Stem cell public dialogue

Desk research

Final report for BBSRC and MRC

July 2007

working with you
to improve social results

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Introduction

This research has been carried out as part of a project commissioned by the Biotechnology and Biological Sciences Research Council (BBSRC) and the Medical Research Council (MRC) on behalf of Research Councils UK. The findings from the project will inform the scope and content of planned public dialogue on stem cell research.

The purpose of the desk research is to provide an overview of past and ongoing projects, events and information which have engaged the public in discussion or communicated with them about stem cell research. The research focuses particularly, but not exclusively, on public dialogue and engagement concerning the public's opinions and concerns about all forms of stem cell research including the use of hybrid / chimera and the perceived benefits and risks of these stem cell therapies. This is in accordance with the recommendations from the UK stem cell initiative report.

The research also notes any other issues raised that it will be important to consider in carrying out the public dialogue project, which begins in the autumn. The focus is on reporting events and their findings. Events and initiatives have not been critiqued in terms of the benefit of such work or the approach used, although they have been set in context.

The review has been circulated to participants in a stakeholder workshop for suggestions of other work that should inform the dialogue project. This helped to ensure the planned public dialogue work takes into consideration the findings from as many relevant projects as possible.

There is a significant body of social science work around public engagement with stem cell research. This aims to contextualise, understand, critique and interpret the public's involvement with this research. It was not within the remit of the desk research to critique public engagement initiatives in this way, but it will nevertheless be important to acknowledge and incorporate this work into the public dialogue project.

Methodology

In order to ensure a rigorous, systematic review of current initiatives in public engagement OPM adopted the principles of systematic reviews set out by the EPPI-Centre.[1] A search strategy and analytical framework were developed by OPM and agreed with BBSRC and MRC. As each piece of literature was found, it was subjected to inclusion criteria and then, where relevant, inputted into a data collection template.[2] The templates are attached at Appendix 2.

The templates were then used to undertake a systematic analysis and synthesis of the initiatives in order to create this report. In order to emphasise the context of each major initiative, these have been documented individually. Smaller scale initiatives, due to time constraints, have been synthesised under broad headings. In addition initiatives involving a considerable depth and extent of public engagement have been analysed and reported in some depth but due to a high overall number of initiatives, other initiatives have not been subjected to such extensive analysis.

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[1] http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=89

[2] Due to the high volume of public engagement initiatives of limited depth, such as media pieces, not all pieces that meet the inclusion criteria have been inputted into the data collection sheets. Every piece is nevertheless referenced in the report.

Full details of the approach used by OPM are attached at Appendix 4.

Executive summary

A large number of public engagement initiatives have been undertaken in the last five years. While it should be noted that the methodologies and objectives of each initiative are different, there are nevertheless a number of themes of concern and/or interest to the public that emerge throughout. The main themes that emerge from this research are as follows:

- **Approval:** The majority of the public approve of and are optimistic and positive about all forms of stem cell research; however, a significant minority, including some religious groups and NGO's taking a moral stance, are strongly against embryonic stem cell research. Few among the general public appear to be against the idea of stem cell research on principle.
- **Objections to stem cell research vary according to the type of research:**
  - Very few people object to adult stem cell research.
  - There is a near-universal sense that **life is 'special'.** Those who object to **embryonic stem cell research** express this objection most strongly because of the idea that the **embryos will be destroyed**, and this objection appears to exist in a weaker form amongst much of the public.
  - Those who **object to human-animal embryo research** do so mainly because of a sense that **humans are 'special'** (as distinct from the sense that all life is special) and because of an instinctive horror of a 'chimera' being created by scientists.
- **Source of embryos**: Members of the public are more comfortable using embryos (or indeed umbilical cords) that already exist and which will be destroyed if not used, rather than harvesting embryos specifically for research purposes.
- **Dangers of over-hyping stem cell research:** Those on all sides of the debate agree that it is very important not to over-hype the potential of stem cell research, and to take sufficient account of the consequences.
- **Donor welfare**: This features regularly in public dialogue, particularly with regard to females. Related issues raised here include **trust** in clinicians and scientists, and concern over the **commercialisation of donations**.
- **Fatalism:** A large proportion of the public think that regulations will not be able to prevent the widespread use and application of stem cell research. Pressures from abroad are cited as a concern here.
- **Lack of information:** When asked, the majority of the public feel that they do not have enough information to make judgements regarding stem cell research.

Main findings

1. Structured public engagement initiatives

For the purposes of this research, structured public engagement initiatives are defined as events where there is a considerable depth of information, interactivity and engagement achieved through a deliberate structuring of the initiative for this purpose. For example, a public debate with talks, interactive discussions and feedback from participants would be seen as a public engagement initiative. However, a talk from an expert where the public views and discussions are not structured or recorded would not be defined in this way. We recognise that the distinction between a structured public engagement initiative and other forms of public dialogue is not well-defined, but feel that the distinction is nevertheless useful in the context of this review in order to highlight those initiatives that involve more extensive public dialogue and which may therefore be of particular interest to BBSRC and MRC.

Five recent or ongoing structured public engagement initiatives have been identified through the desk research.

The Stem Cell Dream

This event was organised jointly by the Institute of Stem Cell Research (ISCR), the Scottish Centre for Regenerative Medicine and EuroStemCell and was held on the 13th April 2007.[3] Around 150 self-selected audience participants *“watched film clips, heard from scientists, regulators and patients, and voted on the issues”.*

Upon arrival at the event, audience members were given a fictitious scenario regarding a clinical trial using umbilical cord blood stem cells to treat Parkinson’s disease. After reviewing the scenario, **they were asked to vote on the following question:**

> *“I am in favour of a clinical trial using umbilical cord blood to treat Parkinson's disease.”*[4]

In response, **51% indicated that they were in favour, 23% that they were not in favour and 26% were unsure**.[5]

The audience then watched a series of film clips, interspersed with panel comments:

> ***“****Clip 1 (extracts from A Stem Cell Story*[6]*) focused on the science of stem cells, covering the following aspects of stem cell research:*
>
> - *when specialised cells die or are used up, they are replaced from reservoirs of stem cells;*

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[3] ISCR 2007 (a). All quotations in this section are taken from this document unless specified.

[4] ISCR, 2007 (b)

[5] Ibid

[6] European Consortium for Stem Cell Research, 2006

> - *stem cells can be found in several tissues of the body: the blood system, the bone marrow, the skin, the brain;*
> - *adult stem cells can normally only make the types of cell of the tissue where it is found;*
> - *stem cells are already being used in medicine: skin stem cells are used in the treatment of burns and blood stem cells are used to treat patients with leukaemia;*
> - *embryonic stem cells are the earliest stem cells to be formed, before the embryo is implanted in the uterus;*
> - *embryonic stem cells offer the greatest potential for understanding and treating disease, since, unlike adult stem cells, they can become heart, blood, muscle, brain or skin cells, depending on how they are grown in the laboratory."*

After this clip some discussion followed in which one panel member stated that: *"a clinical trial such as the fictitious one presented at the event would be exploitative of patients, since he has not seen any convincing scientific evidence that it is possible to make brain cells from cells taken from the umbilical cord."*

> *"**Clip 2** (extracts from Conversations: Ethics, Science, Stem Cells[7]) presents the patient's view on stem cell research, and introduces the following aspects:*
>
> - *Brian Chapman, a Parkinson's disease patient, makes the point of how when somebody has the disease, it is not only the patient who suffers, but the whole family is drawn into the problem;*
> - *Brian describes how easy it is to look at a situation through one set of spectacles, and then seeing the whole thing completely differently, through another pair of spectacles, when a person becomes disabled;*
> - *Brian would readily give consent for his involvement in a clinical trial, because, in his view, the benefits to himself and to a broad proportion of society largely outweigh the risks;*
> - *Göran Hermerén, a medical ethicist, reminds viewers that the interests of those who suffer from incurable diseases and the moral obligation to cure diseases, relieve suffering and restore health are equally as important as the sanctity of life and the protection of the embryo."*

During the discussion that followed this clip, one panel member stated that they were convinced that:

> *"if confronted with a story such as the one presented to the audience at this event – of a company seeking approval to begin a clinical trial – patients and their families would be beating down the doors of the NHS, because even though there is no evidence that any treatment will arise in the near future, expectations are often difficult to control."*

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[7] European Consortium for Stem Cell Research, 2006

> ***"Clip 3** (extracts from Conversations: ethics, science, stem cells[8]) covers some of the issues that need to be considered when transferring stem cells into the clinic:*
>
> - *Göran Hermerén reminds viewers of the danger of hype – talking about the therapy as if it were almost there but actually there being quite a long way to go;*
> - *Olle Lindvall, a neuroscientist and clinician, describes the work his team has been carrying out for the last 20 years, transplanting foetal tissue into the brains of Parkinson's disease patients. The fact that some patients show remarkable improvements shows that this approach forms a promising basis for stem cell therapy for this disease.*
> - *Brain Chapman is confident that huge developments and improvements can be expected, but not in the short term. He is confident that there is a long term benefit in stem cell research for people with Parkinson's disease."*

In the discussion that followed, a panel member explained the regulatory process governing all aspects of such trials and research, and the necessary delays in such a regulatory system before a new scientific discovery could be used to treat patients.

An audience question and answer session between the audience and the panel then followed. The following issues relating to stem cell therapies were raised:

- **Risk**: A question from the audience prompted the expert panel to highlight the risk of cancer in transplanting stem cells, as well as the risk that treatment would not be effective yet would disqualify participants from future trials.
- **Over-hyping the applications of stem cell research**: A panel member made it clear that stem cells were particularly useful in some areas of research, but that claims for their application in, for example, reproductive technology should not be "hyped" by the scientific community.
- **Informed consent**: The audience sought clarification over *"whether blood donors were not automatically consenting to their blood stem cells being used for treatment."* A panel member clarified that, in the UK, consent needed to be sought specifically for stem cells to be separated out from the blood and used for research. She contrasted this with practice in Norway, where blood donors are assumed to have given consent unless they opt out explicitly, and argued that this approach should be adopted in the UK.
- **Private umbilical cord banks**: The audience asked several questions relating to private umbilical cord banks. *"These questions triggered an interesting discussion on the advantages and disadvantages of private cord blood banks, their use and regulation, and the possible exploitation of parents' concerns for commercial gain."*
- **Stem cells in drug testing**: An audience member asked a question about *"the use of stem cells to test drugs and pesticides, as a replacement for animal testing, especially in relation to testing on cells from people of different ethnic origins, so as to make clinical trials more realistic than they are today."* A panel member responded very

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[8] European Consortium for Stem Cell Research, 2006

favourably, particularly in relation to using stem cells from people of different ethnic origin to make drug testing more realistic.

- **Problems of immune rejection after stem cell transplantation**: The audience was interested to know whether there had been any scientific advances to address immune system responses to stem cell transplantation. A panel member noted a number of approaches, focusing particularly on work on mice to create embryonic stem cells from adult stem cells. The panel member suggested that, if this work could be replicated for humans, it would negate the need for foreign stem cells to be transplanted.
- **Realities and expectations**: The audience and the panel discussed the tension between the feeling[9] that *"all the different lines of stem cell research are going to bear fruit, in the future, and the benefits may be enormous but, simultaneously, how it is very difficult to estimate exact timescales and which benefit will be delivered first."*
- **Economic costs of stem cell research and therapies**: In response to a question about who should pay for these treatments, their development and the underlying research on this a panel member emphasised the *"need to develop a viable financial model for taking any cell therapy to the clinic. Such a model would have to take into account the ability of the National Health Service to provide these therapies but also the interests of the companies that have invested large amounts of money in developing the therapy."*
- **Other sources of stem cells**: Sourcing stem cells from animals was seen as unnecessary by a panel member because it is possible to extract human stem cells.

After watching the film clips and discussing the issues with the panel, participants were then asked to **vote on the same question** that they had been asked upon arrival at the event. **In the second round of voting, 40% were in favour, 30% were not in favour and 21% were unsure**.

The shift in opinion away from favouring the clinical trial may have been partly informed by the panel's perspective. All three panel members said that they would have voted against the trial. While two of the panel gave this perspective after the second round of voting had taken place, one had already made his opinion clear during the earlier discussions. In addition, the views of the panel may have been implicit in the answers they gave to audience questions. The report of the event noted that:

> *"In one case the vote had changed from 'yes' (because the person's father has Parkinson's disease) to 'not sure' after hearing the speakers talk about the reality of genuine clinical trials being undertaken using umbilical cord blood."*

The audience were also asked their views on stem cell research in general. Ninety-five per cent were in favour and 5% unsure. No-one was against the research in principle.

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[9] It was not made clear where this feeling was coming from.

With regard to the public dialogue project to be carried out by BBSRC and MRC, it is interesting to note that the format of the event was popular. When asked, 82% of participants said that they would recommend the event to a friend, with only 5% indicating that they would not.

Independent evaluation of the North Cumbria Community Genetics Project (NCCGP)

This piece of research, conducted by Haimes and Whong-Barr at PEALS, involved semi-structured interviews and focus groups with new mothers who had been asked to donate umbilical cord tissue samples to the NCCGP.[10] The sample consisted of forty-three mothers who agreed to donate samples, seven who refused, seven NCCGP team members, two focus group discussions involving ten community mid-wives, and three members of local community groups that opposed the NCCGP when plans for it were first announced in the early 1990s.

> *"Interviews lasted one hour and began with discussions of the respondents' own experiences of, and relationship to, the NCCGP. In most cases, discussions of the NCCGP led to broader conversations about databases, genetics research in general, and the distinctive characteristics of Cumbria as a region of England."*

Topics covered by the interviews and the main findings of those are as follows:

- **Reasons for donating**

  > *"Our analysis of the participating mothers' interviews reveals two very strong strands: the wish to help and the sense that not very much was involved in providing that help. The wish to help was expressed in a number of ways with different views as to who it was they wanted to help. Some felt their donation was helping the future in some unspecified way, others that it would help their own children's generation, others that it would help babies and children in general, or simply 'other people' in the future, including local Cumbrians."*

  > *"The sense that not a lot was involved was expressed in a number of other ways also. Interviews included remarks such as 'it didn't harm either the baby or myself'; 'I wasn't going to do anything with it'; 'it was no use to me'; 'otherwise it would have just been thrown away'; 'nobody is going to miss two inches of cord'; 'it was easy'; 'it's no big deal'; 'no cost to myself'; Interestingly, many women indicated that 'it would probably have been a harder decision' had the request not involved waste material."*

- **Reasons for refusing to donate** *"fell into two broad categories: local factors regarding the funding of the NCCGP and wider concerns over future use and control of the samples."*

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[10] Haimes and Whong-Barr, 2004

- **Risk, communication and understanding**

  > *"Many women felt that compared to other tests and procedures undergone during pregnancy, donating the afterbirth was a minimal risk. One interviewee compared the donation to an amniocentesis. 'Because of my age being over 40 I had an amniocentesis. [The] amnio could have damaged her but nothing in the database could damage her.'"*
  >
  > *"…pregnant women are alert to issues about the health of their child and are likely to be eager to donate to medical research that they perceive might benefit themselves or their children and families."*

It should be noted that the research is four years old. In addition, the research report makes clear that the participants were not given a detailed explanation of the use of the tissue samples, which raises ethical questions regarding the organisation of donations. These were not discussed in detail with the participants, however.

Share your views about donating eggs for stem cell research

This event was organised by the University of Edinburgh's 'Talking about stem cell research' programme in November 2006.[11] The 'talking about stem cell research' programme is a three year study funded by the ESRC & BBSRC to explore the scope for public engagement in stem cell research.

> *"It has two parallel aims: firstly, to explore the social, cultural and ethical issues generated by stem cell research; and secondly, to assess a range of public engagement techniques."*[12]

This event involved 90 people listening to an expert panel, undertaking a question and answer session and having a public discussion. The event focused on *"the issues raised by the two possible sources of donated eggs for research: from women undergoing IVF treatment in 'egg-sharing' schemes, or from women who are not undergoing IVF treatment."* Questions and issues of concern that were raised by the public related to:

- **The drugs used in ovarian stimulation**: *"One audience member thought that too much emphasis was being placed on the side effects of the drugs during stimulation…In response, it was argued that there is a need to distinguish between taking drugs for IVF in which the risks were acceptable because the woman would receive a clinical benefit and taking drugs for research purposes in which the clinician is imposing risks without offering benefits."*
- **The role of the clinician and the scientist**: *"It was argued that it is important to note that the clinician and the stem cell scientist are not the same person and that the clinician would never allow a woman to be exposed to unnecessary risk for the sake of the research, as he or she has no direct interest in it. However, it was also argued that, although they may not be the same person, they are part of the same social and*

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[11] University of Edinburgh, 2006. All quotations in this section are taken from this document unless specified.

[12] University of Edinburgh, no date

professional network and their loyalties to each other may be greater than their loyalties to the patient."

- **The ethics of altruism and informed consent**: *"A question was raised on the ethics of altruism and whether, if altruism had been established and informed consent given, would the opinions of the panelists change. In reply, it was argued that what made altruism ethical was whether there was informed consent. There is no systematic collection of data concerning the impact and risks of ovarian stimulation and, therefore, informed consent is not possible at the moment, as not all the information required is provided…However, it was argued that if this information is provided and women still want to donate, the issue remains whether anyone should circumscribe that right to decide. It was noted that part of informed consent is also understanding that not all the risks can ever be known and that, so long as this is communicated, altruistic donation remains possible…On a slightly different point, it was noted that women are not rushing to donate altruistically and that, even if they did, it would not necessarily be the case that we should accept their generosity."*
- **The time span of stem cell research**: *"It was argued that the clinical objectives of current research in cell nuclear replacement are 20 to 30 years into the future and are by no means imminent. Members of patient groups considered this news as refreshing as they are used to being told that a cure is just around the corner. At the same, however, they found the news to be disappointing. It was also argued that scientists have a duty to be realistic in their claims about research and potential therapies."*
- **Commercialisation and international competition**: *"Worries were raised regarding the patenting stampede for the commercial by-products of women's ovaries. Concerns were also raised about the balance between the need to protect women and the need to maintain the UK's research position with regards to international competition. However, one audience member was glad that people are more interested in protecting women than international competition. It was pointed out that donors could not benefit financially and that the informed consent process does not allow donors to place any conditions on their donation, such as what kind of specific research it can be used for. The idea that there should be some possibility for donors to be able to state what they wished their donation to be used for was aired, although this does raise the question of whether donations would remain altruistic if there are conditions attached to them. Regarding financial benefits, it was argued that a form of benefit sharing or charitable trust needs to be set up so that public benefit is also taken into account, as well as the needs of commercial organisations and funders."*
- **The use of fresh eggs in research**: *"It was posited that it was not yet known whether fresh eggs were needed for cell nuclear replacement[13] (creating a cloned embryo) and that this was a hypothesis that needed to be robustly tested before expanding their use in research by asking women to 'egg share' or donate their eggs as a non-patient donor."*

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[13] *"[Cell nuclear transfer/replacement] involves removing the nucleus from a donated egg and fusing it with a healthy adult cell. The egg-cell combination is then stimulated to develop into a blastocyst, from which embryonic stem cells can be extracted after five days of growth. Obtaining stem cells for potential therapies this way is known as therapeutic cloning."* *http://www.stemcellforum.org.uk/about_stem_cell_research/the_science_of_stem_cells.cfm*

- **Regulation**: *"A further issue considered was that some international stem cell banks may not accept stem cell lines that originate from 'egg sharing'. This is because they may consider the woman as having been coerced rather than donating 'altruistically'. It was argued that this was another reason not to allow 'egg sharing', as it would prevent patients from around the world benefiting."*

A controversial issue raised in this debate was the **instance of a licence bring granted to Newcastle University to perform cell nuclear replacement**, and in particular:

> *"…the discrepancies concerning the number of eggs used in their research and the ability of the HFEA to deal with these issues was raised by one audience member as being worrisome…It was argued that, on the whole, the HFEA does a good job in difficult circumstances but that on the issue of egg sharing it definitely came to the wrong decision by issuing a license to the Newcastle group, at least before the current consultation took place."*

One issue was raised by the research team that is of note for the forthcoming public dialogue event. The team found that they were unable to deal with all of the questions raised at the event, and that the event was not as participatory as hoped, due to the time taken up by the panel's opening remarks.

> *"Overall, this was a successful and lively debate, allowing people to learn about the complex issues that using human eggs in research generates. However, we felt at the end that we had just begun to get to grips with the issues, as the time passed so quickly. Also, the event was not quite as participatory as we had hoped – there was less time for debate from the floor - it did highlight the importance of gaining a broad spectrum of views not just those on the panel."*

This may have been partly because the event was quite short, at 1 ½ hours long.

Public debate on hybrids

As part of the same 'Talking about stem cell research' programme, another public debate will be held later in 2007, focusing on hybrid embryos.[14] Although the event has not yet occurred, we have included it in the desk research because the issue is one of the more controversial aspects of stem cell research and is likely to be run in parallel with the public dialogue project run by the BBSRC and the MRC.

Public perception of stem cell research

The University of Aberdeen in conjunction with the Scottish Stem Cell Network are currently undertaking a study of public attitudes to stem cell research.[15] The researchers are undertaking in-depth interviews with: patients with Parkinson's disease and Type 1 diabetes; those donating surplus embryos through IVF; and members of the public with no personal involvement in stem cell research. The number of participants is not known.

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[14] University of Edinburgh, 2007

[15] University of Aberdeen, 2007

> *"The study will explore the public's knowledge and understanding [of stem cell research] and gauge their views on possible future benefits. It will also examine the public's thoughts on the use of unused embryos."*

The research also seeks to understand the influence of the media on public attitudes to stem cell research.

2. Public consultations

For the purposes of this research, public consultations are defined as initiatives where the public are able to express their views on a matter, but do not have the opportunity to undertake significant discussion either with one another or with experts in the field.

Our desk research identified six public consultations directly relating to stem cell research.

