



## **Stem Cell Public Dialogue**

### **Stakeholder workshop**

Report for the Biotechnology and Biological Sciences Research Council and the Medical Research Council

**July 2007**

working with you

to improve social results

**252B Gray's Inn Road, London WC1X 8XG**

tel: **020 7239 7800** fax: **020 7837 5800** email: [office@opm.co.uk](mailto:office@opm.co.uk) web: [www.opm.co.uk/default.htm](http://www.opm.co.uk/default.htm)

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## Summary

### Background

OPM conducted a stakeholder workshop in London on Thursday, 5 July 2007, as the second stage of a project commissioned by the Biotechnology and Biological Sciences Research Council (BBSRC) and the Medical Research Council (MRC). This project will inform a planned public dialogue project on stem cell research.

The aims of the stakeholder workshop were:

- to ensure that the public dialogue project is fully informed by and coordinated with relevant initiatives;
- to ensure that the project addresses, as far as possible, all stakeholder requirements.

The overall purpose of the workshop was to generate an understanding of:

- the concerns and interests of the various constituencies represented by the workshop participants;
- the issues that need to be communicated to these constituencies;
- the level of awareness such constituents have about the relevant issues.

One hundred and forty people were invited to attend the event. It was also advertised on the BBSRC and MRC websites. Forty-five people accepted the invitation and 36 attended, drawn from the following constituencies:

- science and clinical research
- consumer and patient groups
- social scientists
- funders
- policy-makers
- communication and education roles
- ethicists
- faith groups
- industry
- regulatory bodies
- 'other'

### Main findings

Five main objectives had been identified for the project and were discussed at the workshop. They were:

- Identify the range of views and concerns about the science and ethics of stem cell research amongst the wider public and their societal context

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

Participants agreed that these objectives covered all the important aspects of the project and did not identify any additional objectives. They thought that objective three, relating to raising public awareness, and five, relating to longer-term public dialogue work, were the most important of the five.

Participants felt that the public had a high awareness of stem cell research but little knowledge of specific issues or details. Issues identified as being of interest to the public included the following.

### **Stem cell therapies**

- The hope and potential for new therapies
- The timescale for development of stem cell therapies and their availability to those who might benefit from them: these are often longer than anticipated
- The conditions for which stem cell therapies will be of benefit
- The ethics of non-therapeutic uses of potential stem cell applications – for example, ‘anti-ageing’ treatments
- The economics of stem cell therapies, in particular, around the cost to the NHS
- The safety of stem cell therapies
  - One participant illustrated an area of potential public concern over safety with the example of a heightened risk of tumours in recipients of stem cell therapy.
  - A policy-maker felt that it was important to make the public aware of the safety procedures and frameworks that are in place.

### **Stem cell research**

- The risks and benefits of stem cell research
- The reasons for using embryonic, rather than adult stem cells in research
- The ethical debates surrounding embryonic stem cells, hybrid and chimera
- Possible alternatives to stem cell research
- The difference between research and therapeutic applications, including differences between research using animal subjects and research involving human subjects

## Regulation and legislation

- How is stem cell research regulated? What is future regulation likely to cover?
- The effects of different attitudes expressed through current legislation, in particular between the recent White Paper (December 2006), ruling out research with hybrids and chimera and the more recent draft Human Tissue and Embryos Bill (May 2007)

## Other issues

- The impact of global communication on perceptions of stem research and therapy in the UK, particularly in relation to health tourism
  - One scientist noted a high volume of public queries on this matter, and was keen to be able to provide more comprehensive advice and guidance on new treatments becoming available in countries such as China.
  - Other members of the group added here that the public would like to know from where and when they might be able to receive new treatments.
- The benefits to the pharmaceutical industry of stem cell research and therapies

## Outcomes of the public dialogue

In discussing the outcomes of the public dialogue, stakeholders raised the following points.

- It is important to express clearly the underlying aims and agenda of the work – in particular, whether the focus is on promoting the value of stem cell research or seeking simply to ‘educate and inform’.
- One must make a distinction between seeking to achieve a consensus and recognising the plurality of views. Each of these approaches can be problematic in its own way.
- The public dialogue process should be transparent throughout.
- Scientists wanted information on any possible impact the findings of the public dialogue might have on their research.
- The role of the public dialogue in promoting stem cell research in the UK needs to be clarified.

## Stakeholder groups

In addition to the stakeholder groups represented at the workshop, a number of others were also identified:

- NHS
- patients with experience of particular medical conditions (personally or within their family)
- public without direct personal experience of such conditions, including young people

- genetic counsellors
- Science Media Centre
- science correspondents
- humanists

Participants were keen to emphasise the role of the media as communicators of research findings and stakeholders.

## **The interests of different constituencies**

Of the concerns and interests that were identified, many were held in common across stakeholder groups and coincided with the issues identified as being of interest to the wider public, listed above.

Scientists were most likely to raise concerns not mentioned by other stakeholders, such as: the relationship of public dialogue to their research; the attitudes of colleagues towards scientists who take part in public dialogue; and worries about interest groups targeting them because of their involvement in public dialogue.

## **Scientists and public dialogue**

The scientific community is diverse in composition and attitude towards public dialogue. Involving both young PhD students and experienced researchers who support public engagement is seen as important to the project as a whole and, more generally, to the scientific community. Scientists are generally receptive to public views about their research and, if asked, are often able to give examples of how dialogue with the public has affected their work. However, people also believe that scientists are under-informed about the range of public views and likely to dismiss concerns they see as being 'illogical'. The public dialogue should offer opportunities for direct conversations between scientists and publics, rather than relying solely on consultants and paper-based information.

# 1. Introduction

OPM conducted a stakeholder workshop in London on Thursday, 5 July 2007, as the second stage of a project commissioned by the Biotechnology and Biological Sciences Research Council (BBSRC) and the Medical Research Council (MRC). This project will inform a planned public dialogue project on stem cell research. The first stage involved a systematic review of past and ongoing public engagement initiatives related to stem cell research. Stakeholders received a copy of the report of this research in advance of the workshop, to give them an opportunity to comment and to highlight additional initiatives not identified in the review.

## Aims and purpose of the stakeholder workshop

The aims of the stakeholder workshop were:

- to ensure that the public dialogue project is fully informed by and coordinated with relevant initiatives;
- to ensure that, as far as possible, the project addresses all stakeholder requirements.

The overall purpose of the stakeholder workshop was to generate an understanding of:

- the concerns and interests of the various constituencies represented by the workshop participants;
- the issues that need to be communicated to these constituencies;
- the level of awareness such constituents have about the relevant issues.

## Participating stakeholders

One hundred and forty people were invited to the event. It was also advertised on the BBSRC and MRC websites. Forty-five people accepted the invitation and 36 attended, drawn from the following constituencies:

- science and clinical research
- communication and education roles
- consumer and patient groups
- ethicists
- social scientists
- faith groups
- funders
- industry
- policy-makers
- regulatory bodies
- 'other'

## Workshop structure

The event was divided into two sessions. In the **morning session**, representatives from BBSRC and MRC gave an overview of the project and OPM presented the key findings from the literature review. Participants then split into four groups to discuss the objectives and intended outcomes of the public dialogue project, including whether there should be any additional objectives. A representative from Sciencewise, which is funding the public dialogue project, provided a brief overview of public dialogue as a process and of the remit and role of Sciencewise, which sits within the new Department of Innovation, Universities and Skills.

