

Prepared by the
Neuroethics research unit
at the IRCM

Préparé par l'unité de
recherche en neuroéthique
de l'IRCM

neuroethics@ircm.qc.ca

BRAINSTORM

A newsletter about ethics, neuroscience, and society
Un bulletin sur l'éthique, les neurosciences et la société

Brainstorm

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Editorial team / Équipe éditoriale

John Aspler,
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Dearbhail
Bracken-Roche,
Editor / Éditrice

Eric Racine, PhD,
Editor-in-chief/
Éditeur en chef

IRCM

Profile | Profil



James M. DuBois, PhD, DSc, completed a PhD in philosophy with Barry Smith (the ontologist) at the International Academy of Philosophy in Liechtenstein and a DSc (Dr. rer. nat) in experimental psychology with Giselher Guttman at the University of Vienna in Austria. He is currently the Steven J. Bander Professor of Medical Ethics and Professionalism, Professor of Psychology, and Director of the [Center for Clinical Research Ethics](#) at Washington University School of Medicine. He directs the [Professional and Social Issues Lab](#) in the Division of General Medical Sciences. His work intersects with neuroethics in three ways. First, he has published extensively on ethics in mental health research, including articles in *JAMA Psychiatry* and a book with Oxford University Press, *Ethics in Mental Health Research* (2008; 2nd edition expected in 2016). Second, he has conducted social science research on the ethical issues surrounding mental health research. Finally, he has done policy work and social science research on neurological criteria for determining death (so-called

brain death criteria). He also founded and co-edits a journal, *Narrative Inquiry in Bioethics: A Journal of Qualitative Research (NIB)*, which is published by Johns Hopkins University Press. NIB publishes qualitative research articles on diverse topics, including topics pertaining to neuroethics. NIB also publishes collections of first-person narratives on common themes. Past issues have addressed experiences of psychiatric hospitalization, raising a child with diagnosed with a brain tumor, and living with the label of “disability”. His most recent work has focused on helping researchers do good work, which has included studying factors that contribute to research integrity and deviations from research rules, as well as offering intensive workshop training (the [PI Program](#)) for investigators who have had breaches of integrity or compliance in their labs.

Statement on neuroethics: “I believe that neuroethics must be highly interdisciplinary—involving the collaboration of neuroscientists, philosophers, and social scientists—to meet the challenges posed by novel scientific and therapeutic possibilities.”

Sample Publications:

DuBois, J.M., H. Bante, & Hadley, W. (2011). “Ethics in psychiatric research: A review of 25-years of NIH-funded empirical research,” *American Journal of Bioethics—Primary Research*, 2(4): 5-17.

DuBois, J.M., Cottler, L., Callahan, C., (2009) “The attitudes of females in drug court toward additional safeguards in HIV prevention research,” *Prevention Science*, 10: 345-352.

DuBois, J.M. (2010) “The ethics of creating and responding to doubts about death criteria,” *Journal of Medicine and Philosophy*, 35: 365-380.

If you would like to post any events, announcements, or news of interest please contact us at neuroethics@ircm.qc.ca (subject line: **Brainstorm Events and Announcements**)



Announcements | Annonces

Call for Abstracts: Reductionism and Integration, Bioethics and Behaviour: A Conference Celebrating the Career of Kenneth F Schaffner, 23-24 September 2016, Pittsburgh, PA
Submission Deadline: March 1, 2016, [click here for more info.](#)

Call for Proposals: American Society for Bioethics and Humanities 18th Annual Meeting, October 6-9, 2016, Washington, D. C.
Submission Deadline: March 4, 2016, [click here for more info.](#)

Summer Course: Ethics in Dementia Care, 6-8 July, 2016, Leuven, Belgium
Early Bird Deadline: May 16th, 2016, [click here for more info.](#)

Events | Événements

Leverhulme Lectures: Professor Neil Levy
Lecture 1: The Nature and the Significance of Implicit Bias
Date: Thursday, 4 February, 1.00-3.00pm
Venue: Oxford Martin School Lecture Theatre
Booking: Please book for each lecture separately at bookwhen.com/Uehiro
Lecture 2: Moral Responsibility and Implicit Bias
Date: Thursday, 11 February, 1.00-3.00pm
Booking: Please book for each lecture separately at bookwhen.com/Uehiro

