an ethics of responsibility: Comparison and evaluation of citizen involvement in population genomics. *Journal of Law, Medicine & Ethics* 2003; 31(3): 390-397.

Neuroethical responsibilities. *Canadian Journal of Neurological Sciences* 2006, 33: 269-277

Neurotalk: Improving neuroscience communication. *Nature Reviews Neuroscience* 2010; 11(1): 61-9.

Imaging or imagining: A neuroethics challenge informed by genetics. *American Journal of Bioethics* 2005; 5(2): 5-18.

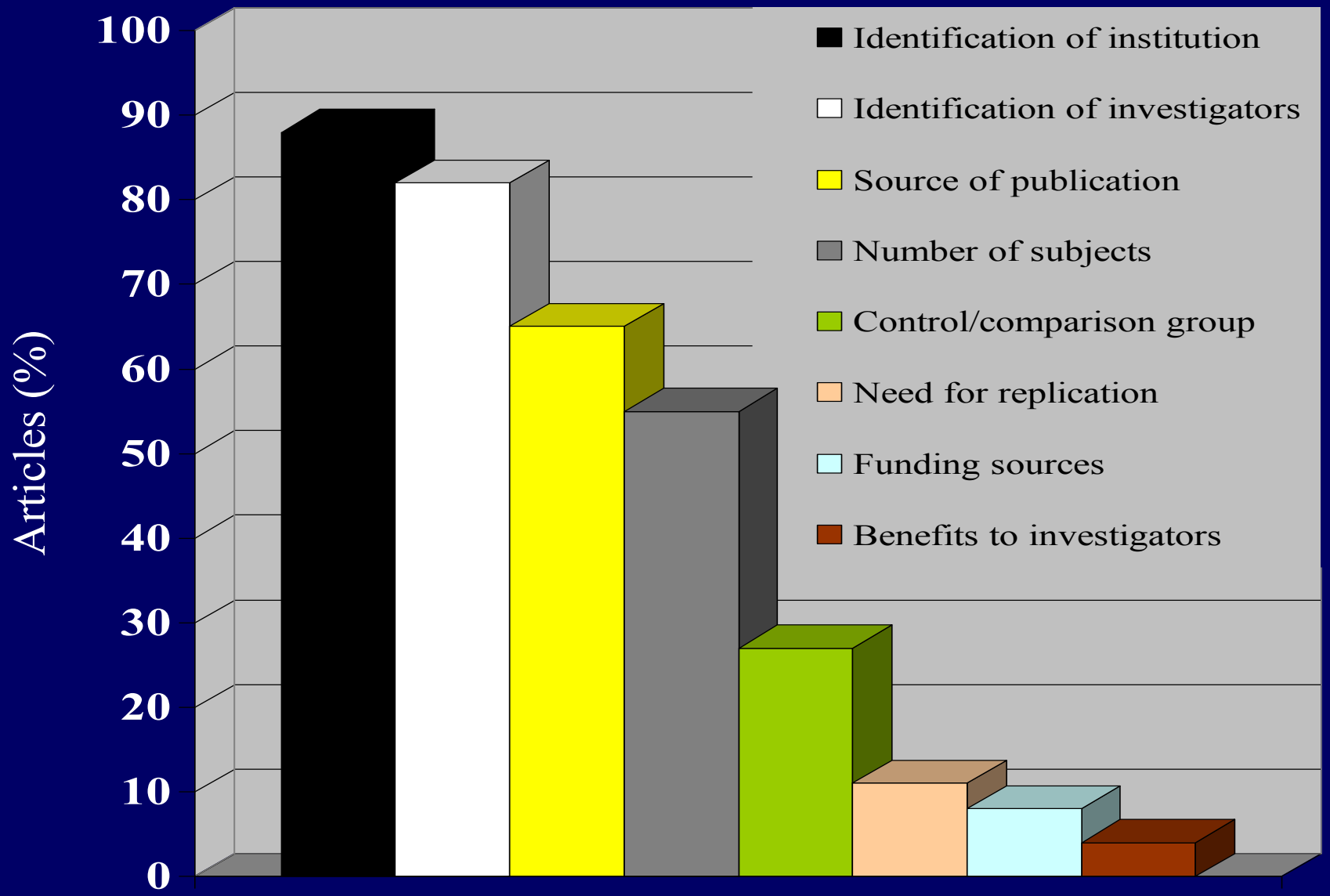
Pragmatic Neuroethics: Improving Treatment and Understanding of the Mind-Brain, MIT Press, 2010