In the **afternoon session**, participants worked in four groups to discuss three areas which relate broadly to the five objectives of the public dialogue project. They had been asked in advance of the workshop which of these areas they would prefer to discuss.

- Public interest in/attitudes to the science and ethics of stem cell research (two groups)
- Public awareness of scientific research on stem cells (one group)
- Scientists' appreciation of public attitudes towards stem cell research (one group)

The purpose of this session was to:

- deepen the morning discussions on content to be addressed in the public dialogue;
- gather participants' informed views on the scope and nature of issues falling within each of the areas above; and
- identify shared views and main points of contention within each of the three areas.

Following these focused discussions, BBSRC outlined what actions would be taken in response to the workshop findings and took questions about the public dialogue project as a whole.

## How this report is organised

Section 2 looks at participants' responses to the project objectives. Section 3 draws on both the morning and afternoon sessions, and focuses on the desired outcomes of the public dialogue, the content to be addressed and the stakeholders who should be involved. In Section 4, we look at the three broad objective areas addressed in the afternoon session. The concluding section highlights some of the recurrent themes and views over the course of the day.

The Appendix includes:

- The workshop agenda
- Copies of presentations given by Sciencewise, BBSRC and OPM

## 2. Response to the project objectives

This section outlines the morning discussion on the stated objectives of the public dialogue. These are as follows:

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

Participants focused on two areas for discussion:

- Whether the set of objectives cover all important aspects of the forthcoming stem cell public dialogue project
- Discussing and clarifying each objective in turn

### Initial discussions

Before focusing on the specific objectives, participants raised a number of general issues in relation to the public dialogue. These included:

- The need to build on and learn from previous public dialogue on stem cell research
- Ensuring dialogue is sufficiently flexible, in process and content, to accommodate emerging scientific findings, therapeutic applications and public aspirations and concerns
- Ensuring that the scope and focus of the project addressed the issues identified by the public as important, rather than reflecting the agenda of any particular stakeholder group

*'... there is a difference between what scientists think we need to know and what we [the public] want to know.'*

- Acknowledging that science does not speak with a single voice and that debate and uncertainty within the scientific community are usual and healthy

- Striving for transparency, if not neutrality, in the underlying aims, agenda, content and process of the dialogue and in the interpretation, analysis and presentation of findings
- Ensuring not only that the public are confident that their views will be heard and taken into account
- Achieving a balance between informing and educating and engaging in dialogue
- Designing materials that are accessible, rather than overly technical and scientific
- Recognising the impact a particular 'lens' can have on the attitudes of participants: for example, starting with a focus on the current and potential therapeutic benefits of stem cell research might generate greater public acceptance of research methods, including use of embryonic stem cells, that starting with a focus on the research itself.

*'People do feel differently (about different types of research], but if you point out what you can achieve they feel less concerned about how you get there.'*

- Ensuring relevant distinctions are made, including those between embryonic and adult stem cells, and hybrids and chimera and between research involving animals and human clinical trials

*'People who don't like embryonic stem cell research support adult stem cell research'.*

- Paying attention to the language used in the dialogue and its impact on attitudes and perceptions. A consumer group representative used the example of the phrase 'spare embryo' to illustrate what a patient group representative saw as unacceptable language.
- Acknowledging the role of the media in informing public attitudes towards stem cell research
- Deciding whether and how the public dialogue should include a global perspective on stem cell research, in particular, the impact of global communications on the UK public's expectations of what treatments should be available in the UK and the rising incidence of health tourism.
- Considering the dynamic relationship between scientific developments and public dialogue and asking: which informs which - or is the process mutual?

## **Focused discussion on the project objectives**

Participants agreed that the objectives covered all the important aspects of the project and they did not identify any additional objectives. They saw objectives three, relating to raising public awareness, and five, relating to longer-term public dialogue work, as the most important. The rest of this section looks at some of the discussions about each of the five objectives.

### **Objective 1: Identify the range of views and concerns about the science and ethics of stem cell research amongst the wider public and their societal context**

Participants felt it was important, when identifying the range of public views and concerns, not to anticipate people's interests or assume that these would lie in a particular area. They also thought it was crucial to ensure the dialogue was sufficiently flexible to allow the public to raise issues and shape the debate. Some participants argued that the public should drive the process itself, as well as the content.

*'Are you actually going to go to the public and ask what they want to know? ... Sometimes we just assume this.'*

There was some debate about the viability of the distinction between ethical and scientific issues and their societal context. One participant saw this as artificial, arguing that it was not possible to address ethical questions in the absence of knowledge about the scientific and social context. During a broader discussion of the societal context of stem cell science and ethics, participants felt that it was important to take into consideration the attitudes of different social groups.

### **Objective 2: Include scientists and other stakeholders and investigate their views about stem cell research and the related social and ethical issues, involving key organisations such as the UK National Stem Cell Network and the UK Stem Cell Communications Coalition**

Discussion of this objective focused on the definition of a 'stakeholder', and the range of stakeholders that should be included in the public dialogue. People thought that the media were crucial stakeholders, and believed it was essential both to consult the media as part of the public dialogue process and to inform them of the findings. It was particularly important to involve tabloid journalists. Participants acknowledged that involving the media was not always easy to do, but reiterated its importance throughout the day. (For further discussion of the role of the media as stakeholders, see page 12.)

One group drew up a list of stakeholders that they felt should be included in the project. It included the following:

- Regulators
- Funding bodies
- NHS
- Patients with experience of particular medical conditions (personally or within their family), patient groups
- Members of the public without direct personal experience of such conditions, including young people.
- Clinicians, researchers, genetic counsellors
- Science media centres
- Science correspondents
- Faith groups
- Humanists

In addition to 'interested' stakeholders, participants emphasised the importance of involving a broad cross-section of the public in the dialogue. They argued that this cross-section should be made both within and across gender, age and religious groups (among

others), reflecting the impossibility of taking the views of a particular individual as representative of the views of the group with which they may be identified.

### **Objective 3: Raise public awareness about the potential opportunities, challenges and uncertainties of stem cell research**

All groups strongly supported this objective. In discussion, participants focused on the need to convey the complexity of the types, methods and outcomes of research. Current public debate was characterised as *'unbalanced and alarmist'*, and as reducing stem cell research to *'killing human embryos'*. One participant suggested that balance might be introduced through a reliable series of trusted publications:

*'...the public needed to be supported by publications from a group that they know and trust.'*<sup>1</sup>

Focusing on the use of the word 'potential', one participant noted that *'where projects are long term you can't be definite about what the end outcomes are'*. This situated discussions around potential within the wider context of discussions of uncertainty. Participants felt it was important to include discussions of uncertainty within the public dialogue but noted that it was very challenging to do so effectively.

People felt that you need a flexible and ongoing process to keeping the public abreast of developments in stem cell research. This helps to ensure that new developments do not appear to come 'out of the blue' – as was the case with the hybrid/chimera debate, one participant suggested. You also need to be clear about the nature and variety of the research. They also thought that focusing on embryonic stem cell research tended to obscure this variety and restrict public attention to one particular field and the issues it encompasses.

An industry representative suggested that the public dialogue should be used as an opportunity to persuade, rather than simply engage the public, offering an opportunity to emphasise the potential applications of research and benefits to UK jobs and industry, which was its *'major selling point'*. Another participant gave the example of a recent successful stem cell public engagement in California, where communicating the economic benefits was a lead objective. The participant felt that *'we need to communicate that the UK is a good place to conduct stem cell research'* and the UK needs to set out *'clear aims and position itself in the global context.'*

Other participants argued that corporate gain and the economic benefits of the research should not be discussed at all in a dialogue with the public, since this would cloud the moral and ethical issues that need to be debated and discussed. Nonetheless, several participants felt it was important not to obscure the economic benefits to the UK of stem cell research.