Consultation on the review of the Human Fertilisation & Embryology Act 1990

This consultation was undertaken by the Department of Health (DH) between August and November 2005.[16] The DH received 535 responses (some of which were collective or organisational responses) to a series of qualitative questions. While there were no opportunities for interaction and debate in the consultation an informal forum was run alongside the consultation, which is analysed separately below.

Topics covered in the wide-ranging consultation included:

- The model and scope of regulation
- The welfare of the child
- The use and storage of gametes and embryos
- Reproductive choices: gametes and embryos
- Information and the HFEA register
- Surrogacy
- Status and legal parenthood
- Research
- The Regulatory Authority for Tissues and Embryos

Findings from the consultation that are particularly relevant to stem cell research are summarised below:

- The model and scope of regulation
  - Some felt that all embryos outside the body should be subject to the **same regulation**, although others felt that the manner of creating embryos affected the type of regulation required.

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[16] People, Science and Policy, 2006

- The use and storage of gametes and embryos
    - In general, some form of **expressed consent**, and preferably written consent, was seen as important, although some felt that in the case of research this was not necessary.
    - Some respondents felt that the **maximum period of storage** for research use should be raised.
    - **Payment for donation** of gametes and embryos for research was seen as acceptable by most and necessary by some in order to encourage people to donate.
- Research
    - The **14 day limit on research** was supported by some, but others argued that it was arbitrary and could be increased. Still others argued that the limit should be reduced.
    - **Cell nuclear replacement** was seen as controversial by many because of its associations with cloning, as was altering the genetic structure of an embryo. Tight control and regulation was seen as necessary for both.
    - The **creation of chimeras** was seen as morally dubious by some on the grounds of the ‘special status’ of human life and by others on the grounds that a new species would be created. However, still others did not see a morally significant distinction between this and using human embryos in research; they supported both types of research.
    - The **scope of research** was raised, with some arguing that the Government should relax the list of purposes for which research can be carried out. Others felt that this should be retained or tightened.
    - The **creation of embryos for therapeutic uses** was also raised and while some respondents argued that this should not be permitted, many of these were against the principle of the creation of embryos for research purposes. Others who were against this idea cited the lack of knowledge with regard to the safety and efficacy of the treatment. Of those who argued that this *should* be permitted, some questioned the logic of a distinction between using embryos “for treatment” and “for research into treatment”.[17]

Two issues were seen as particularly controversial in the consultation:

- Storage of gametes or embryos from those **unable to give express consent**
- The issue of the **creation of chimeras** sparked particularly strong responses on either side of the debate

A separate issue to note regarding the consultation is that it often **conflates opinions regarding embryos for treatment and embryos for research**. Where a distinction has

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[17] Ibid

been made this has been noted above, but in some cases no such distinction has been made in the report.

In addition, the consultation gives no indication of the numbers of responses on either side of any debate, as the consultation was not seen to be representative. As such, **no overall view can be gained of people's attitudes.**

Public Attitudes to Stem Cell Research – establishing the UK stem cell bank

This consultation,[18] run by People, Science and Policy between summer 2002 and autumn 2003, comprised:

- *"a consultation forum with a cross-section of experts;*
- *two groups of men and two of women who are blood donors or who carry an organ donor card or intend to leave their bodies to medical science;*
- *one group of men and one of women non-donors who were not blood donors, did not carry an organ donor card or intend to leave their bodies to medical science;*
- *one group of men and two groups of women who had successfully received in-vitro fertilisation (IVF) treatment; and*
- *one group of men and two groups of women undergoing in-vitro fertilisation (IVF) treatment."*

The numbers involved were unspecified, although the 12 focus groups each consisted of between three and ten participants. The consultation covered the following issues:

- **Views on stem cell research**
- **Stem cell donation**
- **Management and oversight of the Stem Cell Bank**

The public views on these issues were reported in detail, and are available in the data collection templates at Appendix 2.

The following issues were seen as controversial by or of particular concern to those consulted:

- **Cell nuclear transfer (CNT)**[19]
- **The description of stem cell lines as 'immortal'** in the consultation, due to the fact that the stem cell lines would be grown in cultures and could self-replicate.
- **Access to the Stem Cell Bank**; consultees were keen to ensure that the Bank was only made available to researchers studying serious or life-threatening illnesses.

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[18] People, Science and Policy, no date. All quotations in this section are taken from this document unless specified.

[19] See footnote 12 above.

Several issues arose from the consultation that are of particular note for the BBSRC and MRC's forthcoming public dialogue. There was **considerable difference of views between those who had undertaken IVF and those who had not.** The former were more inclined to reject embryonic stem cell research:

> *"Generally the non-IVF participants accepted the use of embryos at a very early stage of development. However, people who had received IVF treatment had quite different views of embryos; the women in particular, viewed embryos as babies and their frozen embryos as potential siblings for their existing children."*

Some participants found it difficult to engage with the distinction between **research** and **therapy**. Lastly:

> *"There was a strong desire expressed by several participants across the focus groups, to be able to specify the diseases for which "your" donation would be used. The difficulties in enabling this were dismissed by many participants."*[20]

Calls to evidence for the House of Lords Select Committee Report on Stem Cell Research

This consultation was conducted in 2001 by the Select Committee on human cloning and stem cell research.[21] Although it is more than five years old, the consultation has been included because of its continuing high profile and relevance to the debate. Nevertheless it must be noted that the science has moved on since the publication of this report. Public opinion is also likely to have shifted.

The report gives a detailed description of the distribution of the call to evidence:

> *"We distributed [the call to evidence] widely—not only to scientific and research organisations, the churches, medical charities, patients' support groups, pro-life groups and others with a close interest in the issues—but also to organisations representing sections of the general public, such as the National Association of Citizens Advice Bureaux, the Townswomen's Guild, the Trades Union Congress and the National Federation of Women's Institutes...*
>
> *We were also concerned to get as broad a view of the scientific issues as possible. We invited the major scientific and medical research organisations to give evidence, and their representatives included people working on both "adult" stem cells and embryonic stem (ES) cells derived from animals; we wrote to scientists and medical practitioners cited as supporting the view that advances in work on adult stem cells made research on ES cells unnecessary and invited them to give evidence; and we made a special effort to obtain the views of some of the leading adult stem cell researchers around the world on the relative merits of adult and ES cells…*

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[20] The difficulties inherent in specifying the use of donated stem cells were not explained in the report.

[21] House of Lords, 2002. All quotations in this section are taken from this document unless specified.

> *We received 52 submissions from representative organisations and 57 from individuals…We held 12 sessions of oral evidence at which 42 people representing 17 organisations (or in some cases giving evidence on their own account) appeared before us. In order to reach a broader range of opinion we also commissioned the Hansard Society to conduct on our behalf an internet debate over a period of four weeks in September and October 2001. One hundred and ninety six people registered to take part in the debate, 110 users logged on to the site and 330 messages were posted."*

The topics covered by the consultation are as follows:

- **Possible alternatives to research on early human embryos**
- **The status of the early embryo**
- **Cell nuclear replacement and cloning**
- **Future legislation and regulation**

The report gives detailed findings under each of these topics, which can be found at Appendix 2.

Consultation on Hybrids and Chimeras

This is a consultation by the Human Fertilisation and Embryology Authority (HFEA), running from the 26th April to the 20th July 2007.[22] As such, the sample and views of respondents are not known at the time of analysis.

Alongside the consultation, there will be several public dialogue events:

> *"…throughout the consultation period, deliberative work will take place across the UK, which will involve a series of discussion groups culminating in a day-long workshop. An opinion poll will also take place in the later stages of the process which will target over 2,000 people."*

The consultation questions are as follows:

"1. The following types of embryo research are already legally permitted and licensed in the UK. Which of them, in your view, are acceptable?

> *Research using human embryos donated by IVF patients*
>
> *Research using human embryos created specifically for research from donated eggs and sperm*
>
> *Research using cloned human embryos created specifically for research through cell nuclear replacement (CNR)*
>
> *No research using human embryos is acceptable*

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[22] HFEA, no date (a). All quotations in this section are taken from this document unless specified.

Not sure/undecided

2. Do you think that the HFEA should issue licences to allow research using cytoplasmic hybrid embryos?

3. Do you think that the law should in future permit the creation of true hybrid embryos for licensed research purposes?

4. Do you think that the HFEA should in future issue licences to allow research using human chimera embryos?

5. If you have answered yes to questions 2 to 4, what limits do you think should be placed upon human embryo research?"

Donating eggs for research: safeguarding donors

The results of this consultation,[23] undertaken by the HFEA in 2006, are not yet available. However, the issue of safeguarding donors is seen as sufficiently important to the public in order to warrant a specific consultation, and so this is of note for the forthcoming public dialogue.

The topics covered in the consultation were:

- Should egg donation for research be allowed?
- If egg donation were to take place:
  - Views on the current safeguarding measures
  - Views on additional safeguarding measures
  - Whether the resulting protection would be adequate

3. Surveys and opinion polls

Through the desk research seven surveys and opinion polls have been identified.

European attitudes survey

In 2006 a survey of European attitudes to stem cell research was undertaken by Gaskell et al.[24] This survey, although Europe-wide, disaggregates some of the data by country and as such is useful to understand attitudes to stem cell research in the UK. The sample for the survey is not known.

The survey areas where UK-specific data are available relate to questions regarding:

- **Familiarity with stem cell research**
- **Approval for embryonic and non-embryonic stem cell research**

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[23] HFEA, no date (b)

[24] Gaskell et al., 2006

- **Beliefs about the nature of the embryo**

In these areas, the attitudes of the UK were surveyed as follows:

- Familiarity with stem cell research: five per cent rated themselves as very familiar, 40 per cent as fairly familiar, 35 per cent not very familiar and 20 per cent not at all familiar with stem cell research.
- Approval for embryonic stem cell research: 28 per cent approve of stem cell research with usual Government regulation, 34 per cent approve if stem cell research is more tightly regulated, 15 per cent do not approve except under very special circumstances, six per cent do not approve under any circumstances and 17 per cent don't know. Overall 74 per cent approve of stem cell research and 81 per cent approve of non-embryonic stem cell research using umbilical cords.
- Beliefs about the nature of the embryo: When participants were asked *"Is the immediately fertilised embryo human?"* 22 per cent totally agree, 26 per cent tend to agree, 23 per cent tend to disagree, 11 per cent totally disagree and 17 per cent don't know.

A further notable finding from the survey relates to **what information people would like to have about stem cell research**. Unfortunately the data are not country-specific, but in Europe as a whole, respondents were asked the following question:

> *"If there was a referendum on embryonic stem cell research and you had to make up your mind how to vote, what would be, among the following, the issue on which you would like to know more?"*

Respondents were then asked to rate two of five statements.

> *"Out of those respondents who expressed a choice 69 per cent selected 'benefits and risks'. 40 per cent wanted to know more about current regulations and about who is enforcing them, 36 per cent express interest in who is responsible for setting moral limits, 33 per cent want to know what scientific processes and techniques are used, and 22 per cent want to know about who is funding the research and who will benefit from it."*

YouGov/Daily Telegraph survey

This survey of 2432 adults was conducted between the 19th and the 24th August 2005 by YouGov on behalf of the Daily Telegraph.[25] The survey took the form of an online questionnaire and therefore did not afford any interaction or discussion.

The topics covered in the survey are as follows:

- Abortion law
- Experimentation on human embryos

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[25] YouGov, 2005. All quotations in this section are taken from this document unless specified.

- Cloning
- Stem cell research
- Genetic modification
- Sex selection
- Euthanasia

There were several questions specifically relevant to stem cell research, with the following results. **Over two-thirds of respondents (68%) felt that it was *"acceptable to use 'spare' early embryos left over from fertility treatment, such as IVF, for the purposes of medical research"***, whereas less than half (41%) felt it was *"acceptable to create human embryos deliberately solely for the purposes of medical research"*. Forty-six per cent felt that this was not acceptable. Two thirds of respondents (66%) agreed that *"the rights of patients are more important than the rights of early embryos"*, with the same percentage believing that *"there should be laws regulating the use of embryos"* rather than it being a matter *"solely for the embryos' parents".* Almost two thirds of respondents (65%) felt that the use of early embryos for medical research should not be used for just "*any medical condition, such as infertility or short sightedness"* but instead should be limited to more serious illnesses, if used at all. 23% felt that early embryos could be used for any medical condition.

The majority of respondents (58%) felt that; *"Embryos are not really human beings from the moment of conception, but there should nevertheless be laws governing the uses to which they are put"*. Of particular relevance to the current research is the fact that **60% of the respondents do not feel well enough informed about the relevant science to make decisions.**

Over half of respondents (52%) felt that *"It will not be possible to keep the lid on: once these new techniques are available, there will be no way of successfully controlling how they are used"*, whereas almost a third (31%) felt that this would be possible. Related to this, well over half of those surveyed (59%) agreed with the statement that *"scientists are so keen to achieve major breakthroughs in medical research that they give too little thought to the moral issues involved."*

Public attitudes to fertility treatment, embryo research and the regulation of this work – Preliminary findings from the UK

This survey of 1,929 adults was undertaken for the HFEA in March 2005, involving quantitative research but with no interaction of discussion.[26]

The key preliminary findings of relevance to stem cell research were summarised by the HFEA as follows:

- *"Openness and honesty are most important to maintain trust in the regulatory system – followed by knowing that there is a system which will stop particular actions if there are concerns*

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[26] HFEA, 2005. All quotations in this section are taken from this document unless specified.

- *Politicians, religious leaders and the media are trusted by relatively few people to be involved in the regulation of fertility treatment or embryo research*
- *73% of people believe that human embryo research can improve the quality of life of future generations with inherited diseases*
- *43% of people believe the benefits of embryo research outweigh the risks (but 20% believe the risks outweigh the benefits)*
- *Opinion is split on the ethics of research. 41% of people believe that embryo research is ethical, while 34% of people believe embryo research is unethical*
- *42% of people believe the rules governing embryo research are strong enough as they stand at present*
- *The UK regulator is most trusted to be involved in decision making on human embryo research and providing information to the public*
- *The public believe that the framework of rules and regulations should be developed by doctors and Parliament working together to develop a consensus. Very few people believe these decisions should be made by Parliament or doctors working alone."*

A number of the recommendations from these preliminary findings will be important to consider in carrying out the public dialogue project:

- *"**A consensus between public, doctors and scientists** is essential to maintain public confidence which allows treatment and research to continue and progress. Public opinion is finely balanced and fragile and requires continued openness, honesty and a consensual approach.*
- ***The public want authoritative and trusted information** and will trust an independent regulator to provide it.*
- *Patients can feel differently about these issues and are influential on others. Therefore, **it is important to track the views of patients separately**."*

Mori public opinion poll

Previous to these two surveys, in February 2003 a consortium of eleven research and other organisations with an interest in stem cell research commissioned a quantitative MORI poll of 2,001 UK residents aged 15 or above.[27]

The headline findings of this survey were that around **70% of the British public support the use of human embryos** for medical research to find treatments for serious diseases and for fertility research. Over half of adults feel that the use of human embryos for medical research is only acceptable for the purpose of developing treatments for serious diseases and for fertility research, but not for most other types of research. One in six feels that the use of human embryos is always acceptable for all types of medical research.

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[27] Ipsos-MORI, 2003

One issue that may be of interest for BBSRC and MRC's public dialogue is that around half of the respondents were provided with additional information in the form of a picture of a human embryo up to 14 days after conception, as well as a picture showing the actual size of such an embryo. The **additional information provided corresponded to a very slightly more positive view of stem cell research** amongst those who received it. Seventy-three per cent of this group felt that it was acceptable to use stem cells for some form of medical research, whereas 70% of the respondents who did not see these pictures felt this was acceptable. It must be noted that the survey is over four years old and public opinion may have moved on since this research was undertaken.

Have your say: Would you use a stem cell bank?

On the 1st February 2007 the BBC news website offered readers an opportunity to engage with a news story regarding the creation of a stem cell bank using children's umbilical cords.[28] Two hundred and thirty eight moderated comments were published on the website. There was a degree of interaction, as those commenting could read and respond to previous posts and flag those they recommended to other readers. The general tone of readers appeared to be in favour of stem cell research, with the top six recommended comments all supportive of the idea of stem cell banks. The top three comments by recommendation are as follows:

> *"Yes. There is good potential and nobody is harmed. Why not?"*
>
> *"Yes, of course I would. Surely it's a no-brainer? These cells could save lives and combat serious, currently untreatable diseases. Who could possibly object to that?"*
>
> *"Yes absolutely. Even if the research saves just one life its a success. I'm just waiting for the "it's immoral and against god" crowd to pipe up."*

The issue of religion was quite controversial, sparking accusations of ignorance regarding the views of Catholics on the issue:

> *"I'm fed up with the ignorance of some commenters on this subject, who lump all stem cell research together and incorrectly claim Catholics are opposed to the lot."*

However it is very important to note that, due to its methodology, this piece of public engagement cannot be seen as representative of the public as a whole.

Have your say: Is human-animal embryo research ethical?

A similar piece of engagement from the BBC was undertaken on the 17th and 18th May 2007 on the ethics of human-animal or chimeric research, with 468 moderated published

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[28] BBC, 2007 (a). All quotations in this section are taken from this document unless specified.

comments.[29] Again there is a degree of interaction as later participants could take account of earlier comments that had already been published.

The overall tone of readers was in favour of the research. The top ten comments by reader recommendations are all in favour of human-animal research. Two of the top three comments are in response to a comment against such research. The top three comments are as follows:

> *“[Comment against human-animal embryo research] “It's about as ethical as feeding cows sheeps brains and look what that brought us (BSE)....Will we ever learn not to play God?”*
>
> *[Response] Ever had a vaccination or taken anti-biotics for an infection? "God" intended for you to take your chances with pneumonia and smallpox.... every time you got to the GP you're "playing God" by refusing to take your chances with nature's vast array of diseases.”*
>
> *“About time too. We must not let medieval beliefs take precedence over curing people of illness.”*
>
> *“[Comment against human-animal embryo research] “It's about as ethical as feeding cows sheeps brains and look what that brought us (BSE)....Will we ever learn not to play God?”*
>
> *[Response] When the human race stops believing in fairy tales such as the existence of a God, will we be ready to move forward in our own evolution and that includes the development of technology such as this. Religious doctrine is a cancer on the rump of mankind and as long as the Vatican and Mecca etc etc hold sway then the cancer will spread.”*

Once again, religious involvement in the debate sparked strong reactions. Nevertheless, this piece of public engagement should not be seen as representative of the wider public.

A very similar ‘Have your say’ piece was undertaken by the BBC a few months earlier, on the 5th and 6th January 2007.[30] This was entitled ‘Should the creation of hybrid embryos be allowed?’ and was similarly positive about the research. Nevertheless, an interesting and popular comment was made regarding the potential of stem cell research:

> *“Don't get carried away by the "it could produce cures for Parkinsons/Motor Neurone Disease etc.” Pigs might also fly. As a Ph.D scientist myself I know how the funding system works and researchers always have to talk up benefits in order to get their grants/approvals etc. Just because something can be done doesn't mean it SHOULD be done.”*

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[29] 2007 (b). All quotations in this section are taken from this document unless specified.

[30] BBC, 2007 (c). All quotations in this section are taken from this document unless specified.

4. Online fora

Three online fora to debate issues surrounding stem cell research have been analysed. The first is a forum created by Progress Educational Trust (PET) on behalf of the Department of Health,[31] and run alongside the DH's consultation on the review of the HFE Act in 2005 (analysed above). The forum was open between 16th August and 25th November 2005, with the pages available to view for a further two months.

> *"In total 3,442 individual visitors came to the discussion forum, making a total of 4,967 separate visits in all. The forum attracted 66 members to join, discussing 31 different topics, and making 178 posts."*

The following discussion topics were offered by the forum:

- Issues in pre-implantation genetic diagnosis (PGD)
- Welfare of children in assisted reproduction
- Embryo research
- Artificial gametes
- The regulation of IVF and currently unlicensed fertility treatments
- 'Saviour Siblings'[32]

An open forum was also created, allowing users to post on any topic.

Both the DH and PET were strongly criticised by some participants due to the fact that a forum intended as a neutral area to exchange views on the review of the HFE Act was organised and run by an organisation that campaigns in favour of regulated stem cell research. It should be noted that this criticism was levelled by at least one participant who alleged that they *"agreed with much of Progress Education Trust's positions".*

An ongoing forum and opportunity to vote on stem cell research is offered by BIONET throughout Europe, including in the UK.[33] Such fora have been used for several years. A third forum was run by the Hansard Society in 2002 in conjunction with the House of Lords Select Committee on Stem Cell Research.[34]

5. Media pieces

There is an enormous quantity of media pieces and position statements relating to stem cell research, each of which could be described loosely as a public engagement initiative. However, it would be neither possible nor desirable to analyse each of these for the

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[31] Progress Educational Trust, 2006. All quotations in this section are taken from this document unless specified.

[32] Defined in the forum as *"a new brother or sister who could also make a potentially life-saving donation of stem cells…"*, Progress Educational Trust, 2006

[33] BIONET, 2002. Unfortunately this forum could not be analysed due to the fact that the web link was broken.

[34] House of Lords, 2002

purposes of this desk research. We have attached a selected list of recent media pieces and position statements at Appendix 1.

One piece of media does include some element of public debate and interaction, however, and we have therefore singled it out for analysis. On the 16th December 2004, BBC2 aired a programme entitled 'IF…cloning could cure us'.[35] The programme involved a potential future scenario of a courtroom drama in which a celebrated researcher illegally takes stem cells from a 19 day old cloned embryo. She injects the stem cells into a patient's spine, in order to regenerate high spinal cord, but is charged with illegal experimentation on human embryos.

The audience was left to decide the verdict of the case, and with 11,616 votes cast **81% of voters were in favour of a not guilty verdict.** A panel on 'Newsnight' then discussed the issue in light of this verdict.

It should be noted that although the BBC claimed that the documentary was 'rigorously researched' the resultant public opinion is based on media portrayal of the issues, rather than direct discussions with experts. In addition, the public who participated cannot be taken as representative of the nation as a whole.