Montreal Neuroethics Network Seminar: "The neuroethics of fMRI-based 'pain-o-meters' for diagnostic, medical-legal, and insurance purposes" - Karen Davis, PhD
Date: March 3, 2016, 12:00pm-1:00pm
Location: 110, avenue des Pins Ouest, Room André-Barbeau, Institut de recherches cliniques de Montréal (IRCM)

Approaching the Sacred: Science, Health and Practices of Care
Date: March 4-6, 2016
Location: Houston, TX, [click here for information and registration.](#)

The Healthcare Ethics Consortium (HEC) and the Emory University Center for Ethics 2016 Annual Conference: Are We Hearing Our Patients' Voices? Georgia, USA
Date: March 17-18, 2016
Location: Evergreen Conference Center, Stone Mountain, Georgia, [click here for more info.](#)

Announcements | Annonces



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Postdoctoral fellowship or graduate student scholarship* Area of research: Vulnerability and mental health research ethics

Neuroethics research unit – Institut de recherches cliniques de Montréal (IRCM)
Supported by the Canadian Institutes of Health Research (CIHR)

*This offer could be transformed into a scholarship for a graduate student supervised at the IRCM

We are seeking a postdoctoral fellow or graduate student to join the Neuroethics research unit (www.ircm.qc.ca/neuroethics/) to lead research examining ethical and social issues in mental health research. Our project will investigate the theoretical assumptions and practical implications of the concept of "vulnerability" in research with psychiatric patients. Outcomes of this project would include novel and original work examining how the concept of vulnerability affects research ethics policies and practices. This position is funded by a grant from the Canadian Institutes of Health Research. This is a 12-month position with possible renewal.

REQUIREMENTS

- PhD training in bioethics or social science or philosophy or health sciences/mental health (undergraduate degree for candidates to the graduate student scholarship)
- Interest in pursuing theoretical and empirical research in neuroethics
- Very good communication and interpersonal skills
- Publication and scientific communication experience
- Organization skills and proficient time management
- Interdisciplinary teamwork experience an asset
- Ideally, experience in action research or stakeholder research

DEADLINES

Position remains open until filled.
Start date: as soon as March 1, 2016

APPLICATIONS

Submit a resume (CV), cover letter and two reference letters to **Eric Racine**, PhD, Director of the Neuroethics research unit, by email at neuroethics@ircm.qc.ca. Please specify whether you are applying for postdoctoral fellowship or graduate scholarship. Only those selected for an interview will be contacted.

Announcements | Annonces



Bourse postdoctorale ou bourse d'études supérieures*

Domaine de recherche : vulnérabilité et éthique de la recherche
en santé mentale

Unité de recherche en neuroéthique - Institut de recherches cliniques de Montréal (IRCM)
Avec l'appui des Instituts de recherche en santé du Canada (IRSC)

*Ce poste peut être transformé en bourse d'études pour un étudiant au 2e ou 3e cycle supervisé à l'IRCM

Nous sommes à la recherche d'un(e) stagiaire postdoctoral(e) ou d'un(e) étudiant(e) diplômé(e) souhaitant se joindre à l'unité de recherche en neuroéthique (<http://www.ircm.qc.ca/neuroethics>) pour mener un projet recherche portant sur les enjeux éthiques et sociaux en recherche sur la santé mentale. Le projet évaluera les suppositions théoriques et les implications pratiques entourant le concept de « vulnérabilité » dans la recherche avec des patients en psychiatrie. Le résultat pressenti est un travail original et novateur, examinant en quoi le concept de vulnérabilité affecte les politiques éthiques de la recherche et les pratiques qui y sont associées. Ce poste est offert grâce à une subvention des Instituts de recherche en santé du Canada. Il s'agit d'un poste de 12 mois avec possibilité de renouvellement.

EXIGENCES

- Études doctorales en bioéthique ou en sciences sociales ou en philosophie ou en sciences de la santé ou en santé mentale (diplôme de 1er cycle pour les candidats visant la bourse d'études supérieures)
- Intérêt à poursuivre de la recherche théorique et empirique en neuroéthique
- Très bonnes habiletés interpersonnelles et de communication
- Habiletés organisationnelles et gestion efficace du temps
- Expérience de publication et de communication scientifiques
- Expérience de travail dans le cadre d'une équipe interdisciplinaire un atout
- Idéalement, expérience en recherche-action ou recherche de terrain

DATES LIMITES

Le poste demeure ouvert jusqu'à ce qu'il soit comblé.
Date d'embauche : dès le 1er mars 2016

CANDIDATURES

Faites parvenir votre CV, une lettre de motivation et deux lettres de référence à l'attention d'**Eric Racine**, Ph. D., directeur de l'unité de recherche en neuroéthique, par courriel à neuroethics@ircm.qc.ca. Nous ne communiquerons qu'avec les personnes dont la candidature aura été retenue.

