

Appendices

Appendix 1: Method of working

Background

The Nuffield Council on Bioethics established the Working Party on *Novel neurotechnologies: intervening in the brain* in October 2011, and the Working Party subsequently met 10 times between November 2011 and April 2013. In order to inform its deliberations, the Working Party launched a consultation in February 2012 and held a series of “factfinding” meetings with clinicians, investors, regulators, patients, academics and those working in the industry. It also commissioned a report looking at novel neurotechnologies and social media.

The Working Party would like to thank all those who gave their time and expertise for the invaluable contribution they made to the report.

Consultation

The Working Party launched a consultation in February 2012 which ran until April 2012. 60 responses were received in total of which 20 were submitted by organisations and 40 were submitted by individuals. Those responding to the consultation included academic researchers, clinicians, patients and faith groups. A full list of respondents is set out in appendix 2. A summary of the responses will be made available on the council’s website. Individual responses will also be made available where permission has been granted.

Factfinding meetings

A series of factfinding meetings were held to help the Working Party benefit from the personal and professional expertise of others. A total of 15 meetings were held, the details of which can be found below.

Clinicians: 16 February 2012:

- Dirk de Ridder, neurosurgeon, University Hospital Antwerp, Belgium
- Declan McLaughlin, research professor of Psychiatry Trinity College Dublin Ireland
- Ludvic Zrinzo, consultant neurosurgeon and senior clinical researcher, UCL institute of Neurology

Conversation with Dr Hilary Walklett: 15 May 2012

Industry: 16 August 2012

- Nicholas Hatsopoulos, previously of Cyberkinetics
- Zack Lynch, Neurotechnology Industry Organization
- John Sinden, ReNeuron
- Andrew Thomas, Rogue Resolutions

Non-therapeutic applications: 7 September 2012

- Roi Cohen Kadosh, Wellcome research career development fellow, Department of Experimental Psychology, University of Oxford
- Femke Nijboer, researcher in the 3TU Centre for Ethics and Technology and Postdoctoral Researcher in the Human Media Interaction group at the University of Twente

Military applications of novel neurotechnologies: Thursday 16th August 2012

- Malcolm Dando, International Security, University of Bradford
- James Revill, research fellow, Harvard Sussex Program, SPRU, University of Sussex

Regulating the technologies: 20 September 2012

- Elaine Godfrey, Clinical Trials Unit, MHRA
- Neil Ebenezer, New and Emerging Technologies, MHRA
- Jane O'Brien, Head of Standards and Ethics, General Medical Council
- Lucia D'Apote, Committee for Advanced Therapies Scientific Secretariat (*by teleconference*)
- Andrew George, chairman of GTAC and chair of the NRES Research Ethics Advisors' Panel

Investment: 21 September 2012

- Cathy Prescott, director, Biolatris Ltd, chair of the UK National Stem Cell Network Advisory Committee, director of the East of England Stem Cell Network

Neuroethics: 5 November 2012

- Paul Root Wolpe, professor of bioethics at Emory University

Meeting with deep brain stimulation patient: 20 November 2012

- Richard Smith

Meetings with those involved in brain-computer interface research: 7 December 2012

Participants:

- Mai Ryan
- Gary Mulligan
- Eoin, Eddie and Karen O'Mahony

Clinicians:

- Áine Caroll, national director of Clinical Strategy Programmes and immediate past chair of the Medical Board of the National Rehabilitation Hospital
- Jacqueline Stow, specialist registrar in rehabilitation medicine, National Rehabilitation Hospital

Researcher

- Damien Coyle, University of Ulster

Meeting with the Royal Academy of Engineers: 11 March 2013

- Philippa Shelton and Katherine MacGregor

NICE: 4 April 2013

- Mirella Marlow, programme director, Devices and Diagnostic Systems

Social media study

As part of factfinding for this report's discussion of the role of the media in communicating about novel neurotechnologies, the Working Party commissioned a study looking specifically at the representation of these technologies in the social media. The purpose of this study was to provide a brief review of the literature relating to the representation of science and technology by social media, a 'snapshot' of content on social media platforms in which novel neurotechnologies are mentioned, and an analysis of the sources responsible for creating or uploading this content. The methodology included categorising and analysing the first 20 results returned by entering the following terms into the search functions of each of the social media platforms Delicious, Facebook, Twitter and YouTube: "deep brain stimulation", "brain computer interface" and "neural stem cell replacement therapy". The generic search engine Google Blog Search was used also to search for blogs. The study necessarily provides only a 'snapshot' of the representations of novel neurotechnologies on social media due to time limitations and the fact that the results returned by any particular search will depend on variables and contingencies such as the precise search terms used, the date on which the search was carried out and the online profile of the researcher. The findings of this study are drawn upon in chapter 9.