6. Public events

Ten examples of public events relating to stem cell research have been identified through the desk research. These have been largely organised by the scientific community, or those who may be expected to be sympathetic to stem cell research. The lectures analysed in the next section can provide counterpoints to these events.

Stem Cell Science – Hope not Hype

This series of events, organised by BBSRC and MRC, has been running since June 2006 and consists of temporary public exhibitions about stem cell research alongside a public discussion at some venues.[36] The programme is described as a *"sustained and coordinated programme of public dialogue on stem cell research over the next decade."* Topics covered by the exhibition and discussions include:

- **Progress of stem cell research**
- **Potential application to diseases**
- **Balancing public expectation with scientific reality**
- **Research Councils' engagement with the public**

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[35] BBC, 2004

[36] MRC, no date. All quotations in this section are taken from this document unless specified.

Reports are available for two of the events under this programme. Participants at the first, a public discussion about stem cell research held in Edinburgh in October 2006,[37] discussed the following themes:

- Chimerical embryos
- Philosophical viewpoints
- Stem cell potential
- Special moral status of human cells
- The moral status of the embryo

For full details of the discussions under each of these themes, see the data collection template at Appendix 2.

The second discussion was held in Dundee in February 2007,[38] and discussed the following themes:

- Stem cell research and the controversies surrounding it
- Legislative challenges
- Ethical issues around stem cell research

Comments from the day suggest both a concern for the ethics surrounding stem cell research and an apparent frustration over the discrepancy between scientific claims and patient realities[39]:

> *"I have two incurable diseases but my philosophy would be that **I would not want somebody else to lose a life in order for me to gain life**."*
>
> *"Why do you need spare embryos, why make more than you need?"*
>
> *"Some of us are, I don't know if "desperate" is the right word, but **we are looking for something to happen now**, not in 20 years time because we probably won't be here."*
>
> "*There is a gap in this country between what's happening in the labs and what's happening to the patient. Why?"*

One further notable issue was raised relating to the **costs of stem cell research[40]**:

> *"An audience member drew a comparison between the £4 million of government money given to set up a new SC research laboratory and the £500 million it costs to bring ONE new drug to the market. He offered this as a "scary perspective" on how much all this research is going to cost."*

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[37] BBSRC, 2006

[38] BBSRC, 2007 (a), (b)

[39] BBSRC, 2007 (b)

[40] Ibid

Centre of the Cell

The Centre of the Cell will be a permanent exhibition and education space in London, opening in spring 2008.[41] It also takes the form of a website with interactive resources including: information about cells, medical research and ethics; patient journeys; and resources for teachers and students.

Although the exhibition space is not yet open, it is included in this research because it is a dedicated, large-scale public engagement initiative in, among other things, stem cell research. Also, the website is an existing example of public engagement, with opinions from a variety of experts and patients.

Café Scientifique

Café Scientifique is a network of science-based discussions and events. Several of the events have discussed stem cells. An example of such a discussion was organised in Exeter in 2004, with 150 people listening to a lecture and then having a question and answer session with the lecturer.[42]

A report of the event suggests that the use of blood banks for new born foetuses sparked particular public interest:

> *"The idea of creating blood banks for newborn foetuses, which could be used to treat them in their future life if needed, seemed to grip the attention of many."*

In relation to BBSRC and MRC's public dialogue event, it is interesting to note that after the event *"…most people there could be heard debating the science involved over their drinks, rather than the ethical dilemmas, which surround this controversial topic."*

Further events

The Juvenile Diabetes Research Foundation ran an event in Cambridge on the 28th April 2007 entitled 'Insights from stem cell research'.[43] The event involved a lecture on work to retain stem cells in their unspecialised state as well as to achieve differentiation into specialised states. This lecture was followed by a question and answer session.

ISCR has organised a large number of events relating to stem cell research. One such example is an interactive educational workshop run from the 7th – 9th February 2007 for around 320 secondary school pupils in Edinburgh.[44] The students

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[41] Centre of the Cell, no date

[42] Kean, S., no date. All quotations in this section are taken from this document unless specified.

[43] JDRF, 2007

[44] ISCR, no date (b)

> *"…looked at live stem cells, made from mouse embryos, down a microscope and simulated a drug test on stem cells, to exclude the toxic drug amongst the several that they were developing to treat heart disease."*[45]

Another example of a series of events organised by ISCR is ongoing and entitled 'Stem cell therapy for spinal cord injuries. Ready or not?'[46] The events take the form of a role play for young people and adults exploring the issues surrounding stem cell research.

> *"Participants role-play members of the research Ethics Committee and different stakeholders in the audience (bioethicist, pro-life activist, patient, sceptical scientists and more). The Committee has to publish and justify its decision.*
>
> *Here are some of the questions that the role-play addresses:*
>
> - *What are the risks involved in this treatment, compared to the benefits?*
> - *Are patients being used as guinea pigs in the rush to fulfill the promise of stem cells?*
> - *Why use stem cells from embryos for this treatment? What about adult stem cells?*
> - *Are we starting down a slippery slope of creating a market for embryos?*
> - *Who will have access to the medical benefits that are promised?*
> - *How does competition between scientists and between clinicians affect research?"*[47]

The Centre for Stem Cell Biology at the University of Sheffield ran an event on the 17th March 2005 entitled 'Stem Cells: Therapies of the 21st Century?' This was a public discussion with an expert panel *"composed of biologist, ethicist, patient and pro-life campaigner."*[48]

The Centre also offers, in conjunction with the new economics foundation, an event based around a card game called 'Democs' (Deliberative meeting of citizens). The concept is described as *"like having a semi-facilitated conversation, where participants find out facts around a topic, learn about the issues, and then decide or revise their views through group discussion."*[49]

Lastly, on the 17th January 2007 CESAGen and nowgen organised a public event in Manchester entitled 'Genetics, risks and publics: What are the issues?'[50] This consisted of a panel and public discussion on the risks, fears and hopes regarding, among other things, stem cell research.

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[45] Ibid

[46] ISCR, no date (c)

[47] Ibid

[48] Centre for Stem Cell Biology, 2005

[49] Ibid

[50] nowgen, no date (b)

7. Lectures

There are a large number of lectures on stem cell research and related topics. For the purposes of this desk research, a sample of three such lectures has been analysed. Two of the lectures were made by ethical opponents of stem cell research, and are included as counterpoints to the largely science-based events analysed above.

The first lecture was made by Lord Winston, the President of the British Association for the Advancement of Science in September 2005 during the Festival of Science.[51] The audience size for the lecture is not known, although the lecture was widely reported in the media at the time, meaning that the total audience would have been UK-wide.

The content of the lecture has been summarised by the BBC:

> *"**The potential benefits of embryonic stem cell research have probably been oversold to the public**, fertility expert Lord Winston says.*
>
> *He fears a backlash if science fails to deliver on some of the "hype" around the cells - as he believes may happen.*
>
> *He says the notion that a host of cures for serious, degenerative disorders are just around the corner is fanciful."*[52]

Of pertinence to public dialogue work is Lord Winston's discussion of the **inadequacy of public engagement events without public education initiatives alongside them**; he suggests that such public education is needed in order to counteract *"misinformed"* and *"polarised"*[53] opinions.

The other two lectures analysed have been made by representatives of organisations opposed to therapeutic cloning and embryonic stem cell research. Both lectures were publicised by the Guild of Catholic Doctors and give a representation of religious and moral opposition to aspects of stem cell research.[54]

The first of these lectures, entitled 'Human Cloning' and organised by the Linacre Centre for the Study of Healthcare Ethics sets out a **moral, ethical and religious opposition to therapeutic cloning because of the destruction of the embryos** used.[55] The lecture also highlights the **potential of adult stem cells**, suggesting that they could be used as an alternative to embryonic stem cells without the problem of compatibility issues. The lecture claims, without supporting evidence, that:

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[51] British Association for the Advancement of Science, 2005

[52] BBC, 2005

[53] British Association for the Advancement of Science, 2005

[54] It should be noted that both lectures are around four years old and such opposition may have shifted its focus in the intervening time.

[55] Guild of Catholic Doctors, 2003.

> *"…there is a near consensus amongst scientists that cloning to live birth should not be attempted because of the risks to health."*[56]

The second lecture, 'The Politics of Cloning', has been organised by the Centre for Bioethics and Public Policy.[57] The author argues that there is **no ethical difference between reproductive and therapeutic cloning**, and that in reality therapeutic cloning is even more unethical because of the destruction of the embryos involved. The author goes on to suggest that there is an institutional bias in the regulation of stem cell research:

> *"In the late 1990s when the HFEA and the Human Genetics Advisory Commission asked a committee of four people to act as an advisory body it appointed them knowing that all four were from scientific backgrounds, that all four had previously expressed support for cloning, and that two had links with the pharmaceutical industry."*[58]

The author also alleges that there is scientific acceptance that therapeutic cloning is neither effective nor necessary, and that *"adult stem cell research is a viable scientific alternative and has clearly overtaken research using human embryos."*[59]

In a passage that is of particular relevance to public dialogue initiatives, the author suggests that despite the polarisation of views on the debate there is common ground on the importance placed on dialogue between the public and the science community on these issues:

> *"Many individuals, such as Baroness Warnock, profoundly disagree with me on the ethics of embryonic stem cell research and cloning. What we do agree on is the* ***need to restore public confidence in science*** *and ensure that the fears of the general public surrounding genetics and the new reproductive technologies are heeded."*[60]

8. Other initiatives/events

There are an enormous number of other events that constitute some form of public engagement. It would be impossible to document or analyse each of them, but a timeline of events from the last year publicised by one institution (ISCR), gives a good sense of the variety of such events:[61]

- In May 2007 the Humanist Society of Scotland held a talk and debate on stem cells
- In November 2006 a public debate was held in Edinburgh to discuss a set of short films about stem cells
- In October 2006 young people were given the opportunity to 'Make your own model cell' at Our Dynamic Earth in Edinburgh

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[56] Ibid
[57] Guild of Catholic Doctors, 2004
[58] Ibid
[59] Ibid
[60] Ibid
[61] ISCR, no date (a)

- In April 2006, at the Carlop Science Fair, participants were given the opportunity to extract DNA from strawberries

Alongside these events, a number of organisations have created a variety of public information resources on stem cell research. Two examples are analysed, from BBSRC and from the European Consortium for Stem Cell Research.

BBSRC has created a series of information packs for schools entitled 'Stem Cells: Science and Ethics'.[62] These are available to download from BBSRC's website.

The European Consortium for Stem Cell Research (EuroStemCell) has created 'Stem Cell Stories: Science and Ethics on screen', a series of short films to highlight the issues surrounding stem cells in an engaging form of media.[63] The four films are:

1. A Stem Cell Story
2. Conversations: ethics, science, stem cells
3. Cell culture
4. Dolly and beyond

The Parkinson's Disease Society is currently **running a campaign** relating to cytoplasmic hybrid embryos. Their description of the campaign is as follows:

> *"The PDS is campaigning to ensure that the [forthcoming Parliamentary] Bill does not include provision to ban the creation of cytoplasmic hybrid embryos and to raise public awareness about the importance of this promising avenue of research for people with Parkinson's. We will be taking opportunities to influence the Bill at all key stages through briefings, letters to Parliamentarians and media work and will prepare responses to relevant consultations in due course."*

Where this campaign involves the public (who are invited to get involved) it will constitute a form of public engagement.

The MRC offer *"various ways in which members of the public have direct input to our scientific activities"* [64] alongside those already reviewed above. Examples of public involvement in relation to stem cell research include invitations for the public to participate in the UK Biobank Ethics and Governance Council, the UK Stem Cell Bank Management Committee, and the UK Clinical Research Collaboration (UKCRC) Patient and Public Involvement Group, in collaboration with the UKCRC.[65]

The MRC, BBSRC and DTI organised an event entitled 'Stem Cells: Shaping the Future' in September 2003.

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[62] BBSRC, no date (b)

[63] European Consortium for Stem Cell Research, 2006

[64] MRC, 2007

[65] Ibid

> *"The…event attracted more than 500 delegates from 12 countries, who included researchers, clinicians, companies, politicians, consumers, and patient, religious and pro-life groups."*[66]

Lastly the MRC list a number of further events or initiatives related to public engagement with stem cell research: [67]

- *"…a small grant scheme to support scientists' involvement in public engagement, which contributed to us running 14 projects during National Science Week; the formats and topics included an* ***open day on Alzheimer's research****…"*
- *"…the* ***Stem Cell Communication Coalition*** *– made up of the MRC and other major funders of stem cell research – developed a media training project aimed at scientists working in stem cell research."*

The Wellcome Trust funds a number of further initiatives relating to public dialogue around stem cell research.[68] Examples include:

- Human embryos, human stem cells: a collaborative science-arts feature documentary organised by the ISCR
- Topical public debates on emerging issues in human genetics, particularly at the interface with assisted reproduction organised by PET
- Social Justice and Science: an IPPR event to explore the social and ethical implications for public policy of the rapid advance of the biosciences organised by the Institute for Public Policy Research (IPPR)
- A film entitled On the Frontline of Science (The Stem Cell Debate) by Richard Fenwick in collaboration with the Centre for Stem Cell Biology and Developmental Genetics at the University of Newcastle.

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[66] Ibid

[67] MRC 2005

[68] The Wellcome Trust, no date

Appendix 1: Sources

Below is an alphabetical list of sources used in the research.

BBC:

2007 (a), *Have your say: Would you use a stem cell bank?* [online]. Available at: http://newsforums.bbc.co.uk/nol/thread.jspa?messageID=2260250&start=180&tstart=0&&edition=1&ttl=20070608115606 [cited 14th June 2007]

2007 (b), *Have your say: Is human-animal embryo research ethical?* [online]. Available at: http://newsforums.bbc.co.uk/nol/thread.jspa?sortBy=2&threadID=6352&edition=1&ttl=20070612224601&#paginator [cited 14th June 2007]

2007 (c), *Have your say: Should creation of hybrid embryos be allowed?* [online]. Available at: http://newsforums.bbc.co.uk/nol/thread.jspa?sortBy=2&threadID=5171&edition=1&ttl=20070613082937&#paginator [cited 14th June 2007]

2005, *Winston warns of stem cell 'hype'* [online]. Available at: http://news.bbc.co.uk/1/hi/sci/tech/4213566.stm [cited 14th June 2007]

2004, *If…cloning could cure us* [online]. Available at: http://news.bbc.co.uk/1/hi/programmes/if/4065719.stm [cited 14th June 2007]

BBSRC:

2007 (a), *Summary of speaker's talks and audience questions/comments* [online]. Available at: http://www.bbsrc.ac.uk/society/engagement/exhibitions/current/SpeakerSummaryFeb2007.pdf [cited 14th June 2007]

2007 (b), *Summary of main points from open floor Dundee* [online]. Available at: http://www.bbsrc.ac.uk/society/engagement/exhibitions/current/OpenFloorSummaryFeb2007.pdf [cited 14th June 2007]

2006, *Public discussion about stem cell research* [online]. Available at: http://www.bbsrc.ac.uk/society/engagement/exhibitions/current/DiscussionReportOctober2006.pdf [cited 14th June 2007]

No date (a), *Stem Cell Science – Hope not Hype* [online]. Available at: http://www.bbsrc.ac.uk/society/engagement/exhibitions/current/stem_cells.html [cited 14th June 2007]

No date (b), *Schools and Young People: Resources to download* [online]. Available at: http://www.bbsrc.ac.uk/society/engagement/schools/resources/download.html [cited 14th June 2007]

BIONET, 2002, *Stem Cells* [online]. Available at: http://www.bionetonline.org/English/Content/sc_intro.htm [cited 14th June 2007]

British Association for the Advancement of Science, 2005, *Who owns the science and what is the role for the scientist in future?* [online]. Available at: http://www.the-ba.net/the-ba/Events/FestivalofScience/FestivalNews/_BAPresidentialAddress2005.htm [cited 14th June 2007]

Centre for Stem Cell Biology, 2004, *Science week activities March* [online]. Available at: http://cscb.shef.ac.uk/GeneralInterest/PREVIOUSEVENTS/Activitiesduringscienceweek2005(11thMarch-20thMarch)/ [cited 14th June 2007]

Centre of the Cell, no date, *Centre of the Cell* [online] Available at: http://www.centreofthecell.org/ [cited 14th June 2007]

European Consortium for Stem Cell Research, 2006, *Stem cell stories: science and ethics on screen* [online]. Available at: http://www.eurostemcell.org/Outreach/outreach_film.htm [cited 14th June 2007]

Gaskell et al., 2006, *Europeans and Biotechnology in 2005: Patterns and Trends,* Eurobarometer 64.3: European Commission

Guild of Catholic Doctors:

> 2004, The Politics of Cloning [online]. Available at: http://www.catholicdoctors.org.uk/CMQ/2004/Feb/The%20Politics%20of%20Cloning%20-%20Lord%20Alton.pdf [cited 14th June 2007]
>
> 2003, *WORCESTERSHIRE CATHOLIC HEALTHCARE NO 8* [online]. Available at: http://www.catholicdoctors.org.uk/Branch_News/worcester_newslet8.htm [cited 14th June 2007]

Haimes and Whong-Barr, 2004, *Key issues in genetic epidemiology: Lessons from a UK based empirical study* [online]. Available at: http://www.ncl.ac.uk/peals/assets/publications/tramesfinal2004.pdf [cited 19th June 2007]

HFEA:

> 2005, *PUBLIC ATTITUDES TO FERTILITY TREATMENT, EMBRYO RESEARCH AND THE REGULATION OF THIS WORK – Preliminary findings from the UK* [online]. Available at: http://www.hfea.gov.uk/docs/2005-01-07_FINAL_European_Consortium_EACC_public_attitudes_to.pdf [cited 14th June 2007]
>
> No date (a), *Hybrids and Chimeras* [online]. Available at: http://www.hfea.gov.uk/en/1517.html [cited 14th June 2007]
>
> No date (b), *Donating eggs for research: safeguarding donors* [online]. Available at: http://www.hfea.gov.uk/en/1417.html [cited 14th June 2007]

House of Lords, 2002, *Stem Cell Research – Report* [online]. Available at: http://www.parliament.the-stationery-office.co.uk/pa/ld200102/ldselect/ldstem/83/8301.htm [cited 14th June 2007]

Ipsos-MORI, 2003, *Seven In Ten Members Of The Public Support The Use Of Embryos For Medical Research* [online]. Available at: http://www.ipsos-mori.com/polls/2003/amrc.shtml [cited 14th June 2007]

ISCR:

> 2007 (a), *The Stem Cell Dream* [online]. Available at: http://www.iscr.ed.ac.uk/outreach/Stem%20Cell%20Dream-summary-popup.html [cited on 14th June 2007]

2007 (b), *The Stem Cell Dream: How did the audience vote?* [online]. Available at: http://www.iscr.ed.ac.uk/outreach/Stem%20Cell%20Dream-popup.html [cited on 14th June 2007]

No date (a), *Public events* [online]. Available at: http://www.iscr.ed.ac.uk/outreach/public%20events.html [cited on 14th June 2007]

No date (b), *Schools* [online]. Available at: http://www.iscr.ed.ac.uk/outreach/schools.html [cited on 14th June 2007]

No date (c), *Stem cell therapy for spinal cord injuries. Ready or not?* [online]. Available at: http://www.iscr.ed.ac.uk/outreach/Role-play.html [cited on 14th June 2007]

JDRF, 2007, *Cambridge* [online]. Available at: http://www.jdrf.org.uk/page.asp?section=00010001000300080001 [cited 14th June 2007]

Kean, S., no date, *Stem cells over a drink* [online]. Available at: http://www.the-ba.net/the-ba/Events/FestivalofScience/AboutFOS/HistoryoftheFestival/Festival2004/_Stem+cells+over+a+drink.htm [cited 14th June 2007]

King, A., 2005, *Most Britons back embryo research - but draw the line at cloning babies* [online]. Available at: http://www.telegraph.co.uk/news/main.jhtml?xml=/news/2005/08/29/nabor129.xml [cited 14th June 2007]

MRC:

2007, *Involving the Public* [online]. Available at: http://www.mrc.ac.uk/NewsViewsAndEvents/InvolvingThePublic/index.htm [cited 14th June 2007]

2005, *Annual Report and Accounts 2004-5* [online]. Available at: http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC002457 [cited 14th June 2007]

2004, *Annual Report and Accounts 2003-4* [online]. Available at: http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC002459 [cited 14th June 2007]

2003, *Annual Report and Accounts 2002-3* [online]. Available at: http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC002465 [cited 14th June 2007]

No date, *Stem Cell Science - Hope not Hype* [online]. Available at: http://www.mrc.ac.uk/NewsViewsAndEvents/Events/Reports/StemCellScience-HopenotHype/MRC003430 [cited 14th June 2007]

nowgen:

No date (a), *Events: Stem Cells: Hope or hype?* [online]. Available at: http://nowgen.org.uk/event/index.php?eid=223 [cited 14th June 2007]

No date (b), *Events: Genetics, risks and publics: What are the issues?* [online]. Available at: http://nowgen.org.uk/event/index.php?eid=77 [cited 14th June 2007]

Parkinson's Disease Society, no date, *Cytoplasmic hybrid embryos* [online]. Available at: http://www.parkinsons.org.uk/about_us/campaigns/current_campaigns/hybrid_and_chimeric_embryos.aspx [cited 14th June 2007]

People, Science and Policy:

> 2006, *Report on the consultation on the review of the Human Fertilisation & Embryology Act 1990* [online]. Available at: http://www.peoplescienceandpolicy.com/downloads/FINAL_HFEA_reportDH.pdf [cited 14th June 2007]
>
> No date, *Public Attitudes to Stem Cell Research – establishing the UK stem cell bank* [online]. Available at: http://www.peoplescienceandpolicy.com/projects/national_stemcell.php [cited on 14th June 2007]

