

International perspectives on engaging the public in neuroethics

Judy Illes, Colin Blakemore, Mats G. Hansson, Takao K. Hensch, Alan Leshner, Gladys Maestre, Pierre Magistretti, Rémi Quirion and Piergiorgio Strata

With an ever-increasing understanding of the brain mechanisms associated with core human attributes and values, there is an increasing public interest in the results of neuroscience research and the ways in which that new knowledge will be used. Here, we present perspectives on engaging the public on these issues on an international scale, the role of the media, and prospects for the new field of neuroethics as both a focus and a driver of these efforts.

The first chapter in Mary Roach's book *Stiff: The Curious Lives of Human Cadavers* is called 'A Head is a Terrible Thing to Waste'¹. That this book holds a top place on the New York Times bestseller list is no surprise. The interest of the public in the workings of the body and the human mind is an age-old phenomenon. Depictions of the anatomy theatres of the sixteenth and seventeenth centuries in Holland by Rembrandt in his famous painting 'The Anatomy Lesson of Dr. Joan Deijman', and elsewhere², show that the dissection of the human form and condition has long been a matter of both public spectacle and education³.

Today, the curiosity and hope that are associated with neuroscience are closely linked to the explicit ethical, legal and social issues that have come to accompany it. In the public arena, there is growing recognition and acceptance that the brain is the seat of the mind, and thus central to our very humanity,

to our 'selves'⁴. Frontier technology that is able to touch on our personhood⁵, especially in bioscience and information science, is shaping our future. The public must have the power — defined by quality of knowledge and ease of access — to help shape that future. Neuroethics has surfaced, and is here to stay, if not for this reason alone. Gone are the days when behaviour was reduced directly to the function of a single gene; instead, behaviour is increasingly seen to be an emergent property of a distributed information processing system, synapses and neurotransmission⁶. Genetics provides crucial bottom-up tools with which to investigate inherited mechanisms linked to illness, and although the ethics of genetics and other neighbouring disciplines provide a legitimate starting point for thinking about neuroethics, they do not suffice. Top-down tools, such as neuroimaging, provided by integrative neuroscience now have an important role in pursuing knowledge about what it is to be human, and responding to the global burden of CNS disease. New challenges are defined by both the sheer complexity of neuroscience research and the interpretation of data that is bound by culture and human anthropology⁷. In anticipation of growing areas in which attention might be paid to neuroethics, we explore neuroethics priorities across international borders, the role of the media and prospects for this burgeoning field, which are likely to have a far-reaching effect on public engagement.

International initiatives

The United States has been a hub of twenty-first century neuroethics activity, and has hosted various key events that have come to define the field. In 2002, for example, the Dana Foundation (BOX 1) sponsored the conference 'Neuroethics: Mapping the Field'⁸. In 2004, the American Association for the Advancement of Science (AAAS) sponsored a meeting on neuroscience and law⁹ and, in 2005, another on neuroethics and religion. The Library of Congress sponsored a neuroethics meeting called 'Hard Science – Hard Choices', also in 2005. With funding from The Greenwall Foundation, a special issue of the journal *Brain and Cognition* was published devoted to ethical issues in advanced neuroimaging¹⁰. The Dana Foundation's journal *Cerebrum* published a special issue on neuroethics in the Fall of 2004 (REF. 11) and the US-based *American Journal of Bioethics* published its own special issue on neuroethics in 2005 (REF. 12). The fierce interest of the American public in their brains, and growing understanding about brain diseases that affect millions of people, has been due, in part, to concerted efforts to share the excitement of neuroscience discoveries as well as their ethical, social and legal implications.

Public engagement efforts in the United States have generally involved two approaches to science literacy and action — education and dialogue. This is consistent with the approaches described by the World Health Organization¹³ for informed decisions about health care, participation in government decisions in research and treatment of new neurological disease and mental illnesses, critical judgement of neuroscience-related material in popular media, and promotion of optimal brain development. The straightforward educational approach encompassing these approaches seeks to increase public understanding and appreciation of neuroscience research. The dialogue approach attempts to engage the public in discussion about the significance of neuroscience discovery for society.

