



NEUROETHICS IN ACTION

NEUROETHICS CANADA
THE UNIVERSITY OF BRITISH COLUMBIA

2211 Wesbrook Mall, Koerner S124, Vancouver, BC, Canada V6T 2B5
www.neuroethicscanada.ca

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From neuroscience to
neurotechnology

Our understanding of the human mind and brain is advancing at an unprecedented rate. Scientific advances enable us to examine, manipulate, and extend the functioning of the brain in ways that were hard to even imagine a decade or two ago.

These neuroscientific advances are now driving a fast growing neurotechnology sector. For example, several major pharmaceutical companies have pivoted to focus primarily on neurological drugs, and over 65 companies and 6 venture capital firms now belong to the Neurotechnology Industry Organization.

As a society, we can let the self-interest of the market dictate how these advances in neuroscience and neurotechnology are applied. Or we can collaboratively make deliberate choices via explicit, evidence-based policy discussions engaging a broad range of people.

Neuroethics:
the interdisciplinary core

Neuroethics is the interdisciplinary core that brings clarity and empirical rigor to the people and institutions making these difficult choices on how neurotechnology will actually be used.

Neuroethics Canada (formerly known as the National Core for Neuroethics) has been doing this work for ten years now. Over \$5M has been invested in the Core by Canadian and US governmental agencies seeking a formal, interdisciplinary process to address all the ethical, legal, and economic issues encountered when neuroscience research is moved from the laboratory into clinical practice or commercial technology.

How is Neuroethics
affecting lives today?

Nine vignettes highlighting the human dimensions and impact of neuroethics accompany this document. These stories show how neuroethics research is already helping people and health-care providers make difficult decisions in areas as diverse as e-health, predicting and preventing Alzheimer Disease, and the banking of personal tissue and data.

What is Neuroethics?

Neuroethics, as practiced by Neuroethics Canada, is not some abstract theoretical or philosophical quest.

Neuroethics is **empirical** research into specific questions concerning the likely impacts of particular neurotechnologies. It is **actionable** research that informs and influences policy-making and implementation, and leads to the development of guidelines for training and best practices.

In order to conduct this research, researchers at the Core have developed several experimental techniques that enable gathering

reliable, reproducible data from:

- small groups of “experts” (such as patients, advocacy groups, medical practitioners, lawyers);
- large public groups (international in scope); and
- thousands of people interacting via social media.

These research techniques have been used to answer questions of broad interest, such as a) the validity and ethical standards of advances in e-health and commercial online tests for Alzheimer's Disease; b) ethics, policy and law in stem cell research; and c) the prescription of antipsychotic drugs for children with mental health disorders.

We have also been commissioned by health research agencies to answer specific questions as to whether and how a particular neurotechnology should be deployed (e.g., using neuroimaging to detect possible signals of consciousness in patients that appear to be vegetative).

Who needs Neuroethics?

The advances in neuroscience and the rise of neurotechnology generate ethical, social, legal, and economic consequences that impact decision-making at many public and private institutions:

- Governments and health-care providers faced with novel neurological diagnoses and treatments;
- Legislatures and courts interpreting new definitions of criminal responsibility;
- CEOs and business committed to quality of life, productivity and fairness in the workforce and society;
- Schools, universities, and corporations coping with the competitive and legal consequences of neurotechnology to enhance performance, attention and focus.

Vignettes written by:

Katelyn Verstaten, MA

2013 National Core for Neuroethics and NeuroDevNet Summer Journalism Intern

The University of British Columbia



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Did you know?

- 70% of adults track at least one health indicator online, such as weight, mood or cognition. eHealth calls for new research into the ethics of online resources and interventions.
- Over 80% of Internet users go online for health information.
- 1 in 5 online resources about dementia are trying to sell you something.
- The majority of online tests for dementia are not scientifically valid.

Imagine if you could rely on online health resources to make the best decisions about your health without worrying about scams and fraud?

The eHealth Research Program of Neuroethics Canada, led by Dr. Julie Robillard, studies how online health information can help and hurt you, and applies this to the development of resources you and your doctor can rely on.