This study was conducted by Allyson Purcell-Davis, a lecturer at the School of Communication, Culture & Creative Arts at St Mary's University College Twickenham and a PhD candidate at Cardiff School of Journalism, Media and Cultural Studies.

External review

A draft version of this report was reviewed by 12 external reviewers listed below:

- Professor Stuart Allan
- Professor Richard Ashcroft
- Dr Damien Coyle
- Dr Dirk De Ridder
- Dr Neil Ebenezer
- Professor Charles French-Constant
- Dr Joseph Fins
- Dr Elaine Godfrey
- Professor Emily Jackson
- Professor Peter Littlejohns
- Professor Paul Martin
- Professor Chris Mason
- Dr Jonathan Moreno
- Dr Cathy Prescott
- Professor John Stein
- Professor Gregor Thut

The Working Party would like to express their gratitude to these individuals for their insightful and detailed comments, which played an important role in the final production of the report.

Appendix 2: Wider consultation for the report

The aim of the consultation was to obtain views from as wide a range of individuals and organisations interested in the area as possible. The consultation document was published on line in February 2012 and remained open until April 2012. The consultation set out the terms of reference for the report, provided some background information and asked a series of questions, reproduced in the box below.

The document was split into three substantive sections:

- Brain-computer interfaces
- Neurostimulation
- Neural stem cell therapy

Consultation questions

- Have you ever used a technology that intervenes in the brain, and with what consequences? Please describe your experience.
- If you have not used a technology that intervenes in the brain before, would you do so if you were ill? Why / why not?
- Would you use a technology that intervenes in the brain for non-medical purposes, such as gaming or improving your cognitive skills? Why / why not?
- What are the most important ethical challenges raised by novel neurotechnologies that intervene in the brain?
- In what ways, if at all, should the development and use of these technologies be promoted, restricted and/or regulated? Please explain your reasons.
- Have you used a BCI, and if so, with what consequences? Please describe your experience
- If you have not used a BCI before, under what circumstances would you do so?
- What are your expectations and concerns for BCIs?
- Are there any particular ethical or social issues associated with BCIs?
- What would robust and effective regulation of research in this area look like? Is more or less regulation needed? Please justify your response
- Have you used neurostimulation and if so, with what consequences? Please describe your experience.
- If you have not used neurostimulation before, under what circumstances would you do so?
- Under what circumstances do you think it might be acceptable to use neurostimulation in non-medical context (that is to say, not for the treatment of a disease or disability)?
- Are there any particular ethical or social issues associated with neurostimulation?
- What would robust and effective regulation of research in this area look like? Is more or less regulation needed? Please justify your response.
- Under what circumstances would you use neural stem cell therapy?
- What do you think of the risks and benefits of neural stem cell therapy?
- Are there any particular ethical social issues associated with neural stem cell therapy?
- How do you feel about neural stem cell therapy being used for non-medical purposes one day, for example for enhancement?
- What would robust and effective regulation of research in this area look like? Is more or less regulation needed? Please justify your response.

In total the Working Party received 60 responses to the consultation, 20 of which were submitted by organisations and 40 of which were submitted by individuals. Those responding to the consultation

included academic researchers, clinicians, patients and faith groups. These responses, along with the factfinding meetings set out in Appendix 1, played an important role in shaping the report and the Working Party would like to express their thanks to all the respondents.

List of respondents to the call for evidence

Anonymous

- Four respondents wished to remain unlisted.