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<sup>1</sup> No indication was given of who or what this group might be.

**Objective 4: Raise awareness among the scientific community, Research Councils and policy makers about the views and concerns of the wider public relating to stem cell research, and of the importance of dialogue**

There was little direct discussion of this objective in the morning groups. It was discussed in more depth by the afternoon group looking at scientists' appreciation and awareness of public attitudes towards stem cell research (reported in section 4, pp 22 onwards).

One participant recommended including science teachers within the group whose awareness of public views and concerns might be raised. Doing so would have a beneficial effect on teaching about stem cell research in schools. An example was given of how public dialogue has worked effectively with school students, through the work of a touring theatre in Scotland that presents a play about stem cell research to 14-16 year olds and another scheme where scientists give talks to younger pupils aged 11-12.

**Objective 5: Inform the development of a plan for a longer-term project of public dialogue and engagement around stem cell research**

There was general agreement across all groups that this was one of the most important objectives. Discussions raised many of the same issues discussed in relation to objective 3, including the need for the dialogue to be ongoing and flexible, taking on new and unexpected issues as they arise. Part of the rationale behind this was to protect research funding. People thought that, given that much stem cell research is publicly funded, negative public responses to unanticipated media reports had the potential to stem the flow of funding.

## 3. The public dialogue

### Outcomes

In discussing the outcomes of the public dialogue, stakeholders raised the following points:

- The underlying aims and agenda of the work need to be clearly expressed – in particular, whether the focus is on promoting the value of stem cell research or seeking simply to ‘educate and inform’
- One must make a distinction between seeking to achieve a consensus and recognising the plurality of views. Each of these approaches can be problematic in its own way.
- The public dialogue process should be transparent throughout
- Scientists in particular wanted information on any possible impact the findings of the public dialogue might have on their research
- The role of the public dialogue in promoting stem cell research in the UK needs to be clarified

### Discussion

#### Aims and agenda

Participants emphasised how important it was to express clearly the aims and agenda underlying the public dialogue. They discussed the difference between adopting a deficit model -- aimed at educating and informing the public, a model whose primary aim was to persuade the public of the benefits of stem cell research -- and a dialogic approach -- in which the views, aspirations and concerns of the public would be acknowledged as valid and information provided as a means of deepening dialogue rather than persuading agreement.

#### Consensus or diversity?

The difference between a dialogue that aimed at consensus and one aiming at reflecting the diversity of views was also highlighted. An industry representative suggested that the project should aim to *‘promote the UK as a centre of excellence for stem cell research’*. Others felt that it would be more appropriate for the project to increase understanding of the debate without seeking such a consensus. Both consensus and plurality had their dangers. They argued that consensus against stem cell research had the potential to cause *‘irreparable damage to the field’*, whilst a plurality of moralities runs the risk of *‘removing ethical safeguards, which could lead to exploitation.’*

#### Transparency

Several participants emphasized the importance of transparency around the intended outcomes of the public dialogue. They expressed the concern that the research councils’

agenda may already have been set, with the aim of persuading the public, rather than engaging them. If this were the case, one representative of a funding body suggested, it would be disingenuous to call the planned work a 'public dialogue' project.

One participant suggested that transparency about the outcomes of the research should include clarifying whether the intention of the project was to raise public awareness of stem cell research or to put in place a framework for future work on raising public awareness.

### **The impact on research**

Scientists focused on the impact of the outcomes on their own research and whether it would demand a response from them. Underlying this was a concern that they should be able to continue stem cell research '*unfettered*' by the findings of the project.

## **Content of public dialogue**

As well as looking at the outcomes that should come out of the public dialogue, stakeholders discussed the issues that should be covered during the process. These included:

- the research process, from laboratory, through to clinical trials, including the timescales between research findings and therapeutic applications
- the risk and uncertainty attached to stem cell research
- the potential benefits of stem cell research.

Scientists and industry representatives identified the following as important messages to convey to the public:

- The robustness of the UK regulatory framework and its status as a global benchmark and model for regulation in other countries
- The diversity of perspectives included within regulatory bodies, including faith groups and bio-ethicists
- The relationship between the risks and benefits of stem cell research
- The specific research value of embryonic stem cells.

### **The research process**

Throughout the day, participants raised the issue of a mismatch between the speed at which stem cell research takes place and public perceptions of the rapidity with which research translates into treatments. They felt that this was an important issue to addressing over the course of the public dialogue. One reason given for emphasising this was the possibility that heightened expectations over imminent stem cell therapies would lead people to refuse other forms of treatment, waiting instead for a '*miracle cure*.' One

participant felt that a *'drip feed of information'* would help to keep the public aware and help to control their expectations.

A further point was raised in relation to this mismatch between public perceptions of the imminence of stem cell therapies and the real time of the research process. Discussions about the science of stem cell research were seen as being *'out of kilter'* with public acceptance, and moving too fast even for scientists.

### **Risk and uncertainty**

The issue of uncertainty had been raised, tangentially, in a discussion of the debates that take place within the scientific research community. This discussion explored the importance of communicating that there is often uncertainty over translating research findings into therapeutic applications. A representative of a funding body emphasised that scientists are themselves frequently uncertain about the direction in which their research might head and that this issue needed to be included within the public dialogue.

It was also important to communicate the risk attached to clinical trials. One participant suggested that doing so was as much to reassure scientists that risk is a reasonable – and unavoidable -- part of their work, as it was to inform the public. The reasoning behind this discussion was, as with uncertainty, that if publics are aware of how clinical trials work and their purpose, they are more able to put into context those occasions on which clinical trials go wrong, with subjects experiencing negative side-effects.

Discussion of the research process should also include, participants suggested, information on scientific accountability and the checks and balances in place to ensure this. This topic has close connections with the discussions on regulation.

### **Benefits of stem cell research**

Some participants felt that communicating the potential outcomes of stem cell research was more important than discussing the process of research (i.e. the use of chimeras or embryonic versus adult stem cells):

*'People do feel differently [about different types of research], but if you point out what they can achieve they feel less concerned with how you get there.'*

Whichever approach was adopted, however, people thought it was important to acknowledge the difference between public dialogue focused on the methods of research and public dialogue focused on the benefits.

## **The public dialogue process**

The primary concern of the stakeholder workshop was to address the content of the planned public dialogue, rather than its process. However, many participants contributed views on and questions about process and we have summarised these in this section.

### **Relationship between content and process**

Some of the issues raised concerned the relationship between the content to be covered and the process designed to address that content. In discussing a project that, for example, focused on the different stages and types of stem cell research, participants felt

that discussions on these different themes would take different forms and could, if not adequately structured through the process, lead to confusion amongst the public. A possible solution suggested was to organise the public dialogue around specific subject areas, so that distinct topics and issues could be covered separately.

### **Dialogue is a two-way process**

Several social scientists and a representative of a funding body argued that dialogue was a two-way process. The project should both raise awareness amongst the public and provide opportunities for the public to communicate their views to scientists and shape the debate. As noted earlier, this should extend to public input into the issues that would be covered over the course of the project, with the use of pre-determined ethical and scientific categories (adult, embryonic etc) being seen as inappropriate.

