



## **An independent evaluation of the BBSRC and the MRC *Stem Cell Dialogue Project 2008***

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## Executive summary

### Introduction

The Biotechnology and Biological Sciences Research Council (BBSRC) and the Medical Research Council (MRC) announced in March 2007 that they would be undertaking an innovative public dialogue project examining the science, and the social and ethical issues, of stem cell research in the UK (BBSRC 2007). The project of activities, sponsored by Sciencewise, aimed to gain an insight into public concerns, views and attitudes towards stem cell research, as well as provide an opportunity for scientists to discuss with the public the challenges that researchers face and the potential benefits from this challenging field of research.

The incentive for conducting the *Stem Cell Public Dialogue* emerged out of the recommendations of the UK Stem Cell Initiative (UKSCI), published in November 2005 (UK Stem Cell Initiative 2005). The report acknowledges that it will be critical for the regulation of stem cell research to take into account attitudes by engaging the UK public in a dialogue on the ethical issues surrounding the sources and uses of embryonic stem cell lines, the use of animal experimentation in stem cell research, and the benefits and risks of stem cell therapies (UK Stem Cell Initiative 2005).

The British Market Research Bureau (BMRB) was commissioned in mid-2007 to design, develop and implement a UK-wide public dialogue on stem cell research. The BMRB was selected because of its in-depth understanding of scientific practices and regulation in the UK, and for its knowledge of the key issues and stakeholders in stem cell research.

The Institute for Science and Society (ISS) was approached by the BBSRC in June 2007 to submit a tender to undertake an independent evaluation of a stem cell dialogue project, according to the broad aims established by the BBSRC/MRC:

- To provide an independent, unbiased evaluation of the project, including assessment of impact and success
- To provide information on developing best practice in public dialogue projects that can be used in the future

We were informed on 16 August 2007 that our proposal was successful.

### A framework for evaluation

In spite of the proliferation of public dialogue and engagement activities in recent decades, little rigorous evaluation has been undertaken. A recent review of academic literature revealed a tendency for papers in this area to focus almost exclusively on the findings and their impact (Rowe and Frewer 2004). Analysis related to the suitability or efficacy of the methodologies employed or to the challenges faced or to different criteria for evaluation was largely overlooked.

In determining the *quality* of a public engagement exercise and its outputs, its level of *success* or *effectiveness* needs to be systematically and comprehensively assessed. To evaluate the quality of the *Stem Cell Public Dialogue* process, and to establish the benchmarks against which it will be evaluated, we begin with three different sets of criteria to provide a comprehensive and methodical assessment of its effectiveness: sponsors' criteria, normative criteria and participants' criteria.

The aims and objectives of the *Stem Cell Public Dialogue*, drawn from the project materials and from our in-depth interviews, provide an insight into the criteria by which the sponsors and the Oversight Group will measure the public dialogue's success or effectiveness.

Normative criteria developed by Rowe and Frewer (2000, 2004) have previously been adapted and used to evaluate a deliberative conference (Rowe et al. 2004) and, more recently, the UK-wide *GM Nation?* public debate (Rowe et al. 2005, Horlick-Jones et al. 2006). The criteria have also been developed recently by Horlick-Jones et al (2007a) in the context of their usefulness in evaluating previous dialogues. We have modified nine useful normative criteria from this literature to fit the particular circumstances of the *Stem Cell Public Dialogue*, including: the public dialogue should be inclusive of the spectrum of relevant views and participants should be broadly representative of the wider public (*representativeness*); the process should be independent and free from bias by sponsors, organisers, stakeholders, etc. (*independence*); public should be involved upstream of the innovation process before value positions become entrenched (*early involvement*); the outputs of the dialogue should have a genuine impact on policy (*policy influence*); the process and its modus operandi (especially with regard to how decisions were taken) should be transparent to those both internal and external to the process (*transparency*); participants should have access to sufficient resources (human, financial and material) to achieve their aims (*resource accessibility*); the roles and responsibilities of each of the participant groups should be (organisers, stakeholders, public etc.) unambiguous and well-defined (*task definition*); the process should encourage and enable effective and inclusive dialogue (*structured dialogue*); and the process should utilise sources of knowledge effectively (*translation quality*). In applying these, we engage with key debates on how they are to be interpreted and on how appropriate they are in particular contexts.