Individuals

- Tipu Aziz and Alex Green
- Ryan Carlow
- Markus Christen, Institute of Biomedical Ethics, University of Zurich
- David Coe
- Fofi Constantinidou, PhD, Professor of Psychology and Director, Center for Applied Neuroscience, University of Cyprus
- Damien Coyle
- Raymond De Vries, University of Michigan, Center for Bioethics and Social Sciences in Medicine
- Dr Patrick Degenaar, Newcastle University
- Cristina Fernandez-Garcia
- Professor James Giordano, PhD
- Dr Judy Illes, Professor of Neurology and Canada Research Chair in Neuroethics, University of British Columbia Illes, Professor of Neurology and Canada Research Chair in Neuroethics, University of British Columbia
- Sara Joaquim
- Thomas R Kerkhoff, PhD, ABPP/RP Clinical Professor, University of Florida, Department of Clinical and Health Psychology
- Patricia Limousin
- Alma Linkeviciute
- Professor Dr Fernando Lolas, Interdisciplinary Center for Studies on Bioethics, University of Chile
- Robin Lovell-Badge
- Michael Madary
- Dr Andrea L Malizia, Psychiatrist and Clinical Psychopharmacologist
- Dr Paul McCullagh
- Femke Nijboer
- Chijioke G Ogbuka, Albert Gnaegi Center for Health Care Ethics Organisations
- Dr Martyn Pickersgill, University of Edinburgh
- Vincenzo Romei
- Jane Rowlands
- Gerwin Schalk
- Mim Schwartz
- Jackie Leach Scully, Janice McLaughlin, Simon Woods and Michael Barr at Policy, Ethics and Life Sciences Research Centre, Newcastle University
- Annette Smith
- Professor David Stanley, School of Health, Community and Education Studies, Northumberland University
- Gilbert Tan, Gilbert Tan TS AKA Oogle
- Gregor Thut
- Dr J H Waters
- Bob Whitcombe
- Professor Lewis Wolpert
- Deng Zhuo

Organisations

- Academy of Medical Sciences
- Addiction Neuroethics, UQCCR, The University of Queensland

- Animal Procedures Committee
- Association of British Neurologists
- British Medical Association
- British Neuroscience Association
- CARE (Christian Action Research and Education)
- CESAGEN – the ESRC Centre for Economic and Social Aspects of Genomics
- Christians Against Mental Slavery
- Christian Medical Fellowship
- Dementia Services Development Centre, University of Stirling
- European Brain Council
- European Medicines Agency (EMA)
- Foresight, Government Office of Science
- Mission and Public Affairs Council, Church of England
- National Bioethics Committee of Jamaica
- Royal College of General Practitioners
- Royal Society for the Prevention of Cruelty to Animals
- The Royal College of Physicians
- The Wellcome Trust

Appendix 3: The Working Party

Professor Thomas Baldwin (Chair)

Tom Baldwin is Professor of Philosophy at University of York. He works across a broad range of issues in contemporary philosophy, including bioethics, and is currently editor of the philosophy journal *Mind*. He has been a member of the Human Genetics Commission (HGC), the Human Fertilisation and Embryology Authority (HFEA), and the Department of Health's expert advisory committee on obesity. He is a co-opted member of the Nuffield Council on Bioethics for the duration of the Working Party on novel neurotechnologies, and has previously contributed to the Council's reports on stem cells, patenting DNA, genetics and behaviour and public health.

Professor Jonathan Cole

Jonathan Cole Consultant in Clinical Neurophysiology at Poole Hospital; Honorary Senior Lecturer in Clinical Neurosciences, University of Southampton; and Professor at the Centre for Postgraduate Medical Research and Education and at the School of Design, Engineering and Computing, University of Bournemouth. His academic research has focused on the effects of sensory deafferentation and motor control. He leads a group at the University of Bournemouth investigating the use of virtual reality therapeutically in neurological impairment, and is part of the Economic and Social Research Council (ESRC) network on brain-computer interfaces (BCIs).

Professor Maria Fitzgerald

Maria Fitzgerald is Professor of Developmental Neurobiology at University College London. She is also a Fellow of the Academy of Medical Sciences, a current member of the Council of the British Pain Society and the Biological Sciences panel of the UK Research Assessment Exercise (REF), and a past member of the MRC Neuroscience and Mental Health Board and of French and Norwegian national research agencies. Her research focuses on neural mechanisms of pain in infants and children.