### **Power dynamics**

In addition to this focus on the initial set-up of the public dialogue content, participants emphasised the need to be aware of the power dynamics involved. These are clearly complex, and of concern both to the publics involved in the dialogue and to the scientists who, as we have seen, have some concerns about the impact of the findings on their research. It is crucial to manage the expectations of participants in the public dialogue and inform them clearly about the processes by which their views will inform decision-making – including the nature of those decisions.

### **Timing**

The timing of public dialogue, the different approaches appropriate to the stage of development of an issue, particularly in relation to policy decisions, and the relative value of upstream and downstream engagement have received considerable attention recently. Workshop participants emphasised the importance of taking into consideration the timing of this dialogue in relation to developing scientific knowledge and the wider policy context. One participant felt that it was premature to engage with the public at this stage, since the full benefits of stem cell research are not yet clear. Others saw public engagement as an integral part of the scientific process as a whole, with effective dialogue not only contributing to public awareness of the issues involved in stem cell research but also minimising scientists' concerns about negative public views, which can affect their own attitudes towards their research.

### **Stakeholders**

We have noted earlier that some participants identified a range of different stakeholders to be included in the public dialogue. In general, participants felt that the project should involve as wide a range of views as possible but emphasised the importance of openness with respect to the interests and agenda that might inform views. Whilst the possibility of neutrality was debated, participants were clear that transparency was essential.

The media and scientists were two stakeholder groups whose involvement was discussed in detail.

## The media

Participants acknowledged that the media does not comprise a single unified group, but ranges from tabloid science correspondents to writers on dedicated scientific journals such as *Nature*. The mainstream media (such as daily and weekend newspapers) were seen as intermediaries between scientists and publics and, as such, critical to the formation of public views on stem cell research. A patient group representative suggested that the rise of internet news helped the public's intellectual journey, creating links between the general public and academic journal articles. People thought it was important to understand the media as a continuum, addressing different levels of interest and need. However, despite recognising this diversity, much of the criticism aimed at science journalists was expressed as criticism of 'the media', without qualification.

Many participants felt that the media was responsible for public awareness of and attitudes towards stem cell research. Coverage of the issues was seen as '*over-hyped*' and sensationalist in tone and language, and science journalists were accused of failing to understand the processes which precede clinical trials and therapeutic application and clinical trials and thereby fuelling unreasonable expectations around timescales. Media stories of research 'breakthroughs' elsewhere in the world can also raise expectations. These stories were seen as potentially very dangerous, as has been noted elsewhere in this report, since regulation of research and therapy may be less stringent in many countries.

A participant commented that the media '*missed the wider picture*'. Another gave an example of the human-animal chimera debate, suggesting that the media's failure to situate this within the context of a progression from previous research using animal-animal chimeras helped to exacerbate public concerns by suggesting it was a '*scientific first*'. In the absence of a wider perspective and understanding of scientific research as a methodical process, rather than a list of facts or discoveries, the value of 'failures' also goes unrecognised: '*even [research] failures can give us vital information*'.

People thought that concern over the presentation of stem cell research was affecting scientists' willingness to communicate their research findings. A patient group representative gave an example of the *Daily Mail* publishing an inaccurate article with the headline 'A Cure for Alzheimer's', as a result of which the Alzheimer's Society was inundated with callers offering to take part in clinical trials. One scientist noted that, in addition to concern over how research might be presented, the attitudes of colleagues were also important and many scientists are seen as taking a disparaging view of communication with the media.

The public dialogue was seen as an opportunity to start addressing some of these issues, by including media as stakeholders in a two-way process. Science correspondents and their respective organisations should be kept well-informed about the current state of research so they are able to convey this information to their readers. In addition, a scientist noted that the project should seek the expertise of the media in understanding '*the public's intellectual journey and how they are informed about scientific developments*'.

## Scientists

We discuss the attitudes across the scientific community towards public dialogue and its perceived value to them in more detail in a later section (section 4. 22). They were seen as a crucial stakeholder group and integral to the overall success of this project. One of

the most important points raised in discussion of their involvement as stakeholders was the diversity of the community. 'Scientists', as a group, can include: consultants; social scientists; those directly engaged in research; people working in industry and academia, for scientific institutions and in charitable organisations such as The Alzheimer's Society. Amongst those directly engaged in research, a social scientist noted that there are likely to be a variety of perspectives, knowledge and attitudes to public debate and these should be reflected during the public dialogue.

A science communicator raised one concern in relation to the involvement of scientists in public dialogue processes. Their experience of this in the past was that initial interest and enthusiasm tended to lapse and many dropped out of the process before its completion. The reason given was scientists' concern that they were not well informed enough to give opinions. This highlights the importance of thorough and sympathetic briefing for scientists, who may be uncertain about the role they are being asked to play and the expectations being placed upon them.

More generally, participants noted that social scientists have done a lot of work on public dialogue in general, public dialogue on science and on stem cell research in particular and those running this project should be aware of this work.

## 4. The three objective areas

The afternoon session focused on three objective areas, broadly related to the five objectives of the public dialogue project. These areas are:

- Public interest in and attitudes to the science and ethics of stem cell research (two groups)
- Public awareness of scientific research on stem cells (one group)
- Scientists' appreciation of public attitudes towards stem cell research (one group)

A number of themes emerged across two or more of these objective areas and we begin this section by outlining these themes. The first is the role of the media in informing the public about stem cell research. Rather than repeat what has been discussed earlier in the report, readers are referred to p12, above.

### Objective area 1: Public interest in and attitudes to the science and ethics of stem cell research

Two groups addressed this issue. Participants were drawn from:

- the scientific community (4);
- policy-makers (2);
- ethicists (1);
- religious groups (1);
- public engagement and communications (1);
- industry (2);
- regulatory body (2);
- consumer/patient groups (4)

### Interests and concerns specific to constituency groups

There was a high level of consensus on the issues discussed under this heading and few conflicting interests between participants' respective constituencies. One participant suggested that the interests of the different constituencies were likely to be coincident, with any differences in view arising from individual's personal ethical and philosophical positions rather than from their 'constituency' perspective.

In one group, most participants argued that once the benefits of stem cell research become evident and widely known, it would be difficult for any interest group to be opposed to it. However, a participant from a group representing the interests of Christian doctors countered this point, stating that *'even if the science moved forward some people will still be against it.'* This participant's concern was that the debate as a whole was being conducted at a level which alienates their constituents, leaving them feeling that there is no longer any space in the discussion for faith-based or moral argument.

Asked about the specific interests of their constituency groups, participants identified the following.<sup>2</sup>

<b>Constituency</b>	<b>Concerns and interests raised</b>
Scientists and clinical researchers	<p>Interests:</p> <ul style="list-style-type: none"> <li>• Gaining public support for their work and working in a strong regulatory environment that will help to engender this support.</li> <li>• That the expertise of the media is used to help scientists understand how to inform the public.</li> <li>• To explain why it is sometimes necessary to use embryonic stem cells rather than adult stem cells in research.</li> </ul> <p>Concerns:</p> <ul style="list-style-type: none"> <li>• That engagement with the public (and particularly the media) may be viewed disparagingly by other scientists.</li> <li>• That being associated with stem cell research may lead to a scientist being targeted by interest groups, in a similar way to those associated with animal testing.</li> <li>• To ensure that the uncertainty and risk associated with their research is effectively conveyed, so that the public have realistic expectations of scientists.</li> <li>• That public perceptions of rapid progress in this field raise unreasonable expectations.</li> <li>• Research 'failures' leading to loss of public interest and restrictions of funding (an issue also raised by public engagement practitioners)</li> </ul>
Science communication and education groups	<p>Interests:</p> <ul style="list-style-type: none"> <li>• Counteracting a simplified view of the science through working with the media and talking directly to the public.</li> <li>• That the media be better informed about stem cell research.</li> <li>• That scientists communicate their research findings more effectively</li> <li>• The scientists' interest in public engagement projects doesn't</li> </ul>

<sup>2</sup> In some cases the interests were expressed by one participant on behalf of another constituency. For example science communicators expressed a number of concerns on behalf of scientists. As such, while this is a valid record of the workshop discussions, constituency groups should have the opportunity to confirm or change these concerns.

