

Mapping Stem Cell Innovation in Action: ESRC Stem Cell Initiative

Monday 16 October 2006

Room 6.13 James Clark Maxwell Building, King's College London

Ethics, regulation, and the development of stem cell therapy?

Introduction

This workshop is designed to encourage dialogue between different groups of researchers and others with an interest in the field of stem cell research and regenerative medicine. We are inviting around twenty speakers and participants from the academic fields of the humanities, social science, medicine, biomedical science, and from a range of user groups. The four papers are short overviews designed to stimulate discussion with a diverse audience. Lunch, tea, and a wine reception will also promote informal networking and dialogue amongst the workshop participants.

12.15 - 13.00 Lunch and Registration

13.00 – 13.05 Welcome and Introduction

Professor Robert Lechler, Vice-Principal (Health), King's College London

Findings from the project

13.05 - 13.30 1. Sociological reflections on the ethics of stem cells and cell transplantation

Dr Steven Wainwright, Medical Sociology, King's College London &
Dr Clare Williams, Medical Sociology, King's College London

13.30 - 14.00 2. Ethics, research and stem cell therapy

Professor Bobbie Farsides, Bioethics, University of Sussex &
Professor Alan Cribb, Public Policy & Bioethics, King's College London

14.00 - 14.30 Discussion

14.30 - 15.00 Tea

Discussants

15.00 - 15.30 3. Ethics and regulation in the social world of the fetus

Dr Julie Kent, Sociology, UWE, Bristol &
Professor Naomi Pfeffer, History of Medicine, London Metropolitan University

15.30 - 16.00 4. The global biopolitics of stem cell science

Professor Brian Salter, Political Science, University of East Anglia

16.00 - 16.30 Discussion

16.30 - 18.00 Wine reception

Ethics, regulation, and the development of stem cell therapy

Participants

1. Professor Alan Cribb, Public Policy & Bioethics, King's College London
2. Professor Bobbie Farsides, Bioethics, University of Sussex
3. Dr Clare Williams, Medical Sociology, King's College London
4. Dr Steven Wainwright, Medical Sociology, King's College London
5. Professor Brian Salter, Political Science, University of East Anglia
6. Professor Naomi Pfeffer, History of Medicine, London Metropolitan University
7. Dr Julie Kent, Sociology, UWE, Bristol
8. Professor Mike Michael, Sociology of Science & Technology, Goldsmiths College
9. Ms Catherine Arkley, Chief Executive, Children's Liver Disease Foundation
10. Professor Simon Howell, Dean of Research, Biomedical Science, King's College London
11. Dr David King, Director, Human Genetics Alert
12. Dr Sarah Parry, Sociology, University of Edinburgh
13. Ms Jessica Watkin, Wellcome Trust Biomedical Ethics Programme
14. Dr Stephen Minger, Director, Stem Cell Lab, King's College London
15. Professor Erica Haines, Sociology, University of Newcastle
16. Dr Nina Hallowell, Sociology, University of Edinburgh
17. Professor Sarah Franklin, Sociology, LSE.
18. Professor Stephen Wilkinson, Bioethics, University of Keele
19. Professor Jane Sandall, Midwifery, King's College London
20. Dr Heather Draper, Bioethics, University of Birmingham
21. Professor Lene Koch, Sociology of Science & Technology, University of Copenhagen
22. Dr Kathryn Ehrich, Medical Sociology, King's College London
23. Reverend James Buxton, Chaplain, Guys Campus, Kings College London
24. Dr Rosamund Scott, Law, Bioethics & Reproductive Technologies, King's College London

Biographies: ESRC SCI Stem Cell 'Ethics Workshop' at KCL (16.10.2006)

* **Catherine Arkley** has been Chief Executive, Children's Liver Disease Foundation, for 15 years. In this time the income for the charity has quadrupled and comprehensive programmes of research, patient and family support and education have been developed. She has developed a number of major campaigns, including Yellow Alert; a campaign to promote early diagnosis and prompt referral of infants with liver disease. Catherine managed the development of patient literature to accompany the UK paediatric liver transplant programme, and is currently working on literature for the UK paediatric intestinal transplant programme. Catherine also serves on the executive council of the Association of Medical Research Charities.

* **James Buxton** is Chaplain of King's College London at Guy's Hospital, and Succentor of Southwark Cathedral, following curacy in Portsmouth. He has a long standing interest in issues of global justice, and previously worked with refugees in Istanbul, and in campaigning and fundraising for Oxfam in the UK.