Participants' criteria are derived from the public participants' own evaluations of the strengths and weaknesses of specific elements of the process (Rowe et al. 2004, Horlick-Jones et al. 2006). The participants, depending on their motives for, and experience of, participation are likely to have different perceptions of what the public dialogue aims to achieve and the manner in which it should be judged. To elicit participants' own criteria for *effectiveness*, the questionnaires included a number of open-answer questions.

Using both qualitative and quantitative evaluation research methods, the evaluation utilised a multi-method approach combining participant questionnaires, ethnographic techniques including structured participant observation and in-depth interviews, media analysis, and documentary analysis of project materials and scoping documents commissioned by the BBSRC/MRC to inform the public dialogue. The evaluation's Internal Advisory Group was called upon regularly to reflect on both the conduct and the progress of the evaluation to ensure intellectual and methodological rigour.

The scope of our proposed evaluation was constrained by the scale of the budget and the number of person days expected to be devoted to the evaluation. This precluded a highly detailed evaluation exercise of the extent that would seem appropriate to the objectives set by the BBSRC and the MRC, especially with regard to longer-term impact. Nevertheless, within these financial, temporal and practical boundaries, we have conducted and delivered a rigorous evaluation that will make a valuable contribution to the growing literature in this area.

### **The *Stem Cell Public Dialogue***

BMRB developed a deliberative process that brought together members of the public with a range of experts including scientists, clinicians, social scientists and ethicists to discuss the science, ethics and governance of stem cell research. A total of fifteen one-day public dialogue workshops, three each in London, Bristol, Cardiff, Edinburgh and Newcastle, were held between mid-March and early June 2008.

A range of stimulus materials was used to inform the debate. BMRB, in partnership with the research councils and the Oversight Group, identified key issues and areas for discussion from the findings of desk research and a stakeholder workshop conducted by the Office for Public Management (OPM), and from telephone interviews with 49 stakeholders conducted by BMRB.

Discussion in each of the workshops was guided by a team of facilitators and prompted by a detailed topic guide. Workshop 1 provided an introduction to stem cells, and explored the participants' aspirations and concerns raised by the science and its clinical applications. Workshop 2 involved an in-depth discussion into the social and ethical issues related to the various sources of stem cells. Workshop 3 focused on the potential future applications of stem cells and the wider social implications of stem cell banks, therapies and clinical trials.

Two hundred public participants were recruited by BMRB to participate in the workshops. The demographic profile of the area in which each of the workshops was held was reflected by quotas set for age, socio-economic status and ethnicity. Attitudes to stem cells were also screened to ensure the sample was broadly reflective of the public attitudes profiled in the results of the BMRB omnibus survey.

## **Evaluation against the criteria**

### *Representativeness*

While the majority of respondents agreed 'there was a wide range of different attitudes towards stem cell research among the participants' our observation data suggest that in many workshops there was very little disagreement among the participants on most issues. Our observations and participants' responses to open-ended questions suggest that the perceived representativeness of the participants was not incontrovertible. Similar observations emerged from our interviews with the Oversight Group and Stakeholders where it was noted that participants in the London workshops held fairly different views on the issues surrounding stem cell research but that unfortunately some of the more contrary views dropped out after the first and second workshops resulting in more homogenised views.

### *Independence*

An Oversight Group of nineteen members was convened by to oversee the public dialogue. Its composition was designed to reflect a broad range of interests relating to stem cell research, with an emphasis on independent voices from universities, charities and public interest groups. However, notable absences in this mix included a clinician and a legal perspective.

The selection of expert speakers to reflect a diversity of expertise and opinions on the topic so as not to promote a particular view or agenda over other possibilities is another important determinant for independence. Practicably, this was not achievable in the individual workshops as only two experts were accommodated: one scientist or clinician and one social scientist or ethicist.

Our questionnaire data reveal that participants largely perceived that the dialogue process was free from signs of bias, presented a balanced range of expert views and was conducted in a way that ensured maximum independence from the sponsors and their agendas. Of those who called into question the dialogue's independence, this perceived bias was for them one of the 'least successful aspects' of the workshops.

Our observation data reveal a slightly different picture. BMRB's independence to the sponsors was not always made clear to the participants, which led some participants to confuse its representatives for research council representatives. Confusion about the relationship between BMRB and the sponsors was further compounded by participants' uncertainty regarding how the agenda for the public dialogue was set and by whom. It was apparent that while some participants understood that BMRB was running the workshops, the sponsors were behind the scenes pulling the strings.

