

Ethics in stem cell research: a social science perspective

British International Congress of Obstetrics and Gynaecology

22nd June 2010

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Centre for Biomedicine & Society - CBAS

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www.kcl.ac.uk/schools/sspp/interdisciplinary/cbas/

Research Programme: Sociology, Ethics & Biomedicine

Wellcome Trust Biomedical Ethics Programme (2001-2004)

Ethical, clinical and policy implications of changing perceptions of the fetus for practitioners and policy makers

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Social and organisational implications of one stop first trimester prenatal screening

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Facilitating choice, framing choice: the experiences of staff working in PGD

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ESRC Stem Cell Initiative (2004-2006)

Mapping stem cell innovation in action: an ethnography of the bench-bedside interface

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ESRC Stem Cell Initiative Senior Research Fellowship (2007-2009)

Spaces of stem cell science: exploring processes of translational research

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Ethical frameworks for embryo donation: views, values and practices of IVF/PGD staff

Clare Williams, Bobbie Farsides, Kathryn Ehrich, **Susan Avery**, Rosamund Scott, Sarah Franklin, **Peter Braude**

Wellcome Trust Biomedical Ethics Strategic Award (2009-2014)

The ethics of translational research: from 'unnatural entities' to experimental treatments

LABTEC - London & Brighton Translational Ethics Centre

Clare Williams, **Peter Braude**, Alan Cribb, Bobbie Farsides, Mike Michael, **Stephen Minger**, Brian Salter, Rosamund Scott, Clive Seale, **Chris Shaw**, Steve Wainwright

Qualitative Social Science Research Methods

- Specialist medical / scientific units
- Formal and informal interviews with staff
- Observations of patient/practitioner consultations etc, lab procedures, team meetings
- Ethics discussion groups for mixed groups of staff
- Stakeholder interviews

The Social Context of Ethics in Innovation

- Where/how are ethical boundaries drawn in innovative clinical/scientific practice?
- Who decides what choices are available to patients?
- Is informed consent attainable?

Mapping stem cell innovation in action: an ethnography of the bench-bedside interface (2004-2006)

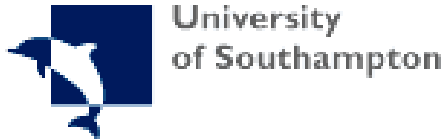
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Spaces of stem cell science: exploring processes of translational research (2007-2009)