Progress Educational Trust, 2006, *Summary report on the informal online discussion of the Department of Health's review of the Human Fertilisation and Embryology Act 1990* [online]. Available at: http://www.progress.org.uk/Events/Downloads/discussion_report.pdf [cited 14th June 2007]

RCUK, no date, *Stem Cell Science – Hope not Hype* [online]. Available at: http://www.bbsrc.ac.uk/society/engagement/exhibitions/current/stem_cells.pdf [cited 14th June 2007]

University of Aberdeen, 2007, *Views sought on stem cell research* [online]. Available at: http://www.abdn.ac.uk/mediareleases/release.php?id=962 [cited 19th June 2007]

University of Edinburgh:

> 2007, *Public debate on hybrids* [online]. Available at: http://www.talkingstemcells.ed.ac.uk/index.php?action=ShowArticle&id=76 [cited on 14th June 2007]
>
> 2006, *Share your views about donating eggs for stem cell research* [online]. Available from the ESRC Society Today website: www.esrcsocietytoday.ac.uk [cited on 14th June 2007]
>
> No date, *Talking about stem cell research* [online] Available at: http://www.talkingstemcells.ed.ac.uk/ [cited 14th June 2007]

Wellcome Trust, no date, *Public engagement funded activities* [online]. Available at: http://www.wellcome.ac.uk/fundedactivities/publicengagement/ [cited 14th June 2007]

YouGov, 2005, *YouGov / Daily Telegraph Survey Results* [online]. Available at: http://www.yougov.com/archives/pdf/TEL050101042_1.pdf [cited 14th June 2007]

Media pieces and position statements

http://news.bbc.co.uk/1/hi/health/4562235.stm

http://news.bbc.co.uk/1/hi/health/6721685.stm

http://www.telegraph.co.uk/news/main.jhtml?xml=/news/2005/08/29/nabor129.xml

http://news.bbc.co.uk/1/hi/health/6722435.stm

http://news.bbc.co.uk/1/hi/programmes/newsnight/5299306.stm

http://news.bbc.co.uk/1/hi/programmes/newsnight/4693578.stm

http://news.bbc.co.uk/1/hi/world/asia-pacific/4697210.stm

http://news.bbc.co.uk/1/hi/sci/tech/4396156.stm

http://news.bbc.co.uk/1/hi/health/4104680.stm

http://www.guardian.co.uk/life/science/story/0,12996,1527425,00.html

http://www.guardian.co.uk/life/thisweek/story/0,12977,1496676,00.html

http://news.bbc.co.uk/1/hi/health/4369185.stm

http://education.guardian.co.uk/higher/sciences/story/0,12243,1496451,00.html

http://news.bbc.co.uk/1/hi/health/4249855.stm

http://education.guardian.co.uk/higher/sciences/story/0,12243,1404132,00.html

http://education.guardian.co.uk/higher/sciences/story/0,12243,1325335,00.html

http://education.guardian.co.uk/higher/sciences/story/0,12243,1324791,00.html

http://news.bbc.co.uk/1/hi/health/6353919.stm

http://news.bbc.co.uk/1/hi/health/6233415.stm

http://www.guardian.co.uk/genes/article/0,,1146574,00.html

http://www.guardian.co.uk/genes/article/0,2763,535023,00.html

http://www.guardian.co.uk/genes/article/0,,2097182,00.html

http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/about/CI/CP/Our_Society_Today/News_Articles_2006/stemcells.aspx?data=%2fFrXHTl993q1louPMjG0OjmSYZrq1akHJdn3wwmNB5NWaxHFtnSRNrnQ84EQo0yUFxifmBZXQ%2fNqFN1P%2bEIDeyDMButCd79uPtuaW9%2bScCcShWUTXhaluv8urfl44edeehaQV35wBTbXPGYSutatkKH0zjQqX9Du%2bKGGu%2fZQeRulyedrQM0f%2bKs0XHXsmJXJ46mLwIfaYWc0GvqLDBNbgnosk%2bO7Dm5hf%2bWnKo0M3KI7qvumcnNOKDoZXZ5xsh1SU%2fVTIHk%2fJ4tmm%2bjmKJdlNA%2fA%2btUpNLTDxgJj8rTvykUYR9GQ8qNOdWfcCfgJbc0m&xu=&isAwardHolder=&isProfiled=&LikeMinds=&AwardHolderID=&Sector=

http://www.jdrf.org.uk/news.asp?section=000100010002&itemid=323

http://www.jdrf.org.uk/news.asp?section=000100010002&itemid=340

http://www.teachers.tv/video/2981

http://www.teachers.tv/video/2982

http://www.cancerhelp.org.uk/help/default.asp?page=3955

http://info.cancerresearchuk.org/publicpolicy/briefings/Science/stemcells/?a=5441

http://www.royalsoc.ac.uk/landing.asp?id=1202

http://www.bma.org.uk/ap.nsf/Content/Humancloningposition?OpenDocument&Highlight=2,stem,cell

http://www.alzheimers.org.uk/News_and_campaigns/Policy_Watch/stemcells.htm

http://www.bbsrc.ac.uk/society/accountability/position_statements/stem.html#

http://www.iscr.ed.ac.uk/news/press-releases-2003apr17.html

http://www.linacre.org/cloneAM.html

http://www.centreofthecell.org/centre/?page_id=13&ks=3

http://www.nature.com/nature/supplements/insights/stem_cells/index.html

http://www.corethics.org/index2.php?d=features&sb=1&item=7

http://www.bbsrc.ac.uk/tools/download/stem_cells/stem_cells_position.pdf

Appendix 2: Data collection templates

Structured public engagement events

Name of event/initiative	Share your views about donating eggs for stem cell research
Organising institution	University of Edinburgh
Date conducted	23/11/2006
Where report published [if any]	ESRC Society Today
Web address [if any]	http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/ViewOutputPage.aspx?data=%2fFrXHTl993rZZHwj4GAb4XV6FQew9AR9XVijsKwQJsYroZxQ118w4eFRFptU%2fuCTIItNbwWm5i5n6IGC9WbL7IPCVdXlwYX7KE%2fD1S3FF7Lq5uI8aJBporEKX2kSi%2fwm3SedqjJM0afwb6hnJet6ZHVoBqOU6%2fjvah7ZBMs9h8K2VZ0DWMhtYeOvoMHJxX3iEkg0374SiUOLn6P7vJOQWiJn5BqlzYNBe9J2fuf3nRFDeS6nGrWIS%2fHQ%2fDTwGpKd6YR%2bkzserkaqr1TGBc%2fWKfodzECpwMhfvHQnjK0v6WnqpkdKMJTAvIvp2EnZfaYs9Z7p4c2qBXtfLiAMZjdcPtvbSCXd7uCJqM%2fPKirIlJ%2b9SUBJhAYbMGkXfcoYAJD1Es8ajjT2%2bPiK88Dz5JVzKxgB21YO4ysXweCrzAAfBRopH1hjAc7J2zKAj2jJySt4BsLjxLBCLER2IimJ93eh9Q%3d%3d&xu=&isAwardHolder=&isProfiled=&AwardHolderID=&Sector=
Sample	90 people
Geographical scope	Edinburgh and surrounding area
Methodology	Structured public engagement event: Panel discussion, Q&A and public discussion
Depth of engagement	Single interactive event, 1 ½ hours, with expert participation
Rationale for inclusion / exclusion	Large scale public engagement event on public views and engagement with donating eggs for stem cell research
Topics covered	*"The focus was on the issues raised by the two possible sources of donated eggs for research: from women undergoing IVF treatment in 'egg-sharing' schemes, or from women who are not undergoing IVF treatment."*
Headline findings	Questions/issues of concern that were raised: • The drugs used in ovarian stimulation • The role of the clinician and the scientist

	- The ethics of altruism and informed consent - The time span of stem cell research - Commercialisation and international competition - The use of fresh eggs in research - Regulation
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	*"It was argued that, on the whole, the HFEA does a good job in difficult circumstances but that on the issue of egg sharing it definitely came to the wrong decision by issuing a license to the Newcastle group, at least before the current consultation took place."*
Any issues that it will be important to consider in carrying out the public dialogue project	The research team noted that they were unable to deal with all of the questions raised at the event, and that the event was not as participatory as hoped, due to the time taken up by the panel's opening remarks. *"Overall, this was a successful and lively debate, allowing people to learn about the complex issues that using human eggs in research generates. However, we felt at the end that we had just begun to get to grips with the issues, as the time passed so quickly. Also, the event was not quite as participatory as we had hoped – there was less time for debate from the floor - it did highlight the importance of gaining a broad spectrum of views not just those on the panel."*
Further notable challenges or issues	

Name of event/initiative	Forthcoming public debate on hybrids
Organising institution	University of Edinburgh
Date conducted	Forthcoming (2007)
Where report published [if any]	N/A
Web address [if any]	http://www.talkingstemcells.ed.ac.uk/index.php?action=ShowArticle&id=76
Sample	Not known
Geographical scope	Edinburgh and surrounding area

Methodology	Structured public engagement event: Panel discussion, Q&A and public discussion
Depth of engagement	Single interactive event
Rationale for inclusion / exclusion	Although forthcoming, the public engagement event is directly relevant to this project.
Topics covered	Hybrid embryos
Headline findings	N/A
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	N/A
Any issues that it will be important to consider in carrying out the public dialogue project	N/A
Further notable challenges or issues	N/A

Name of event/initiative	The Stem Cell Dream
Organising institution	ISCR/Scottish Centre for Regenerative Medicine
Date conducted	13/04/07
Where report published [if any]	ISCR website
Web address [if any]	http://www.iscr.ed.ac.uk/outreach/Stem%20Cell%20Dream-summary-popup.html
Sample	Around 150 self-selected audience participants
Geographical scope	Edinburgh and surrounding area

Methodology	The audience "watched film clips, heard from scientists, regulators and patients, and voted on the issues at The Stem Cell Dream, an interactive, dialogue-based event which took place on Friday, 13th April."
Depth of engagement	Vote, discussion and Q&A, then a second vote
Rationale for inclusion / exclusion	Direct public engagement with issues surrounding stem cell research. Particularly interesting because it gives an indication of the change in public opinion as a result of the discussion.
Topics covered	"Several issues relating to stem cell therapies were covered, including risk, informed consent, the real potential of stem cell therapies and the economic viability of taking stem cells into the clinic. These discussions informed the voting decision that members of the audience were asked to make about a fictitious clinical trial using umbilical cord blood stem cells to treat Parkinson's disease."
Headline findings	**Questions from the audience** *The risks of transplanting stem cells* The first question from the audience was about the actual risks of implanting stem cells into a patient's body. Austin replied that cancer is one of the risks. He explained that this is particularly important if the cells that are transplanted have been grown in the laboratory for some time during which they may have accumulated mutations and become cancerous. Another problem is that cells do not function correctly when transplanted into the body, and may actually worsen the condition, rather than improve it. Austin mentioned how in some trials in the USA, where Parkinson's disease patients received fetal cell transplants, a few actually became significantly worse. He pointed out that transplanting cells is more complex than administering a drug, and consequently, there's certainly potential for things to go wrong. Alistair added that because patients believe, as he does, that the potential for benefit is huge and exists, many are willing to go in search of that potential at the risk of not seeing any improvements at all, or even at the risk of suffering unfortunate side-effects. Quentin introduced a further complexity into the discussion: the fact that if a patient tries out a maverick therapy which has absolutely no effect, he or she will not be considered for a subsequent clinical trial. According to Alistair, for many patients that is a risk they are willing to take. *Over-hyping the applications of stem cell research* There was a question about the potential of stem cell therapy in reproduction technology, namely in replacing a woman's eggs after they have been lost or damaged due to chemo- or radiotherapy. In answering this question, Austin made the point that reproduction technology is a case in point of an area of research where stem cells are not really relevant or clinically needed. Indeed, there is a large amount of research being undertaken into maturing immature

oocytes (eggs) which are removed before chemotherapy. This research, and the existing treatments, are completely unrelated to stem cell therapy. In Austin's view, it is important for the stem cell research community and the medical community to focus on areas where new therapies are effectively needed, and where there are good scientific grounds for believing that stem cells have potential to provide that therapy.

Informed consent

The issue of informed consent was brought up by the audience. There was a question about whether blood donors were not automatically consenting to their blood stem cells being used for treatment. Heather clarified that blood donors need to consent specifically for the stem cells to be separated out from the blood and be used for treatment. This situation is a result of current regulation in the UK, whereby donors need to consent to specific applications, rather than opting-out. In Heather's view, an opt-out system, similar to the one used in Norway, would be much more in keeping with a publicly funded national health service, since the public would then be supporting research for a range of applications. Heather advocated for lobbying at the political level for an opt-out system to be introduced in the UK.

Private umbilical cord blood banks

Several questions were asked about giving consent to store umbilical cord blood in private banks, and who actually gets to use it. These questions triggered an interesting discussion on the advantages and disadvantages of private cord blood banks, their use and regulation, and the possible exploitation of parents' concerns for commercial gain.

Heather began by pointing out that the private banks need to be regulated too, to ensure that the material they have within them is safe to be injected into patients. She described one other layer of concern, which needs to be fully resolved - the ownership of the cells (Do they belong to the child or the parents who gave consent?). Heather raised concerns about the inherent risks in collecting the cord blood at the time of birth, when it is so important to provide good, dedicated care to the mother and child.

On this issue Austin is very much in favour of public bone marrow and cord blood banks, whereby all patients have access to shared stem cells, as long as a match can be found. He reminded everyone that the likelihood of using a person's own cord blood is 1:20 000. He explained how, in the rare case that a child does develop leukaemia, for example, a sibling's cord blood or an unrelated matched sample would be preferable to use for therapy, since the child's stem cells are very likely to already contain the mutation that predisposes to leukaemia. In Austin's view, parents are being tricked into banking their children's cord blood by stories that this tissue contains stem cells that could generate other kinds of cells, which could be used to treat all sorts of diseases, including neurological diseases. In reality, there is no evidence for this.

Alistair made the point of how this matter of banking cord blood for personal use illustrates the different perspectives of the patient and the scientist when it comes to stem cell therapies. Indeed, people go out and buy a lottery ticket at odds of 1:20 000 or lower, so betting a few thousand pounds, if you can afford it, on a potentially life-saving therapy is not unreasonable for many patients.

Stem cells in drug testing
There was a question about the use of stem cells to test drugs and pesticides, as a replacement for animal testing. Especially in relation to testing on cells from people of different ethnic origins, so as to make clinical trials more realistic than they are today. Austin replied very favourably to this proposal. Indeed, in his view, this is going to be the most important benefit of stem cells, and the scientific community is increasingly agreeing on this. However, Austin pointed out, this does not mean that scientists are not considering the transplantation applications of stem cells, rather these applications are recognised as being some way off, and restricted to very particular diseases for which there is no alternative.

There followed a brief discussion on how the media pick up on the use of stem cells for transplantation, but do not seem to be interested in their use in drug testing, because the latter is seen as less interesting to media consumers.

Problems of immune rejection after stem cell transplantation
There were a few questions about the problems of immune rejection associated with transplanting stem cells. In particular, whether the panel knew of any scientific developments which had not yet been made it into the clinic. Austin described how immunosuppression treatment is always required for any stem cell transplant, unless the patient receives his or her own stem cells. The risks associated with immunosupression treatment means that it is only justified when the disease is very serious and/or chronic. Type 1 diabetes would be such a disease. Austin mentioned some of the research that is going on into developing more sophisticated tolerisation regimes, based on understanding and manipulating particular types of blood cells, called regulatory T cells.

Austin also described recent work carried out in mouse cells. Scientists were able to create embryonic stem cells from adult stem cells, by genetically manipulating these. In his view, these studies are very exciting, since if they could be reproduced in humans, it would open the way to creating a patient’s own stem cells and thus get round the problem of immune rejection.

Realities and expectations
There was some discussion on the problems of managing expectations around stem cell research: how there is the feeling that all the different lines of research are going to bear fruit, in the future, and the benefits may be enormous, but, simultaneously, how it is very difficult to estimate exact timescales and which benefit will be delivered first.

Austin reminded everyone that there are several stem cell-based therapies in the clinic today, which have been used for decades: bone-marrow transplantation, skin grafting and corneal repair. All these therapies save many lives.

There was a question about appropriate timescales for establishing efficacy and safety of any therapy. In response, Heather stated that regulators would always decide based on the numbers of patients that need to be enrolled and studied in a clinical trial, and not on the length of time. For a Stage II trail, for example, a year or two is necessary to obtain all the permissions and recruit the patients.

Alistair made the point about how, for patients, a day or a year almost doesn't make a difference, since in whatever period of time, someone's condition is going to get worse.

Economic costs of stem cell research and therapies

In response to questions to each of the speakers about who should pay for these treatments, their development and the underlying research, several issues were brought up. Austin emphasised the need to develop a viable financial model for taking any cell therapy to the clinic. Such a model would have to take into account the ability of the National Health Service to provide these therapies but also the interests of the companies that have invested large amounts of money in developing the therapy.

Alistair pointed out that patients will pay as much as they have (or are able to borrow) for therapies which they see as life-changing. Some of this money will be paid to pharmaceutical companies, which in his view is totally justified, since the research carried out by these companies has resulted in many life-saving treatments.

Other sources of stem cells

There was a question about the possibility, and advantages, of using stem cells from pigs or other animals, in analogy to what is done with organ transplant. Austin replied that since scientists are able to obtain human stem cells, there is no need to resort to animal stem cells.

Reasons for changing vote

In one case the vote had changed from 'yes' (because the person's father has Parkinson's disease) to 'not sure' after hearing the speakers talk about the reality of genuine clinical trials being undertaken using umbilical cord blood.

In another case the vote changed from 'not sure' to 'yes' because initially this person felt he did not know enough and was confused, but decided that to vote for the clinical trial might help him in the future, since there are several cases of Parkinson's disease in his family.

Speakers' final statements and take-home messages

Heather would have voted against the clinical trial as it stands because she felt she did not have enough information about the company and their previous research. Heather was not surprised by the audience voting, and was pleased with the comments made about informed consent. She emphasized the need to push this agenda, for the benefit of everyone using the NHS.

Alistair would have voted against the clinical trial, too, because he does not believe companies are at the stage to undertake these clinical studies yet. The results of the voting did not surprise him as it bears out other studies which show that the public is generally confused about stem cell research. Alistair believes that events such as this one are extremely useful in providing information and educating not only the general public but also for politicians and other stakeholders.

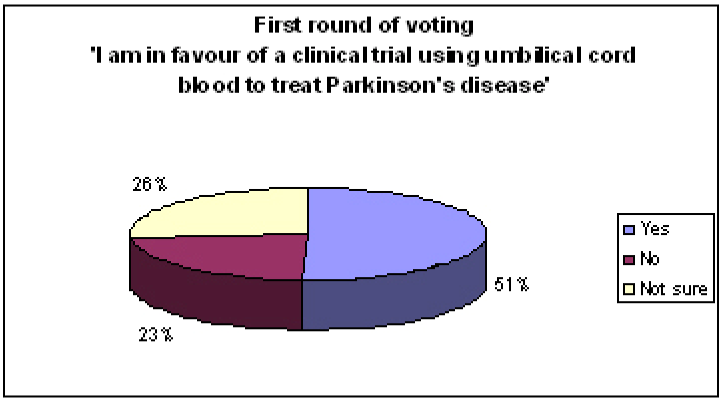
Austin would also have voted against the clinical trial, simply because not enough is known. He was not surprised at the way the voting went and finds it quite reassuring that the audience is in favour of stem cell research, is optimistic and positive about treatments arising from this research. He stressed that scientists share this optimism, but that it is also their job to keep a perspective on their work and not give people false hopes.

Quentin concluded that *perspectives* and *tensions* are the two take-home messages from this event.

The Stem Cell Dream

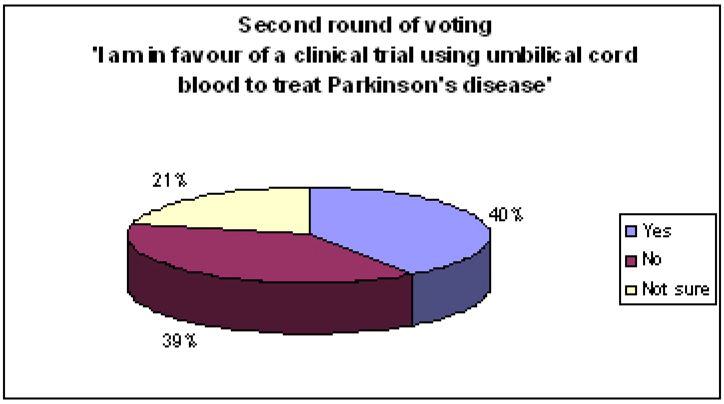
How did the audience vote?