### *Early Involvement*

It is difficult to evaluate the dialogue's effectiveness in terms of early involvement as the results of the report have not yet had sufficient time to feed into the policy process of either the research councils or the government. The intended link between the *Stem Cell Public Dialogue* process and government policy was not clearly defined either in the dialogue's objectives or in the welcome speech to participants.

Responses to our questionnaires indicate that while most participants agreed that the public dialogue took place early enough to influence policy a significant number were sceptical of the appropriateness of the timing for it to have a genuine influence on policy and future research in this area. The dialogue's potential impact on future research was even more equivocal.

### *Policy influence*

In the workshops, policy influence was generally discussed in terms of how the public dialogue would enable research councils to understand the public's views on which areas of stem cell research to prioritise. The ways in which government policy-makers and the scientific community might also use the results of the public dialogue received less attention even though these particular goals were also among the dialogue's objectives.

While respondents were largely sceptical of the government's commitment to translating the results of the public dialogue into policy, the commitment of the sponsors to act on the views and recommendations of the participants was seen as more reliable, but not significantly so. As the public dialogue progressed participants became increasingly uncertain about the sponsors' intentions. This uncertainty was, for a small minority who did not believe the public dialogue would make a difference, one of the 'least successful aspects' of the workshops.

While a BMRB representative admitted that there was no precise decision context for the public dialogue to feed into, he felt there was always an openness from the research councils to take the findings very seriously (Interview with Darren Bhattachary 16 December 2008). The MRC and the BBSRC hosted a workshop for policy decision-makers from their own organisations and from the Department of Health to consider the preliminary findings of the public dialogue. Participants' feedback regarding cord blood stem cells was purportedly used by the Department of Health to inform its study of cord blood banking policy and practice in the UK. However, there is no specific mention of the dialogue and the participant's views on cord blood stem cells in the Department's report published on 12 January 2009 (Technopolis Ltd for Department of Health 2009).

### *Transparency*

The objectives of the dialogue and the role and composition of the Oversight Group were not explicitly mentioned in the workshop, although the objectives were publicly available on the BBSRC website. In some cases, how the findings will be used was not discussed; other times it was explained that BMRB would take the key messages from the dialogues and spend a few months communicating these to the research councils.

What the public dialogue aimed to achieve was transparent to the participants, but a lack of understanding of how the results of the public dialogue would be used suggests that this important stage of the dialogue process was not explained as clearly by the organisers or sponsors. However, responses to our questionnaires indicate that by the third workshop, participants had a much clearer understanding of how the results of the dialogue would be used compared to earlier workshops. Better conveyed to the participants was how they could take the debate forward after the public dialogue had come to an end.

In our interviews with the Oversight Group and stakeholders, we explored whether public engagement can be considered meaningful in the context of the clear mandate for stem cell research expressed in the UKSCI's terms of reference. The BMRB representative agreed that the public dialogue had a meaningful role to play. However, he warned that if you only look at the top



line message from the dialogue and see it as a green light for innovation, you will miss the caveats; conditions that need to be met that are fundamental to the participants' vision of stem cell research.

### *Resource accessibility*

Our observations revealed that participants' generally responded positively to the resources introduced to the workshops to stimulate dialogue. Each workshop was attended by two experts: one with a scientific or clinical research background and one with a social science or ethical perspective. The relative influence of the scientists and clinicians compared to the social scientists and ethicists on the opinions of the participants emerged both from our observations and from our interviews. The participants tended to be fairly sceptical and critical of the presentations by the ethical and social experts whereas they appeared more favourable towards the scientists. We observed that the scientists/clinicians were typically in favour of stem cell science and the ethicists/social scientists were generally reluctant to criticise it.

There was an absence of industrial, clinical or social science experts willing to discuss the problems that have already been encountered with stem cell research and regenerative medicine and other novel therapeutics and the potential problems we are likely to encounter in the future. The positive framing of stem cell research limited the range of participants' discussion and increased the potential creation of hyperbolic public expectations, and the potential for obtaining positively-biased indications of public approval and acceptance.

The participants responded more enthusiastically to animated and articulate speakers. These attributes were influential in changing participants' views on certain issues. Where expert speakers failed to enthuse with their presentations, we noticed that participants' were less keen to question them in the break-out sessions and were therefore managing only to discuss the issues on a more superficial level.