Steven Wainwright & Clare Williams



Stem Cell Labs Fieldwork in the UK & USA



University of London

UNIVERSITY OF
BIRMINGHAM



Institute of **Psychiatry** at the Maudsley

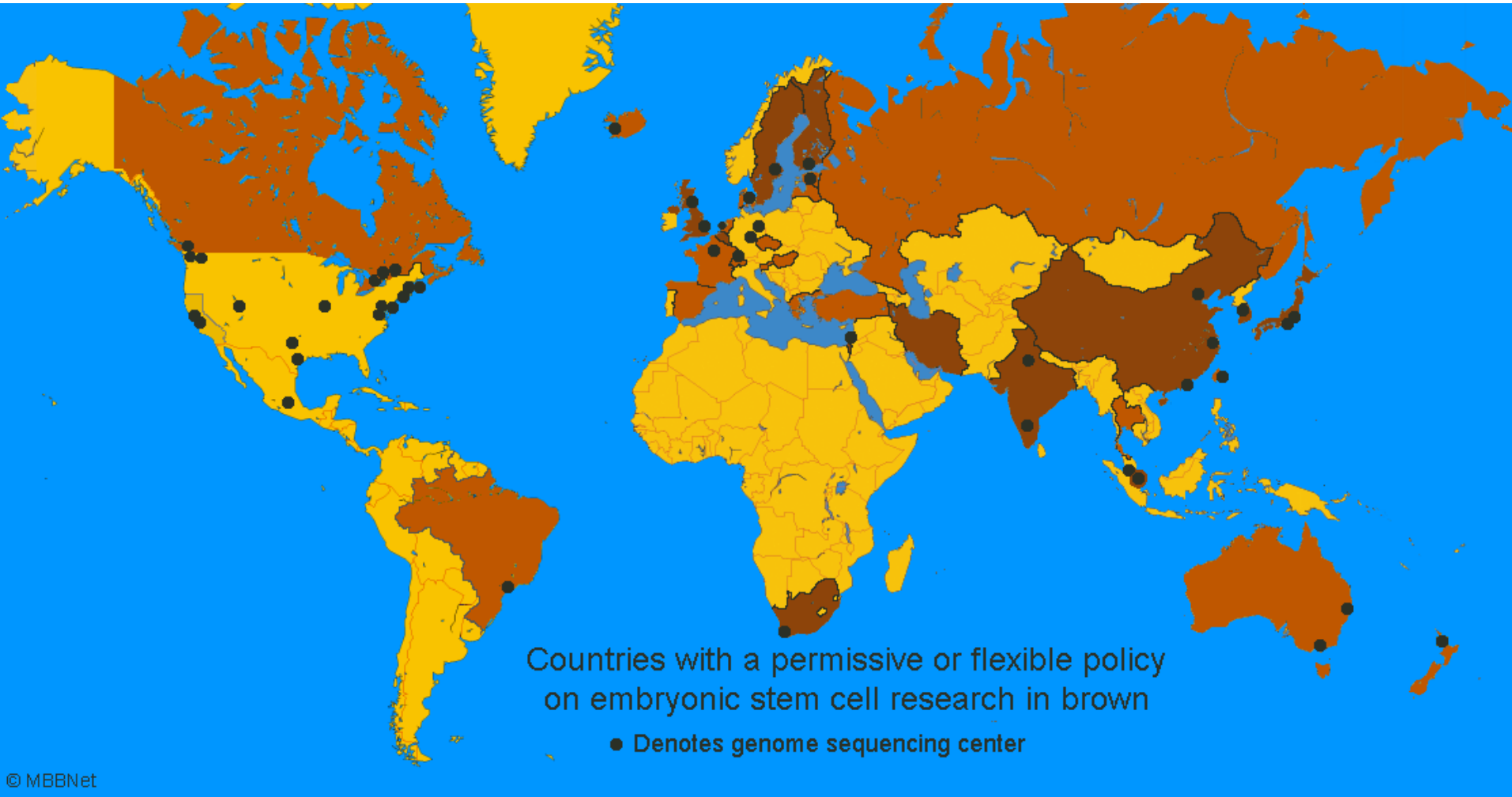


Imperial College
London



Levels of Global Embryonic Stem Cell Regulation

Key: Restrictive Flexible Permissive



Ethical Boundary-Work

Wainwright, Williams et al (2006) Sociology of Health & Illness

Themes:

1. Perceptions of embryos and stem cells
 - i. As 'just cells'*
 - ii. Gradualist approach*
 - iii. Implantation*
 - iv. Respect for all tissues*

2. 'Ethical' sources of embryos and stem cells
 - i. 'Spare' embryos*
 - ii. Only PGD embryos*
 - iii. Unsure about IVF embryos*
 - iv. Using embryos created solely for research*

Sources of Embryos

Creating Embryos for Research?

We get embryos from IVF... and those embryos would be thrown away so it's not as if we're making them specifically for cell work. I wouldn't do that, I wouldn't be happy to produce just a continuous supply of fertilised embryos for lab work.

Senior Scientist 2

At the moment the way you grow human stem cells is you get embryos that will be thrown away if you don't use them... I think it would be unethical to let those embryos be thrown away when there's a choice. But I wouldn't agree with working with embryos that have been created solely for the purpose of harvesting stem cells – I would definitely refuse to work on those cells. Senior Scientist 1

Biosphere: Laboratory (Alexis Rockman, 1993)



Sources of Embryos

Spare and otherwise discarded

With rare exceptions, the embryos that are used in stem cell research are embryos that have no future... If all we're doing is using something left over and destined to be discarded, then if some good can come out of it, it's worth doing.