On arrival at the Royal Museum Lecture Theatre, audience members were handed a mock news story about a fictional company's plans to start a clinical trial using stem cells from umbilical cord blood to treat patients with Parkinson's disease. Based solely on the mock news article, the audience then voted on the following question: 'I am in favour of a clinical trial using umbilical cord blood to treat Parkinson's disease'.
This is how they voted:



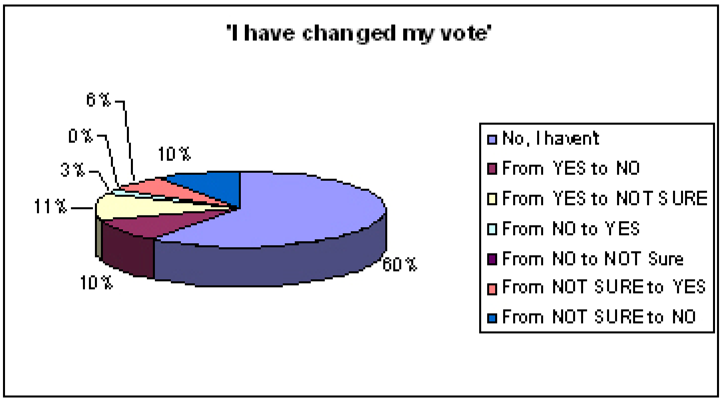
Total number of votes=77

And this is how the audience voted on the same question after watching film clips, hearing from scientists, patients and regulators, both on screen and on stage:



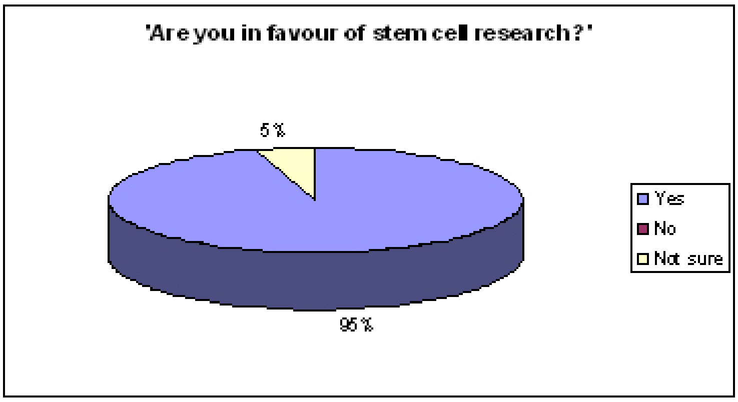
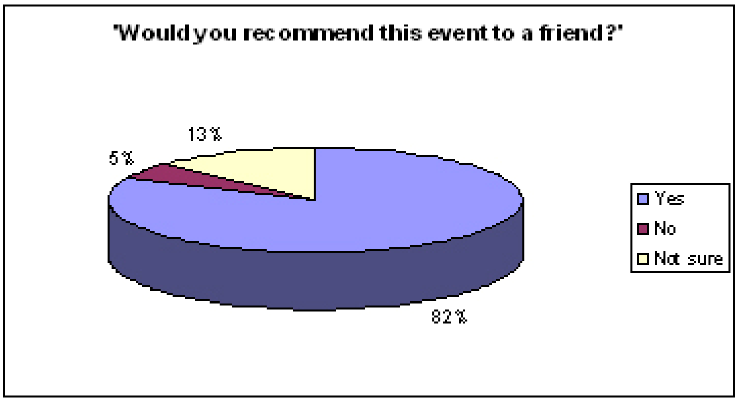
Total number of votes=72

We wanted to know how the audience members had changed their vote...if at all. So we asked them to answer the following multiple choice question:
'I have changed my vote'.



Total number of votes=63

To gather the audience's views on stem cell research in general, we asked the following question:
'Are you in favour of stem cell research?'
These were the results:

	 Total number of votes=65
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	Obviously we wanted to have feedback from the audience on the event itself. Rather than a long questionnaire, we asked one simple question: 'Would you recommend this event to a friend?' We were very pleased with the results!  Total number of votes=61
Further notable challenges or issues	Other events from the ISRC: **May 2007: Humanist Society of Scotland, Edinburgh** Josh Brickman gave a talk on the science and ethics of stem cells, followed by an animated question and answer session.

	November 2006: *Stem Cell Research* public debate at Greenbank Church, Edinburgh Clare Blackburn (ISCR group leader), Amy Hardie (Scottish Documentary Institute) and Kate Doherty (EuroStemCell) debated the issues around stem cell research illustrated in the EuroStemCell films. **October 2006: "Make your own model cell"** Our Dynamic Earth, Edinburgh October 2006 **April 2006: Extracting DNA from Strawberries**, at the Carlops Science Fair *"Fascinating! Wish I had done this 20 years ago at school!"* **Café Scientifique in Glasgow** Prof Austin Smith gave a talk entitled '*Stem cells-what's all the hype about?*'

Name of event/initiative	Key issues in genetic epidemiology: Lessons from a UK based empirical study
Organising institution	Policy, Ethics and Life Sciences Research Centre, University of Newcastle upon Tyne
Date conducted	01/95-04/03
Where report published [if any]	PEALS website
Web address [if any]	http://www.ncl.ac.uk/peals/assets/publications/tramesfinal2004.pdf
Sample and methodology	This report summarises an independent evaluation of the North Cumbria Community Genetics Project (NCCGP). "The NCCGP enjoyed a high response rate. Nearly ten thousand samples were collected, which means that nearly 90% of the pregnant women approached agreed to provide umbilical cord samples and maternal blood specimens (Chase et al, 2000). However, only 60% of those approached completed the 'mother's questionnaire' (a health and lifestyle questionnaire for the woman and her partner) as well as donating samples. "The fieldwork for our study involved semi-structured qualitative interviews with forty-three women who donated tissue samples to the NCCGP, seven who refused, seven NCCGP team members, two members of the NCCGP's Ethics Advisory Group, two focus group discussions involving ten community mid-wives, and three members of local community groups that opposed the NCCGP when plans for it

	were first announced in the early 1990s. Interviews lasted one hour and began with discussions of the respondents' own experiences of, and relationship to, the NCCGP. In most cases, discussions of the NCCGP led to broader conversations about databases, genetics research in general, and the distinctive characteristics of Cumbria as a region of England."
Geographical scope	North Cumbria
Methodology	See 'sample' above.
Depth of engagement	Questionnaire, with in-depth qualitative interviews with 62 people and two focus groups for 10 people
Rationale for inclusion / exclusion	Discusses the reasons for donating or withholding umbilical cord tissue samples from those who are asked to donate these.
Topics covered	• Reasons for participating • Reasons for refusal • Risk, communication and understanding
Headline findings	• Reasons for participating: "*Our analysis of the participating mothers' interviews reveals two very strong strands: the wish to help and the sense that not very much was involved in providing that help. The wish to help was expressed in a number of ways with different views as to who it was they wanted to help. Some felt their donation was helping the future in some unspecified way, others that it would help their own children's generation, others that it would help babies and children in general, or simply 'other people' in the future, including local Cumbrians."* *"The sense that not a lot was involved was expressed in a number of other ways also. Interviews included remarks such as 'it didn't harm either the baby or myself'; 'I wasn't going to do anything with it'; 'it was no use to me'; 'otherwise it would have just been thrown away'; 'nobody is going to miss two inches of cord'; 'it was easy'; 'it's no big deal'; 'no cost to myself';*[2] *Interestingly, many women indicated that 'it would probably have been a harder decision' had the request not involved waste material (M036)."* • Reasons for refusal: *"fell into two broad categories: local factors regarding the funding of the NCCGP and wider concerns over future use and control of the samples."* • Risk, communication and understanding: *"Many women felt that compared to other tests and procedures undergone during pregnancy, donating the afterbirth was a minimal risk. One interviewee compared the donation to an amniocentesis. 'Because of my age being over 40 I had an amniocentesis. [The] amnio could have damaged her but nothing in the database could*

	damage her.' (M037)” *“pregnant women are alert to issues about the health of their child and are likely to be eager to donate to medical research that they perceive might benefit themselves or their children and families.”*
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	Participants were notably poorly informed about the research, and were asked to donate at a time when they associated it with the birth of their child, and potential for protection for that child. This was seen as fairly controversial.
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	

Name of event/initiative	Public perception of stem cell research
Organising institution	University of Aberdeen in conjunction with the Scottish Stem Cell Network
Date conducted	Ongoing
Where report published [if any]	N/A
Web address [if any]	http://www.abdn.ac.uk/mediareleases/release.php?id=962
Sample	Patients with Parkinson’s Disease and Type 1 diabetes, those donating surplus embryos through IVF, members of the public with no personal involvement. Number not known.
Geographical scope	Aberdeen and surrounding area.
Methodology	20-30 minute interview “The researchers have already spoken to patients with two of the diseases that perhaps, in the future, might benefit from this area of

	research – Parkinson's Disease and Type 1 Diabetes. They have also heard from fertility patients who are helping further the science by donating surplus embryos for stem cell research at the end of their In-vitro Fertilisation Treatment (IVF). Now researchers are turning their attention to people with no personal involvement and who are not currently potential beneficiaries of research on stem cells."
Depth of engagement	Single in-depth interview
Rationale for inclusion / exclusion	Although ongoing, this research should be taken into consideration in the public dialogue project. In particular, the research seeks to understand the influence of the media on public attitudes to stem cell research.
Topics covered	Attitudes to stem cell research; media influence. "The study will explore the public's knowledge and understanding and gauge their views on possible future benefits. It will also examine the public's thoughts on the use of unused embryos."
Headline findings	Not known
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	Not known
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	

Consultations

Name of event/initiative	Consultation on the review of the Human Fertilisation & Embryology Act 1990

Organising institution	Department of Health
Date conducted	16/08 – 25/11/2005
Where report published [if any]	Department of Health website; People Science and Policy website
Web address [if any]	http://www.peoplescienceandpolicy.com/downloads/FINAL_HFEA_reportDH.pdf
Sample	535 responses (some of which were collective or organisational responses)
Geographical scope	UK-wide
Methodology	Public government consultation with open, self-selecting participation
Depth of engagement	Responses to qualitative questions but no level of interaction/debate. Informal forum run alongside the consultation for ongoing debate of the issues.
Rationale for inclusion / exclusion	High profile, UK-wide public consultation exercise that indicates the views of interested parties in the HFE Act 1990. The Act regulates the use of embryos and therefore is relevant to stem cell research.
Topics covered	• The model and scope of regulation • The welfare of the child • The use and storage of gametes and embryos • Reproductive choices: gametes and embryos • Information and the HFEA register • Surrogacy • Status and legal parenthood • Research • The Regulatory Authority for Tissues and Embryos
Headline findings	• The model and scope of regulation o Some felt that all embryos outside the body should be subject to the same regulation, although others felt that the manner of creating embryos affected the type of regulation required. • The use and storage of gametes and embryos o In general, some form of expressed consent, and preferably written consent, was seen as important, although some felt that in the case of research this was not necessary. o Some respondents felt that the maximum period of storage for research use should be raised. o Payment for donation of gametes and embryos for research was seen as acceptable by most, and necessary by some in order to encourage people to donate.

	• Research o The 14 day limit on research was supported by some, but others argued that it was arbitrary and could be increased. Still others argued that the limit should be reduced. o Cell nuclear replacement was seen as controversial by many because of its associations with cloning, as was altering the genetic structure of an embryo, and therefore both should be tightly regulated and controlled. o The creation of chimeras was seen as morally dubious by some, although others did not see a distinction between this and other research. o The scope of research was raised, with some arguing that the Government should relax the list of purposes for which research can be carried out. Others felt that this should be retained or tightened. o The creation of embryos for therapeutic uses was also raised and both sides of the argument were made.
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	• The use and storage of gametes and embryos o Storage of gametes or embryos from those unable to give express consent – this was seen as controversial • Research o The issue of the creation of chimeras sparked particularly strong responses on either side of the debate
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	The consultation often conflates embryos for treatment and embryos for research. Where a distinction has been made this has been noted, but in some cases no such distinction has been made in the report. In addition, the consultation gives no indication of the numbers of responses on either side of any debate, as the consultation was not seen to be representative. As such, no overall view can be gained of people's attitudes.

Name of event/initiative	Public Attitudes to Stem Cell Research – establishing the UK stem cell bank
Organising	People Science and Policy

institution	
Date conducted	Summer 2002 – Autumn 2003
Where report published [if any]	People Science and Policy website
Web address [if any]	http://www.peoplescienceandpolicy.com/projects/national_stemcell.php
Sample	Numbers unspecified – composition of sample described in methodology below.
Geographical scope	England-wide
Methodology	This consultation exercise comprised: o a consultation forum with a cross-section of experts; o two groups of men and two of women “who are blood donors or who carry an organ donor card or intend to leave their bodies to medical science”; o one group of men and one of women ‘non-donors’ who were not blood donors, did not carry an organ donor card or intend to leave their bodies to medical science; o one group of men and two groups of women who had successfully received in-vitro fertilisation (IVF) treatment; and o one group of men and two groups of women undergoing in-vitro fertilisation (IVF) treatment. The 12 focus groups were run in eight English towns. There were between three and ten participants in each group. The groups were run in the summer of 2002 and the spring and autumn of 2003. We distinguish between potential donors, which includes virtually everyone, and likely donors, that is, people in situations where they are likely to be asked to donate.
Depth of engagement	Single focus group for each group of participants.
Rationale for inclusion / exclusion	Directly relevant as it discusses public attitudes to stem cell research
Topics covered	o Views on stem cell research o Donation o Management and oversight of the Stem Cell Bank
Headline findings	***“Views on stem cell research*** *Generally the non-IVF participants accepted the use of embryos at a very early stage of development. However, people who had received IVF treatment had quite different views of embryos; the women in particular, viewed embryos as babies and their frozen embryos as potential siblings for their existing children.* *The creation of embryos for research was generally rejected, whether*

	this was by IVF procedures using eggs and sperm or by cell nuclear transfer (CNT). CNT was viewed with great suspicion, despite the potential for compatibility with patients. It was recognised as cloning by many participants and there was a general fear and dislike of human reproductive cloning. *Obtaining stem cells from aborted fetuses was, for many people, more acceptable than creating embryos for research, providing the decision to abort was made separately from the decision to donate the fetus for research. Some participants felt that donation of the fetus might bring some comfort to those in a very difficult situation.* *Some participants found it difficult to engage with the idea of research, finding it easier to focus on therapies. As previous work has established, there was general support for the benefits offered by advances in healthcare but this was balanced, to some degree, by concerns regarding adequate control of research.* *Concerns about private sector users generating excessive profits were particularly prevalent in the IVF groups, where some participants had paid for their own treatment. However, there was widespread recognition that the involvement of the private sector was unavoidable in the development of medicines.* *It was explained that stem cells would be turned into lines, that is, grown in culture so that they continue to divide and that the line will therefore be immortal. Some participants reacted to this description of the cells as "immortal" with unease, partly because of concerns about what might be done in the future.* ***Donation*** *The complex and invasive procedure required for the donation of adult stem cells meant that participants did not regard this as a likely source. They felt that they would be more likely to donate for therapeutic reasons than for research. Taking stem cells from the brains of cadavers was seen as acceptable if the person had given consent during their lifetime. Several groups recommended that this be added to organ donor cards.* *It was generally agreed that donors should not be paid for donations, although the invasive nature of the procedures led to discussions of in-kind payments such as time off work or sick pay. Some of those who had received IVF treatment perceived that the IVF clinics saw their relationship with the "patients" as fundamentally commercial in nature.* *There was a strong desire expressed by several participants across the focus groups, to be able to specify the diseases for which "your" donation would be used. The difficulties in enabling this were*

	dismissed by many participants. ***Implications*** *Our findings suggest that members of the public are not likely to be stem cell donors unless they find themselves in particular circumstances. This report shows that for those who are likely donors, the option of donation will be associated with traumatic periods of their lives. This amplifies the role and responsibilities of intermediaries (those who raise the issue of donation and gain consent from potential donors). The MRC and the Bank should therefore continue to build relationships with intermediary organisations and to develop material for likely donors in partnership with them.* ***Management and oversight of the Bank*** *The main benefit of a central Bank was seen to be the control it offers over the uses to which the stem cell lines are put, who has access to them and the objectives of the research conducted. Given that there is some ambivalence towards the actual conduct of this type of research, this provides reassurance both to the general public and to likely donors. Transparency was seen as the fundamental basis upon which management and control systems should be built.* *Participants wanted to see clear lines of ownership and responsibility with accountability to some form of oversight body that was independent from the Bank and the "users". Participants felt that the sanctions for breaking the rules should be severe enough to deter individuals and organisations from doing so.* *There was great concern amongst the donor and non-donor groups that only researchers and clinicians working on "serious" or "life-threatening" diseases and illnesses should have access to the Bank. Some of the IVF women also wanted to ensure that the Bank played a role in supporting infertility research.* *Participants saw a trade-off between the need to draw-in private sector investment to yield medicines and therapies, and allowing excessive commercial exploitation of a national resource provided by donors. Ultimately, private sector companies must be willing to be open to the same levels of scrutiny as academic researchers. It was also felt that some element of the profits made from any treatments developed should be re-invested in the bank to support further research or to support treatment."*
Any issues that were seen as particularly controversial, of particular interest to the	CNT seen as particularly controversial The idea of stem cell lines as 'immortal' was viewed with concern. Access to the Stem Cell Bank was of great concern to participants – they were keen to ensure that the Bank was only made available to researchers studying serious or life-threatening illnesses.

public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	Difference of views between those who had undertaken IVF and those who had not – the former were more inclined to reject embryonic stem cell research. Some participants found it difficult to engage with the idea of research as opposed to therapy. Strong desire to specify the disease for which donations would be used to combat, despite the difficulties of this.
Further notable challenges or issues	

Name of event/initiative	Consultation on Hybrids and Chimeras
Organising institution	HFEA
Date conducted	26/04 – 20/07/2007
Where report published [if any]	Consultation document published on the HFEA website
Web address [if any]	http://www.hfea.gov.uk/en/1517.html
Sample	Not known (consultation ongoing at time of review)
Geographical scope	UK-wide
Methodology	Open consultation for members of the public and organisations to respond. Public meeting to discuss issues.
Depth of engagement	Two levels of engagement – response to consultation and opportunity to debate at public meeting. In addition, *"throughout the consultation period, deliberative work will take place across the UK, which will involve a series of discussion groups culminating in a day-long workshop. An opinion poll will also take place in the later stages of the process which will target over 2,000 people."*
Rationale for inclusion / exclusion	Although ongoing, this consultation is directly relevant to stem cell research and particularly to a controversial aspect of it. The current project should therefore take note of the outcomes of this consultation.
Topics covered	Consultation questions: 1. The following types of embryo research are already legally permitted and licensed in the UK. Which of them, in your view, are acceptable? Research using human embryos donated by IVF patients

	Research using human embryos created specifically for research from donated eggs and sperm Research using cloned human embryos created specifically for research through cell nuclear replacement (CNR) No research using human embryos is acceptable Not sure/undecided 2. Do you think that the HFEA should issue licences to allow research using cytoplasmic hybrid embryos? 3. Do you think that the law should in future permit the creation of true hybrid embryos for licensed research purposes? 4. Do you think that the HFEA should in future issue licences to allow research using human chimera embryos? 5. If you have answered yes to questions 2 to 4, what limits do you think should be placed upon human embryo research?
Headline findings	N/A
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	

Name of event/initiative	Donating eggs for research: safeguarding donors
Organising institution	HFEA
Date conducted	2006

Where report published [if any]	Not yet published
Web address [if any]	http://www.hfea.gov.uk/en/1417.html
Sample	Not known
Geographical scope	UK-wide
Methodology	Not known
Depth of engagement	Open public consultation
Rationale for inclusion / exclusion	Although the report is not yet published, safeguarding donors is seen as a key issue in egg donation, and so this consultation is relevant to the project.
Topics covered	• Should egg donation for research be allowed? • If egg donation were to take place: o Views on the current safeguarding measures o Views on additional safeguarding measures o Whether the resulting protection would be adequate
Headline findings	Not known
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	