OVERVIEW OF STUDIES ON MEDIA COVERAGE OF NEUROSCIENCE AND ETHICS

1. **Reporting practices are sub-optimal**
2. Balanced tone is not predominant
3. Shortcomings in scientific and medical explanations
4. Multiples sources of ethics debates and controversies
5. **Media coverage could lead to public misunderstanding, hype and false expectations**
6. **Media coverage could influence health behaviors and ethical views**
7. **Public understanding identified by different stakeholders as one of the key socio-ethical issues but limited guidance is available in this area**

Reviewed in Racine, 2011, OUP

OBSERVATION 1: REPORTING PRACTICES ARE SUB-OPTIMAL



From: large-scale study of neuroscience in international media

Racine MIT Press, 2010

OBSERVATION 5: MEDIA COVERAGE COULD LEAD TO PUBLIC MISUNDERSTANDING, HYPE AND FALSE EXPECTATIONS

SCIENCE AND SOCIETY

fMRI in the public eye

Eric Racine, Ofek Bar-Ilan and Judy Illes

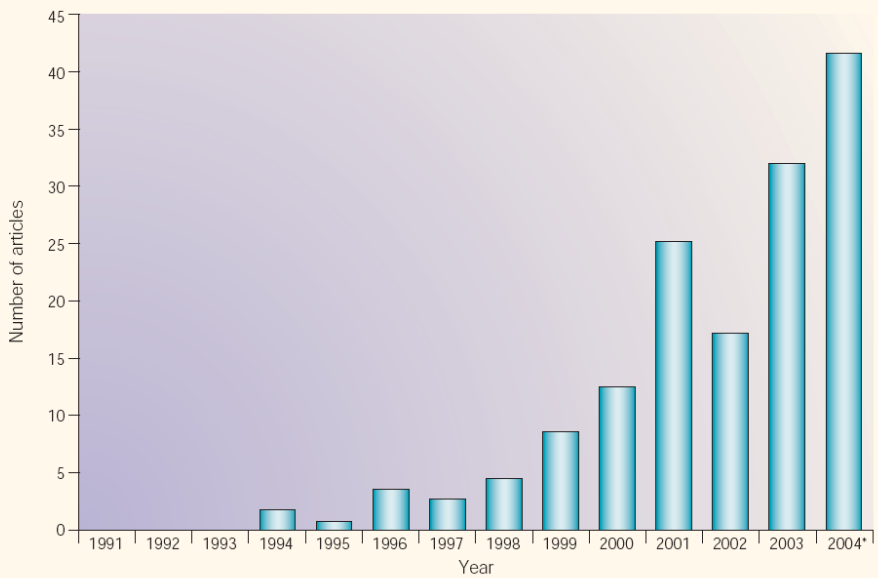


Figure 1 | **Composition of the sample of articles returned to a search of print media coverage (general and specialized sources combined) of fMRI from January 1991 to June 2004.**
*Projected value for 2004.

Neuro-realism

Our concept of 'neuro-realism' describes how coverage of fMRI investigations can make a phenomenon uncritically real, objective or effective in the eyes of the public. This occurs most notably when qualifications about results are not brought to the reader's attention. For example, commenting on an fMRI study of fear, one article[9] states, "Now scientists say the feeling is not only real, but they can show what happens in the brain to cause it." Many occurrences of neuro-realism deal with the effectiveness of health-related procedures

From: study of fMRI in international media

Racine et al. *Nature Reviews Neuroscience*, 2005

OBSERVATION 6: MEDIA COVERAGE COULD INFLUENCE HEALTH BEHAVIORS AND ETHICAL VIEWS

Figure 1. Print media coverage of neurostimulation techniques (1995–2004).

