

Case Study

Stem Cell Dialogue

A public dialogue around the science, and social and ethical issues

Vital statistics

Commissioning bodies:

Biotechnology and Biological Sciences Research Council (BBSRC) and the Medical Research Council (MRC)

Duration of process:

13 months: November 2007 - December 2008

Number of public participants: 200

Number of experts/stakeholders involved: 45

Oversight Group members: 19

Cost of project: £300,000 total, Sciencewise-ERC funding = £300,000

A stem cell is one of the basic building blocks of the human body. Stem cells are important because they have the ability to become different cell types, and can be used to repair or regenerate damaged organs or tissues. Stem cells can now be artificially grown and transformed into specialised cell types. This leads to possible therapies for a whole range of conditions such as heart disease, diabetes, Parkinson's disease or Alzheimer's.

The UK has been at the forefront of stem cell research. However, although stem cell science and technologies are progressing rapidly, the sources of stem cells (embryonic stem cells, adult stem cells and foetal stem cells in both human and animal tissue), together with advances in potential therapeutic and clinical applications, create ethical issues and challenges for regulation. Ethical and religious questions have been asked about what it means to be human and what restrictions, if any, should be placed on research in this area.

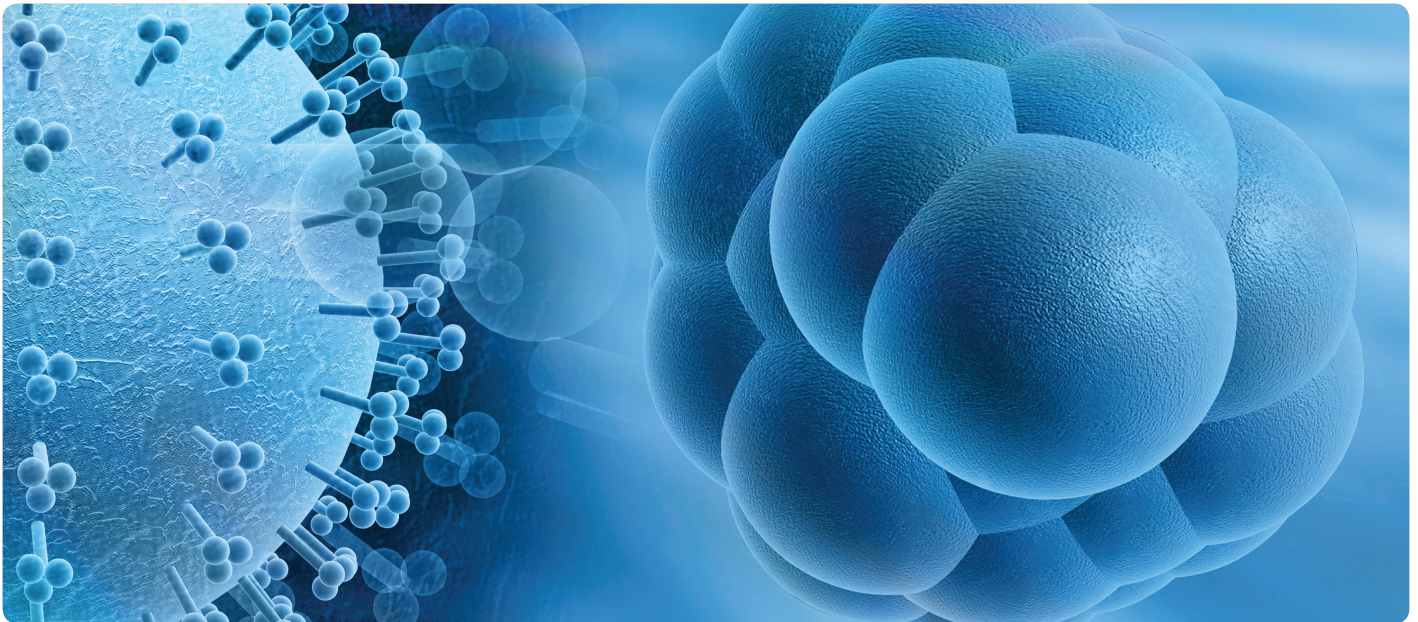
Key messages from the public

- The results of the dialogue indicated high levels of public support for stem cell research, but this was highly conditional on ensuring that Government funding is focused on 'serious' medical conditions rather than cosmetic uses, and on therapies that reflect public rather than solely commercial interests
- The responses to the evaluation questionnaires indicated that while most participants agreed that the dialogue took place early enough to influence policy, a significant number were sceptical of the appropriateness of the timing of the public dialogue for it to influence policy and future research in this area

- Although awareness of the term 'stem cells' was generally high among public participants, there was little knowledge of specific issues or details. Issues identified as having some initial familiarity with public included stem cell therapies, and the risks and benefits of stem cell research
- While the moral status of the embryo was a significant factor in much of the public discussions, overall, it was one factor among many, with concerns around the collection of women's eggs and clinical ethics being as, if not more, important for many participants
- For clinical research, priority should be given to serious diseases or injuries for which the current treatments are limited
- Participants felt that uncertainties in stem cell research should be communicated more widely.