Box 1 | **The Dana Alliance**

The Dana Alliance, which includes the Dana Alliance for Brain Initiatives in the United States and Canada, and the European Dana Alliance for the Brain, is a non-profit organization. It is supported by the Dana Foundation, whose membership includes 400 leading neuroscientists, including 15 Nobel laureates. The Dana Alliance is committed to advancing public awareness about the progress and benefits of brain research, and to disseminating scientific information to the general public in an understandable and accessible fashion.

Since the May 2002 conference on neuroethics, co-sponsored with Stanford University, USA, and the University of California San Francisco, USA, and published proceedings, the Dana Alliance has followed up by sponsoring and hosting symposia, forums and workshops, publishing newsletters and articles, and advancing discussion on this crucial new field in the United States and Europe. The latest book from the Dana Press is *The Ethical Brain* by Michael Gazzaniga.

The Dana Centre at the Science Museum in London is a new focus for public engagement. It provides a lively programme of talks, debates and other events on many aspects of science that are aimed at an audience of young adults. Because the offices of the European Dana Alliance for the Brain are housed in the same building, the programme of events has quite a strong emphasis on neuroscience, but it extends across the whole of science. The Centre has state-of-the-art facilities for digital communication: James Watson took part in a webcast discussion, and earlier this year a transatlantic video-conference on neuroethics was held between the Dana Centres in London and in Washington around the theme 'The Ethical Brain'¹⁴.

For more information on the Dana Alliance, its grants, outreach activities, and free publications, visit www.dana.org.

Specific public education efforts have originated from funding agencies, including many at the National Institutes of Health (NIH), from professional societies, such as the Society for Neuroscience (SfN), and more specialized groups focused on both neurology and psychiatry, and from patient advocacy groups, such as the National Alliance for the Mentally Ill (NAMI). A dramatic effort was the initiative that culminated in the declaration of the 'Decade of the Brain' in 1990. The efficacy of the effort was evident, in part, from the ever-growing public acceptance — gained after decades of intensive work by scientists, clinicians, and patients and their families — of the fact that severe mental illnesses such as schizophrenia and bipolar disorder are brain diseases rather than simply symptoms of weak wills or poor parenting.

Dialogue with the public has led to increasing recognition that advances in neuroscience and their application in clinical settings could have significant ethical and legal ramifications that require discussion not only among scientists but with all stakeholders. For example, the US President's Council on Bioethics, which was created by an executive order in 1995, has devoted some effort to issues related to neuroethics. Another example is that of Huda Akil, who dedicated her presidential year (1998) at the American College of Neuropsychopharmacology to working on ethical issues relating to basic and clinical neuroscience. She convened a series of meetings and workshops that considered the ethical conduct of neuroscience

research as well as the societal implications of neuroscience advances. She also began discussions of how to broach these subjects with the public.

In *The Ethical Brain*¹⁴, Gazzaniga introduces ethical issues that concern the development and expression of human consciousness — issues that are central to understanding the nature of humanity and our very existence. For example, understanding at what developmental stage consciousness first emerges has implications for embryological research and its applications. A study by Kosfeld and his colleagues on neuroendocrine influences of human trust provides another example of ways in which neuroscience research might get closer than ever before to elucidating core human traits and values¹⁵. These extend naturally to other neuroethics issues, including issues of personal responsibility in brain diseases that affect behaviour¹⁶, vulnerability of individuals with addictions or dementia¹⁷, and privacy¹⁸.

Canada is following closely on the heels of US leadership in promoting opportunities for engaging the public in neuroscience, and the support for specific research initiatives in neuroethics, largely through multi-year team grant programme funding, surpasses that of the United States. Led by the Institute of Neuroscience, Mental Health and Addiction (INMHA), one of the Canadian Institutes of Health Research, a partnership has been formed that includes the Dana Foundation, the Canadian Chapters of SfN and non-government voluntary sector organizations

to engage in neuroethics activities, especially in the context of the annual Brain Awareness Week, which is now a global event. Many Canadian chapters hold outreach events aimed at explaining the impact of recent discoveries on the treatment of neurological disorders and mental illnesses to the public. INMHA has observed that public participation is markedly enhanced if target topics are disease-oriented or particularly provocative (for example, music and the brain, or sex and the brain). Public participation is also notably strong in Canada where graduate students are directly involved in organizing the events, including visits to primary and junior high schools. Canadian leadership believes, as others have observed¹⁹, that it is vital to engage the public with neuroethics as early as possible in life.