	<p>wane .</p> <ul style="list-style-type: none"> <li>• Conveying the complexity of the types, methods and outcomes of research.</li> <li>• Engendering public trust through the use of a reliable series of trusted publications to disseminate information on stem cell research.</li> </ul> <p>Concerns:</p> <ul style="list-style-type: none"> <li>• To ensure that the public dialogue is transparent. Representatives felt strongly that the dialogue should be either neutral or be clear that it is not attempting to be so.</li> <li>• To reassure the public regarding the accountability of scientists.</li> </ul>
Consumer and patient groups	<p>Interests:</p> <ul style="list-style-type: none"> <li>• The development of therapies, and accurate information on this.</li> <li>• That information is available to the public about stem cell therapies (including those abroad) and how to access them.</li> </ul> <p>Concerns</p> <ul style="list-style-type: none"> <li>• To ensure that the timescales, risks and uncertainty of research are communicated effectively to the public to reduce the risk of public backlash and political pressure against stem cell research.</li> <li>• To ensure that the public dialogue is driven by and controlled by the public, rather than scientists or public engagement experts making decisions or assumptions on the public's behalf.</li> <li>• That the public as a whole do not have a sufficiently clear understanding of the science of stem cell research to develop a clear ethical position.</li> </ul>
Social scientists	<p>Interests:</p> <ul style="list-style-type: none"> <li>• To ensure that a cross-section of the public is involved in the dialogue.</li> <li>• To ensure that a cross-section of the scientific community is involved in the dialogue.</li> <li>• To ensure that the project relates to existing social science literature on science and society and public engagement in stem cell research.</li> </ul> <p>Concerns:</p> <ul style="list-style-type: none"> <li>• That the public dialogue takes note of issues and information</li> </ul>

	from abroad that affect UK public opinion.
Faith groups (note that only one representative was present; others had been invited but were unable to attend)	<p>Interests:</p> <ul style="list-style-type: none"> <li>• Clarifying the distinction between adult and embryonic stem cell research and exploring the possibilities of adult stem cell research.</li> <li>• Maintaining a voice in the debate despite suggestions of majority approval for stem cell research.</li> </ul> <p>Concerns:</p> <ul style="list-style-type: none"> <li>• Ethical concerns about the fundamental idea of embryonic research and the destruction of human embryos</li> <li>• That their views will not be heard because there is no space to debate or listen to faith-based convictions.</li> <li>• That conscientious objections to stem cell research or to the approach taken to it in education would be seen as unacceptable – this issue was raised in relation to teachers and doctors in particular</li> </ul>
Industry	<p>Interests:</p> <ul style="list-style-type: none"> <li>• Ensuring that the public dialogue will emphasise the benefits to the UK economy of being a leader in stem cell research.</li> <li>• Persuading the public of the benefits of stem cell research; less desire to be neutral than to be persuasive.</li> </ul>
Policy-makers and regulatory bodies	<p>Concerns:</p> <ul style="list-style-type: none"> <li>• To clarify that the regulatory framework in the UK is strong and effective and that this facilitates rather than prevents research.</li> </ul>

Some groups, for example funding bodies, are not represented in this table, because the interests and concerns that they expressed related to the project as a whole, rather than their specific constituencies' views. Some of the issues identified here were recurrent throughout the day and were raised in the wider context of general debate about the public dialogue project as a whole. We have discussed these elsewhere in the report.

### **Issues of interest to the wider public**

The information gathered at this workshop provides no basis for drawing a clear line between issues of interest to constituency groups and those of interest to the wider public. In part, this may be because participants do not remove their 'stakeholder lens' when identifying the issues that will awaken public interest. Their knowledge of the interests of their constituencies are likely to inform, to some extent, their ideas of what will interest

publics who have no direct engagement with stem cell research. In part, the interests of specific constituencies are, in any case, likely to overlap with those of the wider public. Hence, there is some crossover between the points outlined in the table above and those outlined below.

Public interest in stem cell research was seen as focused primarily on three main areas: therapies, the research process and regulation. Taking the recommendation of some participants in the workshop, who felt the dialogue process should allow the public to define their own interests and shape the debate in their own terms, we should note that these are not necessarily the issues which *will* be of interest or concern to the public.

### **Stem cell therapies**

- The hope and potential for new therapies
- The timescale for development of stem cell therapies and their availability to those who might benefit from them: these are often longer than anticipated
- The conditions for which stem cell therapies will be of benefit
- The ethics of non-therapeutic uses of potential stem cell applications – for example, ‘anti-ageing’ treatments
- The economics of stem cell therapies, in particular, around the cost to the NHS
- The safety of stem cell therapies
  - One participant illustrated an area of potential public concern over safety with the example of a heightened risk of tumours in recipients of stem cell therapy.
  - A policy-maker felt that it was important to make the public aware of the safety procedures and frameworks that are in place.

### **Stem cell research**

- The risks and benefits of stem cell research
- The reason for using embryonic, rather than adult stem cells in research
- The ethical debates surrounding embryonic stem cells, hybrid and chimera
- Possible alternatives to stem cell research – for example, gene therapies
- The difference between research and therapeutic applications, including differences between research using animal subjects and research involving human subjects

### **Regulation and legislation**

- How is stem cell research regulated? What is future regulation likely to cover?
- The effects of different attitudes expressed through current legislation, in particular between the recent White Paper (December 2006), ruling out research with hybrids and chimera and the more recent draft Human Tissue and Embryos Bill (May 2007)

## Other issues

- The impact of global communication on perceptions of stem research and therapy in the UK, particularly in relation to health tourism
  - One scientist noted a high volume of public queries on this matter, and was keen to be able to provide more comprehensive advice and guidance on new treatments becoming available in countries such as China.
  - Other members of the group added here that the public would like to know from where and when they might be able to receive new treatments.
- The benefits to the pharmaceutical industry of stem cell research and therapies

## Discussion

The distinction between ‘constituencies’ and the ‘wider public’ is not clearly drawn. One group noted that circumstance was a major factor in prompting people to take a closer interest in the issues, this being primarily the onset of a disease or condition that could potentially be improved by stem cell therapies. In this case, people’s first concern was likely to focus on how quickly treatments might become available and how they could be accessed.

The primary concern identified amongst the wider public related to the speed of developments in stem cell research. We have noted already that the participating scientists feel that the perception of stem cell research as fast moving is misplaced. In addition to – and possibly related to – the concern raised earlier about the potential for loss of public interest and of funding, if science ‘fails to deliver’, stakeholders suggested that the public may feel unable to keep abreast of developments and, as a consequence, see stem cell science as out of control.