In response to a closed-answer question, the participants generally agreed that the information provided both in the topic guides and by the expert speakers in their presentations was sufficient. However, responses to a number of closed-answer questions reveal contradicting opinions regarding the clarity of the information provided. While the comprehensible way in which the expert speakers communicated their information was seen as one of the 'most successful aspect of the workshops', problems with information delivery were seen as one of the 'least successful aspects of the workshops'.

For the most part, sufficient time appeared to have been given across the workshops but our observations suggest that the time management of some sessions could have been handled better to ensure the introduction and discussion of all relevant issues. The majority of respondents were of the opinion that they had been given sufficient time to engage in comprehensive discussions. For those who listed poor use of time resources as one of the 'least successful aspects of the workshops', these participants were mostly concerned with the lack of time allocated to the experts for their presentations.

### *Task definition*

Our observations revealed mixed results when it came to defining the roles of the participant groups in the context of the dialogue's objectives. The nature and scope of their role was described to the participants' by one facilitator as 'you are all part of a big experiment'. On occasion, the facilitators reminded the participants in their break-out groups that their opinions will inform future research and funding priorities. We also observed that a small number of the experts had not been properly briefed about the specific information they should aim to convey and the level at which to pitch their presentation – leading to talks that were far too complex or covered issues that were off-topic, confusion and boredom among participants and poor engagement with key issues.

Even though we observed little explanation of the dialogue's objectives and sometimes vague descriptions of their roles and responsibilities, responses to the questionnaires confirm that the participants were clear about the nature of the public dialogue and the role they were expected to play. Their responses indicate a high level of satisfaction with the way in which their particular role in the public dialogue was defined and that of the purpose and structure of the process itself.

In our interviews with the Oversight Group and stakeholders, we asked them to reflect on the public dialogue's success or effectiveness against the stated objectives. Of the five objectives, two were considered, for the most part, to have been successfully achieved, while the third was considered partially successful. The extent to which the fourth was achievable, or even realistic, was questioned, and the fifth was considered too vague to be able to measure its effectiveness.

### *Structured dialogue*

The plenary sessions were largely controlled by the lead facilitator for organisational purposes. The break-out sessions were less controlled and participants were arranged in a circle to facilitate group discussion. Participants were regularly encouraged by the facilitators to contribute to the discussions. Discussions were generally allowed to flow freely with interventions from the facilitators only when one participant interrupted another, to follow up an unclear statement or to encourage a participant to elaborate on a particularly interesting remark. We observed little disruptive behaviour by the participants who seemed satisfied rather than frustrated with the process, although one or two participants in some workshops did leave during the workshop for unknown reasons.

While providing a clear structure to guide dialogue ensures that discussions do not become unwieldy, the structure cannot be so rigid as to prevent participants from introducing new topics that they think are important or relevant to the discussion at hand. From the participants' point of view, the *Stem Cell Public Dialogue* process managed to achieve a workable balance between both structured and flexible dialogue.

### *Translation quality*

The participants' dialogue was largely framed by the topic guides and the workshop handouts and they showed a strong tendency to follow and explore the key issues raised in the experts' presentations. Occasionally participants tried to extend the range of debate by introducing new topics, but the discussions were generally steered by the facilitators back to the issues raised in the topic guides. Conclusions, able to be used as a platform for subsequent discussions, were not always drawn at the end of each workshop nor were the findings from previous workshops always recapitulated. Little evidence was presented by the facilitators that the public dialogue was also learning from and building upon previous consultations and dialogue projects.

The integration of stakeholder and public voices and opinions was considered one of the main strengths of the public dialogue's methodology by the Oversight Group. Summarising the breadth of this opinion however presented certain challenges when it came to drafting the conclusions and a set of recommendations for BMRB's report. We observed certain Oversight Group members imposing their own opinions on the content of the recommendations. Furthermore, it was not clear to us how feedback from the public participants that differed or conflicted with that of the stakeholders would be distinguishable in the recommendations. The final list of recommendations is more nuanced in terms of projecting the ambiguity of opinions; however when read in isolation to the broader conclusions, any tension among the views within and between the participant and stakeholders group is indiscernible.

### *Additional criteria*

A number of additional criteria were identified from our various data sets, but mostly from participants' responses to the open-answer questions in our questionnaires. Understandably, the

participants' criteria overlap to a certain extent with the normative criteria identified by the literature. However the participants' experience of this particular dialogue process enables a more nuanced analysis and reveals supplementary criteria not fully encapsulated by the normative criteria, including: 'participant learning', 'hearing other people's views', 'engagement with experts', 'opportunity to participate', and 'media as an information source'.