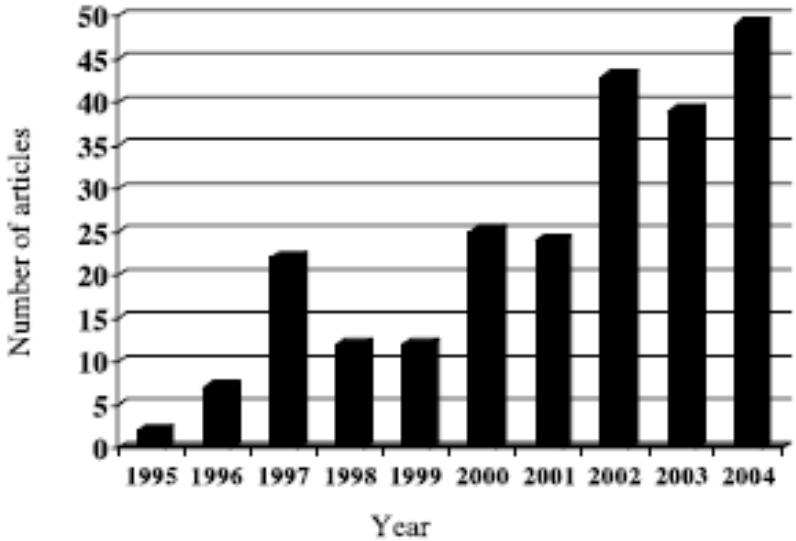


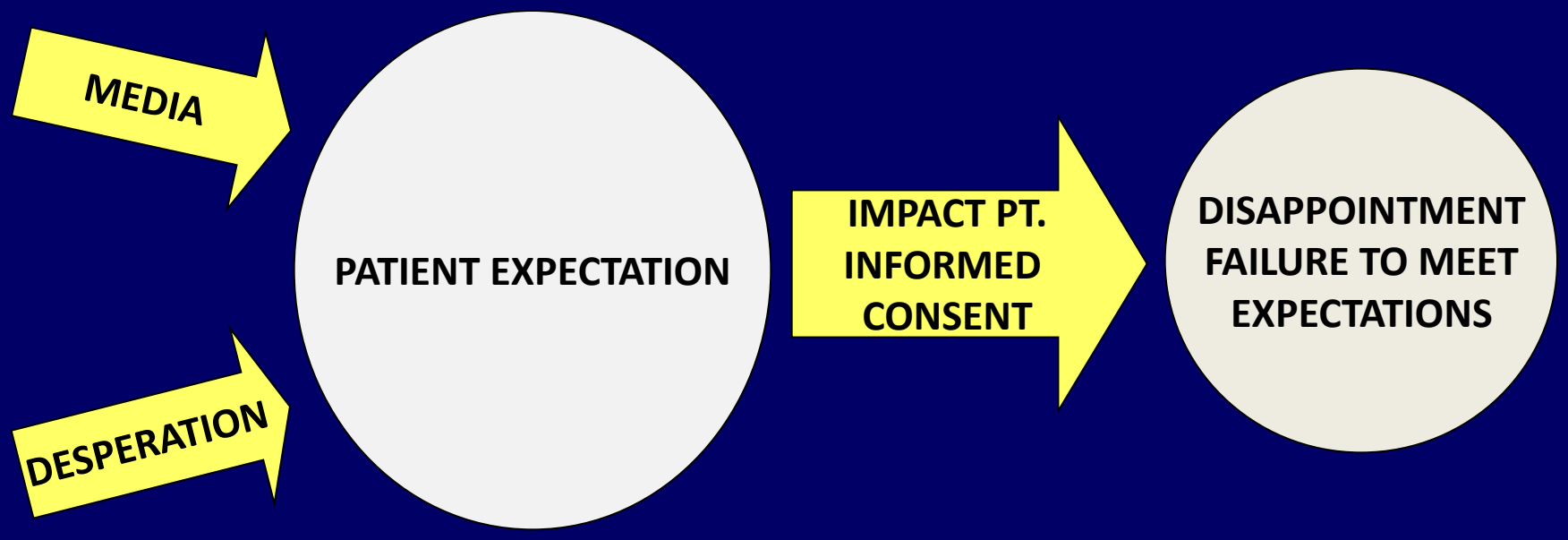
Table 1. Sample Headlines for Print Media Coverage of Neurostimulation Articles

New treatment headlines (41%)
"The potential of brain pacemakers. Implanted devices may alter treatment of many disorders" (*The Washington Post* 6 Mar 2006)
"Currents of hope—A revolutionary device. An electrical pacemaker implanted in the brain gives welcome relief to people afflicted by the shakiness of Parkinson's disease" (*Buffalo News* 11 May 2002)
"Magnetic appeal. New therapy that fights depression sparks a current of optimism" (*The Seattle Times* 27 Mar 2001)
Scientific breakthrough headlines (19%)
"With tiny brain implants, just thinking may make it so" (*The New York Times* 13 Apr 2004)
"Are cyborg troops our future army?" (*The Times* 16 Nov 2003)
"Brain signals shown to move a robot's arm" (*The New York Times* 16 Nov 2000)