This program has already delivered results on the topics of gene therapy, stem cell therapy, and dementia prevention and diagnosis. As online platforms and tools are becoming a dominant influence in how we make decisions about our health, we continue to vigorously study and monitor the dynamic online environment to ensure our connected health world benefits you and those you care about.

Our eHealth research is focused on:

- Scientific validity
- Conflict of interest
- Privacy and confidentiality
- Validity of online consent
- Impact on health decision-making
- Limitations of potential harms
- Integration of resources in the patient-physician relationship
- Attitudes towards technology
- Outreach to vulnerable populations



Kathy Rupert's father was 68 when he died of pneumonia after living with Alzheimer's disease (AD) for five years. She remembers how quickly he deteriorated towards the end of his life – and is concerned about her own future.

"The months before he died, he couldn't remember who I was, who my mother was, who he was," she said. "It terrifies me to think I could end up like that one day. I never want to get to that place."

Scientists researching preventive drugs for AD hope people like Kathy may not have to. Clinical trials are being planned to test for the genetic risk of AD. Some participants would then begin preventive drugs to see if the disease progression is stopped or slowed down.

The problem: preventive drugs would be given to still healthy people potentially decades before they would develop AD, exposing them to side effects and potential psychological distress for prolonged periods of time.

Alzheimer's disease is a progressive brain disease with symptoms such as memory loss, mood swings and confusion. Around 500,000 Canadians currently live with Alzheimer's disease, and within a generation these numbers are expected to increase to 1,100,000 people. There is currently no cure or viable treatment.

The lack of treatment for Alzheimer's disease concerns Rupert. She is a candidate for genetic testing for AD, but prefers not to know her risk.

"I don't want to take the test," she said adamantly. "There's no cure, so what's the point? Some things are better not knowing."

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Neuroethics Canada at the University of British Columbia not only develops empirically-based guidelines and protocols for issues like this, but actively seeks ways to interact with and help the affected patients, families, professionals, and institutions.

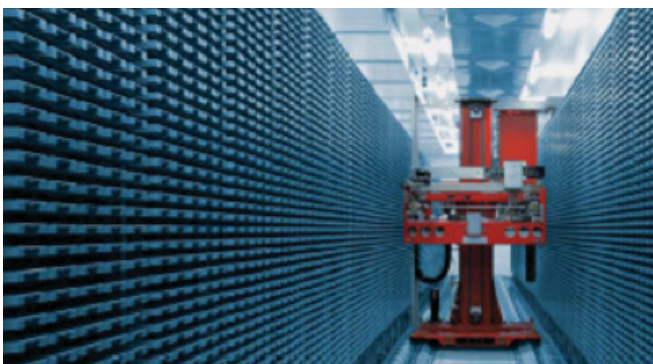
"We've upheld in neuroethics forever that people have both the right to know - and not to know - in appropriate circumstances," said Dr. Judy Illes, Director of Neuroethics Canada. "But how do we do clinical trials on these people absent symptoms? And how early do we intervene if there's no cure? We're starting to put forward what the ethical challenges are in terms of prediction, early intervention, and culture so that researchers can think about these variables proactively when they are designing their research protocols. We have to anticipate the ethics challenges here. They are huge and we are leading the way."



When David Kennedy went to the hospital for a brain biopsy, he assumed the two milliliters of brain tissue removed would be for his clinical diagnosis only. This was not the case; the consent form permitted the sample to be kept for further research.

The sharing of data and tissue stored in biobanks is a growing trend in medical research. Human biological matter – such as DNA, tumors, cells and blood – are stored in a 'bank' for research purposes. Samples can be analyzed for a vast number of purposes - even for developing personalized patient healthcare treatments.

Yet biobanks are not without their ethical challenges. To be successful, they rely on the generosity of human contributors and their samples. While hospitals may obtain generalized consent for research, more specialized consent is difficult to achieve. Just take into consideration the large numbers of both participants and studies, and the inability of anyone to really predict what future studies might look like. It is impossible to know exactly where their samples end up.



This can be distressing for some donors, such as Kennedy.