Name of event/initiative	Calls to evidence for the House of Lords Select Committee Report on Stem Cell Research
Organising	Select Committee on human cloning and stem cell research

institution	
Date conducted	2001
Where report published [if any]	Parliamentary publications and records online
Web address [if any]	http://www.parliament.the-stationery-office.co.uk/pa/ld200102/ldselect/ldstem/83/8302.htm#a5
Sample	*“We distributed [the call to evidence] widely—not only to scientific and research organisations, the churches, medical charities, patients' support groups, pro-life groups and others with a close interest in the issues—but also to organisations representing sections of the general public, such as the National Association of Citizens Advice Bureaux, the Townswomen's Guild, the Trades Union Congress and the National Federation of Women's Institutes...* *We were also concerned to get as broad a view of the scientific issues as possible. We invited the major scientific and medical research organisations to give evidence, and their representatives included people working on both "adult" stem cells and embryonic stem (ES) cells derived from animals; we wrote to scientists and medical practitioners cited as supporting the view that advances in work on adult stem cells made research on ES cells unnecessary and invited them to give evidence; and we made a special effort to obtain the views of some of the leading adult stem cell researchers around the world on the relative merits of adult and ES cells…* *We received 52 submissions from representative organisations and 57 from individuals…We held 12 sessions of oral evidence at which 42 people representing 17 organisations (or in some cases giving evidence on their own account) appeared before us. In order to reach a broader range of opinion we also commissioned the Hansard Society to conduct on our behalf an internet debate over a period of four weeks in September and October 2001. One hundred and ninety six people registered to take part in the debate, 110 users logged on to the site and 330 messages were posted.”*
Geographical scope	UK-wide
Methodology	Open consultation, 12 oral evidence sessions and an internet forum
Depth of engagement	Up to two opportunities to give evidence, and a further opportunity for informal debate.
Rationale for inclusion / exclusion	Although more than five years old, the high profile and relevance of this consultation gives a rationale for its inclusion.
Topics covered	• Possible alternatives to research on early human embryos • The status of the early embryo • Cell nuclear replacement and cloning • Future legislation and regulation
Headline	*“The Committee's detailed conclusions and recommendations are as*

findings	*follows:* ***stem cell research*** *(i) Stem cells appear to have great therapeutic potential for the treatment of many disorders that are both common and serious and for the repair of damaged tissue.* *(ii) Until recently most research on stem cells has focused on ES cells from animals and the derivation of ES cell lines from them; cell lines from human ES cells have the potential to provide a basis for a wide range of therapies.* *(iii) Recent research on adult stem cells, including stem cells from the placenta and umbilical cord, also holds promise of therapies; and research on them should be strongly encouraged by funding bodies and the Government.* *(iv) To ensure maximum medical benefit it is necessary to keep both routes to therapy open at present since neither alone is likely to meet all therapeutic needs.* *(v) For the full therapeutic potential of stem cells, both adult and ES, to be realised, fundamental research on ES cells is necessary, particularly to understand the processes of cell differentiation and dedifferentiation.* *(vi) Future developments might eventually make further research on ES cells unnecessary. This is unlikely in the foreseeable future; in the meantime there is a strong scientific and medical case for continued research on human ES cells. (i-vi paragraph 3.22)* ***status of the early embryo*** *(vii) Whilst respecting the deeply held views of those who regard any research involving the destruction of a human embryo as wrong and having weighed the ethical arguments carefully, the Committee is not persuaded, especially in the context of the current law and social attitudes, that all research on early human embryos should be prohibited (paragraph 4.21).* *(viii) Fourteen days should remain the limit for research on early embryos. (paragraph 4.22)* *(ix) Embryos should not be created specifically for research purposes unless there is a demonstrable and exceptional need which cannot be met by the use of surplus embryos. (paragraph 4.28)*

	cell nuclear replacement and cloning *(x) Basic research is a necessary step to developing treatments and facilitating the potential use of adult stem cells and should be permitted under the Regulations in the same way as more directly applied research to which it is designed to lead, provided that it is subject to strict regulation. (paragraph 5.4)* *(xi) Although there is a clear distinction between an IVF embryo and an embryo produced by CNR (or other methods) in their method of production, the Committee does not see any ethical difference in their use for research purposes up to the 14 days limit. (paragraph 5.13)* *(xii) Even if CNR is not itself used directly for many stem cell-based therapies, there is still a powerful case for its use, subject to strict regulation by the HFEA, as a research tool to enable other cell-based therapies to be developed. However, as with embryos created by IVF for research, CNR embryos should not be created for research purposes unless there is a demonstrable and exceptional need which cannot be met by the use of surplus embryos. (paragraph 5.14)* *(xiii) If CNR is permitted in certain limited circumstances, oocyte nucleus transfer should also be allowed for research purposes. (paragraph 5.20)* *(xiv) Given the high risk of abnormalities the scientific objections to human reproductive cloning are currently overwhelming. (paragraph 5.21)* *(xv) There are further strong ethical objections in addition to those based on the risk of abnormalities, although not all the arguments deployed against reproductive cloning are equally valid. The most powerful are the unacceptability of experimenting on a human being and the familial and child welfare considerations arising from the ambiguity of the cloned child's relationships. (paragraph 5.21)* *(xvi) The Committee unreservedly endorses the legislative prohibition on reproductive cloning now contained in the Human Reproductive Cloning Act 2001. (paragraph 5.21)* *(xvii) The HFEA has an excellent record in ensuring that IVF clinics comply with the law, and we are satisfied that its regulatory powers, now reinforced by a specific statutory prohibition, provide sufficient protection against the development of CNR leading to reproductive cloning in the United Kingdom. (paragraph 5.24)* *(xviii) The Government should take an active part in any*

	move to negotiate an international ban on human reproductive cloning. (paragraph 7.22) ***legislation and regulation*** *(xix) At an appropriate time, perhaps towards the end of the decade, the Government should undertake a further review of scientific developments, particularly of the progress of adult stem cell research and therapies, and of the development of stem cell banks, with a view to determining whether research on human embryos is still necessary. (paragraph 8.4)* *(xx) The Government should keep the funding of the HFEA under review and ensure that its resources are commensurate with its increased responsibilities. (paragraph 8.5)* *(xxi) The HFEA and the Department of Health should consider how a review of the outcomes of research licensed under the Act might be undertaken and updated on a regular basis (paragraph 8.6)* *(xxii) The Department of Health should examine with the HFEA the possibility of drawing up indicative guidance as to what constitutes serious disease (paragraph 8.9)* *(xxiii) When the Government bring forward legislation they should consider making express provision for such basic research as is necessary as a precursor for the development of cell-based therapies (paragraph 8.15)* *(xxiv) The separation of clinical and research roles should be standard practice for donation of eggs or embryos. The prohibition in the United Kingdom of payment to donors for gametes has been an important element in preventing undesirable commercialisation of this aspect of assisted reproduction and should be strictly maintained (paragraph 8.21)* *(xxv) The Department of Health should consider either establishing a body similar to the Gene Therapy Advisory Committee with oversight of clinical studies involving stem cells, or extending the membership and remit of GTAC to achieve the same ends. The Committee sees no other special need at present for additional regulation of the use of stem cells in the treatment of patients (paragraph 8.23)* *(xxvi) The Department of Health's proposals to establish a stem cell bank overseen by a steering committee, responsible for the custody of stem cell lines, ensuring their purity and provenance and monitoring their use, are endorsed. As a condition of granting a research licence, the HFEA should require that any ES cell line generated in the United Kingdom*

	in the course of that research is deposited in the bank. Before granting any new licence to establish human ES cell lines, the HFEA should satisfy itself that there are no existing ES cell lines in the bank suitable for the proposed research. (paragraph 8.29) *(xxvii) The HFEA should ensure that the implications arising from the "immortality" of stem cell lines are fully covered in obtaining informed consent from donors giving embryos for the potential establishment of ES cell lines for research. To prevent future restrictions in using ES cell lines (and therefore minimise the need to generate new ES cell lines) the HFEA should not permit ES cell lines be generated from donated embryos unless informed consent places no specific constraint on their future use. Where parents wish to restrict the type of research which can be undertaken, for example specifically for reproductive purposes, the embryos donated should be used for purposes other than the generation of ES cell lines. (paragraph 8.33)"*
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	It must be noted that this consultation is over five years old and that both the science and public opinion will have developed in the intervening years.

Polls and surveys

Name of event/initiative	YouGov/Daily Telegraph survey
Organising institution	YouGov
Date conducted	19 – 24/08/05
Where report published	YouGov website

[if any]	
Web address [if any]	http://www.yougov.com/archives/pdf/TEL050101042_1.pdf http://www.telegraph.co.uk/news/main.jhtml?xml=/news/2005/08/29/nabor129.xml
Sample	2432 adults aged 18+
Geographical scope	Throughout Britain
Methodology	Online questionnaire
Depth of engagement	Answering a quantitative survey. No interaction or discussion
Rationale for inclusion / exclusion	Asks several questions directly related to stem cell research and the use of embryos.
Topics covered	• Abortion law • Experimentation on human embryos • Cloning • Stem cell research • Genetic modification • Sex selection • Euthanasia
Headline findings	British scientists are legally permitted to carry out a limited range of experiments using early human embryos up to 14 days after conception (at which point they are a cluster of about 2,000 cells). Do you believe that it is, or is not, acceptable to use 'spare' early embryos left over from fertility treatment, such as IVF, for the purposes of medical research? Yes, it is acceptable 68 No, it is not 20 Don't know 12 Do you believe that it is, or is not, acceptable to create human embryos deliberately solely for the purposes of medical research? Yes, it is acceptable 41 No, it is not 46 Don't know 14 Do you agree or disagree that the rights of patients with diseases such as cancer are more important than the rights of early embryos? Agree - the rights of patients are more important than the rights of early embryos 66 Disagree - the rights of patients are NOT more important than the rights of early embryos 15 Don't know 19 In your view, should there be laws regulating the use of early embryos for

medical research, or should the issue of whether or not they are used for research be a matter solely for the embryos' parents?
There should be laws regulating the use of embryos 66
Their use should be solely a matter for the parents 25
Don't know 9

For what purposes, if any, do you think it is acceptable to use early embryos for medical research?
For any medical condition, such as infertility or short sightedness 23
Only for life-threatening diseases, such as cancer or heart disease, whether in adults or children
48
Only for life-threatening diseases affecting CHILDREN, such as leukaemia and immune deficiencies
6
It is never acceptable to use early embryos in medical research 11
Don't know 11

Which of these statements comes closest to your own view?
'Human embryos are human beings from the moment of conception and should be given the same legal protection as new-born babies'
16
'Embryos are not really human beings from the moment of conception, but there should nevertheless be laws governing the uses to which they are put'
58
'Until the first signs of a nervous system appear two weeks after conception, embryos are not human beings and therefore do not need any legal protection'
17
Don't know 10

Some scientists plan to use cloned early human embryos as a source of 'stem cells' – the flexible parent cells that produce every kind of tissue in the body. By growing embryo stem cells, these scientists hope to create unlimited supplies of tissue to treat diseases such as diabetes, Alzheimer's disease and heart disease.
In your view, when, if ever, is the use of stem cells in this way acceptable?
For any medical purpose including cosmetic purposes 7
For any medical purpose but excluding cosmetic purposes 27
To help treat all serious diseases, such as diabetes and arthritis 25
To help treat only life-threatening diseases, such as cancer and heart disease 20
The use of stem cells in this way is never acceptable 9
Don't know 11

Some people say they do not feel well enough informed about the relevant science to make decisions about things like cloning and stem-cell research.
Do you PERSONALLY feel you are well enough informed or not?
Yes, I think I am well enough informed 33

	No, I don't think I am well enough informed 60 Don't know 7 Thinking back to the questions relating to new medical research and techniques, which of the following statements comes closer to your own view? It will be possible to keep the lid on and to limit the uses to which these new techniques are put – for example, by preventing doctors from using stem cells for purely cosmetic purposes 31 It will not be possible to keep the lid on: once these new techniques are available, there will be no way of successfully controlling how they are used 52 Don't know 17 Some people say that scientists are so keen to achieve major breakthroughs in medical research that they give too little thought to the moral issues involved. From what you know, are you inclined to agree or disagree with this view? I am inclined to agree 59 I am inclined to disagree 27 Don't know 14
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	

Name of event/initiative	PUBLIC ATTITUDES TO FERTILITY TREATMENT, EMBRYO RESEARCH AND THE REGULATION OF THIS WORK – Preliminary findings from the UK
Organising institution	HFEA

Date conducted	03/05
Where report published [if any]	HFEA website
Web address [if any]	http://www.hfea.gov.uk/docs/2005-01-07_FINAL_European_Consortium_EACC_public_attitudes_to.pdf
Sample	A representative sample of 1,929 adults
Geographical scope	UK-wide
Methodology	Survey
Depth of engagement	Quantitative study. No interaction or discussion
Rationale for inclusion / exclusion	Gives an indication of public opinion with regard to embryo research and its regulation.
Topics covered	Embryo research and its regulation
Headline findings	**Key Findings of UK Public Opinion** • Openness and Honesty are most important to maintain trust in the regulatory system – followed by knowing that there is a system which will stop particular actions if there are concerns. • Politicians, religious leaders and the media are trusted by relatively few people to be involved in the regulation of fertility treatment or embryo research • 73% of people believe that human embryo research can improve the quality of life of future generations with inherited diseases • 43% of people believe the benefits of embryo research outweigh the risks (but 20% believe the risks outweigh the benefits). • Opinion is split on the ethics of research. 41% of people believe that embryo research is ethical, while 34% of people believe embryo research is unethical • 42% of people believe the rules governing embryo research are strong enough as they stand at present. • The UK regulator is most trusted to be involved in decision making on human embryo research and provide information to the public • The public believe that the framework of rules and regulations should be developed by doctors and Parliament working together to develop a consensus. Very few people believe these decisions should be made by Parliament or doctors

	working alone. **Key Recommendations for the Future** • A consensus between public, doctors and scientists is essential to maintain public confidence which allows treatment and research to continue and progress. Public opinion is finely balanced and fragile and requires continued openness, honesty and a consensual approach. • The public want authoritative and trusted information and will trust an independent regulator to provide it. • It is important for regulators to assess and evaluate public opinion on an ongoing basis to maintain confidence in the face of scientific developments. • Patients can feel differently about these issues and are influential on others. Therefore, it is important to track the views of patients separately.
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	Discrepancy between patient views and the views of the public generally.
Further notable challenges or issues	

Name of event/initiative	Europeans and Biotechnology in 2005: Patterns and Trends
Organising institution	Centre for the Study of Bioscience, Biomedicine, Biotechnology and Society (BIOS), London School of Economics
Date conducted	05/06
Where report published [if any]	Eurobarometer 64.3

Web address [if any]	Not known
Sample	Not known
Geographical scope	Europe-wide, but with lots of UK information
Methodology	Survey
Depth of engagement	Answering survey questions. No interaction
Rationale for inclusion / exclusion	Although European in focus, there is lots of relevant information in the UK context and the survey is relatively recent.
Topics covered	• Familiarity with stem cell research • Approval for embryonic and non-embryonic stem cell research • Beliefs about the nature of the embryo
Headline findings	Related to the UK: • Familiarity with stem cell research: 5% very familiar, 40% fairly familiar, 35% not very familiar, 20% not at all familiar • Approval for embryonic stem cell research: 28% approve with usual Government regulation, 34% approve if more tightly regulated, 15% do not approve except under very special circumstances, 6% do not approve under any circumstances, 17% don't know. Overall 74% approval for stem cell research and 81% approval for non-embryonic stem cell research (using umbilical cords) • Beliefs about the nature of the embryo: When asked 'Is the immediately fertilised embryo human?', 22% totally agree, 26% tend to agree, 23% tend to disagree, 11% totally disagree and 17% don't know.
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	Although in the Europe-wide context, one question is particularly notable for the public dialogue project: *"If there was a referendum on embryonic stem cell research and you had to make up your mind how to vote, what would be, among the following, the issue on which you would like to know more?"* Respondents were then asked to rate two of five statements. *"Out of those respondents who expressed a choice 69 per cent selected 'benefits and risks'. 40 per cent wanted to know more about current*

	regulations and about who is enforcing them, 36 per cent express interest in who is responsible for setting moral limits, 33 per cent want to know what scientific processes and techniques are used, and 22 per cent want to know about who is funding the research and who will benefit from it."
Further notable challenges or issues	

<table>
<tr><td>Name of event/initiative</td><td>Seven In Ten Members Of The Public Support The Use Of Embryos For Medical Research</td></tr>
<tr><td>Organising institution</td><td>Alzheimer's Society; Association of Medical Research Charities; Biotechnology and Biological Sciences Research Council; British Heart Foundation; Cancer Research UK; Diabetes UK; ESRC; Medical Research Council; Parkinson's Disease Society; Royal Society and The Wellcome Trust.</td></tr>
<tr><td>Date conducted</td><td>20-25/02/03</td></tr>
<tr><td>Where report published [if any]</td><td>Ipsos MORI website</td></tr>
<tr><td>Web address [if any]</td><td>http://www.ipsos-mori.com/polls/2003/amrc.shtml</td></tr>
<tr><td>Sample</td><td>2,001 respondents aged 15+</td></tr>
<tr><td>Geographical scope</td><td>Throughout Britain</td></tr>
<tr><td>Methodology</td><td>Survey</td></tr>
<tr><td>Depth of engagement</td><td>Quantitative study. No interaction or discussion</td></tr>
<tr><td>Rationale for inclusion / exclusion</td><td>Covers a question on stem cell research. Particularly interesting because it compares two sets of survey results, one in which respondents are given additional information.</td></tr>
<tr><td>Topics covered</td><td>The use of human embryos for medical research</td></tr>
<tr><td>Headline findings</td><td>Around 70% of the British public support the use of human embryos for medical research to find treatments for serious diseases and for fertility research. Over half of adults feel that the use of human embryos for medical research is only acceptable to find treatments for serious diseases and for fertility research, but not for most other types of research. Further, one in six feel the use of human embryos is always acceptable for all types of medical research.</td></tr>
<tr><td>Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant</td><td>
<table>
<tr><td colspan="3">Q1. Current law allows the use of human embryos up to 14 days after conception to find treatments for serious diseases and for fertility research, but the law does not permit the use of human embryos for most other types of research.

On this card is a list of options. Which, if any, most closely describes your view about the use of human embryos in medical research?</td></tr>
<tr><td></td><td>Version 1 (957)
%</td><td>Version 2 (1,044)
%</td></tr>
<tr><td>The use of human embryos is always acceptable for all types of medical research</td><td>17</td><td>15</td></tr>
</table>
</td></tr>
</table>

<table>
<tr><td>debate</td><td><table><tr><td>The use of human embryos for medical research is only acceptable to find treatments for serious diseases and for fertility research, but not for most other types of research</td><td>56</td><td>55</td></tr><tr><td>The use of human embryos for medical research is never acceptable</td><td>17</td><td>20</td></tr></table>Version 1 of the survey included two additional pictures: a picture of a human embryo up to 14 days after conception, and a picture showing the embryo’s actual size. This gives an indication that with additional scientific information, the public may become more amenable to stem cell research.</td></tr>
<tr><td>Any issues that it will be important to consider in carrying out the public dialogue project</td><td></td></tr>
<tr><td>Further notable challenges or issues</td><td>It must be noted that the survey is over 4 years old and public opinion may have changed in that time.</td></tr>
</table>

Name of event/initiative	Have your say: Would you use a stem cell bank?
Organising institution	BBC
Date conducted	01/02/07
Where report published [if any]	BBC website
Web address [if any]	http://newsforums.bbc.co.uk/nol/thread.jspa?messageID=2260250&start=180&tstart=0&&edition=1&ttl=20070608115606
Sample	238 published comments
Geographical scope	Worldwide, though a UK focus
Methodology	Moderated comments in response to a news piece
Depth of engagement	Free commenting (though moderated). Real-time updates allowing the views of others to be taken into consideration.
Rationale for inclusion / exclusion	Direct engagement with the public on their views regarding stem-cell banks.

Topics covered	Stem cell banks using a child’s umbilical cord
Headline findings	Top 6 comments (by recommendations of other readers) supportive of the idea of stem-cell banks. Top 3 comments: Yes. There is good potential and nobody is harmed. Why not? **Elias Kostopoulos**, Athens, Greece Recommended by **57** people yes, of course I would. Surely it's a no-brainer? These cells could save lives and combat serious, currently untreatable diseases. Who could possibly object to that? **Mb**, London Recommended by **44** people Yes absolutely. Even if the research saves just one life its a success. I’m just waiting for the "its immoral and against god" crowd to pipe up. **Atheist Woody**, Burton on Trent, United Kingdom
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	Catholics support stem cell research and the Church has provided funding for umbilical and adult stem cell research, but is opposed to creating embryos just to be destroyed. I'm fed up with the ignorance of some commenters on this subject, who lump all stem cell research together and incorrectly claim Catholics are opposed to the lot. Stem cell research is an umbrella term and adult stem cell research and umbilical cord stem cell research are perfectly good alternatives to embryo research. **John Sobieski**, Bury, United Kingdom
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	This form of public engagement cannot be seen to be representative of the population as a whole.

Name of event/initiative	Have your say: Is human-animal embryo research ethical?
Organising institution	BBC
Date conducted	17-18/05/07

Where report published [if any]	BBC website
Web address [if any]	http://newsforums.bbc.co.uk/nol/thread.jspa?sortBy=2&threadID=6352&edition=1&ttl=20070612224601&#paginator
Sample	468 published comments
Geographical scope	Worldwide, though a UK focus
Methodology	Moderated comments in response to a news piece
Depth of engagement	Free commenting (though moderated). Real-time updates allowing the views of others to be taken into consideration.
Rationale for inclusion / exclusion	Direct engagement with the public on their views regarding human-animal embryo research.
Topics covered	Ethics of hybrid embryo research
Headline findings	Top 10 comments (as recommended by other readers) all in support of human-animal embryo research. Top 3 comments: It's about as ethical as feeding cows sheeps brains and look what that brought us (BSE)....Will we ever learn not to play God? Northern Monkey, Oldham Ever had a vaccination or taken anti-biotics for an infection? "God" intended for you to take your chances with pneumonia and smallpox.... every time you got to the GP you're "playing God" by refusing to take your chances with nature's vast array of diseases. **[Peter_Sym]**, Nottingham Recommended by **98** people Added: Thursday, 17 May, 2007, 11:09 GMT 12:09 UK About time too. We must not let medieval beliefs take precedence over curing people of illness. **Mike Malone**, Aberdeen, United Kingdom Recommended by **87** people Added: Thursday, 17 May, 2007, 11:28 GMT 12:28 UK It's about as ethical as feeding cows sheeps brains and look what that brought us (BSE)....Will we ever learn not to play God? Northern Monkey, Oldham When the human race stops believing in fairy tales such as the existence of a God, will we be ready to move forward in our own evolution and that includes the development of technology such as this. Religious doctrine is a cancer on the rump of mankind and as long as the Vatican and Mecca etc etc hold sway then the cancer will

	spread. **Jabba DeHutt**
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	Religious involvement in the debate.
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	This cannot be taken as a representative view of the public. Very similar to another ‘Have your say’.

Name of event/initiative	Have your say: Should creation of hybrid embryos be allowed?
Organising institution	BBC
Date conducted	05-06/01/07
Where report published [if any]	BBC website
Web address [if any]	http://newsforums.bbc.co.uk/nol/thread.jspa?sortBy=2&threadID=5171&edition=1&ttl=20070613082937&#paginator
Sample	805 published comments
Geographical scope	Worldwide, though a UK focus
Methodology	Moderated comments in response to a news piece
Depth of engagement	Free commenting (though moderated). Real-time updates allowing the views of others to be taken into consideration.
Rationale for inclusion / exclusion	Direct engagement with the public on their views regarding hybrid embryos
Topics covered	Ethics of hybrid embryo research
Headline findings	Top 12 comments (by reader recommendation) in favour of the creation of hybrid embryos. Top 3 comments:

	Added: Friday, 5 January, 2007, 09:18 GMT 09:18 UK Absolutely! I have no ethical problems with this research and it should continue unhindered. I await objections from the religious crowd though! **James**, Oxford Recommended by **134** people Alert a Moderator Added: Friday, 5 January, 2007, 09:13 GMT 09:13 UK Where's the dilemma? Do we return to the dark ages or move forward? Medical research is essential and these are just clusters of cells. The alternative is to experiment on people. I'm sure those that try to claim the moral high ground would be the first to ask for medical treatment if they or their loved ones needed it. K. **Kevan**, Reading, Berks Recommended by **97** people Added: Friday, 5 January, 2007, 10:51 GMT 10:51 UK I once saw a birthday card with a cartoon of a drowning man on the front. A lifeboat came to rescue him and he refused, saying "My God will save me". A helicopter and a water-ski came and he again refused. Later, he asks St Peter "Why did God not save me?". Peter replies "He sent a water-ski, a lifeboat, and a helicopter. What more could he do??". It may seem a ludicrous comparison, but this stem-cell stuff seems much the same. Who's to say it isn't God's way of helping us cure desease (sic)? **Mike**, Bracknell Recommended by **95** people
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	Added: Friday, 5 January, 2007, 11:26 GMT 11:26 UK Don't get carried away by the "it could produce cures for Parkinsons/Motor Neurone Disease etc. Pigs might also fly. As a Ph.D scientist myself I know how the funding system works and researchers always have to talk up benefits in order to get their grants/approvals etc. Just because something can be done doesn't mean it SHOULD be done. **Adrian**, Newbury Recommended by **60** people
Any issues that it will be important to consider in carrying out the public dialogue project	

Further notable challenges or issues	This should not be seen as representative of the public. Very similar to another 'Have your say'.