[Click here
for more
info!](#)

Announcements | Annonces



Postdoctoral Fellowship or Graduate Student Scholarship*

Area of research: Ethical, legal and social aspects of brain-computer interfaces (BCI)

Neuroethics research unit – Institut de recherches cliniques de Montréal (IRCM)

With the support of the: Canadian Institutes of Health Research (CIHR), Fonds de recherche du Québec – Santé (FRQ-S) & NEURON-ERANET

*This offer could be transformed into a scholarship for a graduate student supervised at the IRCM

We are seeking a postdoctoral fellow or graduate student to join the Neuroethics Research Unit (www.ircm.qc.ca/neuroethics/en/) to lead research examining ethical and social issues in the use of brain-computer interfaces (BCI). In partnership with European research centers, this project aims to pursue online survey research and novel translational ethics and social science research approaches on BCI. The outcomes of this project will include, for example, a policy brief for decision-makers and the creation of a video podcast informing the public about ELSA aspects of BCI. This position is funded by a grant from the Canadian Institutes of Health Research and the Fonds de recherche du Québec – Santé. This is a 12-month renewable position.

REQUIREMENTS

- Ph.D. training in social science or bioethics or relevant health sciences*
- Interest in pursuing theoretical and empirical research in neuroethics
- Very good communication and interpersonal skills
- Publication and scientific communication experience
- Organization skills and proficient time management
- Interdisciplinary teamwork experience an asset
- Ideally, experience in online survey research and novel knowledge translation methods

DEADLINES

Position remains open until filled.
Start date: as soon as March 15, 2016.

APPLICATIONS

Submit a resume (CV), cover letter and two reference letters to **Eric Racine**, PhD, Director of the Neuroethics research unit, by email at neuroethics@ircm.qc.ca. Please specify whether you are applying for a postdoctoral fellowship or graduate scholarship. Only those selected for an interview will be contacted.

*Undergraduate degree for candidates to the graduate student scholarship

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Announcements | Annonces



Bourse postdoctorale ou bourse d'études supérieures*

Domaine de recherche: Aspects éthiques, légaux et sociaux des interfaces cerveau-ordinateur (ICO)

Unité de recherche en neuroéthique - Institut de recherches cliniques de Montréal (IRCM)

Avec l'appui des Instituts de recherche en santé du Canada (IRSC), du Fonds de recherche du Québec – Santé (FRQ-S) & NEURON-ERANET

*Ce poste peut être transformé en bourse d'études pour un étudiant au 2e ou 3e cycle supervisé à l'IRCM

Nous sommes à la recherche d'un stagiaire postdoctoral ou d'un étudiant gradué souhaitant se joindre à l'Unité de recherche en neuroéthique (<http://www.ircm.qc.ca/neuroethics>) pour mener un projet de recherche portant sur les enjeux éthiques et sociaux associés à l'utilisation des interfaces cerveau-ordinateur (ICO). En partenariat avec des centres de recherche européens, ce projet vise à réaliser une recherche par sondage en ligne ainsi que mettre en œuvre de nouvelles approches de recherche translationnelle en éthique et en sciences sociales au sujet des ICO. Cette recherche inclura, entre autres, la rédaction d'un document d'orientation destiné aux décideurs politiques ainsi que la création d'un podcast visant à informer le public des enjeux éthiques, sociaux et légaux des ICO. Ce poste est offert grâce à une subvention des Instituts de recherche en santé du Canada et des Fonds de recherche du Québec – Santé. Il s'agit d'un poste de 12 mois avec possibilité de renouvellement. affecte les politiques éthiques de la recherche et les pratiques qui y sont associées. Ce poste est offert grâce à une subvention des Instituts de recherche en santé du Canada. Il s'agit d'un poste de 12 mois avec possibilité de renouvellement.