Alan Cribb is Professor of Bioethics & Education at KCL. His research relates to applied philosophy and health policy, and he has a particular interest in developing interdisciplinary scholarship that links philosophical, social science and professional concerns. His current research is examining pharmacy ethics and virtues in medical education. He is the former Editor of *Health Care Analysis: An International Journal of Health Care Philosophy & Policy*.

Heather Draper is Reader in Biomedical Ethics, Centre for Biomedical Ethics University of Birmingham. She has been involved in the teaching of ethics and law to medical students and the training of qualified health care professionals in ethical issues for all of her professional life. Her research interests centre on reproductive technologies and reproductive responsibilities. Her interest in stem cell technologies mainly centres on the ethical issues surrounding how human eggs for use in stem cell research are obtained and our obligations to the human embryo.

Kathryn Ehrich is Research Fellow, School of Nursing, KCL. Her academic background is in medical sociology and anthropology. Her research interests include social and moral aspects of parenting, reproductive and child health services; patient safety; professional regulation; and the construction of ethical value in biomedicine. Her current research, funded by the Wellcome Trust Biomedical Ethics Programme, and working with Dr. Clare Williams, is on the experiences of staff working in pre-implantation genetic diagnosis.

Bobbie Farsides is Professor of Clinical & Biomedical Ethics at the Brighton and Sussex Medical School, University of Sussex. Her research interests span the ethics of palliative and end of life care, antenatal screening, stem cell research, and pre-implantation genetic diagnosis. She has a particular interest in the interconnections between philosophical and empirical ethics, and the ethical views of health professionals as reflected in her collaborations with Clare Williams on three major research projects. In March 2006 she became Co-Editor of the new Royal Society of Medicine journal *Clinical Ethics*.

Sarah Franklin is Professor of Social Studies of Biomedicine and Acting Director of the BIOS Centre at the LSE. She has an interdisciplinary background in anthropology, cultural studies, and feminist theory. Her work on IVF, stem cells, cloning, embryo research, and the new genetics combines ethnographic empiricism with analysis of media representations and public debate to produce a cultural account of the changing facts of life. She has written, co-authored, edited and co-edited 15 books and has published more than 100 articles and chapters which contribute to several recent fields of scholarly enquiry including the anthropology of reproduction, the new kinship studies, theories of the body and embodiment, debates about gender and sexual difference, visual cultures of science and medicine, and the emerging sub-discipline of biosocial studies. Her forthcoming monograph on cloning entitled *Dolly Mixtures: the remaking of genealogy* will be published by Duke University Press in February 2007.

Erica Haines is Professor of Sociology at the University of Newcastle. She is also Executive Director of the Policy, Ethics and Life Sciences (PEALS) Research Institute, a joint venture between the universities of Newcastle and Durham and the International Centre for Life. Her research interests include: the relationships between states, medicine and families, with particular reference to the sociology of assisted conception and of genetics; the relationship between Sociology and ethics; the sociology of identity. She is PI on a Wellcome Trust-funded project investigating potential donors' views of the use of IVF embryos for stem cell and other research.

Nina Hallowell is a Reader in Social Science and Public Health at the University of Edinburgh's Medical School. Her research interests are in the social and ethical implications of the introduction of innovative health technologies within the clinic. She has published widely on the introduction of predictive DNA testing in cancer genetics clinics. She teaches a postgraduate course on bioethics and biotechnology at the University of Edinburgh.

* **Simon Howell** is currently Professor of Endocrine Physiology, and Research Dean in Biomedical Sciences at KCL. His research interests are in diabetes and in particular in the mechanism and regulation of insulin secretion. He was awarded the RD Laurence Lectureship of the British Diabetic Association and the Minkowski Prize of the European Association for the Study of Diabetes in recognition of his research. He has previously been a member of Council of the European Association for the Study of Diabetes and of the Association of Medical Research Charities. He is presently Chairman of the Board of Trustees of the charity Diabetes UK.

Julie Kent is Reader in Sociology of Health Technology at the University of the West of England, Bristol. She has research interests around the regulation and governance of health technologies, the emergence of new tissue and cell based technologies and the implications for conceptions of the body, self and identity. She is currently writing a book on regenerative medicine. She is a member of the Medicines and Healthcare products Regulatory Authority, Committee on Safety of Devices.