Talks and speeches

Name of event/initiative	Human Cloning
Organising institution	Linacre Centre for the Study of Health care Ethics
Date conducted	25/09/03
Where report published [if any]	Newsletter of the Worcestershire branch of the Guild of Catholic Doctors
Web address [if any]	http://www.catholicdoctors.org.uk/Branch_News/worcester_newslet8.htm
Sample	N/A
Geographical scope	Not known
Methodology	Public lecture
Depth of engagement	Listening to the views of an ethicist. No interaction, discussion or public input.
Rationale for inclusion / exclusion	Sets out the views of an ethicist associated with the Guild of Catholic Doctors on, among other things, 'therapeutic cloning' in order to harvest stem cells.
Topics covered	Human cloning, embryonic stem cells, adult stem cells, issues of identity
Headline findings	So called "therapeutic cloning" is a misnomer too suggesting a benign purpose but the cloned embryo is used as a source of embryonic stem cells, the harvesting of which, kills the embryo. This should be more accurately termed "cloning for experimentation" or "cloning for research". Man has not been cloned as yet and it has so far proved impossible to clone rhesus monkeys. From cloned animals we could anticipate that in man there would be many abnormalities, premature deaths, perhaps large babies and risks to maternal health. In any event a long period of experimentation and induced abortions could be anticipated before cloning to birth takes place even if it were possible at all. Stem cells which retain the ability to differentiate into many different tissues could be obtained from cloned embryos but they also occur naturally as so called "adult stem cells". These can be found in bone marrow and liver, are also versatile and

	can be differentiated into tissues as different as heart muscle and neurones and they have the advantage of being compatible with the body's immune system. On the other hand, stem cells from an unrelated embryo could be rejected, and on some occasions will results in tumour formation if implanted. Turning now to the ethical aspect, there is a near consensus amongst scientists that cloning to live birth should not be attempted because of the risks to health but amongst the public there is a intuitive repugnance to cloning to birth and there is a moral wisdom in this. For one thing it is reproduction without the complimentarity of the sexes. Indeed the male can be excluded entirely form the process, and a woman could clone herself producing her virtual twin decades after her own conception. Or she could clone a lost child or a chosen other, whether related or not. The child so born would not be unique but genetically a copy of another person alive or dead. There is an expectation upon that child to be like the person copied, and their lack of genetic uniqueness and the fact they were chosen to conform at least bodily to another, makes them like a commodity. Not only is this fundamentally unjust as they would not seen as equals but would also cause an identity crisis for the cloned person. The psychological harm is potentially very great.
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	"there is a near consensus amongst scientists that cloning to live birth should not be attempted because of the risks to health"
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	The speech is almost four years old and therefore opposition to stem cell research may have moved on since then.

Name of event/initiative	The Politics of Cloning
Organising institution	Centre for Bioethics and Public Policy
Date conducted	24/11/03
Where report published [if any]	Guild of Catholic Doctors website
Web address [if any]	http://www.catholicdoctors.org.uk/CMQ/2004/Feb/The%20Politics%20of%20Cloning%20-%20Lord%20Alton.pdf
Sample	N/A
Geographical scope	Not known
Methodology	Conference lecture
Depth of engagement	Listening to the views of an ethicist. No interaction, discussion or public input.
Rationale for inclusion / exclusion	Sets out the views of an ethicist associated with the Guild of Catholic Doctors on, among other things, 'therapeutic cloning' in order to harvest stem cells.
Topics covered	Stem cell research, cloning, Parliamentary legislation, lack of accountability in the HFEA.
Headline findings	No difference between reproductive and therapeutic cloning; therapeutic cloning even more unethical.
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	"In the late 1990s when the HFEA and the Human Genetics Advisory Commission asked a committee of four people to act as an advisory body it appointed them knowing that all four were from scientific backgrounds, that all four had previously expressed support for cloning, and that two had links with the pharmaceutical industry." Alleged scientific acceptance that therapeutic cloning is neither effective nor necessary. "Adult stem cell research is a viable scientific alternative and has clearly overtaken research using human embryos."
Any issues that it will be important to consider in carrying out the public dialogue project	"Many individuals, such as Baroness Warnock, profoundly disagree with me on the ethics of embryonic stem cell research and cloning. What we do agree on is the need to restore public confidence in science and ensure that the fears of the general public surrounding genetics and the new reproductive technologies are heeded."
Further notable challenges or issues	Speech is almost four years old.

Name of event/initiative	Who owns the science and what is the role for the scientist in future?

Organising institution	British Association for the Advancement of Science
Date conducted	09/05
Where report published [if any]	The BA website, BBC news website
Web address [if any]	http://www.the-ba.net/the-ba/Events/FestivalofScience/FestivalNews/_BAPresidentialAddress2005.htm http://news.bbc.co.uk/1/hi/sci/tech/4213566.stm
Sample	N/A
Geographical scope	Not known
Methodology	Public lecture and media report
Depth of engagement	Listening to the views of the President of the BA. No interaction, discussion or public input.
Rationale for inclusion / exclusion	Sets out the views of a scientist regarding the uncertainties around stem cell research, particularly using embryos
Topics covered	Impact of embryonic stem cell research on disease
Headline findings	**“The potential benefits of embryonic stem cell research have probably been oversold to the public, fertility expert Lord Winston says.** He fears a backlash if science fails to deliver on some of the "hype" around the cells - as he believes may happen. He says the notion that a host of cures for serious, degenerative disorders are just around the corner is fanciful.” (BBC)
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	The author discusses the inadequacy of public engagement events without public education initiatives alongside these in order to counteract the ‘misinformed’ and ‘polarised’ opinion.
Further notable challenges or issues	

Events

Name of event/initiative	Stem Cell Science – Hope not Hype
Organising institution	MRC and BBSRC
Date conducted	06/06-06/07
Where report published [if any]	BBSRC website
Web address [if any]	http://www.mrc.ac.uk/NewsViewsAndEvents/Events/Reports/StemCellScience-HopenotHype/MRC003430 http://www.bbsrc.ac.uk/society/engagement/exhibitions/current/stem_cells.pdf
Sample	N/A
Geographical scope	UK-wide
Methodology	Public exhibition
Depth of engagement	Exhibition and public discussion events at some venues. Exhibition alone at others.
Rationale for inclusion / exclusion	Described as a “sustained and coordinated programme of public dialogue on stem cell research over the next decade.”
Topics covered	Progress of stem cell research, potential application to diseases, balancing public expectation with scientific reality, Research Councils engagement with the public.
Headline findings	Not known
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	Not known
Any issues that it will be important to consider in carrying out the	

public dialogue project	
Further notable challenges or issues	Project is ongoing and so not much information on the public reaction is available at present. However, a number of individual events from the exhibition have reports available. A selection are analysed below.

Name of event/initiative	Public discussion about stem cell research
Organising institution	MRC and BBSRC
Date conducted	31/10/06
Where report published [if any]	BBSRC website
Web address [if any]	http://www.bbsrc.ac.uk/society/engagement/exhibitions/current/DiscussionReportOctober2006.pdf
Sample	Not known
Geographical scope	Edinburgh and surrounding area
Methodology	Public exhibition and discussion with experts
Depth of engagement	Single interactive event, with educational exhibition to help understand the issues.
Rationale for inclusion / exclusion	Direct public engagement with issues surrounding stem cell research
Topics covered	Chimerical embryos, philosophical viewpoints, stem cell potential, special moral status of human cells, moral status of embryo.
Headline findings	**i) Chimeric embryos** When we consider chimeric embryos, in which you take an animal’s egg, empty it of its genetic material, then put the nucleus of a human cell inside – someone said this might be considered as a human embryo. Given that 98% of the chimp genome is exactly the same as a human being's, what is the definition of a “human embryo”? It is not a case of a chimp “being 98% human”. This question is irrelevant because a chimp is 100% chimp, not 98% human. In legal terms the definition of a “human embryo” is very pertinent, and one that the HFEA should strive to address. What you seem to be asking is whether there a percentage cut -off point between when a chimeric embryo can be defined as human or vice versa. **ii) A philosophical view**

	A participant stated that the fundamental issues commonly debated do not appear to be resolvable in philosophical terms – this wipes out the entire discipline of philosophy. As regards to whether philosophy can provide an answer, I would ask why philosophers haven't yet found a consensus? I believe these questions are resolvable and will be resolved quite soon. The concept of cells is less than 200 years old – until recently no one even had any idea of what an embryo was. It's an extraordinarily new question in human thinking. The pro-life movement seems to have given no thought to what their commitments mean when it comes to biological intervention in prolonging the basic human life span. They assume you shouldn't do that, but have no idea why. With reference to the international situation, all speakers gave examples from Europe and US ignoring the Far East. The moral dilemmas we are debating here in the West simply do not exist in China. **iii) Stem cell potential** Before we try and deal with all the ethical issues, we should explore some of the pragmatic issues - what is likely to be achieved by stem cell research? For example: if we use eggs from different species, how effectively can we reprogram gene expression? Would we be able to trace traits of late onset genetic disorders? These questions need to be addressed first. When we consider what can or cannot become a baby – for example, frozen embryonic stem cells in cold units in labs – this is a long way from an embryo implanted in a womb. A great deal of intervention has to take place before that entity ever has a hope of becoming a baby. In terms of genetic identity, surely every cell in my body has the potential to become a baby if we intervened? Where does the argument of stem cell potential interface with these issues? The cells used in research have come from embryos – not just any cells in the body – the fact that a stem cell has potential in the first place is what some people have a problem with. **iv) Special moral status of human cells** The church's view of the debate seems to imply that

	human embryonic stem cells are in some way special. In my view all life is pretty special. You can't equate a cow as having the same moral status as a human. Just because cows don't sit around having meetings about stem cell research, doesn't make them less special. We have to ask, how does God see these things? Human beings are made in God's image; we have a unique way of relating to God that is separate to that of other animals. If the HFEA recognises the special status of embryos, should the law be taking its lead from the Church? The Church argues that humans are special in a divine way – should legislation relate to or take its lead from this religious perspective? **v) Moral status of embryo** Is a human embryo a human being? If it is, logic says we need to legislate to protect the dignity of the human embryo, because of the potential it has. This is not a perceived or future potential – it is a living potential – it exists now. It's a question of human dignity - is a human being worth protecting? We have to work out where a human begins, and logic follows that's where you legislate from – if it's an embryo, then it has the same dignity, the equivalent status, as anyone alive today. I don't understand why somatic nuclear transfer products are regarded as “human embryos”. For me, a much bigger moral dilemma is egg donation on a large scale. Nor do I don't understand the moral dilemma of using animal eggs in labs to study disease, as we have no intention of taking these further. These cells will never become animals. A nuclear transfer is regarded as an embryo because Dolly was a real sheep…ergo she came from a real embryo.
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	

Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	

Name of event/initiative	Public discussion of stem cell research in Dundee
Organising institution	MRC and BBSRC
Date conducted	02/07
Where report published [if any]	BBSRC website
Web address [if any]	http://www.bbsrc.ac.uk/society/engagement/exhibitions/current/stem_cells.html http://www.bbsrc.ac.uk/society/engagement/exhibitions/current/SpeakerSummaryFeb2007.pdf http://www.bbsrc.ac.uk/society/engagement/exhibitions/current/OpenFloorSummaryFeb2007.pdf
Sample	Not known
Geographical scope	Dundee and surrounding area
Methodology	Public exhibition and discussion with experts
Depth of engagement	Single interactive event, with educational exhibition to help understand the issues.
Rationale for inclusion / exclusion	Direct public engagement with issues surrounding stem cell research
Topics covered	Stem cell research, controversies surrounding it, legislative challenges, ethical issues around stem cell research
Headline findings	**SUMMARY OF MAIN POINTS FROM OPEN FLOOR DUNDEE** 1. The legislative and decision-making processes of several countries were discussed and compared when examining the comment that ordinary members of the public seem to be a lot more liberal than their leaders. 2. The challenges faced by some people of faith - who believe that all human life is sacred (from the moment of conception) - were debated from both a Christian and secular point of view. Embryonic status, embryonic surplus and alternative SC therapies derived from ASC were discussed, and concepts of self-sacrifice and choice were touched upon in terms of how moral and ethical ESC research is. 3. The regulations around SC research vary from country to country

	and from continent to continent: bearing this in mind, it was asked whether it would be right for UK or US scientists to take up and use SC research that had been carried out in countries where the law is either less robust and stringent, or where other nations and cultures interpret some of the moral and ethical issues differently. 4. Medical trade journals and the entire concept of the review and regulation of scientific research literature were discussed. At present scientists tend to review each other and there is no external regulatory body overseeing what is published. One way forward would be to create an external and objective mechanism to do this job of reviewing the literature. 5. The effectiveness of SC research in treating spinal chord injuries was discussed. Animal models have shown some success in allowing injured rats, previously unable to move, to regain movement in their hind legs. However, humans are not rats and SC research is very much that – at the research stage. The gap between what is happening in labs, and therapies available to patients was explored with some possible factors responsible for this transitional gap being forwarded by the panel. 6. A comment was made about recent news reports of large sums of government money being invested in SC research in the UK. In particular, a member of the audience had read a news report that £4million has been granted to set up a new lab in the north of England. The economic viability of SC therapies was explored and the reasons why SC research has a lot of set-up costs to produce one-off and bespoke therapies were debated. 7. A member of the audience commented on the fact that the cost of taking a single new drug to market was somewhere in the region of £500 million. When compared to the reported £4 million of government money granted to build a new lab, he asserted that the two figures offered a “scary kind of perspective” on how much SC research and therapies will cost in the future. 8. There was a discussion on the work, processes and aims/objectives of the UK Stem Cell Foundation. (http://www.bbsrc.ac.uk/society/engagement/exhibitions/current/OpenFloorSummaryFeb2007.pdf) **SOUNDBITES FROM THE OPEN-FLOOR DEBATE** Why is it that ordinary people always seem much more liberal than their leaders? I have two incurable diseases but my philosophy would be that I would not want somebody else to lose a life in order for me to gain life. Why do you need spare embryos, why make more that you need? If there was a breakthrough in China should the Americans take up that breakthrough if it used research techniques, which they had outlawed? We could talk about ethics, we could talk about rights or wrongs, we’ll never get any consensus on this, but from a personal point of view is there any hope that spinal injuries might be able to be reversed in the future? Some of us are, I don’t know if “desperate” is the right word, but we are looking for something to happen now, not in 20 years time

	because we probably won't be here. When are trials actually going to begin in this country? There is a gap in this country between what's happening in the labs and what's happening to the patient. Why? (http://www.bbsrc.ac.uk/society/engagement/exhibitions/current/SoundbitesFeb2007.pdf)
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	"An audience member drew a comparison between the £4 million of government money given to set up a new SC research laboratory and the £500 million it costs to bring ONE new drug to the market. He offered this as a "scary perspective" on how much all this research is going to cost." (http://www.bbsrc.ac.uk/society/engagement/exhibitions/current/SpeakerSummaryFeb2007.pdf)
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	A similar event is being run by nowgen: http://nowgen.org.uk/event/index.php?eid=223

Name of event/initiative	Insights from stem cell research
Organising institution	JDRF
Date conducted	28/04/07
Where report published [if any]	Not known
Web address [if any]	http://www.jdrf.org.uk/page.asp?section=00010001000300080001
Sample	N/A
Geographical scope	Cambridge and surrounding area
Methodology	Open public event
Depth of engagement	Speech by a scientific expert, then Q&A.
Rationale for inclusion / exclusion	Example of a scientist engaging with the public around stem cell research.
Topics covered	"I will be discussing our recent work defining the conditions for growing human embryonic stem cells in their unspecialised state, as

	well as for achieving their differentiation into specialised tissues with potential clinical value, such as ectoderm (precursors of nerves) and endoderm (precursors of beta cells)."
Headline findings	Not known (report not available)
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	No report available to explore public reaction to the speech.

Name of event/initiative	Using stem cells to discover new drugs
Organising institution	ISCR
Date conducted	07-09/02/06
Where report published [if any]	Not published
Web address [if any]	http://www.iscr.ed.ac.uk/outreach/schools.html
Sample	Around 320 Edinburgh S2 (secondary two) students came through our stand.
Geographical scope	Edinburgh and surrounding area
Methodology	Workshop
Depth of engagement	Interactive educational workshop. Single event

Rationale for inclusion / exclusion	Engaging with young people regarding stem cell research
Topics covered	Stem cell research and scientific testing
Headline findings	“They looked at live stem cells, made from mouse embryos, down a microscope and simulated a drug test on stem cells, to exclude the toxic drug amongst the several that they were developing to treat heart disease.”
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	Small scale event.

Name of event/initiative	Stem cell therapy for spinal cord injuries. Ready or not?
Organising institution	ISCR
Date conducted	Ongoing
Where report published [if any]	Not published
Web address [if any]	http://www.iscr.ed.ac.uk/outreach/Role-play.html
Sample	Not known
Geographical scope	Not known
Methodology	Role-play to educate young people and adults about the issues surrounding stem cell research
Depth of engagement	Single role-play event, with interactivity between participants but no interaction with experts.
Rationale for inclusion /	Public engagement initiative relating to the potential of, ethics and risks around stem cell research.

exclusion	
Topics covered	The use of human embryonic stem cells to treat spinal cord injuries. Participants role-play members of the research Ethics Committee and different stakeholders in the audience (bioethicist, pro-life activist, patient, sceptical scientists and more). The Committee has to publish and justify its decision. Here are some of the questions that the role-play addresses: • What are the risks involved in this treatment, compared to the benefits? • Are patients being used as guinea pigs in the rush to fulfill the promise of stem cells? • Why use stem cells from embryos for this treatment? What about adult stem cells? • Are we starting down a slippery slope of creating a market for embryos? • Who will have access to the medical benefits that are promised? • How does competition between scientists and between clinicians affect research?
Headline findings	N/A
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	Not known
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	

Name of event/initiative	Centre of the Cell

Organising institution	Centre of the Cell
Date conducted	From Spring 2008
Where report published [if any]	N/A
Web address [if any]	http://www.centreofthecell.org/
Sample	N/A
Geographical scope	London and UK
Methodology	Permanent exhibition and education space in London
Depth of engagement	Visits to the exhibition, discussions, as well as online interactive resources including: information about cells, medical research and ethics; patient journeys; and resources for teachers and students.
Rationale for inclusion / exclusion	Although the exhibition space is not yet open, it is a dedicated, large-scale public engagement initiative in, among other things, stem cell research. Also, the website is an existing example of public engagement, with opinions from a variety of experts and patients.
Topics covered	Information about cells, medical research, ethics and patient journeys.
Headline findings	N/A
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	The exhibition will not be open until Spring 2008

Name of event/initiative	Stem Cells: Therapies of the 21st Century?