Racine *et al*. *Cambride Quarterly of Healthcare Ethics*. 2007

From: study of neurostimulation in international media

In the clinical context, this media "hype" has interacted with hope and expectations in DBS for movement disorders challenge understandings of informed consent



Bell et al. (2010) *J Clin Ethics;* 21(2)

From: Multi-site study of DBS in Canadian neurosurgical programs

OBSERVATION 7: PUBLIC UNDERSTANDING IDENTIFIED AS KEY SOCIO-ETHICAL ISSUES BUT LIMITED GUIDANCE AVAILABLE

Ethical, legal and social issues	Very Poorly	Poorly	Adequately	Well	Very Well
Incidental findings	4%	25%	36%	18%	16%
Transfer of knowledge and public understanding	**8%**	**19%**	47%	18%	8%
Commercialization	5%	18%	49%	22%	6%
Risk assessment	2%	16%	37%	20%	25%
Scientific validity	2%	11%	39%	35%	13%
Conflict of interest	3%	12%	38%	33%	14%
Privacy of thought	1%	10%	24%	30%	34%
Identification of risks	2%	8%	32%	23%	24%
Stigma and discrimination	2%	4%	38%	30%	26%
Confidentiality	0%	4%	23%	34%	38%
Vulnerable populations	1%	2%	26%	39%	32%
Recruitment practices	0%	3%	33%	33%	31%
Decisional capacity	1%	0%	27%	44%	28%
Informed consent	0%	1%	23%	36%	40%

From: study of Canadian neuroimagers

Deslauriers et al. 2010

LIMITED GUIDANCE IN A REVIEW OF EXISTING INTERNATIONAL RESEARCH ETHICS POLICIES

	Public Understanding	Knowledge Translation	Social Outcomes	Public Participation
Nuremberg Code Intl, 1947	---	Scientific research should produce "fruitful results" for the benefit of society.	Excessive harms to the individual should not be justified by the social benefits of research.	---
Declaration of Helsinki Intl, 1964*, 2004	---	Authors and publishers have ethical obligations to make both negative and positive results of research publicly available.	Before research begins there should be an assessment of "foreseeable benefits to the subject or to others."	---
CIOMS Guidelines for Biomedical Research Involving Human Subjects Intl, 1993*, 2002	Care should be taken in publication of research when it could increase stigma and discrimination.	Research which presents "risks to the interest of communities" should be published in a manner that is respectful of the interests of those concerned, or in some cases not published.	Some research "may present risks to the interest of communities, societies, or racially or ethnically defined groups" by contributing to the stigma of those groups.	---
International Conference on Harmonisation, Good Clinical Practice Intl, 1997	---	---	"The Institutional Review Board should not consider possible long-range effects of applying knowledge gained in the research (e.g., the possible effects of the research on public policy)."	---
The Belmont Report US, 1979	---	The "improvement of knowledge (…) the development of novel medical, psychotherapeutic, and social procedures" are risks and benefits of research translation.	Social harms to the individual should be considered in the review of harms and benefits of research.	---
Title 45 Code of Federal Regulations, Part 46 US, 1991	---	---	---	---
Tri-Council Policy Statement CA, 1998	---	Journal editors, journalists, and peer review boards have an obligation to disseminate both positive and negative results of research to the research community and to the public.	The merit of research should not be judged on whether it is "controversial, challenge(s) mainstream thought, or offend(s) powerful or vocal interest groups."	Research involving aboriginal peoples should "respect the culture, traditions" and involve them in "the conduct, direction, sponsorship or implementation of the research."
National Statement on Ethical Conduct in Human Research AUS, 2007	Research involving aboriginal peoples should involve these communities in the interpretation of the research.	Researchers are responsible for the dissemination and communication of results of both positive and negative results for "public knowledge and understanding."	"Researchers should consider the potential psychological, social and cultural significance of their research."	Research with aboriginal peoples should "draw on their knowledge and wisdom" and allow them to take an "active engagement in the research processes."
Medical Research Council Good Research Practice UK, 2005	---	In the reporting of results it is unethical to "exaggerate the importance of results for medical practice or policy."	---	---
Economic and Social Research Council Research Ethics Framework UK, 2005	---	Research ethics covers the whole process, from "inception through to completion and publication of results and beyond."	The REB should give "due regard to the consequences of the proposed research for (…) those (…) who might benefit or suffer from its outcomes in the future."	---

From: review of international ethics guidance

Zimmerman & Racine, *Accountability in Research*

OUTLINE

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- **What are some potentially problematic aspects of public communication/understanding?**
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"The pessimist sees difficulty in every opportunity.