Canadian schools lead additional initiatives that expose students to various aspects of neuroscience and the career opportunities in the field. One particularly popular venue is a free movie series held at the campus of the Douglas Hospital Research Center in Montreal. At the end of the show, neuroscientists comment on the movie and answer questions from the audience. Movies shown during the past 2 years include *A Beautiful Mind* (schizophrenia), *Rain Man* (autism), *Pollock* (alcoholism) and *Fourth of July* (post-traumatic stress disorder). Both positive and negative messages must be carefully considered with events that feature such popular films, as stereotypical depictions of the mentally ill that "may seem like harmless Hollywood distortions"²⁰ have a way of working themselves into society's subconscious. In 2004, in partnership with the Canadian Alliance for Mental Health, INMHA organized 'Mindscape', an art exhibition presented at the National Art Gallery of Canada in Ottawa that was aimed at reducing the stigma and discrimination linked to brain disease and mental illness. INMHA also actively supports the development of a bilingual, interactive public-oriented web site on the functional organization of the normal and pathological brain (**The brain from top to bottom**, based at McGill University). This site represents many different levels of expertise and is among the most frequented by major search engines.

In Japan, one of the world's most educated and most rapidly ageing societies, government efforts to promote brain research at both ends of the life spectrum are being encouraged. In 1995, sleep disorders were recognized as both a health and a social problem²¹. Studies were designed to focus not only on the medical features but also on the

characteristics and role of sleep and dreaming in Asian culture and philosophy. In 2003, the research initiative ‘Nurturing the Brain’ was launched to focus on the development and maintenance of ‘normal’ brain function. These new efforts encompass embryonic and postnatal maturation as well as education, adult learning and prevention of mental decline with ageing²². The honorary president of the International Brain Research Organization, Masao Ito, was among the first to embrace the Brain Awareness Week concept, which has seen increasing participation in Japan since its launch almost 6 years ago. He also promoted current initiatives of the Organisation for Economic Co-operation and Development (OECD) to link brain science and education in the form of international research networks on literacy, numeracy and life-long learning.

One of the greatest societal demands in Japan is for accurate information about critical periods in brain development. When is the best time to begin teaching English? Or sports? What is the influence of video games, cell phones and ‘anime’ (Japanese animations) on children? Many of the modern ills emerging among Japanese youth are attributed to excessive technology. Staggering increases in violent crimes, vagrancy and suicide among this sector of the population raise many questions about what can be done for children who burn out (known as ‘kikeru’). In response, large cohort studies that will follow 10,000 Japanese children during the first several years of life have been launched under the rubric of ‘Brain Science and Education’. This links paediatricians, educators, parents and scientists on a scale that has not previously been attempted²³. Privacy and confidentiality are key issues for the nascent ethics committees across the country.

Scientists in Japan are at the forefront of understanding the cellular and molecular bases of critical periods in brain development²⁴. One need only consider the synchronized, photic seizures that were induced in almost 1,000 Japanese children by an episode of Pokemon to see the relevance of the basic biology of neural plasticity to humans²⁵. Stem cell research²⁶ is also facing ethical scrutiny, but, in general, the largely Buddhist culture views the research as a positive contribution to society. Similarly, although Japanese researchers have revealed signature changes on functional MRI (fMRI) that accompany second language learning²⁷, concerns about mind reading and neural discrimination, which have emerged in other parts of the world, have not penetrated this island nation.

Japanese scientists were also the first to develop MRI techniques for the early detection of amyloid plaque deposits in the brain *in vivo* well before the onset of dementia²⁸. Similar advances might motivate the design of brain–machine interfaces (neural prostheses) beyond primary sensory systems²⁹. As recently introduced in an inaugural symposium on ‘Neuroethics of Nurturing the Brain’ at the Japanese Society for Neuroscience meeting in 2005, a significant issue in these discussions is the definition of an optimal or ideal brain. Both cultural and personal interpretations must be honoured, and neuroethics must co-evolve with the science that upholds the importance of individual differences.