* **David King** is a geneticist, who has been writing and campaigning on genetics issues since 1990. His PhD in molecular biology from Edinburgh University was on RNA splicing, using yeast as a model organism. Prior to that he studied at Cambridge University and the Weizmann Institute of Science in Israel. He was the first Director of The Genetics Forum, a campaigning pressure group, and was the founder of GenEthics News, an independent newsletter on genetics issues, which he edited for seven years. He is the founder and Director of Human Genetics Alert, a leading watchdog group on genetics issues.

Lene Koch is Professor of the History of Reproductive and Genetic Technologies at the Institute of Public Health, University of Copenhagen. She has completed work on the development of IVF, and on eugenics and compulsory sterilisation. She is currently heading a research project on stem cell research in Denmark.

Mike Michael is Professor of Sociology of Science and Technology at the Sociology Department, Goldsmiths College, University of London. His interests include public understanding of science, the relation between everyday life and science and technology, and biotechnological and biomedical innovation and culture. He is currently working on ethical aspects of stem cell research, and technoscience and everyday life. Recent books and upcoming publications include (with Alan Irwin) *Science, Social Theory and Public Knowledge* (Open University Press, 2003), *Technoscience and Everyday Life* (Open University Press, in press), and (with Lynda Birke and Arnie Arluke) *The Sacrifice: How Scientific Experiments Transform Animals and People* (Purdue University Press).

Stephen Minger is Director of the Stem Cell Biology Laboratory and a Senior Lecturer in the new Wolfson Centre for Age Related Diseases at KCL. Over the last 15 years, his research group has worked with a wide range of somatic stem cell populations, as well as mouse and human embryonic stem (ES) cells. In 2002, together with Dr Pickering and Professor Braude, Dr Minger was awarded one of the first two licenses granted by the HFEA for the derivation of human ES cells. His group subsequently generated the first human embryonic stem cell line in the UK and was one of the first groups to deposit this into the UK Stem Cell Bank. They have gone on to generate four new human ES cell lines, including one that encodes the most common genetic mutation resulting in Cystic Fibrosis. His lab also focuses on the generation of a number of therapeutically relevant human somatic stem cell populations from embryonic stem cells. Dr Minger has established collaborations with a number of specialist groups in many areas of clinical interest throughout the UK, and is one of the co-organisers of the London Regenerative Medicine Network, and the Senior Editor of *Regenerative Medicine*. Dr Minger's research is supported by the MRC, the EU, GlaxoSmithKline, The Novartis Institute, The Oliver Bird Foundation, The Wellcome Trust, The UK DTI, The Huntington's Disease Association, The Alzheimer's Research Trust, The Charitable Foundation of Guy's and St Thomas' Hospitals, the BBSRC, and the EPSRC amongst others.

Sarah Parry is Lecturer in Sociology, University of Edinburgh. Sarah's doctoral research focused on the UK public debates in stem cell research (SCR) and is underpinned by her academic background in sociology, cultural studies and science and technology studies. Her PhD explored: (i) the Parliamentary debates that led to changes to the Human Fertilisation and Embryology Act (ii) views of scientists working in the field of SCR, (iii) people involved in fertility treatments who may be asked to donate embryos for this area, and (iv) patient support groups of people who may benefit from this area of research. Sarah has written about the Parliamentary debates, fertility patients' views of embryo research and scientists accounts of SCR. This work is being extended in a three-year ESRC project "The Social Dynamics of Public Engagement in Stem Cell Research". This is a collaborative project with Sarah Cunningham-Burley (Public Health Sciences & CRFR), Wendy Faulkner (Science Studies Unit) and Austin Smith (Institute for Stem Cell Research). This project critically explores the scope for establishing a dialogue between a range of groups, including people working on different aspects of SCR and various patient and community groups.

Naomi Pfeffer is Professor of Social and Historical Studies of Health at London Metropolitan University. Her research investigates controversial developments in medicine during the second half of the twentieth century, specifically reproductive technologies, human tissue collections and the development and conduct of medical research ethics. Her latest book, *Insider trading: collecting human tissue for medicine in the USA and UK* (Yale University Press), will be published in 2008. Naomi has been involved in CERES (Consumers for Ethics in Research) since it was established in 1989 and is currently its chair. She is currently serving on the Human Remains Advisory Service established by the Department of Culture, Media and Sport.

Brian Salter is Professor of Biopolitics and Director of the Global Biopolitics Research Group in the Institute of Health at the University of East Anglia. A political scientist specialising in the analysis of public policy, he has studied the political forces at work in the policy arenas of education, health and, most recently, the life sciences. Here his work focuses on the global politics of new health technologies and the international governance issues surrounding the bioethics and regulatory policies of stem cell research. He has published numerous books and articles including *The new politics of medicine* (2004) and *The politics of change in the Health Service* (1998). Closely associated with his academic work is his role as policy adviser to government, funding agencies, professional and international bodies and his contribution as ethical adviser to the European Framework Six Programme. An experienced flight instructor and flight examiner, he is probably the only UK professor to have flown a World War II Spitfire.