## **Conclusions**

### *Outcomes*

Beginning with the dialogue report (BMRB 2008), we found that, it conveyed a significant level of complexity in its picture of the wider scientific, social, policy and ethical issues at stake in stem cell research. Having said this, the diversity of perspectives found in the report did not quite match the level of discussion that we observed at the public workshops. One of our most surprising findings was that there was remarkably little disagreement amongst participants in the public workshops given that they were discussing an ethically fraught topic.

In retrospect, the relative complexity of the written report was achieved by the amalgamation of public voices at the workshops with stakeholder views gathered from a prior set of interviews. This meant that a rich variety of perspectives found their way into the final report, but unfortunately, many of them were not explored at the public workshops. Rather than a symmetrical deliberation of different value commitments, the workshop discussions tended to be led more by the presentations from experts. On the other hand, stakeholder impact on the dialogue was rather more problematic in one respect as we observed some members of the Oversight Group imposing their own opinions on the drafting of the final report. Where feedback from stakeholders and publics differed, the distinctions and conflicts with minority views were not evident insofar as a single set of shared conclusions and recommendations were presented in BMRB's report.

The dialogue report (BMRB 2008) observed that a striking finding of their work was the very high level of support amongst workshop participants and stakeholders for stem cell research. Although the report goes on to nuance this finding by outlining various ways in which support is conditional, subsequent press releases from BBSRC and MRC focused on high public support as the headline message from the dialogue.

### *Process*

In general, a significant majority of public participants responding to our questionnaires were very positive about the nature and organisation of the dialogue workshops. However, as we have noted, our multi-method approach was crucial for putting these statements in context and for giving due space to the minority views.

One point on which a significant number of respondents expressed scepticism about the dialogue concerned the link with policy and future research on stem cells. Many did not think that policy-makers would take the results of the discussions into account in making their decisions. The lack of a clear link to a decision context was also noticeable. As the dialogue progressed, participants became increasingly uncertain about the sponsors' intentions.

Though there were few disagreements explored at the workshops, we would stress that this was not an outcome of any facilitation problems. In retrospect, the homogeneity of responses appears to have been shaped by the role played by experts in framing the discussion.

### *Lessons and emerging themes*

We have suggested that the high levels of support for stem cell research noted in the dialogue report and the low levels of disagreement found at the workshops need to be interpreted with

some caution. We would also warn against the common tendency to treat public dialogue as an exercise in gathering data on public attitudes which can then be used to justify policy decisions.

Public engagement exercises are starting to generate more critical evaluation. Lezaun and Soneryd (2007) suggest that engagement exercises should be evaluated not only in terms of the dialogue organisers' work and its impact on public participants, but also in terms of their impact on the sponsors themselves and their capacity to respond. A related criterion raised in this context is the capacity of dialogues to help articulate *new* positions on the issues . This is an area that we have not been able to explore given resource constraints, but it deserves further attention if public engagement is to fulfil more of its democratic potential.

## 1. Introduction

### 1.1 Background

The Biotechnology and Biological Sciences Research Council (BBSRC) and the Medical Research Council (MRC) announced in March 2007 that they would be undertaking an innovative public dialogue project examining the science, and the social and ethical issues, of stem cell research in the UK (BBSRC 2007). The project of activities, sponsored by the Department for Innovation, Universities & Skills' (DIUS) Sciencewise Expert Resource Centre for Public Dialogue in Science and Innovation (Sciencewise), aimed to gain an insight into public concerns, views and attitudes towards stem cell research, as well as provide an opportunity for scientists to discuss with the public the challenges that researchers face and the potential benefits from this challenging field of research. The BBSRC, established by Royal Charter in 1994, views 'engaging with publics and being led by the publics' interests and expectations on which areas of research to prioritise for funding inception' as part of its mission (Interview with Sharon Fortune 5 December 2008). The BBSRC, most notably, sponsored the 1994 UK Consensus Conference on Plant Biotechnology that was organised by the Science Museum. The MRC received its Royal Charter in 1919 and, in accordance with its mission to 'promote dialogue with the public about medical research', also has a history of conducting public dialogue exercises on areas of research where there is uncertainty or controversy that raise numerous ethical and social issues. For both research councils, this was the largest public engagement exercise – in terms of the number of participants, the number of events and the length of the project – that either had initiated (Interview with Simon Wilde 15 December 2008). For the MRC, at least, this was also the first time that such a process had been independently evaluated from the outset rather as an ad hoc addendum.