Applications of stem cell research were seen as awakening most excitement amongst both constituency groups and the wider public group, but participants emphasised the need to differentiate between applications. Participants referred to the possibility of spinal cord repair being commercialised soon, but noted that treatments, such as cardiac repair and a cure for Parkinson’s disease, are still in the early stages of research. They urged caution too, particularly in relation to what they saw as less serious applications such as a cure for baldness or wrinkles. Perceptions of acceptable risk are likely to differ in these cases and the group felt it was important to clarify that there is always a risk something might go ‘*spectacularly wrong.*’

Some issues were debated. Opinions differed on the level of public interest in the ethical issues surrounding stem cell research and the reasons behind ethical concerns. A scientist felt that publics had limited interest in the ethics and, rather than being concerned by the debates around chimeras and hybrids, they were more interested in practical questions about funding or access to therapies.<sup>3</sup> One member representing Christians working in the medical profession challenged this point, arguing that their organisation dealt regularly with such questions. The majority view was that ethical concerns about

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<sup>3</sup> It is important to note, here, that the majority of the group might be expected to represent constituents broadly in favour of stem cell research. This finding would need to be confirmed or challenged through direct discussion with the public.

stem cell research have no single source. They may arise out of strong religious conviction, from philosophical principles or be a consequence of limited knowledge about the research. Some raising ethical questions may do so simply to prompt scientists to take note of the wider context surrounding their research.

A further area of debate surrounded the extent to which publics were interested in the '*finer details of research*'. Some participants felt that attitudes towards the use of animals as experimental subjects in stem cell research and animals as stem cell donors and that it was important for these distinctions to be made during the course of the public dialogue. Similarly, publics were felt to have different attitudes towards embryonic and adult stem cell research.

Funders and policy-makers involved in this discussion supported a general move to eliminate the over-simplification and sensational presentation of findings. The impact of the failure to communicate effectively some of the complexities around the research process and regulation was highlighted by the example given of a young British girl with autism. The girl had visited China, to see Dr Wang, regarded by one participant as having '*no evidence base supporting his trials*'. The unavailability in the UK of the treatment being offered in China generated strong interest amongst public and politicians and led to questions in Parliament. This discussion led, once more, to the role of the media in raising public awareness of stem cell research.

Others questioned public interest in the finer details of the research, feeling that broader questions about the safety and risks associated with stem cell research overall and general reassurance about the soundness of regulation were more pertinent.

## **Objective area 2: Public awareness of scientific research on stem cells**

One group addressed this issue. Participants were drawn from:

- the scientific community (2);
- consumer/patient groups (2); and,
- 'other' (2).

### **Public awareness of stem cell research**

Participants felt that whilst awareness of stem cell research was '*relatively high*', it was generally '*superficial*'. They thought that while members of the public were alert to existing therapies and the potential for new therapies, they lacked knowledge about the different types of stem cell research and, as noted elsewhere, about the speed at which research moves and is translated into applications.

Awareness, it was felt, was noticeably higher amongst specific public groups – in particular, amongst patient groups and individual suffering from specific conditions. People such as this were also seen as more sympathetic to the research itself. Extending this point to differences in attitude across age groups, a patient group representative suggested that younger people, who are likely to be healthier, have both lower awareness

of and interest in stem cell research than older people. This point was challenged by a scientist, who argued that a *'huge swathe'* of the UK public are healthy yet in favour of stem cell research and that it is important to develop a way of targeting and representing the views of this *'silent majority'*.

### **The nature of public awareness of stem cell research**

Whilst awareness of the potential applications of stem cell research was seen as relatively high, scientists in particular felt that the public lacks basic scientific knowledge about the nature of stem cells, their sources and the reasons for using embryonic stem cells in some research, rather than adult stem cells.

Awareness of regulation was also seen as high and there was some suggestion that the public see stem cell research as perhaps over-regulated, compared with other countries. This contrasted with the view that the public see the regulatory framework as too weak. A scientist emphasised this point, suggesting that the public do not understand the extent to which the regulatory framework in place in the UK covers issues of ownership and prohibits profit or personal gain from donations, as well as the research process itself.

### **Concerns over lack of public awareness**

Throughout this report, we have noted a number of issues about which participants felt the public should be better informed. In the following, we focus on additional issues raised in the discussion of this specific objective area.

A scientist identified a number of misconceptions relating to stem cell research. These included the effect of IVF drugs on patients and the view that stem cell research involves *'killing babies'*. Other participants suggested that such a view may be linked with the political and ethical motivations of particular individuals and interest groups. Citing a poll run by the Alzheimer's Society, a participant pointed to a lack of understanding about the nature and origin of hybrids.

The importance of language in communicating with the public about stem cell research was highlighted by this group. This issue was raised in relation to the description of embryos as *'spare'* when they are not needed for IVF treatment but could be donated for use in research. In more general discussions of embryo donation, it was seen as important to raise awareness of what *'informed consent'* meant in this context and how complex the information might need to be for a patient to be considered fully informed.

### **Messages about stem research to communicate to the public**

There is considerable cross-over in views on what interests the public (see page 16) and views on the issues about which the public should be informed. The following draws on the specific discussion around the second objective area as well as comments made over the course of the day. Suggestions included:

- The purpose of stem cell research and its outcomes: research may not lead to specific therapies in the short-term, but may contribute instead to scientific understanding and, potentially, to future therapeutic applications. A patient group representative

emphasised that their interest in stem cell research is to find specific cures in as short a timescale as possible.

- The position of the UK as a global leader in stem cell research, a position that needs to be maintained, not least because it brings great economic benefits
- Publics need to have a realistic view of the potential treatments to which stem cell research might lead in the future
- That dissent and disagreement amongst scientists is ‘a healthy and normal state of affairs’
  - This uncertainty was seen by a science communicator as something that particularly worries the public
- Information on regulation and the comparative strength of regulatory frameworks across different countries, in particular with relation to:
  - the risks that might be attached to health tourism
  - expectations raised by ‘breakthroughs’ in countries with less robust regulation of stem cell research
  - the impact of sound regulation on the availability of therapies in the UK
- Information on the conditions which might benefit from stem cell therapies
- Information on how to access stem cell therapies

It should be noted, however, that comments throughout the workshop suggest that many stakeholders would disagree with an attempt to prescribe what the public should know about stem cell research or to second guess the relationship between knowledge of the science and ethical concerns.

### **Objective area 3: Scientists’ appreciation and awareness of public attitudes towards stem cell research**

One group addressed this issue. Participants were drawn from:

- social scientists (2)
- funders (2)
- ethicists (1)
- policy-makers (1)
- the scientific community (1)
- public engagement and communications experts (2)

### **Why is it important for scientists to understand public attitudes?**

The initial focus of this discussion was the definition of ‘scientist’. Participants argued that the scientific community was diverse, encompassing a range of groups and interests and with differing levels of contact with the public. Including social scientists within the definition was seen as crucial.

A social scientist noted that attitudes amongst the scientific community towards public engagement in stem cell research were not uniform. Whilst some groups are enthusiastic about getting involved, others see it as poor use of their time and show little or no interest. One explanation for this was that some scientists see little value in public dialogue and those who do participate in projects fear losing credibility amongst their colleagues. This view was challenged through a distinction between communication – most often through the media – and engagement. Whilst media work is often frowned upon, a considered and focused engagement was seen as useful and as being supported by the scientific community. One participant argued that scientists depend on the public and therefore engaging them is central to a scientists' work.

