

## **Stem Cells and Public Debate in the UK:**

Public Engagement Dialogues  
on the Commercialisation of Stem Cells

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# Talking About Stem Cells: The Social Dynamics of Public Engagement in Stem Cell Research

## Two parallel aims

- 1) To investigate a range of peoples' views and concerns about stem cell research (SCR)
- 2) To explore the scope for increasing public engagement in SCR, through a range of methods

## Project team

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# Pattison Report (Nov 2005)

- **SCR strategic for wealth generation**; major weaknesses identified — *“unknown business model and return on investment, lack of big pharma involvement, lack of venture capital investment and lack of clarity on IPR and licensing issues”* — but not examined.
- **Public dialogue and acceptance of SCR critical** for realising ambitions — but commercialisation not identified as an issue warranting public engagement.

# Public attitudes to commercialisation of research

- Less trust of research from companies than academic and NGOs
- ‘Legitimate’ concerns about commercial interests in public science (Wynne, Irwin)
- The ‘innovation agenda’ drives S&T policy but is never subject to public debate
- Strong reactions (more broadly) to ‘corporate greed’ at the expense of ordinary people

# Our aim today...

- is to explore how such ambivalence plays out in relation to SCR
- ... and so deepen understanding of PUS concerning commercialisation,
- by sharing evidence and reflections from a two stage public engagement exercise in May 2008.

# Scepticism & ambivalence

- Mistrust: “As soon as there’s profit to be made...”
- Tendency to counter-pose private profit and public good
- Limited knowledge of innovation processes, including roles of public & private sector R&D

NB *Many practitioners hold a ‘deficit model’: public acceptance of commercialisation would increase with greater awareness*

# Staged, dialogic PE event

- “Developing applications from stem cell research: What role for the private sector?  
... An opportunity to learn about and reflect on issues raised by the commercial development of stem cell research”
- 31 participants (21 at each event)
  - ‘**practitioners**’: business developers, SC scientists, entrepreneurs, research commercialisers
  - ‘**others**’: patient groups, research nurses, ethicists, wider publics

# What happened?

- **Two aims: education and deliberation**
  - Pre-circulated briefing and participants learning from one another
  - Small group format, w/ 'rules of engagement'
- **Participants chose the agenda for 2nd event:**
  - *Practitioners*: more on public and private sectors roles for development of SCR technologies
  - *Others*: various issues surrounding patenting and commercialisation of donated eggs and embryos



# Cost, regulation and risk

- Participants told of huge time and cost for ‘normal’ drug development
- Regulatory ‘hurdles’ singled out as key issue
- Little mention of underlying scientific uncertainty, though:
  - Complexity of SCs stressed
  - Fears of a ‘gene therapy’-type disaster voiced

# Likely companies, products & business models

- Big pharma waiting for proof of principle
  - SCR may not yield SC therapies
  - No workable business model for these
- > **‘hybrid’ strategies likely**, pegged to other businesses and ‘simpler’ SC applications

# Roles for public and private sector

- Boundaries extremely muddy in SCR devt
  - SNBTS as possible model?
- Some practitioners polarised the issue
- Most ‘others’ accepted the arguments for private sector investment
  - ... but felt this raised various dilemmas

# Patenting, ownership of SC lines & donation for SCR

- Unease about 'owning' parts of the human body
- Sense of 'entangled' ownership of products from donated eggs or embryos
- Fully informed consent vital to cover commercial applications
- Significant minority favour financial return to donors
- Significant majority favour some form of benefit sharing

# Implications for public acceptance

- *Research nurses* fear drop in recruitment of donors, because
  - publics “don’t see the bigger picture”, and
  - “why should companies make money out of my embryos, which I am donating altruistically?”
- *Ethicists* feel these issues need to be aired: “pupils might be appalled actually if they knew about people making profit”

# Outcomes for participants

1. People learned things they valued
2. Some people's views or understandings shifted
3. Some practices will change ... including public engagement practices

# ‘Gut reactions’ to commercialisation: two possible views

1. These reactions are founded on ignorance and unjustified opposition  
*-> they need to be remedied by more information about why private sector investment is needed*
2. These reactions are rational and legitimate  
*-> they should be acknowledged as such and included in the framing of public debate on SCR*

# The deficit model & public acceptance of SCR

- Participants did learn from the deliberations ... including practitioners!
- Redressing the 'deficit' of knowledge can increase acceptance of SCR (by some)
- Real dilemmas and concerns nonetheless remain (or grow) ... with potentially major significance



# Implications for public engagement

- The challenge of working with groups with quite **divergent agendas** for PE
- More **informed** and genuine **dialogue** are worthwhile objectives in their own right
- It is vital to **open up the framing** of PE around S&T: if all voices are to be heard and not further alienated – *from science and from politics*



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