Professor Jenny Kitzinger

Jenny Kitzinger is Professor of Communications Research at Cardiff School of Journalism, Media and Cultural Studies, Cardiff University. She comes from a background in social and political sciences, anthropology and communications studies. Her work focuses on examining social and ethical debates around science and medicine. Her previous research has examined issues such as human genetics, stem cell research, and serious brain injury. Recent appointments include serving on the Royal College of Physicians Working Party on the management of disorders of consciousness. She is a Member of Cesagen (The ESRC Centre for Economic and Social Aspects of Genomics).

Professor Graeme Laurie

Graeme Laurie is Professor of Medical Jurisprudence and Director of Research at School of Law, University of Edinburgh and Founding Director of the JK Mason Institute for Law, Medicine and Life Sciences at the University of Edinburgh. His research interests are in medical law and intellectual property law. He has previously served as Chair of the UK Biobank Ethics and Governance Council and is current Chair of the Privacy Advisory Committee in Scotland. He is member of the BMA Medical Ethics Committee and sits on a Working Party of the Royal Society examining Science as an Open Enterprise. He is a member of the Nuffield Council on Bioethics, and has previously contributed to the Council's report on the forensic use of bioinformation.

Professor Jack Price

Jack Price is Professor of Developmental Neurobiology and Director at the Centre for the Cellular Basis of Behaviour, King's College London. He is a neuroscientist with a specific interest in stem cells. His research is pursuing stem cells both as therapeutics for neurodegenerative diseases, and as cellular models of neurodevelopmental disorders. He also acts as consultant to ReNeuron Ltd, a UK Biotech company developing stem cells for therapeutic and drug discovery applications.

Professor Nikolas Rose

Nikolas Rose is Professor of Sociology and Head of Department of Social Science, Health and Medicine at King's College London. He initially trained as a biologist and psychologist. His current research is on the social and political implications of the new sciences of the brain. He was a member of the Nuffield Council on Bioethics until 2013, and has previously contributed to the Council's reports on personalised healthcare and pharmacogenetics.

Professor Steven Rose

Steven Rose is Emeritus Professor of Neurobiology, Department of Life, Health and Chemical Sciences at Open University and Emeritus Professor, Genetics and Society, Gresham College, London. He is a neuroscientist whose research has focussed on the molecular and cellular mechanisms of learning and memory. His books include *The 21st Century Brain*, *Lifelines and The Making of Memory*, and, with Hilary Rose, *Genes, Cells and Brains: the promethean promises of the biosciences*. He has received several awards, including the Edinburgh Medal and the silver medal of the Scottish Royal Society of Arts. He has had a long term engagement with the ethical, legal and social aspects of the neurosciences, and was for several years a regular panellist on the BBC's Moral Maze.

Professor Iliana Singh

Iliana Singh is Professor of Science, Ethics and Society, Department of Social Science, Health and Medicine at King's College London. Iliana has a doctorate in Human Development and Psychology from Harvard University, and spent four years as an affiliated lecturer in Social and Political Sciences at the University of Cambridge before moving to the LSE in 2004 and Kings College London in 2012. Her work explores the psycho-social and ethical implications of advances in bioscience and biomedicine for young people and families. Her current projects focus on psychotropic drugs, neuroimaging, cognitive and other forms of enhancement, and biomarkers associated with the development of criminality, psychopathy and psychiatric disorder.

Professor Vincent Walsh

Vincent Walsh is Professor of Human Brain Research, Institute of Cognitive Neuroscience at University College London. He is interested in all aspects of visual cognition including: visual search; awareness; motion and colour perception; eye movements; and visual memory. He also studies the perception of time; numerical representation; synaesthesia; plasticity in visual and motor systems; and all aspects of human brain stimulation, including DBS and TMS. He is on the Editorial Board for the journal *Brain Stimulation: Basic, Translational, and Clinical Research in Neuromodulation*.

Professor Kevin Warwick

Kevin Warwick is Professor of Cybernetics at University of Reading. His studies have focused on direct interfaces between computer systems and the human nervous system, as well as artificial intelligence, control systems and robotics. He presently heads a research project supported by the Engineering and Physical Sciences Research Council which investigates the use of machine learning and artificial intelligence techniques in order to suitably stimulate and translate patterns of electrical

activity from living cultured neural networks in order to utilise the networks for the control of mobile robots. He heads the University of Reading team in a number of European Community projects such as FIDIS looking at issues concerned with the future of identity and ETHICBOTS which is considering the ethical aspects of robots and cyborgs.