EXIGENCES

- Études doctorales en bioéthique ou en sciences sociales ou en sciences de la santé*
- Intérêt à poursuivre de la recherche théorique et empirique en neuroéthique
- Très bonnes habiletés interpersonnelles et de communication
- Habiletés organisationnelles et gestion efficace du temps
- Expérience de publication et de communication scientifiques
- Expérience de travail dans le cadre d'une équipe interdisciplinaire un atout
- Idéalement, expérience en recherche par sondage en ligne et dans les nouvelles méthodes d'application des connaissances

*Diplôme de 1er cycle pour les candidats visant la bourse d'études supérieures

DATES LIMITES

Le poste demeure ouvert jusqu'à ce qu'il soit comblé.
Date d'embauche : aussi tôt que le 15 mars 2016.

CANDIDATURES

Faites parvenir votre CV, une lettre de motivation et deux lettres de référence à l'attention d'**Eric Racine**, Ph. D., directeur de l'unité de recherche en neuroéthique, par courriel à neuroethics@ircm.qc.ca. Nous ne communiquerons qu'avec les personnes dont la candidature aura été retenue.

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International Neuroethics Forum

Communication in Severe Brain Injury

Walter Glannon, PhD
University of Calgary

One of the most controversial ethical issues in neurology is whether patients with severe brain injury can reliably communicate with caregivers. Observational techniques can enable some patients to respond with 'Yes' or 'No' answers to questions, and these responses may correlate with changes in neural activity confirmed by EEG and functional brain imaging. Yet this is at best only an indirect and imperfect means of knowing what a patient is feeling or thinking. Imagine if we had more effective tools and could use them to communicate with patients about their medical wishes. For example, in the 2011 case of *W v. M*, the English Court of Protection ruled that it would be unlawful for M's family to withdraw artificial hydration and nutrition. M had been in a minimally conscious state (MCS) for 8 years, at the high end of the MCS spectrum, suggesting a considerable degree of cognitive capacity remained intact. Had she been able to communicate her treatment wishes, the conflict between the Court and her family would have been resolved, and ensured that medical decisions about her care were in her best interests.

Advanced fMRI- and EEG-guided brain-computer interfaces (BCIs) might enable some locked-in, or minimally conscious, patients to make informed decisions about their care when they are unable to do this otherwise. Output from an interface system in theory could confirm they had decisional capacity, and allow clear expression of their experiences and wishes. For example, BCI-mediated communication could confirm that a minimally conscious or completely locked-in patient was in pain, which could be relieved with analgesia.

Davinia Fernandez-Espejo and Adrian Owen acknowledge that, with current interface technology, simple affirmative or negative responses by MCS patients to questions about whether they wanted to continue living would not be sufficient to establish the "cognitive and emotional capacity to make such a complex decision", yet they also say that "it is only a matter of time before all of these obstacles are overcome". Even with advances in BCIs, however, what a patient could express through this technique would not necessarily constitute evidence for the capacity to make decisions about life-sustaining treatment.

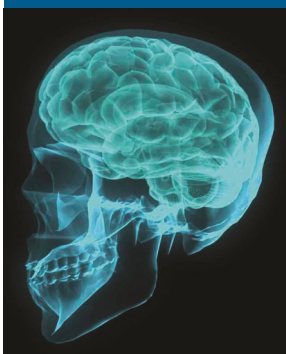
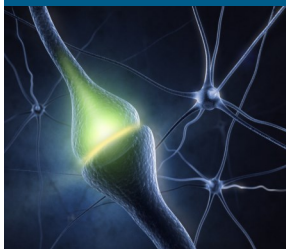
Medical professionals and caregivers must be cautious not to read too much into BCI-mediated responses, or interpret them as having a meaning they lack. By the same token, they must not be overly paternalistic in ignoring a meaning these responses might have. Even if BCIs could assist patients express their wishes about treatment, there will be variation among patients in attitudes and clarity of expression. Some investigators indicate that locked-in patients with some ability to communicate have reported a good quality of life, which may be attributed to family and

International Neuroethics Forum

caregiver support. However, not all minimally conscious or locked-in patients would, if able, express a positive attitude about their condition. For example, [Tony Nicklinson](#), who was locked-in and paralyzed from the neck down for 7 years following a stroke, requested to the United Kingdom Supreme Court to be allowed to end his life with the help of a physician. The Court rejected his request in August 2012 just six days before he died from pneumonia at age 58. Communicating via a computer, which he operated by eyelid movements, [Nicklinson said](#) that he wanted to end his “dull, miserable, demeaning, undignified and intolerable life”.