"I'm all for helping out with medical research," he said. "But what are they using my brain tissue for? What if it's for a study I don't approve of?"

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"An especially difficult challenge is how to protect children who are considered a vulnerable population in this era of growing biobanking" said Dr. Judy Illes, Director of Neuroethics Canada. "Whatever data come from them and go into a bank are there potentially forever, even as the children grow into adulthood and might have different preferences from when their data were taken and consented to by a surrogate decision maker on their behalf. We're exploring what the procedures are across biobanks for managing data from and for children, and best practice guidelines for biobanks to follow."

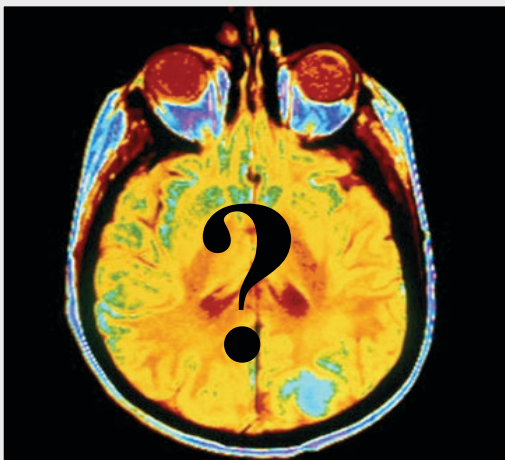
"Whether we like it or not, we are all data sources really. All of us – young and old. Good responsiveness from neuroethics benefits us all."

Eight-year-old Emily Wallace sits on her living room couch, bouncing up and down. She jumps up, runs into the kitchen, then speeds back to the couch and resumes her bouncing. This level of energy is not unusual for children to display occasionally – but for Emily, who has attention deficit-hyperactivity disorder (ADHD), it is just a typical day.

“She has such challenges focusing,” said her mother, Gloria Wallace. “Every day is a fight to get her to sit down, relax, think things through. She is literally moving all the time.”

ADHD is the most prevalent childhood mental health disorder, affecting between five and 12 percent of young people in the US and Canada. ADHD is thought to be a result of a chemical imbalance in the brain, although some researchers believe there could be other brain differences that may be detectable with a brain scan.

For Wallace, a brain scan confirming Emily’s diagnosis of ADHD would come as a relief. “If you break your arm, people can see that,” she said. “But with ADHD, people assume it’s just a bad child, or bad parenting. If a brain scan could show a physical problem with the brain...well...it would prove this disorder is not our fault.”



Biomedical ethicists and medical professionals, however, are hesitant to recommend brain scans as a method of diagnosis for ADHD or any other psychiatric disorder. Not only are brain scans expensive and possibly risky for children, but they don’t provide consistent results.

“It is absolutely not time for parents to be taking their children in for scans,” said Dr. Manzar Ashtari, an Associate Professor of Radiology and Psychiatry at North Shore-Long Island Jewish Health System in an interview with American Medical News.

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“A mental health disorder is just not visible on a brain scan. It is not like a broken bone,” said Dr. Judy Illes, Director of Neuroethics Canada. “However, brain scans can offer some concrete evidence consistent with a mental health disorder. And it can be, for some patents, a powerful confirmation of what’s troubling them. Right now our biggest concerns are about the salience of scans and the movement of them into the commercial sector where they’re being sold to a vulnerable population – like parents of children with ADHD.”

Ten years after witnessing the collapse of the World Trade Centre on September 11, 2001, the images are still present in Dr. Margaret Dessau's mind. She remembers a massive hole in one of the towers, orange flames licking at the edges. A man waves a white towel – then he jumps. Children scream as he hits the ground.

"My husband kept yelling at me, 'stop looking at it, stop looking at it!'" she said in an interview with the New York Times. "But I couldn't tear myself away from it."

Dessau was diagnosed with post-traumatic stress disorder, or PTSD. Symptoms include insomnia, depression, physical symptoms such as headaches and weight loss, and the experience of constantly reliving the trauma. Unlike a normal reaction to trauma, which eventually subsides, PTSD is a chronic condition. In Canada the lifetime prevalence of PTSD is nine per cent.