Jane Sandall is Professor of Midwifery and Women's Health in the Division of Health & Social Care Research at KCL. She was a member of the UK National Service Framework for Children, Young People and Maternity Services Evidence Group and of the Maternity Working Group, and is a member of the UK National Stem Cell Bank Steering Committee. Research has been funded by the ESRC/MRC Innovative Health Technologies Programme, Department of Health, NCCSDO, Wellcome Trust, and a range of Medical and Health Charities. Her current interests are focused on developing greater understanding of the relationship between context and health care practice using frameworks for evaluation of complex interventions and institutional ethnography. They are theoretically informed by theories of risk and safety, and occupational jurisdiction. She is currently leading a Cochrane Review of midwifery led care, the evaluation of a programme of community based midwifery led continuity of care for women in disadvantaged areas, and an ethnographic study of transfer and handover in midwife led units. She is working with others on a national study of outcomes for low risk women and babies in midwifery led and obstetric led units; the development of access, quality, optimal outcome indicators in maternal health care, and the social and ethical implications for staff working with Pre-implantation Diagnostic Technologies.

* **Rosamund Scott** is Reader in Law at the Centre of Medical Law and Ethics and School of Law, KCL. Her academic background is in philosophy and law and she is also a barrister. Her research interests are largely in the field of reproductive law and ethics. In 2002 her first book, *Rights, Duties and the Body: Law and Ethics of the Maternal-Fetal Conflict*, appeared. She has since published a number of articles on prenatal screening, selective abortion and preimplantation genetic diagnosis and is currently writing a book on this area. She is a member of the Ethics Committee of the Royal College of Obstetricians and Gynaecologists; a member of the Editorial Advisory Board of *Clinical Ethics*; a member of a research group looking at the attitudes and experience of staff involved in the provision of preimplantation genetic diagnosis.

Steven Wainwright is Senior Lecturer, Division of Health & Social Care Research, and School of Nursing, King's College London. His research focuses on three areas: the connections between Medical Sociology and Science & Technology Studies (especially innovative medical technologies); Medical Humanities; and the Sociology of the Body. He is currently working on this ESRC funded ethnography of stem cell research, and some of this study forms the basis of his forthcoming research monograph (with Clare Williams) on *The Body, Biomedicine & Society: Reflections on High-Tech Medicine* (Palgrave Macmillan). He is an Editor of the leading Sociology journal published in the UK: *Sociology of Health & Illness*.

Jessica Watkin is a policy adviser in the Biomedical Ethics Department of the Wellcome Trust. Her main responsibilities include contributing to the development of Trust policy and working with Trust funded grantholders to help disseminate their research findings into policy and practice.

Stephen Wilkinson is a Professor of Bioethics and a member of the Centre for Professional Ethics at Keele University. His most recent research is on reproductive ethics and the regulation of reproductive technologies and this has been supported by the Wellcome Trust's Biomedical Ethics Programme and by the AHRC. A previous phase of research focused on the commercial exploitation of the human body and his book, *Bodies for Sale: ethics and exploitation in the human body trade* was published by Routledge in 2003.

Clare Williams is Reader in Social Science of Biomedicine, Division of Health & Social Care Research, KCL. Her research and writing focuses on the clinical, ethical and social implications of innovative health technologies, particularly from the perspective of health care practitioners and scientists. She holds grants from the Wellcome Trust Biomedical Ethics Programme on the experiences of staff working in pre-implantation genetic diagnosis; and the ESRC Stem Cell Initiative on mapping stem cell innovation in action. Clare is on the Editorial Board of *Clinical Ethics* and is an Editor of *Sociology of Health & Illness*. She is UK member of the European Science Foundation Committee which awards EU Framework networking grants.

* **Member of project Advisory Group.** Other members of the Project Advisory Group are: **Gemma Bradley** (Press & Publications, KCL); Professor **Renee Fox** (Annenberg Professor Emerita of the Social Sciences and Senior Fellow of the Center for Bioethics, University of Pennsylvania, USA); Professor **Peter Jones** (Professor of Endocrine Biology, KCL); & Dr **Angela Wilson** (Director of Research, Diabetes UK).