In 2005, the UK Government established the UK Stem Cell Initiative (UKSCI), chaired by Sir John Pattison, to conduct a high-level review to formulate a ten-year vision for UK stem cell research and create a platform for coordinated public and private funding of research (Department of Health 2005). The incentive for conducting the *Stem Cell Public Dialogue* emerged out of the recommendations of the UKSCI, published in the Pattison Report in November 2005 (UK Stem Cell Initiative 2005). Of the 11 recommendations, the last one states, 'The Research Councils, charitable funding bodies, and Government Departments should develop a sustained and coordinated programme of public dialogue on stem cell research over the next decade'. The report acknowledges that it will be critical for the regulation of stem cell research to take into account attitudes by engaging the UK public in a dialogue on the ethical issues surrounding the sources and uses of embryonic stem cell lines, the use of animal experimentation in stem cell research, and the benefits and risks of stem cell therapies (UK Stem Cell Initiative 2005).

The research councils also had their own motivations for engaging publics on the issues raised by stem cell research. The public dialogue was partly prompted by the progressive translation into clinical use of the results of the research, and the subsequent establishment of spin-out companies, funded by the BBSRC and the MRC (Interview with Monica Winstanley 5 December 2008). The research councils have a fundamental interest in public attitudes towards stem cell research so that these may inform their funding decisions and the ways in which they communicate their objectives to wider publics (Interview with Simon Wilde 15 December 2008). Conducting a public dialogue on stem cell research was therefore seen as a natural progression for the research councils given their public engagement remit, the increasing prominence of stem cell research (and its associated controversies) in the media and their leadership role in demonstrating that they are responsive to public opinion. The BBSRC and MRC's decision to undertake public engagement in this area coincided with Sciencewise identifying public engagement on stem cell research as a priority. Sciencewise provided an initial grant of £300,000 to cover the costs of the public dialogue and the independent evaluation, to which the BBSRC and the MRC added top-up funding.

From the BBSRC's point of view, the *Stem Cell Public Dialogue* 'would create an opportunity for a range of stakeholders [including publics] to identify their priorities' for stem cell research (Interview with Monica Winstanley 5 December 2008). The staging of the public dialogue was also considered important by the BBSRC to make sure it addressed all possible issues considered important by the public as this is an area of research in which public attitudes are prone to change in response to high profile case studies, legal battles or campaigns. The research councils probably acted in response to the evolving culture of stem cell research in the UK and uncertainty about the political and social contexts in which it operated (Interview with Chris Mason 9 December 2008, Interview with Jack Stilgoe 18 December 2008). The public dialogue coincided with the Commons and wider public debate surrounding the Human Fertilisation and Embryology (HFE) Bill that provides for revised and updated legislation on assisted reproduction and for changes to the regulation and licensing of embryo use in research and therapy. The research councils would have considered it an important time to engage with publics as awareness of the issues surrounding stem cells would be heightened by the Bill's deliberation.

In July 2007, a stakeholder workshop was convened in London by the Office for Public Management (OPM) prior to the national dialogue project commencing, which aimed to ensure that all interested parties had an opportunity to express their views about the areas and topics the dialogue project should focus on as a guide to its scope and content. The stakeholders took into account recently published desk research by the OPM which synthesises the findings and implications of a range of engagement initiatives and consultations in relation to stem cell research and of recent research conducted by social scientists within the ESRC funded 'Stem Cell Programme'. The OPM desk study underlines the importance of a distinction between members of the public being in favour of stem cell research *in general*, and the concerns that arise in the *case of particular scenarios*, trials, and applications (OPM 2007). In this context, the input of information and expert opinion about a particular scenario may well reduce the proportion of those in favour of a particular 'clinical trial scenario, as was reported by the 'Stem Cell Dream' (ISCR 2007).

The BBSRC and the MRC convened an Oversight Group comprising nineteen members, representative of a broad range of interests relating to stem cell research, with an emphasis on independent voices from universities, charities and public interest groups (see Table 1.1 below). The British Market Research Bureau (BMRB) was commissioned in mid-2007 to design, develop and implement a UK-wide public dialogue on stem cell research. The BMRB was selected because of its in-depth understanding of scientific practices and regulation in the UK, and for its knowledge of the key issues and stakeholders in stem cell research. The Oversight Group was particularly attracted to the proposal put forward by BMRB because it incorporated stakeholder interviews in the process rather than there being a separate process for publics and stakeholders (Interview with Simon Wilde 15 December 2008).