Senior Scientist 8

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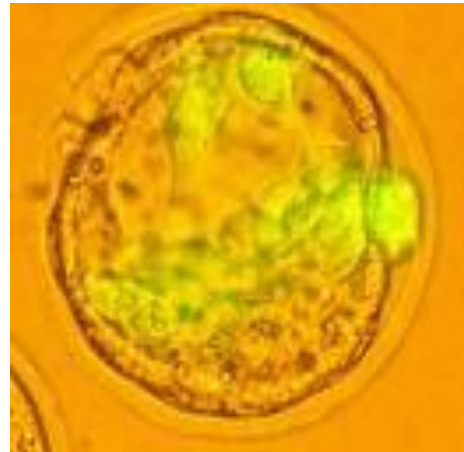
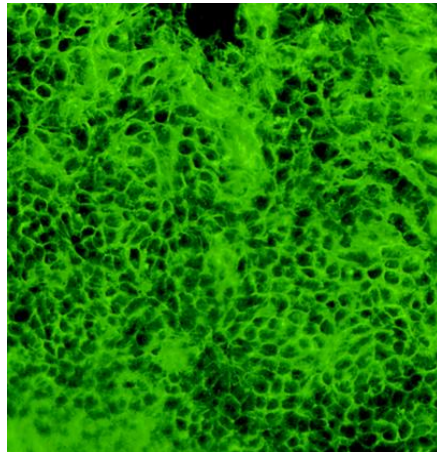
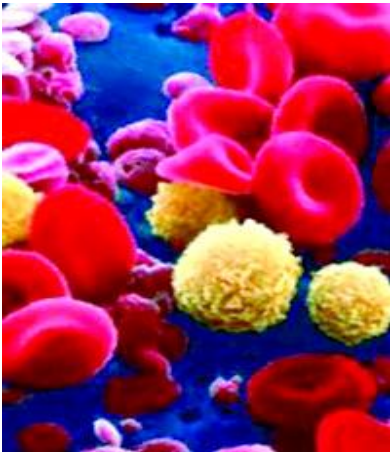
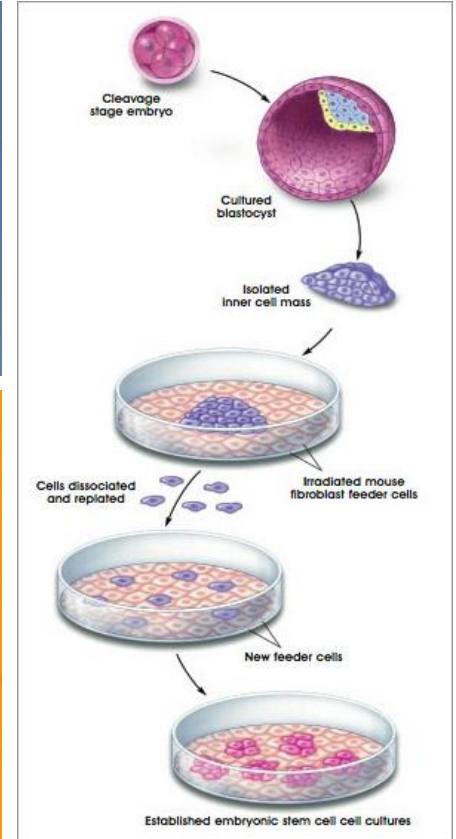
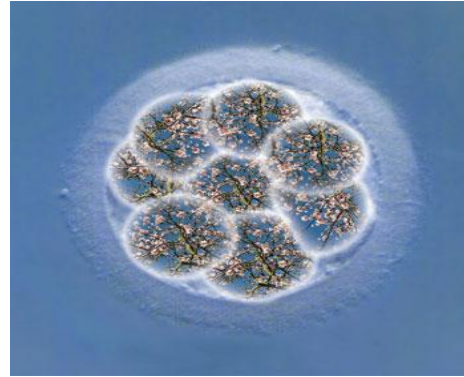
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Ethical Frameworks for Embryo Donation

From assisted conception to human embryonic stem cells?



Ethical Frameworks For Embryo Donation

2007 - 2010

- Three UK teaching hospitals: ACU's/stem cell labs
- 44 staff interviews
- 6 discussion groups
- Observations in clinics, labs, staff meetings
- Ethics and Policy Workshop

Reducing Uncertainty and Regret

- “Donating fresh embryos is relinquishing chances because they don’t know whether the embryos that they’re using are going to create a pregnancy or not.”
Counsellor
- “I can’t imagine anyone who would be happy that they’d donated half their embryos for research and not been able to get pregnant.”
Embryologist

Prioritising Clinical Treatment Over Research

- “I prefer crypreserved embryos because...it’s the end of their treatment and they’ve forgotten about them. They’re, ‘That’s it, I don’t want any more to do with the embryos, but they might as well be used for research.’”