The optimist sees the opportunity in every difficulty."

Winston Churchill

THE "NEUROTALK" MODEL

Table 3 | **Recommendations and action for improving neuroscience communication**

Individual neuroscientists	Academic institutions	Professional organizations	Research sponsors
Introduce and promote a shift in academic culture			
• Give public lectures; participate in public discussions and debates • Support the efforts of trainees and junior faculty to lead interactive public events • Explore and become familiar with uses of new media • Organize local training opportunities, including interactions with experienced communicators and journalists • Participate in ongoing research, including the identification of the needs and priorities as well as the qualities of good neuroscience communicators	• Develop metrics for valuing neuroscience communication towards career advancement • Invest in opportunities for internships and attendance by trainees and faculty at communication programmes • Provide financial and staff resources for faculty and trainee-led public events • Provide time off from teaching, research and administration for neuroscience communication • Attribute awards for outstanding public-communication accomplishments • Integrate neuroscience communication into graduate training curricula • Consider neuroscience communication accomplishments in the evaluation of faculty for promotion and advancement	• Build on existing programmes to create customized communication programmes for neuroscience • Proactively encourage academic institutions to include neuroscience communication activities in faculty career advancement	• Support neuroscience communication in requests for proposals and open competitions • Develop funding opportunities for public engagement activities and collaboration
Train and support communication specialists in neuroscience			
• Volunteer to serve as neuroscience communicators and knowledge brokers • Pursue specialized training experiences for all aspects of neuroscience communication: basic, clinical, ethical and societal • Provide mentorship to junior faculty and develop relevant curricula • Master new forms of communication tools such as podcasts and webcasts • Actively attend to neuroscience in the news and be available to clarify and comment • Develop relationships with trusted journalists and disseminate potentially newsworthy results	• Send trainees and faculty who self-identify and who exhibit potential excellence in neuroscience communication to specialized programmes • Identify excellent communicators and nurture them with academic currency • Develop cross-disciplinary academic programmes that will yield Master's- and PhD-level experts in neuroscience communication	• Create new programmes for neuroscience communication and public engagement • Provide material and resources for quotes and easy fact checking in press coverage • Enable journalists to acquire specialized training in neuroscience	• Create funding opportunities for training in neuroscience communication
Develop and carry out research in communication and public engagement			
• Develop and participate in research on science communication and public engagement • Explore and embrace relevant new research approaches and methods to support evidence-based practices • Engage in the development, implementation and testing of new initiatives on public neuroscience literacy • Encourage trainees showing interest in an alternative career in science to pursue research on communication and public and engagement	• Seed in-house pilot research on neuroscience communication and public engagement • Create metrics for the outcome and impact of communication and public engagement • Encourage the evaluation of public events and recognize excellence • Value interdisciplinary collaboration and grant funding in neuroscience communication • Encourage flexibility in training curricula to take into account new empirical data on neuroscience communication	• Update existing tools and create new programmes based on emerging empirical data.	• Develop dedicated research funding opportunities in the area of neuroscience communication and public engagement

Illes et al. Nature Reviews Neuroscience, 2010

IN CONCLUSION…

PUBLIC COMMUNICATION AND PUBLIC UNDERSTANDING OF NEUROSCIENCE:

- **Represent a potential source of "harms" and "ethical challenges" (e.g.,** create pressures for premature uses; support unwarranted use; fuel misleading expectations)

- **Constitute a terrain of "ethical duties" and "benefits" (e.g.,** promote sounder public understanding; engage researchers in public information and outreach; adopt proactive strategies to handle ethical and social issues)

- **Is a relevant and interesting area where several empirical and normative questions need to be addressed**

Acknowledgments

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FONDATION BROCHER

SSHRC CRSH

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

IRCM
Institut de recherches cliniques de Montréal

Fonds de la recherche en santé Québec

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