“One of the greatest societal demands in Japan is for accurate information about critical periods in brain development.”

With a proactive focus on the overall understanding and dissemination of information about brain function and diseases, a Brain Awareness Week has been held in Switzerland every year since 1998 with considerable success. In 2005, a joint ‘Festival Science et Cité — Brain Awareness Week’ focused on the theme of consciousness, and involved 19 cities with more than 500 events, including exhibits, films and open conferences. Artists-in-residence and actors stayed in research laboratories or hospitals and produced a theatre piece that was shown during the festival. These events, which were co-sponsored by the European Dana Alliance for the Brain (EDAB) in partnership with the Swiss Society for Neuroscience and held under the patronage of the Minister of Education and Research, also led to the creation of other structures designed to bridge the gap between science and the public. Among the most innovative are ‘cafés scientifiques’, a movement originating in the United Kingdom that provides an informal setting for dialogue between scientists and the public.

Brain Awareness Week is also a recurring initiative in Italy. Originally undertaken by several individual scientists and now coordinated on a broader scale by the Italian Neuroscience Society, it involves 100 events spread across the entire national territory. The Italian Government was the first in the world to endorse the US-led initiative for the Decade of the Brain in the 1990s, and

publications such as *Travel in the Brain*³⁰, and a newly founded National Institute of Neuroscience place neuroscience literacy among their core objectives. Television, magazines and public lectures by scientists, particularly in high schools, further respond to the Italian public’s interests in and call for neuroscience information. In 2004, a meeting on the ethics, social, humanitarian and ecological aspects of robotics was held in Sanremo, Italy³¹. This event was representative of the growing interest in ‘technoethics’, in which the initial emphasis was on neurally-controlled implantable devices. This interest is gaining momentum in other parts of Europe (as indicated by events such as the International Conference on Robotics and Automation 2005 Workshop on Robo-Ethics in Barcelona³²), and in the United States.

In Sweden there is a long tradition, upheld by universities, hospitals and research foundations, of advancing public awareness about the progress and benefits of brain research. The activities of the Decade of the Brain in the 1990s reached all sectors of society, and the Swedish Brain Foundation has collaborated with local hospitals and schools for several years during their Brain Awareness Week. Yearly conferences held on a regional basis, and publications such as *The Brain of the Child* (Royal Swedish Academy of Sciences, 2005) are successful mechanisms in this country for disseminating information about neuroscience research and discoveries that might alleviate suffering for patients with brain diseases.

In 2005, eight sponsors of research from both the public and private sectors undertook an ambitious initiative to specifically promote public engagement in matters relating to brain research and neuroscience in Sweden. The effort includes collaborations with local science museums and schools. **Forskning**, a public web site, is a core resource for stimulating debate and discussion. This project differs from previous ones in Sweden in that it includes a comprehensive section on neuroethics. Issues that relate to personal responsibility and identity, discussions about what is normal and the potential benefits of enhancing brain function are raised, as are the consequences of manipulating complex human behaviour.

The strong current commitment to science communication in the United Kingdom was launched by the Bodmer Report from the Royal Society, the British Association for the Advancement of Science and the Royal Institution in 1985. The establishment of a national Committee on the Public Understanding of Science in 1986

led to a wide range of activities, from an annual National Science Week to graduate courses in science communication. A shift of emphasis from didactic communication to active dialogue came in 2000 with a report entitled 'Science and Society' from the House of Lords Select Committee on Science and Technology, and now there is robust debate about whether and how the public should be involved in setting the strategic agenda of academic science, as well as their well established participation in ethical debate.

EDAB, often working in partnership with the British Neuroscience Association, the Science Museum, the British Association and others, and with strong support from the academic and clinical neuroscience communities, has been influential in raising public interest and awareness of neuroscience in the United Kingdom. EDAB now has its headquarters in a building on London's Science Museum site — which also houses the Dana Centre — and has a busy schedule of varied science-related events, many of them concerned with neuroscience. Neuroethics has become a subject of considerable interest.