Stem Cell Scientist

- “They know that every embryo that could possibly have potential has been frozen for their use, research is a secondary option... It’s totally different to taking embryos out of a fresh cycle and saying, ‘These aren’t good enough for you, we’ll have them.’”

Clinician

Technological Developments

Blastocyst culture

“We don’t do any freezing now on the third day, even if we put the embryos back on that day. If we were thinking about freezing, we would keep the embryos until the 5th day – if they make it to good quality blastocysts, we would freeze them...we don’t want to freeze embryos that don’t have that potential to carry on developing.”

Embryologist

“Any embryo that has the capacity to make an inner cell mass and to make a stem cell line should be kept for the patient... nobody really says that embryos for research are good quality embryos that have the potential to make a pregnancy”.

Embryologist

Informed Consent

Long term uncertainties

“With stem cell research...the actual patient’s cells will be growing, forever growing and developing – I think that’s quite a difficult issue to explain to patients, and for them to come to terms with...so I think there are a lot more ethical issues surrounding stem cell research than with other embryo research projects.”

Embryologist

“We can only tell them how it is at the moment, our knowledge is limited – so that’s quite risky to take consent to anything on..we can’t guarantee that there won’t be some future legislation that decrees all stem cell lines are to be used and they’re going to make it retrospective because it’s deemed to be of such benefit to society”.

Counsellor

Ethics & Policy Workshop: Restricted Consent

- Separate consent for hESC lines for research/treatment
- Restriction on creation of gametes

Two Tier Restricted Consent Model

- hESCs with *unrestricted* consent to the UK SC Bank
- embryos with *restricted* consent only used in labs which would honour restrictions; Bank deposit not required

Three Category Restricted Consent Model

(1) basic hESC research

(2) hESC research & treatment; no gamete derivation

(3) 'unrestricted' hESC research & treatment

Phase 1 Trial Initiation (Geron ESC4SCI)

A trial of one application, not a trial of all ES cells... but

- This... marks the dawn of a new era in medical therapeutics. This approach is one that reaches beyond pills and scalpels to achieve a new level of healing

Thomas Okarma, Geron CEO

- Today's news... is a milestone in the new era of hope

Amy Comstock Rick, Coalition for the Advancement of Medical Research

- This is what we've all been waiting for

Robert Lanza, Advanced Cell Technology

- The announcement boosted the price of shares in [Geron]... up 56% from the day before the announcement

Meredith Wadman, Nature, Jan 27, 2009

Interface Between Research & Experimental Treatment

If I'm not prepared to do something, someone else will do it. There's someone right behind me, who's going to clamber over my back, prepared to do that. There is great pressure on individuals and institutions to 'push ahead'.

(Consultant Surgeon, Ethics Discussion Group)

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Prof Williams (King's, Sociology, CBAS)

Prof Braude (King's, Medicine)

Prof Cribb (King's, Ethics, SSPP)

Prof Farsides (Brighton & Sussex, Ethics)

Prof Michael (Goldsmiths, Sociology)

Dr Minger (King's, Stem Cell Science)

Prof Salter (King's, Politics, CBAS)

Prof Scott (King's, Ethics & Law, Law)

Prof Seale (QMUL, Sociology)

Prof Shaw (King's, Neuroscience, IOP)

Prof Wainwright (King's, Sociology, CBAS)

- Significant contribution to empirical /normative ethics
- Build interdisciplinary research programme
- Develop research capacity and expertise
- Build local, national, and international collaborations
- Engage with policy makers, users and publics
- Contribute to public debates and the policy process

Ethical Worlds of Stem Cell Medicine

- Resource allocation (research priorities)
- University-industry R&D partnerships
- Commercialization/patenting
- Species integrity (human-nonhuman chimeras)
- ‘Slippery slopes’
 - Genetic enhancements
 - New forms of eugenics
- Privacy and confidentiality
- Research ethics review and oversight
- Sources of stem cells
- Commodification of human life, human reproduction, human reproductive tissues
- Free and informed choice (potential coercion, exploitation of tissue donors)
- Human cloning
- Issues of distributive, social and global justice (equitable access to benefits of research, is stem cell research best for public health?)