Organising institution	Centre for Stem Cell Biology, University of Sheffield
Date conducted	17/03/05
Where report published [if any]	Not published
Web address [if any]	http://cscb.shef.ac.uk/GeneralInterest/PREVIOUSEVENTS/Activitiesduringscienceweek2005(11thMarch-20thMarch)/
Sample	Not known
Geographical scope	Sheffield and surrounding area
Methodology	Expert panel and public discussion
Depth of engagement	Interaction with members of the public and experts at a single event.
Rationale for inclusion / exclusion	Public event to discuss stem cell research
Topics covered	Science and ethics of stem cell research
Headline findings	“Stem cell research is currently one of the hottest areas of biomedical research, as well as being one of the most controversial because it requires the destruction of human embryos. These embryos are surplus from in vitro fertilisation treatments. The excitement about the potential use of stem cells in medicine comes from the idea that damaged cells (through diseases or injuries) could be replaced by healthy cells derived from stem cells. This new type of therapy is called regenerative medicine. It is bringing hope to many patients suffering from various diseases such as Alzheimer or diabetes. However, this area of research is still in its infancy. What will it really do for us? Come and discuss the science and the ethics with a panel composed of biologist, ethicist, patient and pro-life campaigner.”
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	Not known
Any issues that it will be important to consider in carrying out the public dialogue	

project	
Further notable challenges or issues	

Name of event/initiative	Playing a card game to debate about ethics in stem cell research
Organising institution	Centre for Stem Cell Biology, University of Sheffield
Date conducted	Ongoing
Where report published [if any]	N/A
Web address [if any]	http://cscb.shef.ac.uk/GeneralInterest/PREVIOUSEVENTS/Activitiesduringscienceweek2005(11thMarch-20thMarch)/
Sample	- For 6th Form colleges/ small groups. - Can be organised as a parents evening with several groups playing games at the same time, where pupils, parents and teachers play together. - Can be organised for any local, community group. Three schools in Sheffield have booked to play the game already.
Geographical scope	Sheffield and surrounding area
Methodology	"The Democ game has been developed by the New Economics foundation. Democ stands for Deliberative Meetings of citizens. Democ is a card game played in a group of 6-8 people. The game contains story cards, fact cards and issue cards. It provides information and encourages constructive discussion. An important part of the game is the opportunity to vote on public policies related to the topic. A game lasts for 1.5-2.5 hours. In many ways it is like having a semi-facilitated conversation, where participants find out facts around a topic, learn about the issues, and then decide or revise their views through group discussion. It is a way to make it easy for people to work out, share and express their views on complex topical issues."
Depth of engagement	Interactive discussion with participants, facilitated by the information contained within the game. No interaction with experts.
Rationale for inclusion / exclusion	Interactive public engagement event undertaken in an unusual format.
Topics covered	Choice of games: • The ethics of using human embryonic stem cells for biomedical research • Pre-Implantation Genetic Diagnosis (when one cell taken from an

	embryo created by IVF is tested for a small number of genetic diseases).
Headline findings	N/A
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	

Name of event/initiative	Café Scientifique event: Stem cells
Organising institution	Café Scientifique
Date conducted	2004
Where report published [if any]	The BA website
Web address [if any]	http://www.the-ba.net/the-ba/Events/FestivalofScience/AboutFOS/HistoryoftheFestival/Festival2004/_Stem+cells+over+a+drink.htm
Sample	150 people
Geographical scope	Exeter and surrounding area
Methodology	Speech by an expert, and then public debate and discussion
Depth of engagement	Single interactive event
Rationale for inclusion / exclusion	Public discussion of stem cell research
Topics covered	Science and ethics of stem cell research
Headline findings	“Starting with some background information on stem cell research, Minger promised to include a discussion of the ethics as well as

	elaborating on his own group's research. Based at King's College London, his research team was the first to be granted a license to create a human embryonic stem cell line by the Human Fertilisation and Embryology Authority (HFEA) in the UK. The work he spoke about involved using mouse stem cells, as well as those from humans, in attempts to develop cures for diseases such as Parkinson's and type I diabetes. Talking about his work of the past fifteen years, he explained why existing transplantation techniques were unable to provide cures for such diseases, emphasising the importance of stem cell work as a means of providing sufficient amounts of tissue to treat the many patients who are suffering."
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	"The idea of creating bloodbanks for newborn foetuses, which could be used to treat them in their future life if needed, seemed to grip the attention of many."
Any issues that it will be important to consider in carrying out the public dialogue project	"Indeed most people there could be heard debating the science involved over their drinks, rather than the ethical dilemmas, which surround this controversial topic." "The audience did not seem to mind the vast amount of data and scientific jargon that was being thrown at them, possibly because they were aware that an hour was reserved for their questions at the end of the evening. To Minger's credit, he did show some fascinating video footage of scientists manipulating stem cells, which undoubtedly took the edge off some very monotonous tables and graphs."
Further notable challenges or issues	"It was a shame that the ethical side of the debate about stem cell research was neglected somewhat. Minger seemed to forget that he had promised to mention it, whilst the audience queries were more concerned with the possibilities of actually curing disease in the future."

Name of event/initiative	Genetics, Risk and Publics: what are the issues?
Organising institution	CESAGen and nowgen
Date conducted	17/01/07
Where report published [if any]	N/A
Web address	http://nowgen.org.uk/event/index.php?eid=77

[if any]	
Sample	Not known
Geographical scope	Manchester and surrounding area
Methodology	Public seminar
Depth of engagement	Panel and public discussion. Single event.
Rationale for inclusion / exclusion	Public discussion on risks, fears and hopes regarding, among other things, stem cell research.
Topics covered	Governance as Risk Control: filling out the public agenda Stories of risk, fears and hopes: cloning, stem cells and the media Epigenetics and risk Behavioural genetics and risk Pharmacogenomics and individualised risk Stem cell research: framing the issues Risk, adverse drug reactions and pharmacogenetics Risk in clinical genetics from the patient perspective
Headline findings	Not known
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	

Media pieces

Name of event/initiative	IF…cloning could cure us
Organising institution	BBC

Date conducted	16/12/04
Where report published [if any]	BBC website, BBC 2 programme
Web address [if any]	http://news.bbc.co.uk/1/hi/programmes/if/4065719.stm
Sample	11,616 votes, viewing figures unknown. National audience
Geographical scope	UK-wide, with international scope online
Methodology	TV programme on BBC 2, with an audience vote at the end, and then a panel discussion
Depth of engagement	Voting on the verdict in the programme, but otherwise no interactivity. Single evening of programming.
Rationale for inclusion / exclusion	Public engagement with potential future issues in the stem cell debate.
Topics covered	Moral and legal dilemmas in future issues surrounding unlegislated stem cell research.
Headline findings	“The IF series of drama-documentaries returns with an interactive courtroom drama set 10 years in the future, bringing the issues of cloning and stem cell research to life. It is 2014. A climbing accident has left 28-year-old Andrew Holland paralysed from the waist down. Celebrated researcher Dr Alex Douglas wants to inject stem cells into Andrew's spine, to regenerate his spinal cord. If the treatment works, it could help Andrew to walk again. However the only way that Alex can get the stem cells she needs is to break the law and to take them from a 19-day-old cloned embryo. Her work is exposed by a whistleblower, and Alex is charged with "illegal experimentation on human embryos". A landmark trial follows, exploring the revolutionary science and the key issues of current cloning and stem cell research. Leading scientists and experts, such as Suzi Leather, head of the Human Fertilisation and Embryology Authority, and pro-life campaigner Josephine Quintavalle, expand on the arguments. As the judge summed up, the audience was left to decide the verdict in Dr Alex Douglas's case. The audience voted 81% in favour of a not-guilty verdict (9,381

	votes). 19% (2,235 votes) were in favour of a guilty verdict."
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	Although the BBC documentary was 'rigorously researched', the resultant public opinion is based on media portrayal of the issues, rather than direct discussions with experts.

Public information

Name of event/initiative	Stem cells: Science and ethics
Organising institution	BBSRC
Date conducted	Ongoing
Where report published [if any]	BBSRC website
Web address [if any]	http://www.bbsrc.ac.uk/society/engagement/schools/resources/download.html
Sample	N/A
Geographical scope	UK-wide
Methodology	Information packs for schools
Depth of engagement	Information, but no interaction
Rationale for inclusion / exclusion	Public information and engagement in science, although little interaction

Topics covered	Stem cells: science and ethics
Headline findings	N/A
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	

Name of event/initiative	Stem cell stories: science and ethics on screen.
Organising institution	European Consortium for Stem Cell Research
Date conducted	N/A
Where report published [if any]	EuroStemCell website
Web address [if any]	http://www.eurostemcell.org/Outreach/outreach_film.htm
Sample	N/A
Geographical scope	Europe-wide, including UK
Methodology	Short films
Depth of engagement	Information but no interaction
Rationale for inclusion / exclusion	Public engagement initiative using an unusual and engaging form of media.
Topics covered	1. A Stem Cell Story 2. Conversations: ethics, science, stem cells 3. Cell culture 4. Dolly and beyond
Headline	N/A

findings	
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	

Campaigns

Name of event/initiative	Cytoplasmic hybrid embryos campaign
Organising institution	Parkinson’s Disease Society
Date conducted	ongoing
Where report published [if any]	N/A
Web address [if any]	http://www.parkinsons.org.uk/about_us/campaigns/current_campaigns/hybrid_and_chimeric_embryos.aspx
Sample	N/A
Geographical scope	UK-Wide
Methodology	Public campaign
Depth of engagement	“The PDS is campaigning to ensure that the Bill [banning the use of hybrid and chimeric embryos in research] does not include provision to ban the creation of cytoplasmic hybrid embryos and to raise public awareness about the importance of this promising avenue of research for people with Parkinson’s. We will be taking opportunities to influence the Bill at all key stages through briefings, letters to Parliamentarians and media work and will prepare responses to relevant consultations in due course.

	If you would like to support the PDS campaign to ensure that this promising area of research can continue please contact us on campaigns@parkinsons.org.uk or call 020 7932 1325”
Rationale for inclusion / exclusion	Public engagement and campaign on issues directly relevant to stem cell research
Topics covered	Hybrid and chimeric embryo creation for stem cell research
Headline findings	N/A
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	

Web fora

Name of event/initiative	Summary report on the informal online discussion of the Department of Health’s review of the Human Fertilisation and Embryology Act 1990.
Organising institution	HFEA
Date conducted	16/08 – 25/11/05
Where report published [if any]	Progress Educational Trust website
Web address [if any]	http://www.progress.org.uk/Events/Downloads/discussion_report.pdf
Sample	“In total 3,442 individual visitors came to the discussion forum, making a total of 4,967 separate visits in all. The forum attracted 66 members to join, discussing 31

	different topics, and making 178 posts."
Geographical scope	UK-wide, open internationally also.
Methodology	Open online discussion forum, with moderation limited to offensive postings
Depth of engagement	Ongoing interaction and discussion over a period of three months, along with an opportunity to view the forum posts for a further two months.
Rationale for inclusion / exclusion	Interactive public engagement initiative run alongside the Department of Health consultation on a review of the HFE Act
Topics covered	The following issues were covered by separate fora: • *"Issues in pre-implantation genetic diagnosis (PGD): This forum was headed by this prompt from the facilitator: 'Who should make decisions around PGD for severe, life-limiting conditions with an onset in adulthood, such as Alzheimer's disease or certain cancers? How should we balance the views of affected families, who may have experienced living with these conditions with those of other groups?'"* • *"Welfare of children in assisted reproduction: This forum was headed by this prompt from the facilitator: 'What questions (if any) must we ask potential parents who need medical help to start their families? Should consideration of future children's 'need for a father' be required before fertility treatment can be given? Does this consideration prejudice single women and lesbian couples seeking to start a family, or is it central to the needs of future children?'"* • *"Embryo research: This forum was headed by a prompt posted by the facilitator: 'How should we best reflect the status of the embryo in legislation? What should showing appropriate respect to the embryo in research mean in practice? What are the main the issues for legislators around research using (for example) animal-human chimeras and hybrids?' The forum attracted three topics posted by participants, entitled 'Animal-human hybrid or chimera embryos', 'if we allow abortion why shouldn't we allow embryo research?' and 'Rights for non-existent beings' with 9 messages in response across all these topics.* • *Artificial gametes: This forum was headed by this prompt from the facilitator: 'Artificial gametes could enable people who are not currently regarded as 'infertile' per se, such as same sex couples and post menopausal women to have genetically-related children, but this may raise questions about what it is to be a parent, and who should have access to fertility treatments.' The forum attracted four topics posted by participants, variously entitled 'shortage of donated gametes more action needed', 'children for same sex couples?, 'The end of the menopause', ' Religious input into*

	formation of new law/public bioethics discussion', with 23 messages in response across all these topics. The most popular topic in the forum was 'Shortage of donated gametes' with 10 replies. • *The regulation of IVF and currently unlicensed fertility treatments: This forum was headed by a prompt posted by the facilitator: 'What should be the aim of the legislation and regulation of fertility treatments? Does IVF need special scrutiny and safeguards or should we now allow a lighter touch? Should unlicensed internet traders facilitating the supply of donated gametes become subject to the same regulation as licensed fertility clinics?' The forum attracted four topics posted by participants, entitled 'Issues on ISP (internet sperm suppliers)', 'Unlicensed fertility treatment', 'Should regulation reflect the majority opinion?', 'Cost of private fertility treatment- should regulator be empowered to set limits?' with 33 messages in response across all these topics.* • *'Saviour Siblings': This forum was headed by a prompt from the facilitator, with the question 'who should make decisions where families with a seriously ill child hope to conceive a 'saviour sibling'- a new brother or sister who could also make a potentially life-saving donation of stem cells?' The forum received 4 replies to the facilitator's prompt.* • *Open forum: The Open forum by its nature generated the most number of new topics created by respondents. The chance to initiate the topics for discussion and respond to the views of others in a public forum clearly proved popular with participants. The Open forum was headed by this prompt from the facilitator: 'The review of the 1990 Human Fertilisation and Embryology Act covers many important areas. Please feel free to start your own discussion here. Others are discussing: Sex selection/family balancing, older mothers, donor conceived people tracing relatives, single embryo transfer.' The forum attracted participants to begin 13 new topics with 58 response postings across the topics. Topic headings were: 'What is the point of this forum?', with eight responses, 'Abortion Reform' with six, 'Proposed reduction of number of embryo's to be tf' [tf meaning embryo transferral to the woman's womb in IVF treatment, with the hope of establishing pregnancy], with four responses, 'Welfare of the unborn child- Security and medical checks to determine whether a couple is fit to have fertility treatment' with two, 'Definition of Father- Effect of Marriage' with seven, 'The average infertile couple' with one, 'DC people finding their siblings' with three responses, '"A baby is a woman's right ... even if she is 50"', with two, 'Sex selection for non-medical reasons- How many births of one gender before*

	family balancing is allowed?' with three responses, 'spending money on research' with three, 'refused ivf treatment' with one, 'Amnesty for pre-1990 donors' with two, and 'Donor record-keeping by unlicensed sperm providers - Should internet sperm providers be made to preserve their records?' with three responses.
Headline findings	
Any issues that were seen as particularly controversial, of particular interest of the public or sparked significant debate	It should be noted that there was sustained criticism of the forum because it was run not by a neutral body, but by a campaigning organisation sympathetic to stem cell research.
Any issues that it will be important to consider in carrying out the public dialogue project	
Further notable challenges or issues	

Appendix 3: Excluded sources

Source	**Rationale for exclusion**
http://www.hgc.gov.uk/UploadDocs/DocPub/Document/Making%20Babies%20Report%20-%20final%20pdf.pdf	Related to reproduction, rather than stem cell research
http://www.peoplescienceandpolicy.com/projects/genetics_reproductive.php	Related to reproductive decision-making, rather than stem cell research
Global stem cell policy forum (http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC002446 p.1)	Global and focused on scientists not the public
http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC003440	Not aimed at the public
http://www.hfea.gov.uk/docs/Choices_and_boundaries_Report_2006.pdf	Discusses screening embryos, rather than stem cell research
http://www.isscr.org/public/index.htm	US focus
http://www.innogen.ac.uk/Research/The-Social-Dynamics-of-Public-Engagement-in-Stem-Cell-Research	Focused on the benefits of public engagement, not public engagement itself
http://www.innogen.ac.uk/Publications/Trust-brokers-and-confidence-builders-The-ambivalent-role-of-th	Focused on the benefits of public engagement, not public engagement itself
http://www.the-ba.net/NR/rdonlyres/78D32C57-EB15-4B8B-9386-57873788BD07/0/Strengthsofpublicdialogue.pdf	Focused on the benefits of public engagement, not public engagement itself
http://www.york.ac.uk/res/sci/projects/res340250003williams.htm	Not public engagement (although it will inform future public engagement work)
http://bbsrc.mondosearch.com/cgi-bin/MsmGo.exe?grab_id=0&EXTRA_ARG=&host_id=42&page_id=387&query=stem%20cell&hiword=CELLED%20STEMS%20CELLBASED%20CELLS%20stem%20cell%20	Consultation focused on the research community not the public
http://www.catholicunion.org.uk/page203.html	Speech to the Lords not the public, and five years old
http://www.regenmednetwork.com/	Meeting of scientists rather than the public

Appendix 4: Detailed methodology

Parameters of the review

In order to meet the key aims and objectives of the review a set of defined search parameters was agreed and adopted prior to the start of the research. The parameters agreed are as follows:

Overall focus	All stem cell-focused public engagement and information sharing events and initiatives of all types conducted in recent years. The desk research will focus particularly, but not exclusively, on public dialogue and engagement concerning the public's opinions and concerns about all forms of stem cell research including the use of hybrid / chimera and the perceived benefits and risks of these stem cell therapies. This is in accordance with the recommendations from the UK stem cell initiative report. We would also note any other issues raised that it will be important to consider in carrying out the public dialogue project, which begins in the autumn. The focus will be on reporting events and their findings. Events and initiatives will not be critiqued in terms of the benefit of such work or the approach used, although they will be set in context.
Scope	Events and initiatives conducted in or pertaining to the UK from 2002 onwards and those considered to be particularly significant to the study that were conducted pre-2002
Type of initiative	To include relevant media pieces, surveys, structured public engagement events, science festivals, lectures and any other initiatives identified during the search. This will include identifying unpublished reports and accounts identified through discussions with organisations and individuals identified below.
Initial sources of information (not exhaustive)	• Websites: MRC; BBSRC; ESRC; EPSRC; Juvenile diabetes research foundation; Wellcome Trust; Cancer Research UK; The Royal Society; BMA; Human Tissue authority; Alzheimer's society; HFEA; Parkinson's disease society of the UK; AMRC; Action Medical Research; Scottish Stem Cell network Ltd.; National institute for biological standards and control; BHF; The UK stem cell bank; Diabetes UK; Dept. of Health; Stem Cell PE Centre; Religious groups such as the Association of Catholic

	Doctors; Café Scientifique; Centre of the Cell; UK Clinical Research Collaboration; UK National Stem Cell Network, the International Society for Stem Cell Research; regional Stem Cell networks; UK Stem Cell Foundation; Alzheimer's Society; Academy of Medical Sciences; Council for Science and Innovation; HFEA • Other published sources: Select Committee report on stem cell research; Parliamentary debates that reference public engagement with constituents; BA festival lecture by Robert Winston from 2005; Newspaper public opinion polls and public attitude surveys; Academic and journal reports describing public engagement initiatives with stem cell research • Calls to specific individuals identified through discussion with the BBSRC and the MRC, including those who are attending the stakeholder workshop and those identified through the search of published documentation above.
Initial search terms (not exhaustive)	• Public engagement, dialogue, involvement, understanding, public opinion, opinion poll (separated using Boolean search term 'or' where appropriate) combined with (using Boolean term 'and'): • Stem cell, stem cell research, Alzheimer's (research), Parkinson's (research), hybrid, chimera, embryo, leukaemia, embryonic, umbilical, cord banks, MND, heart disease (separated using Boolean search term 'or' where appropriate)

Development of a search strategy

To ensure a rigorous, comprehensive review of current initiatives in public engagement we adopted the principles of systematic reviews set out by the EPPI-Centre.[69]

Our search strategy used mainly web searches, with some searches of key electronic (academic) databases. In addition, we searched for grey literature through key networks and drew on the knowledge of existing contacts. We searched for public engagement initiatives from the following sources:

- The websites of: MRC, BBSRC, ESRC, EPSRC, JDRF, BMA, Cancer Research UK, The Royal Society, HTA, Alzheimer's Society, Parkinson's Disease Society of the UK, Action Medical Research, Scottish Stem Cell Network Ltd, National Institute for Biological Standards and Control, BHF, The UK Stem Cell Bank, Diabetes UK, DH, DTI, Guild of Catholic Doctors, The Catholic Union, Independent Catholic News, The

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[69] http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=89

Linacre Centre for Healthcare Ethics, Café Scientifique, The UK Clinical Research Network, The UK National Stem Cell Network, East of England Stem Cell Network, North East England Stem Cell Institute, The International Society for Stem Cell Research, London Regenerative Medicine Network, Cambridge Stem Cell Initiative, The UK Stem Cell Foundation, Academy of Medical Sciences, Council for Science and Technology, Comment on Reproductive Ethics, Association for Science Education, The BA, DEMOS, Forum for the Future, nowgen, PEALS websites (using the search terms agreed with BBSRC and MRC as appropriate.)

- Hansard in last five years (using the keyword ‘stem cell/s’.)
- BBC, Guardian and Telegraph websites (using the keywords ‘stem cell/s’ and ‘opinion polls’)
- IngentaConnect (with keywords ‘stem cell public engagement’, ‘stem cell public opinion’.)[70]

In addition, we reviewed:

- The Wellcome Trusts ‘public engagement funded activities’ web pages
- HFEA ‘public consultations’ web pages
- AMRC webpage on stem cell research – ‘public opinion’ section
- Institute for Stem Cell Research ‘outreach’ pages
- Review of the UK Clinical Research Collaboration ‘Patients and Public’ web pages
- The Centre of the Cell website

The desk research focused particularly, but not exclusively, on public dialogue and engagement around: the ethical issues surrounding embryonic stem cell research; the use of animal experimentation; and the benefits and risks of stem cell therapies. This is in accordance with the recommendations from the UK stem cell initiative report. We also noted any other issues raised that it will be important to consider in carrying out the public dialogue project, which begins in the autumn.

Search terms used

In accordance with the principles of a systematic review we identified and agreed broad search terms that are of relevance to this work. Terms included:

- Public engagement, dialogue, involvement, understanding, public opinion, opinion poll (separated using Boolean search term ‘or’ where appropriate)

combined with (using Boolean term ‘and’):

- Stem cell, stem cell research, Alzheimer’s (research), Parkinson’s (research), hybrid, chimera, embryo, leukaemia, embryonic, umbilical, cord banks, MND, heart disease (separated using Boolean search term ‘or’ where appropriate)

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[70] No publicly available or subscriber-available articles were found. Due to time constraints and the wealth of information found through web searches, it would not have been an efficient use of resources to purchase the individual articles that were available.

Due to the fact that we found large number of sources of public engagement initiatives, it was not possible to use every search term on the website of every source. We therefore searched each website using search terms deemed appropriate for that site. For example, when searching newspapers and online media sites, our search focused on terms such as ‘public opinion’ and ‘opinion poll’, rather than ‘public involvement’.

Development of analytical framework

To guide the process of desk research and ensure that the most relevant initiatives were brought to the fore, we constructed and populated a framework that has simple inclusion criteria and used basic data collection templates to catalogue the initiatives reviewed. The use of data sheets also enabled quick and thorough analysis and synthesis of the initiatives in order to construct a systematic overview. Smaller scale initiatives, due to time constraints, have been synthesised under broad headings. In addition initiatives involving a considerable depth and extent of public engagement have been analysed and reported in some depth but due to a high overall number of initiatives, other initiatives have not been subjected to such extensive analysis.

The data collection templates were agreed as follows:

Name of event/initiative	
Organising institution	
Date conducted	
Where report published [if any]	
Web address [if any]	
Sample	
Geographical scope	
Methodology	
Depth of engagement	
Rationale for inclusion / exclusion	
Topics covered	
Headline findings	
Any issues that were seen as particularly controversial, of particular interest to the public or sparked significant debate	
Any issues that it will be	

important to consider in carrying out the public dialogue project	
Further notable challenges or issues	