The UK government recently announced an ambitious 10-year plan for increasing its total investment in an already wide portfolio of science innovation to 2.5% of the Gross Domestic Product by 2014, and public engagement is an integral part of this plan. The European Commission also has relevant projects in its current Sixth Framework Programme. These include new initiatives in the ethics of biobanking, human embryonic stem cells and dual-use human research.

In comparison to other international efforts, public engagement activities in Latin American countries, such as Venezuela, are limited. One such effort is being led by families and patients with disorders such as autism or Alzheimer's disease. It calls on scientists to become involved in translating their research findings and directing their research to applied areas. Financial support is available from the pharmaceutical industry. The second effort involves government-run public campaigns. For example, a campaign on drug prevention has been designed to generate responses from the public and develop strategies for fighting drug consumption. The third involves initiatives led by groups of academics that obtain most of their support from international agencies rather than from their own Universities nor from the Venezuelan government. Most of these are related to science education and, again, the Brain Awareness Week. Faculty at the University of Zulia have also developed a programme that runs all-year-round to

help teachers understand the workings of the brain, behaviour that has an impact on brain health, and the basis of individuality and personal style.

The response to these initiatives in Venezuela has been excellent in terms of quality and numbers of discussions in public forums, but they do not reach enough people to have an impact on public policy. The public's low average level of education does not seem to be the limitation, as Venezuelan people are eager to learn. Rather, the involvement of more scientists with well-honed skills and special funding for their research are needed. With new initiatives underway thanks to recent political changes, optimism is high for improvements in awareness about public engagement in public policies. 'Science for the people' is the phrase that accompanies every letter and every announcement coming from the Ministry of Science and Technology. Although more is still said than actually done, the impact is evident among researchers and advocacy groups who have a new feeling of empowerment and an even deeper sense of urgency and immediateness. This is also evident in Brazil, where a web site dedicated to neuroscience receives 300 'hits' per day, with the greatest number on topics relating to memory and consciousness³³.

“The media have played a powerful part in bringing and translating science to the public arena on an international scale.”

In developing countries, there are unique practical barriers to caring for patients with neurological diseases; engaging the public in discussions about their ethical implications is even more difficult. The two main challenges are disease identification (especially if disease is associated with stigma, as epilepsy is among certain African populations) and ethical allocation of limited resources to achieve patient benefit³⁴. Social marketing with mass media campaigns may work for urban areas, but in rural settings grass roots efforts aimed at recruiting and educating community leaders are more powerful. The incorporation of education about certain diseases proactively into culturally-appropriate curricula is essential, but success is challenged by a lack of funding, isolation, few research students, a low level of interest

in neuroscience across the academic community, government and general public, and skepticism that brain research can bring concrete benefits when minimum standards of living are barely being met³⁵. However, specific challenges brought out by disparities relating to poverty, ethnicity and low education are undifferentiated between developed and developing countries.

Public engagement and the media

“Between the scientist and the public stand the media”³⁶, and we must work effectively with them to defend and uphold science and scientific values.

The media have played a powerful part in bringing and translating science to the public arena on an international scale, and neuroscience has had its fair share of attention, although the partnership has sometimes been an uneasy one given different professional orientations and goals³⁷. Advances in research for HIV/AIDS, Alzheimer's disease, mental illness, genetics and the development of neurotechnology have all been the focus of attention, bringing enthusiasm and, at the same time, trepidation. In one study of the media's treatment of fMRI results published in the United States and internationally³⁸, the authors showed how easily deterministic messages about the human brain can be conveyed.

In Switzerland, the important role of the media was illustrated several years ago by the outcome of a referendum against genetic engineering and, in 2004, by the results of one against stem cells. Neither referendum succeeded: the role of the newspaper, magazine, radio and TV media in providing a forum for the views of many scientists cannot be underestimated.

In Italy, despite a lack of media centralization, many initiatives are advanced by radio and television programmes. The most popular scientific radio programme, Quark, includes a topic on the brain every week. Another programme, Radio3scienza, regularly features scientists who speak about new data appearing in the scientific literature. However, despite the vocal support in Italy, in the summer of 2005, of a large number of scientists to abolish a restrictive law regulating *in vitro* fertilization, their efforts through the media and elsewhere paled in comparison to the campaign mounted by the Catholic Church. As a result, limitations stand on creating new frozen human embryos, carrying out tests on the embryo before implantation to diagnose genetic diseases, and the scientific use of embryonic material that is already frozen.