A science communicator suggested a useful distinction between the value of public dialogue to individual scientists and the wider culture among scientists who do not recognise that value. The group felt that scientists faced competing pressures in relation to getting involved in public dialogue and saw a need for greater recognition of the issues they face when participating in engagement. Despite these pressures, one participant argued that, *'the culture of the institutional context of science is changing... because public engagement now has centre stage in the way science is done'*. This cultural shift was due in part to a new generation of younger scientists bringing more positive views to public engagement and beginning to assume positions of authority and power within their field. Nevertheless, the debate about whether public engagement is *'the type of work you should be spending your time on'* was still seen as a live one.

Younger scientists were, in general, seen as more supportive of public engagement, but there was some discussion over whether they would be more effective participants in public dialogue. One social scientist felt that younger scientists may be less eloquent, because they were less experienced. However, this view was countered by a science communicator, who noted that young scientists tend to be better trained, with more transferable skills. The group agreed that involving both young PhD students and senior scientists who are well versed in public engagement was the optimal solution. The group felt too that rather than *'protecting [scientists] with communication experts and consultants,'* dialogue should involve *'the core set of scientists who are actually working on stem cell research.'*

Participants thought that understanding of public attitudes was deepest amongst those whose day-to-day work brings them into contact with patients and their families. Earlier in the day, a patient group representative had emphasised the importance of 'educating the educators' and this point was referred to here by another patient group representative, who suggested that a majority of consultants who work with Alzheimer's sufferers know very little about stem cell research and so are unable to educate the public.

### **How will the dialogue affect public attitudes?**

In-depth, detailed and well-run public dialogue may be viewed as an effective way of increasing support for stem cell research. However, it should be noted that increasing public support was not addressed as the *purpose* of dialogue, being seen rather as a consequence of processes which lead to increased knowledge and understanding of the field and its current and potential applications. A scientist illustrated this point, arguing that evidence from polls and surveys suggests *'public resistance is mythical'*, and the planned current initiative *'doesn't need to and shouldn't aim to bolster support for stem cell research.'*

A science communicator suggested that public views are often different to and sometimes opposite to what is expected by politicians, suggesting that *'once [the public] understand the volume of findings that come from science they are in support of funding.'* However, this point was felt to apply only in the case of sustained dialogue. This point was supported by a research funder too, who suggested that public support for stem cell research *'rockets up once [the public] think they understand the science and the outcomes that may be achieved'*. Developing a more nuanced view of public attitudes was seen as beneficial to the scientific community, helping to dispel concerns about negative attitudes impacting on funding and providing a wider context for their research interests.

### **How the science community receives public views**

One science communicator suggested that many scientists are very responsive to public views of their work, though qualified this by noting that if public opinions and arguments are seen as illogical they are likely to be dismissed. *'Scientists are interested in public opinion...but have an uninformed view of this.'* The science community is not, however, a uniform group and differences in the reception of public views were noted. A representative of a funding body voiced the suspicion that *'dyed in the wool scientists'* were probably least open to public engagement and also likely to be most vocal. This suggests that a view of scientists as closed or resistant to public attitudes towards their work may be misplaced.

A social scientist said that scientists are often able to provide direct evidence of the impact on their work of public views. They might point, for example, to occasions on which their position has been challenged by the public and to a subsequent change in their views. Challenges were seen as arising both from other research findings or from one-to-one discussion with a member of the public. Both sources of challenge were seen as effective.

### **Messages about stem cell research that scientists should be communicating?<sup>4</sup>**

The issue of research timescales recurred in the discussion of the messages about the potential opportunities of stem cell research that scientists should be communicating. A social scientist noted the possibility of a *'real and disturbing impact on current therapy because of an impression that stem cell research will provide cures.'* This comment was made in the context of patients avoiding existing treatments, on the basis that stem cell research will deliver something more effective in the near future. However, a scientist argued that the science community should take some responsibility for raising public expectations, suggesting that scientists can be *'their own worst enemies'*, on occasions making promises that their research institutions cannot keep.

A social scientist suggested an alternative way of addressing the issue over which messages should be communicated was to look at public engagement as a dialogue. Rather than 'sending messages', scientists would engage in an exchange of ideas and views, a process seen as benefiting both the public and scientists themselves. Dialogue removes the burden on scientists to act as 'communicators' and provides a more rounded

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<sup>4</sup> Many of the messages that participants felt needed to be conveyed by scientists are covered elsewhere in this report. Where this discussion included additional details, these are noted in this section.

view of both public engagement and the way in which science now operates. The group as a whole supported this point.

Whilst public dialogue, rather than straightforward unilateral communication, was seen as beneficial, however, it was not seen as straightforward. A social scientist focused on the need to look for new and creative ways for promoting such dialogue and for all those involved to be clear about their respective roles and responsibilities during and towards the process. One participant said there were *'untapped opportunities for the joint production of science between scientists and the public'* and saw public dialogue as a means of *'open[ing] up the 'science question' not just on issues of regulation and ethics but also for how [science] might change and progress.'*

## 5. Conclusions

Over the course of the workshop, a number of common themes emerged. In addition, the different stakeholder groups had shared views of the importance of these themes to the public dialogue work. This brief conclusion highlights these themes.

### Content of public dialogue

- The research process, from laboratory to therapy, including time-scales involved
  - including use of animals and the value of pure research without identifiable therapeutic application
- Potential benefits of stem cell research
- Different types of stem cell research, different sources of cells and specific value of embryonic stem cells
- Ethical debates around stem cell research, including:
  - the research process
  - embryonic and adult stem cells, hybrids and chimera
  - non-therapeutic uses of potential stem cell applications – for example, ‘anti-ageing’ treatments
- The economics of stem cell research
  - the cost to the NHS
  - the value to the UK economy as a whole
- Possible alternatives to stem cell research
- Issues around safety, risk and uncertainty
- Regulation and legislation
  - including its impact on the availability in the UK of treatments being used elsewhere in the world
- The impact on the UK of global stem cell research and therapies
  - including health tourism
- The value of dissent and disagreement amongst scientists

### Outcomes of the public dialogue

- The underlying aims and agenda of the work need to be clearly expressed
- The distinction between seeking to achieve a consensus and recognising the plurality of views needs to be taken into consideration.
- The public dialogue process should be transparent throughout

- Scientists in particular wanted information on any possible impact the findings of the public dialogue might have on their research
- The role of the public dialogue in promoting stem cell research in the UK needs to be clarified

### **Process of public dialogue**

- The relationship between content and process should be considered
- Ensuring that dialogue is seen as a two-way process
- Power dynamics need to be taken into account
- The timing of the dialogue in relation to the current state of research needs to be considered
- The inter-relationships between scientific, social and ethical issues needs to be reflected in the dialogue
- The process should be sufficiently flexible to allow publics to shape its content and course

### **Stakeholders**

Stakeholders participating in the workshop were drawn from the following groups:

- science and clinical research
- communication and education roles
- consumer and patient groups
- ethicists
- social scientists
- a faith group;
- funders
- industry
- policy-makers
- regulatory bodies;
- 'other'

Additional stakeholders identified were

- NHS
- patients with experience of particular medical conditions (personally or within their family)
- public without direct personal experience of such conditions, including young people
- genetic counsellors
- Science Media Centre
- science correspondents
- humanists

Throughout the workshop, the role of the media in communicating to the public about stem cell research was emphasised and their involvement in the public dialogue was seen as essential.