Both the BMRB *Stem Cell Dialogue* report and our evaluation report and their respective findings will be considered by the BBSRC's Bioscience for Society Panel. The panel is composed of bioethicists, social scientists, science communicators, public engagement experts, and representatives of consumer portfolios, who will analyse the reports to identify any salient lessons for the BBSRC and then advise the Strategy Advisory Board that reports to the council and the Chief Executive on how to respond (Interview with Monica Winstanley 5 December 2008). The reports will also be distributed via the BBSRC's Institutes and through the UK Stem Cell Network and made widely available through its website. Likewise, the report will be forwarded to the MRC's Council and it will be discussed by their relevant Boards (Interview with Simon Wilde 15 December 2008). Sciencewise will use the reports to inform the appropriate Ministers and publicise it across government departments (Interview with Alison Crowther 10 December 2008).

**Table 1.1: The Oversight Group**

<b>Members</b>	<b>Organisation/Affiliation</b>
Dr Mark Bale	Department of Health
Ann Bruce	Innogen, University of Edinburgh
Helen Richens	Human Fertilisation and Embryology Authority (HFEA)
Professor Sarah Cunningham-Burley	Centre for Research on Families and Relationships, University of Edinburgh
Dr Belinda Cupid	Motor Neurone Disease Association
Jacky Engel	Christian Medical Fellowship
Professor Jon Frampton	University of Birmingham
Dr Matthew Harvey	Royal Society
Dr Kerry Kidd	Anglican Minister
Dr Chris Mason	University College London
Professor Andrew Webster	University of York
Dr Emma Weitkamp	University of the West of England
Josephine Quintavalle	Comment on Reproductive Ethics (CORE)
Aisling Burnand	BioIndustry Association
Dr Monica Winstanley	BBSRC
Dr Sharon Fortune	BBSRC
Simon Wilde	MRC
Jane Gizbert	MRC
Alison Crowther	Sciencewise

## 1.2 The aim and scope of our evaluation

The Institute for Science and Society (ISS) was approached by the BBSRC in June 2007 to submit a tender to undertake an independent evaluation of a stem cell dialogue project, according to the broad aims set out in Box 1.1 below. At the time we were preparing our proposal the main dialogue contractor, BMRB, had yet to be appointed. As we had no information about what the public dialogue might entail, we had to guess its scale and scope and the methods it might employ, and plan our evaluation activities and estimate our budget accordingly. We estimated the number of days we would spend on each (hypothetical) activity and its cost, and indicated how our proposed methodology could be scaled up or down. We also included a daily rate for the evaluator which, along with the timing and cost estimates of the activities, was tempered by an expected time commitment of up to 30 person days and the competitiveness of our costs per person days compared with other bidders (Email from Sharon Fortune 23 July 2007). A Commissioning Team made up of representatives from the BBSRC, MRC and the Sciencewise Review Panel considered the proposals. We were informed by Simon Wilde of the MRC on 16 August 2007 that our proposal was successful.

At the inaugural meeting of the Oversight Group on 12 October 2007, BMRB and ISS introduced their respective projects. At this meeting we began a process of negotiation with the sponsors about the scope of the evaluation, and with BMRB about gaining access to their proposed data sets. The Sciencewise representative also asked that the evaluators demonstrate knowledge of Sciencewise's guiding principles on evaluation (see Box 1.2 below). The Oversight Group's discussion of the evaluation, as recorded in the minutes of 29 October 2008, focused on (i) the

need for good communication between the evaluators and BMRB, (ii) the involvement of participants in shaping the evaluation, and (ii) removing the media analysis from our original proposal as the Group thought this was already adequately covered by the literature. The Group also discussed the possibility of the evaluation assessing the impact of the project over the longer term.

#### **Box 1.1: Aim and scope of the evaluation**

The purpose of the evaluation is twofold:

- To provide an independent, unbiased evaluation of the project, including assessment of impact and success
- To provide information on developing best practice in public dialogue projects that can be used in the future

It is anticipated that the evaluation will provide a critique of the public engagement programme, including success and impact assessment against the original objectives. The main contractor will be responsible for collecting individual participant feedback, for example from discussion meetings, but the evaluator will have access to all materials and be able to observe meetings and interview participants as required.