Press briefings at professional meetings, information pages on the Internet, and modern blogging have also emerged as solid forces in the effort to bridge gaps in neuroscience and neuroethics knowledge. Experience has shown that large lectures or town meetings can be unbalanced and even become hijacked by extremist views. Inefficient as they might seem, smaller group sessions that are focused on specific questions and action items are more effective. In this regard, Timpane's³⁹ urgings for a bottom-up deliberative process of public engagement in neuroethics that uses citizen groups to form consensus recommendations are much appreciated. In 2003, Rose⁴⁰ wrote: "teach science and teach about science". Indeed, the movement for public understanding is a two-way street where scientists come to understand the public, and science is communicated both in its social context and in socially just ways. This ensures that the requirements for public understanding of both the research process and the process of generating knowledge and scientific evidence are met.

Risks of public engagement?

A risk of public engagement is that of creating false hopes and expectations by releasing results too early, especially in the context of devastating CNS diseases. Misunderstandings resulting from oversimplified scientific facts can lead to activism (for example, animal rights activists and the early education 'hot-housing' movement), and a sense of obligation to take a particular social or ethical stance⁴¹, even in matters that are not well understood (for example, nuclear cell transfer or stem cells). New developments in neuroscience can challenge established values and attitudes, and even political views and, as in other areas of life sciences, forestalling progress can be an easy way out. More complex arguments — that failure to act may be at least unethical — are frequently lost. It is therefore essential that evaluation of emerging ethical issues in neuroscience is based on sound research and scholarship. International conferences that are bringing scholars from the humanities and social sciences to work together with neuroscientists are positive steps towards advancing awareness of neuroethical issues and public engagement in the future.

There is a legitimate civic duty and democratic gain in engaging the public^{42,43}. Ethical issues should not be left to the experts alone, nor be discussed in closed rooms. There is ample opportunity to capitalize on lessons from the past. Recent examples, such as the

Box 2 | Some international initiatives in neuroethics and public engagement

United States

- Conferences, including Neuroethics: Mapping the Field; Neuroscience and Law; and Neuroscience and Religion
- Special journal issues on neuroethics in *Brain and Cognition*; *Cerebrum*; and *The American Journal of Bioethics*
- Special research funding, professional and academic events (for example, National Institutes of Health; Society for Neuroscience; National Alliance for the Mentally Ill)
- Brain Awareness Week events

Canada

- Multi-year team grant funding for research
- Public events on mental health
- Art exhibitions
- Bilingual, interactive and public-oriented web sites on the functional organization of the brain
- Brain Awareness Week events

Japan

- 'Nurturing the Brain' research initiative and accompanying special professional and public events at the Japanese Society for Neuroscience
- Japan-promoted Organisation for Economic Co-operation and Development initiatives and international research networks on literacy, numeracy and life-long learning
- Brain Awareness Week events

Switzerland

- Brain Awareness Week events and expanded joint activities, including Festival Science et Cité
- Cafés scientifiques

Italy

- Special educational publications
- Newly founded National Institute of Neuroscience with neuroscience literacy among its core objectives
- Public and academic lectures, and information dissemination through the media
- Brain Awareness Week events

Sweden

- New annual conferences that specifically promote public engagement of neuroscience, which involve museums, schools and universities
- Brain Awareness Week events

United Kingdom

- Establishment of a national Committee on the Public Understanding of Science
- Initiatives by the European Dana Alliance for the Brain, in partnership with the British Neuroscience Association, the Science Museum, the British Association for the Advancement of Science and other organizations
- Brain Awareness Week events
- Cafés scientifiques

European Commission

- Current Sixth Framework Programme includes new initiatives in the ethics of biobanking, human embryonic stem cells, and dual-use human research

Venezuela

- Family-led initiatives funded by the pharmaceutical industry, which emphasize translational research
- Government-run public campaigns such as drug prevention
- Brain Awareness Week events