Some doctors have prescribed beta-blocker drugs to patients like Dessau to help ease the symptoms of PTSD. Beta-blockers help extinguish the emotional edge of bad memories by preventing a memory from forming or dulling it afterwards. But what consequences might result from blocking memories – even bad ones?

"Removing bad memories is not like removing a wart or a mole," said Dr. Daniel Sokol, a medical ethicist at St. George's University London in a BBC interview. "It will change our personal identity since who we are is linked to our memories. It may perhaps be beneficial in some cases, but before eradicating memories, we must reflect on the knock-on effects that this will have on individuals, society and our sense of humanity."

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"We've contributed analyses to constructively evaluate the benefits and risks of these treatments so that no one is caught off guard down the road," said Dr. Judy Illes, Director of Neuroethics Canada. "This technique may be extremely beneficial to mitigate the emotional state of victims of violence. But if we block the emotions linked to such horrible and tragic events, to what extent would this compromise their ability to testify in court, or communicate the evil they witnessed to the rest of society? By anticipating the consequences of highly charged interventions like this, we can help ensure they do more good than harm."

David Lei was at the lake with his friends on a balmy July Sunday when he decided to dive off a rock face. Unbeknownst to Lei, a submerged log was hidden from his sight. He collided with it head first – and suffered a severe spinal cord injury. He was only 26 years old.

Today, Lei is paralyzed from the waist down. He is the ideal candidate for controversial treatments, such as those with stem cells – but is not willing to participate in trials.



“What happens if I participate in one of these trials and it makes me worse?” Lei asked. “On the other hand, I sure would be happy if even just my bladder control improved, let alone if I stood up and ran a half-marathon.”

Around 130,000 people around the world are affected by a spinal cord injury every year. The severity of these injuries vary, and are a result of a sudden physical trauma unlike a disease that can have a long onset over time.

Many researchers assume people who are the most injured would be the most willing to take risks in their treatment options. However, this is often not the case. The things that are important to patients with spinal cord injuries are not always what researchers would expect. “It would be wonderful to walk again, obviously,” said Lei. “But I don’t know if that’s possible. There are things that would make me happy now, like having sex again. That’s what I want to focus on – people should be researching that.”

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“We have worked with people with spinal cord injury, as well as their family members and health care providers, to understand their perspectives on risk, consent, and decision making,” said Dr. Judy Illes, Director of Neuroethics Canada. “The priority for spinal cord injury therapeutics is not full mobility, but measurable quality of life, independence, and autonomy. By delivering these results we are able to bring resources to health care providers, families, and people with spinal cord injuries themselves in terms of supporting them through their recovery and their decisions about clinical trials.”

It was supposed to be a routine brain scan for a research study.

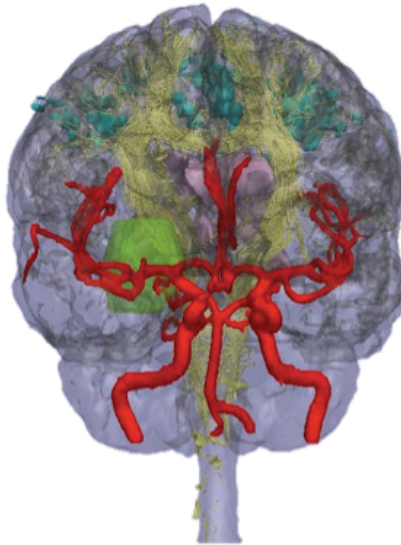
Yet instead of contributing to science, first-year Stanford medical student Sarah Hilgenberg found herself in the middle of her own medical crisis. The research scan revealed a malformed web of veins and arteries in her brain that could kill her.

Incidental findings like this are not unusual, says Dr. Judy Illes, a neuroscientist and Director of Neuroethics Canada at the University of British Columbia. Up to 20 per cent of MRI scans reveal anomalies that have nothing to do with the study. Around two per cent of these findings require urgent medical attention, such as in the case of Hilgenberg.

