Stem cell dialogue: key findings, conclusions and recommendations

Dr Darren Bhattachary, Director BMRB
Objectives

Engage the public and stakeholders on stem cells: policy development

- Views and concerns
- Raise awareness
- Future dialogue
Approach

- 200 members of public
- 5 deliberative workshops – reconvened 3 times
- 49 stakeholders
- Depth interviews
- Q methodology
- Framework analysis

Locations:
- Edinburgh
- Newcastle
- Cardiff
- Bristol
- London
Issues discussed

Interviews

Workshops

W1
Visions
Social and economic drivers

W2
Sources
Tissue Specific
Embryonic

W3
SC banks
Applications
Clinical trials
Key findings
Value of basic and applied research

High levels of support - but conditional
Value of basic and applied research

High levels of support - but conditional

What is a serious disease
What is a serious disease?

- Cosmetics
- Enhancement
- Baldness
- Dentistry
- Diabetes
- Deafness
- Injury
- Cancer
- Degenerative diseases

- use
- use

Contested space
Value of basic and applied research

High levels of support - but conditional

What is a serious disease
## Value of basic and applied research

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Adult and embryonic
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What is a serious disease

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Adult and embryonic

Uncertainties

People valued basic research
Ethics of stem cell sources

- Ethical concerns across a range of sources
  - Embryos
  - Protection of women
  - Rights of patients
  - Clinical concerns
Investment: commercialisation and public value

**Investment needed for clinical applications**
- Gap (and opportunity) for funding between public, private and charitable sector
- Healthcare pull from NHS
- Rainbow coalition for support

**Public concerns around private investment**
- Ends of technology
- Process: openness, transparency, disclosure
- Affordability of treatments

**Trust**
Governance

Hard infrastructure systems and institutions that control of science - government and regulators

Tension between permissive legislation and tight regulation

However, important for provenance stem cell lines – ethical and safety

Competent authorities as science develops Therapeutic or device HTA, MHRA, HFEA, EMEA

Informed consent

Risk and clinical trials
Governance

Soft infrastructure

- Social relations, informal networks, and professional cultures that shape field

Future dialogue

- More than big events
- Cultures and practices
- How openly discuss uncertainties and public value of research
- Future role of research councils
Key conclusions and recommendations

1. Funding
   - Conditional support for all avenues of stem cell research
   - Priorities on basic and translational research
   - Clinical priority - treatments are limited

2. Ethical approval ES cells
   - Reflect the views of public and donors
   - Necessity and how 'serious' disease is defined
   - Difficult to establish firm guidelines on donor consent in future
Key conclusions and recommendations

3. Health and wealth opportunities
   - Greater investment and coordination between public and private sectors to achieve this goal
   - Charity campaign - raise resources and profile

4. Private sector
   - Concerns: means and the ends of research
   - Use for socially valued purposes
   - Need to disclose information in the public interest
   - Research councils and universities mindful when commercialising research
Key conclusions and recommendations

5. Governance
- Legislation supported, regulation viewed as cumbersome by certain groups
- Coordination between regulators in move to clinical practice
- Governance clinical trials - experimental therapies with patients

6. Future dialogue
- Focus on the cultures and practices of research
- Uncertainties in stem cell science should be communicated
- Key issues to look out for: private banking of cord blood and Induced Pluripotent Cells