BCI-enabled communication might clarify patient interests in continuing or discontinuing artificial hydration and nutrition. It could help to resolve conflicts between families and practitioners about appropriate care when patients’ interests are not known. In many cases, evidence of consciousness may give families hope in recovery, and move them to request continuation of, if not an increase in, treatment. Yet the extent of the brain injury in some cases may mean palliative care is a more reasonable course of action, and more in line with the patient’s wishes. [Leigh Hochberg and Merit Cudkowicz](#) recently pointed out that technology enabling decision-making about life-sustaining care “by proclamation rather than by proxy will be revolutionary”. The capacity to reliably communicate wishes and make decisions could give patients some control over their lives. Device makers, investigators and clinicians should encourage patients and their families to become involved in the development and application of this technology, so that it will promote their best medical and psychological interests. This could come through participation in clinical trials testing BCI safety and efficacy. Still, questions remain about whether these brain interventions could confirm that patients had these capacities, and could in fact enable them to make and clearly express such momentous decisions.

Walter Glannon (wglannon@ucalgary.ca) is a professor of philosophy at the University of Calgary. He writes and speaks about theoretical and clinical neuroethics and is the editor of [Free Will and the Brain](#) (Cambridge, 2015), and author of both [Brain, Body and Mind](#) (Oxford, 2011) and [Bioethics and the Brain](#) (Oxford, 2007).



Literature | Littérature

ARTICLES

[Parent ratings of ability to consent for clinical trials in fragile X syndrome.](#)

Bailey DB Jr, Raspa M, Wheeler A, Edwards A, Bishop E, Bann C, Borasky D, Appelbaum PS. J Empir Res Hum Res Ethics. 2014 Jul; 9(3): 18-28.

[Getting Serious About Reducing Suicide: More "How" and Less "Why".](#)

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[Ethics rounds do not improve the handling of ethical issues by psychiatric staff.](#)

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[Disclosure of positron emission tomography amyloid imaging results: A preliminary study of safety and tolerability.](#)

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[Are neurosurgeons prepared to electively resample glioblastoma in patients without symptomatic relapse? A qualitative study.](#)

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[You Present like a Drug Addict: Patient and Clinician Perspectives on Trust and Trustworthiness in Chronic Pain Management.](#)

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["Decision-making capacity for research participation among addicted people: a cross-sectional study".](#)

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[Values and DSM-5: looking at the debate on attenuated psychosis syndrome](#)

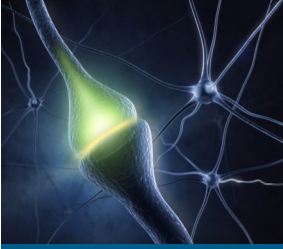
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[Neuroethics beyond Normal.](#)

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Literature | Littérature

[Drinking During Pregnancy and the Developing Brain: Is Any Amount Safe?](#)

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[Newspaper reporting and the emergence of charcoal burning suicide in Taiwan: A mixed methods approach.](#)

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NEWS AND SOCIAL MEDIA

[The story behind a vegetative patient's shocking recovery](#)

Lunau K. Macleans. December 31, 2015.

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[Where Are We Now? – David Bowie and Psychosis](#)

Bell V. Mind Hacks. January 13, 2016.

[When Healing Hurts: Psychological Trauma in the ICU](#)

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[6 Hospitalized, One of Them Brain-Dead, After Drug Trial in France](#)

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[This mother drank while pregnant. Here's what her daughter's like at 43.](#)

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Resources | Ressources

[University of British Columbia, National Core for Neuroethics](#)

[Neuroethics at the University of Pennsylvania](#)

[International Neuroethics Society](#)

[Neuroethics Research Unit / L'Unité de recherche en neuroéthique](#)

[Journal of Ethics in Mental Health](#)

[Novel Techethics](#)

[Neuroethics at the Stanford Center for Biomedical Ethics](#)

[Berman Institute of Bioethics' Program in Ethics and Brain Sciences](#)

[Centre interfacultaire en bioéthique et sciences humaines en médecine](#)

[The Neuroethics Blog](#)

[Emory Program in Neuroethics](#)

[American Journal of Bioethics Neuroscience](#)

[Neuroethics Women \(NEW\) Leaders](#)



Brainstorm 110, avenue des Pins Ouest, Montréal (Québec) H2W 1R7

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