Policy influence

- The findings directly informed the Department of Health's study of cord blood banking policy and practice
- The findings were considered by a workshop of policy makers from BBSRC, MRC and Department of Health
- The findings were used as a form of 'social intelligence', considered by the BBSRC Bioscience for Society Panel and used to make recommendations to the BBSRC Strategy Advisory Board. The Strategy Advisory Board advises [the BBSRC] Council on strategic issues relevant to BBSRC's science and innovation obligations, including training, skills and science in society.



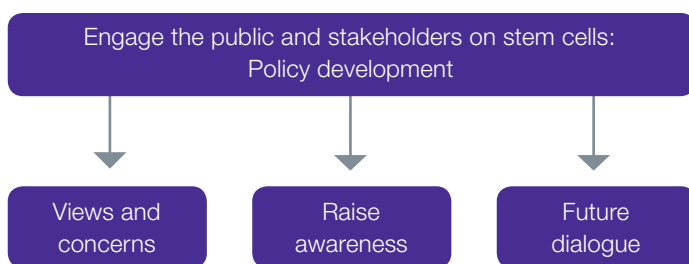
Background

In March 2005, the UK Stem Cell Initiative (UKSCI) was established to ensure that the UK remains one of the global leaders in stem cell research. It produced a wide-ranging report¹ on the central role of stem cell research in the life sciences and its importance to the wider UK economy. As well as highlighting the need to fund basic science, clinical and translational research, the recommendations also included the need to extend the favourable regulatory climate to include clinical applications, and to develop a sustained and co-ordinated dialogue with the public over the next decade. The stem cell public dialogue project provided opportunities for the public to discuss the social and ethical issues of stem cell research in response to the recommendations of UKSCI. The project was initiated by the BBSRC and MRC.

The dialogue activities

The objective of the dialogue was to provide an understanding of views and concerns around stem cell research from diverse groups, including scientists, which could then feed into the strategic decision-making of policy makers.

The overarching aims of the public dialogue are illustrated in the following diagram:



In addition to these overarching aims, five objectives were identified:

- Identify the range of views and concerns about the science and ethics of stem cell research among the wider public and their societal context
- Include scientists and other stakeholders, and investigate their views about stem cell research and the related social and ethical issues. Involve key organisations, such as the UK National Stem Cell Network and the UK Stem Cell Communications Coalition
- Raise public awareness about the potential opportunities, challenges and uncertainties of stem cell research
- Raise awareness among the scientific community, research councils and policy makers about the views and concerns of the wider public relating to stem cell research, and of the importance of dialogue
- Inform development of a plan for a longer-term project of public dialogue and engagement around stem cell research.

Deliberative, public-dialogue workshops were held in five locations, with each workshop group meeting three times. Learning from each stage was fed into the next stage(s). 200 public participants were recruited to reflect the demographic profile of the areas and to reflect the breadth of views revealed in an initial survey. Each workshop had 35-40 participants. The workshops included a wide range of activities to encourage deliberation among the participants and some electronic polling to capture individual views.

¹ Stem Cell Dialogue – for full report visit: <http://tinyurl.com/6kp2anj>

The structure of the workshops:

- Workshop 1 provided an introduction to stem cells. It explored the participants' aspirations and concerns raised by the science and its clinical applications
- Workshop 2 involved an in-depth discussion of the social and ethical issues related to the various sources of stem cells
- Workshop 3 focused on the potential future applications of stem cells and the wider social implications of stem cell banks, therapies and clinical trials.

Participants at each of the deliberative workshops were provided with a variety of materials to support and stimulate discussion including handouts, quizzes, social trend data, pen portraits and presentations in person from experts in the field.