Are researchers obligated to examine every brain scan and disclose any incidental findings to study participants? Some neuroscientists say no, arguing that reviewing brain scans in research from apparently healthy people is not an effective way to screen for disease.

Yet some neuroethicists, such as Dr. Illes, believe that all studies using brain scans for research should involve a physician. Dr. Illes has worked to advance these views into a set of guidelines for neuroscientists in collaboration with the US National Institutes for Health.

After Hilgenberg's incidental finding, the malformed web of arteries was successfully removed. Today, she has a two-year-old daughter and is a pediatrics instructor at Lucile Packard Children's Hospital at Stanford. She sometimes wonders what would have happened had she not been told about her incidental finding.



"I feel lucky to have fallen into the hands of these folks," she said in a recent *Science Magazine* interview. "They provided me with a second go at life, and they weren't obligated to do that at all."

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"We've led the world in terms of reviewing and exploring different pathways for incidental findings," said Dr. Illes. "We've worked very closely with the NIH to craft guidelines for handling incidental findings in all subjects whether healthy or suffering from a brain or genetic disease. Researchers must anticipate incidental findings in their work. Whether we like it or not, these issues affect us all – in research and in the everyday that our health systems take care of us."

The last thing ten-year-old Maggie Thomson remembers was running down the soccer field after the ball. The next thing she knew, she was on her back gazing up at the sky and feeling like the world was swirling around her.

"It felt really strange," Thomson said. "I wasn't sure what had happened, but my head hurt. I wanted to keep playing because it was an important game."



One week later Thomson was back on the field, despite being diagnosed with a concussion. After suffering brain injuries in sports, many children are sent back into the game too soon – a trend that alarms Carol DeMatteo, an occupational therapist from McMaster University.

"Families say to us, 'No, it's OK, my child doesn't have a brain injury, she only has a concussion,'" DeMatteo recalled in an interview with the CBC.

Yet concussions are brain injuries. If undetected or ignored, childhood concussions can lead to prolonged symptoms, brain damage, or even death. Brain injuries kill more children in Canada and the US than all other injuries combined.

As technology advances, it becomes increasingly critical that the latest scientific research is connected to both ethical and policy issues within a social context, especially for children who are considered to represent a vulnerable population. Neuroethics Canada at the University of British Columbia not only develops empirically-based guidelines and protocols or issues like this, but actively seeks ways to interact with and help the affected patients, families, professionals, and institutions.

"We looked at how we can use neuroimaging to make good and better assessments of when not only youth but adults should be returned to play," said Dr. Judy Illes, Director of the Neuroethics Canada. "We have offered a framework for addressing these really important questions as new technologies emerge, and our ability to detect residual effects after brain injury, however mild, is also emerging."

When Cristina Puno's 10-year-old son Paolo was diagnosed with autism, she turned to the Internet to answer her questions.

"It felt overwhelming, like something big fell on my chest," she recalled in an interview with the Vancouver Sun. "I couldn't believe that this was happening."

One in 150 children are diagnosed with autism in North America. The disorder ranges in severity: high-functioning children may experience speech impairment or mild social inhibitions, while those more severely affected may not be able to speak or engage in any form of social interaction.

There is currently no cure for autism, and the causes remain unknown. This lack of information often sends confused parents online searching for answers.

"The concern is that parents of autistic children, desperate for hope, are often misled", says Deborah Pugh, Executive Director of Autism Community Training in Burnaby BC. Pugh is aiming to turn parents like Christina Puno into more critical consumers of this information overload.

"Families are often amazed and horrified to learn that [some of] the service providers that they initially come into contact with are not ethical," she said in a Vancouver Sun interview.

"Their assumption is that when they have a diagnosis of autism they will be surrounded by well-meaning people that will work very hard for them. That's not always the case."

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"We discovered that despite the best intentions of advocacy groups for example, there's a lot of misinformation and omitted information out there on their websites," said Dr. Judy Illes, Director of the Neuroethics Canada. "What we did was enlighten key communities of the various pitfalls about online information using the rigorous evidence we acquired in our studies, and offer concrete, positive recommendations for improving those resources."