## Appendix 1. Workshop Agenda

- 10.00 – 10.10 **Welcome and introduction (OPM)**
- 10.10 – 10.45 **Stem Cell Public Dialogue**  
Overview and background (BBSRC/MRC)
- 10.45 – 11.00 **Key findings from literature review**  
(Presentation)
- 11.00 – 11.15** *Coffee break*
- 11.15 – 12.00 **Stem cell public dialogue**  
Outcomes and issues (small group discussions)
- 12.00 – 12.15 **Feedback on key discussion points**  
(Plenary)
- 12.15 – 12.30 **OSI/Sciencewise presentation**
- 12.30 – 13.30** *Lunch*
- 13.30 – 14.45 **Objectives and issues**
- Public attitudes to science and ethics of stem cell research
  - Public awareness of scientific research on stem cells
  - Scientists' appreciation and awareness of public attitudes towards stem cell research
- 14.45 – 15.00** *Tea break*
- 15.00 – 15.45 **Feedback on key discussion points / review outcomes of public dialogue**  
(Plenary)
- 15.45 – 15.55 **Response from BBSRC/MRC**
- 15.55 – 16.00 **Closing remarks (OPM)**

## Appendix 2. OPM opening presentation

### Agenda

- Welcome and introductions – OPM
- Background to the project – MRC
- Key findings from literature review – OPM
- Outcomes and issues
- Presentation from Sciencewise
- Objectives and issues
- Response and next steps – BBSRC
- Close



### Objectives of public dialogue

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



## Appendix 3. Presentation on desk research

### Introduction and methodology

- **Overview of past and ongoing public engagement and communication projects relating to stem cell research.**
- **Aim to ensure that the forthcoming public dialogue project builds on existing work:**
  - Avoiding duplication
  - Focusing on issues of particular interest to the public
- **Systematic review**
  - Agreed search strategy and review parameters
  - Findings analysed and synthesised into report form



### Emerging themes of public attitudes, interest and concern (1)

- **Majority approval**
- **Objections vary according to type of research**
  - Destruction of embryos
  - Instinctive concern about chimeras
- **Sources of embryos**
- **Over-hyping research**



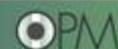
## Emerging themes of public attitudes, interest and concern (2)

- **Ensuring donor welfare**
- **Fatalism about regulatory control**
  - Pressures from abroad
- **Public feel insufficiently informed**



## Sources

- The websites of: Academy of Medical Sciences, Action Medical Research, Alzheimer's Society, AMRC, Association for Science Education, The BA, BBSRC, BHF, BMA, Café Scientifique, Cambridge Stem Cell Initiative, Cancer Research UK, The Catholic Union, The Centre of the Cell, Comment on Reproductive Ethics, Council for Science and Technology, DEMOS, DH, Diabetes UK, DTI, East of England Stem Cell Network, EPSRC, ESRC, Forum for the Future, Guild of Catholic Doctors, HFEA, HTA, Independent Catholic News, The Institute for Stem Cell Research, The International Society for Stem Cell Research, JDRF, The Linacre Centre for Healthcare Ethics, London Regenerative Medicine Network, MRC, National Institute for Biological Standards and Control, North East England Stem Cell Institute, nowgen, Parkinson's Disease Society of the UK, PEALS, The Royal Society, Scottish Stem Cell Network Ltd, The UK Clinical Research Collaboration, The UK Clinical Research Network, The UK National Stem Cell Network, The UK Stem Cell Bank, The UK Stem Cell Foundation, The Wellcome Trust
- Hansard
- BBC, Guardian and Telegraph websites



## Appendix 4. Sciencewise Presentation




### Sciencewise - DIUS



Alison Crowther, Dialogue Director  
Tel 020 7 690 1056 or 07749 657 665  
[Alison.crowther@aeat.co.uk](mailto:Alison.crowther@aeat.co.uk)

Beth Chesney-Evans, Programme Manager  
Tel 0870 190 6072 (DL)  
Fax 0870 190 6320  
[beth.chesney-evans@aeat.co.uk](mailto:beth.chesney-evans@aeat.co.uk)  
[www.sciencewise.org.uk](http://www.sciencewise.org.uk)

Responsible to Karen Folkes  
[Karen.Folkes@dti.gsi.gov.uk](mailto:Karen.Folkes@dti.gsi.gov.uk)



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### Sciencewise Explained

Sciencewise, helps policy makers ***commission and use public dialogue*** to inform *national decisions* and policy making in emerging areas of science and technology. Its core aim is to ***develop the capacity of Government to engage*** in successful two-way communication with the public, scientists and other stakeholders and to ***embed the principles of good dialogue*** into internal Government processes.



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## Projects

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10 projects so far:

- 6 are/were run from a grants scheme (Nanotechnology, Climate Change, Animal experimentation, IT security)
- 4 owned directly by central government departments agencies (*Drugsfutures*, *sciencehorizons*, Hybrid/Chimeras, Use of Forensic DNA) linked directly with policy formulation, now the only way of working

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## Focus - 3 areas

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- **Managing:** Hands on help for policy makers to identify, formulate, commission and manage S&T dialogue projects.
- **Capacity building:** Using current and past projects to produce guidelines and case studies which will enable other policy makers to learn quickly and seek the appropriate help
- **Embedding:** For there to be time in any policy making process for public dialogue there needs to be an overall strategy which gives the time and budget to allow it. This strand works strategically with senior civil servants and ministers to create that space

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## Good Practice - Guidelines

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- USP - Face to face dialogue between scientists and the public
- Direct link to decision-making processes on science or science research policy
- Processes designed and facilitated by professional dialogue practitioners
- Stakeholders are part of the process, often in the design - "Very Important Perspectives"

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## Good Practice - Guidelines (2)

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- Independent Evaluation process - preferably linked into the design process
- Reconvened groups - time to think and consider between meetings, discuss with neighbours and in the pub
- Appropriate groups - sometimes specialist - eg drug users, people with mental health issues
- Appropriate reach and publicity - internet, media etc
- Transparency - "where will my comments go?"

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## Results so far - Public Dialogue process

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- Publics, stakeholders and scientists very much enjoy and value the process. (10/12 would want to be involved again)
- Face to face discussions between scientists and small groups of the public creates lasting change
  - a) impact on how citizens see themselves and their role in society (unexpected)
  - b) impact on scientists - their part in society and the trust given to them (hoped for)
- Vastly more effective and efficient when owned by the policy maker

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## Results so far - Challenges

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- The media seem not to be interested in agreement/engagement, hampering efforts to engage widely
- Clarity that there is no one size fits all process - vastly different scopes, timeframes, technologies
- Lack of practitioners with sufficient experience and skill to deliver excellent dialogue on complex, potentially conflictual issues.
- Creating sufficient space and budget in the policy making process for upstream engagement to occur when it is most efficient and helpful to policy-makers

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## Appendix 5. BBSRC presentation

### How outputs from today will be used

- OPM will compile a report of the day, which will be available to participants on request and sent to all tendering contractors
- Desk research has already been sent to tendering contractors
- Oversight group members will also be given these reports



### Key dates

September 07 Appoint contractor

September/October 07 Oversight Group meets first time

October/November 07 Dialogue programme begins

October/November 08 Dialogue programme ends

December 08 Report launched



## Thank you!

We welcome on-going feedback and comments, to

**[sharon.fortune@bbsrc.ac.uk](mailto:sharon.fortune@bbsrc.ac.uk)**

If you wish to be kept informed of progress, please let us know.