Summary of good practice and innovation

- The project began with a desk research study² of previous public engagement on stem cell research (by OPM) and then BMRB carried out the rest of the process. This included an omnibus public-opinion survey (to 1,013 individuals) and 49 stakeholder interviews (recruited on the basis of a detailed stakeholder analysis)
- An oversight group contributed to the design of the dialogue process and the information materials to be used by the public. The Group's 19 independent and diverse members represented a broad range of interests including universities, non-government organisations and others
- One scientist and one social scientist/ethicist attended each workshop. Their role was to provide information to assist participants in their deliberations and to engage in the process, listen to the public and contribute to the discussions
- A key focus in the workshop design was creating the time and the space to encourage debate between the public and specialists. This two-way sharing of information was critical to the development of the project and the understanding of all those involved
- The final report integrated the feedback from the public at the workshops and from stakeholders who had taken part in the initial interviews.

Lessons for future practice include:

- It is important that there is clarity from the outset about how the findings from a dialogue process will be used, especially in relation to any potential or intended policy impacts
- It is important that expert speakers represent a diverse range of skills and knowledge, especially where the expert speakers' input largely frames participants' discussion
- Sufficient time and resources are needed to ensure expert speakers are briefed effectively about the length of their presentations, the level of complexity that is appropriate to their audience, and the nature of the event and how it fits with the wider process
- The initial regional meetings would have benefited from greater involvement from scientists and experts so that public participants had more time to ask questions before the scientists moved to the next group
- A higher specialist to public ratio would help individuals to gain more from dialogue workshops

- It can be particularly useful for final reports to identify points of agreement and disagreement (consensus and conflict) within, and between, the public and stakeholders
- The focus in evaluating public dialogue may increasingly need to go beyond the design and delivery of the process, and impacts on public participants, and consider the impacts on the commissioning bodies themselves and their capacity to respond to the results of the dialogue, and the extent to which public dialogue can help them develop and articulate new positions on the issues.

Impacts

Policy impacts are covered on the first page of this summary. This section examines the impacts on all the participants in the process.

Influence on policy makers

- The dialogue contributed to the development within BBSRC of 'a culture and the appropriate structures with which to feed the findings of the public dialogue into its decision-making processes'
- The dialogue enabled the Department of Health and the MRC to continue to progress in the current direction with greater confidence
- The dialogue contributed to the organisations' public image and reputation, and was built on in a range of major reports.

Impacts on public participants

- Public participants gained confidence in their ability to engage with scientific issues. They found they were able to take on board the information provided on these often highly technical scientific issues and felt confident in asking questions when they needed clarification
- 81% of public participants said that taking part made a difference to what they thought about stem cell research. 25% of the public participants said they had become more in favour of, or had increased confidence in, stem cell research. Most explained this by referring to greater knowledge and understanding of the issues surrounding stem cell research. For nearly half of the participants, this learning was one of the most successful aspects of the workshop.
- The dialogue increased participants' willingness to get involved in future engagement activities: 92% said they were more likely to get involved with similar events in the future as a result of taking part in this project
- The dialogue demonstrated public enthusiasm for dialogue: 99% of public participants said they felt it was important to involve the public in discussing these sorts of issues.

Impacts on scientists/experts and other stakeholders

- The dialogue exposed the expert speakers to how the public discussed these complex scientific issues and alerted them to a range of assumptions that hadn't previously been considered
- Scientists and other experts taking part learnt a lot from listening to the diverse range of views. This allowed scientists taking part to 'set their barometer at a more appropriate level' in understanding where the public had concerns.

²Stem Cell Public Dialogue – for full report visit: <http://tinyurl.com/5r6mrdq>

“ The Government takes public dialogue extremely seriously. In areas such as stem cell research which are so important to this country’s future – it is vital that any public concerns are listened to and acted upon. ”

Former Minister of Science, Lord Drayson

“ The issues involve society as a whole and not just the scientists doing the research. We need to be accurately informed about the actual research and what is happening without media hype or hindrance. ”

Public participant

“ For participants, interaction with others in a collaborative and communicative atmosphere was a significant factor in their judgement of the success of the workshops. ”

Working Group member

Overall impacts

This project was a good example of the start of a long-term process of public dialogue on a complex and contentious issue. The overall public support for future stem cell research (for certain purposes), and for public involvement in policy on these issues, has enabled the two research councils (BBSRC and MRC) to continue to progress in the current direction with greater confidence. The findings have already been considered as part of the research councils’ strategic planning on these issues.

Contacts and links

Commissioning bodies

BBSRC and the **MRC**

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Reports

Full project and evaluation reports available from Sciencewise-ERC on www.sciencewise-erc.org.uk/cms/stem-cell-dialogue-2/