#### **Box 1.2: Sciencewise guiding principle of 'evaluation'**

Evaluation:

- Be evaluated in terms of process and outcome, so that experience and learning gained can contribute to good practice
- Ensure that evaluation commences as early as possible, and continues throughout the process
- Ensure that evaluation addresses the objectives and expectations of all participants in the process
- Be evaluated by independent parties (where appropriate)

We were invited to comment on the minutes. In response, we agreed to communicate regularly with BMRB, where possible and feasible. We also agreed, in principle, that public participants should be involved in the shaping of the evaluation (reflexivity). However, this was not to be done to the detriment of our independence. Accordingly, as a nod towards reflexivity, we agreed that we would: (i) include a University of Nottingham-based stem cell scientist (Dr Rhodri Jones) on our Internal Advisory Group; (ii) seek reflexive feedback during our proposed interviews with key representatives of the scientific, stakeholder and policy-making communities; and (iii) seek reflexive feedback from selected public participants identified in conjunction with BMRB via informal interviews at the workshops or via telephone interviews after the workshops. With regard to the media analysis, we reiterated that we did not propose to conduct a wholesale media analysis, only that of reports that emerge during the course of the consultation and that may have a tangible effect on the deliberations. As the details of public dialogue itself were still being finalised, we stressed that the extent to which we would be able to pursue interviews with the public participants and to undertake an analysis of media reports coinciding with the consultation was time and resource dependent. Furthermore, we reiterated that assessing the impact of the public dialogue over the longer term was not possible within the time and resources to be allocated to the evaluation by the sponsors.

The scale and scope of our evaluation and a budget of £23,690 was eventually agreed with the BBSRC on 8 February 2008. The framework for our evaluation is detailed below in Section 2. This section will include a brief review of the literature on evaluating public engagement activities,



from which we drew inspiration for the criteria against which we will measure the success or effectiveness of the *Stem Cell Public Dialogue*. This section also outlines the methods we used to collate our data sets and concludes with a brief discussion of a number of constraints placed on the evaluation. Section 3 of this report will provide an overview of the *Stem Cell Public Dialogue* process as it unfolded over spring-summer of 2008 and chronologises its key events and outputs. Section 4 details our evaluation of the public dialogue process and measures its success or effectiveness against three sets of criteria: the sponsors' criteria extracted from the dialogue's objectives and our interviews with the Oversight Group and key stakeholders, the normative criteria identified in the literature, and the participants' criteria identified from their responses to open-answer questions in our questionnaires. In Section 5 we conclude by considering and reflecting on the overall effectiveness and quality of the dialogue process and by outlining a number of lessons for future dialogue and evaluation processes.

## 2. A framework for evaluation

### 2.1 Brief literature review

The House of Lords Select Committee on Science and Technology in their influential report, *Science and Society* (House of Lords 2000), detected a 'new mood for public dialogue' in the UK that embodied a genuine two-way communication between science and society on science-related issues. The report juxtaposed increasing levels of scientific uncertainty, especially related to issues of risk, surrounding new technologies with increasing levels of public distrust and ambivalence towards science and innovation policy.

This high degree of scientific uncertainty combined with a plurality of value-based perspectives renders policy-making on emerging technologies very complex. Thus numerous philosophical foundations and methods for public engagement with science issues have been developed and debated by a variety of authors over the past two decades (Renn et al. 1995, Chess and Purcell 1999, Dryzek 2000). Calls for engaging the public in dialogue about new technologies rest upon three broad sets of argument, which according to Fiorino and Stirling (1990, 2008) are characterised as normative, instrumental and substantive.

The *normative* argument is that dialogue is a good thing in and of itself, as one element of a broader political approach to addressing controversial questions in a democratic society. It is argued that technological decision-making should be opened up to wider ethical or value judgments on democratic grounds, irrespective of the impact on governance outcomes. *Instrumental* arguments, by contrast, invoke public engagement as a means of improving the acceptability of end-state decisions, and through this enhancing such things as public confidence and trust in the policy-making process. *Substantive* arguments, finally, stress the role that dialogue can play in improving the 'quality' of technology assessment, with the objective of generating a more robust evidence base, by distinguishing between actual, rather than imagined, needs and concerns of the end users and understanding how different social actors interpret visions of innovation. In substantive terms, public engagement is viewed as a means of achieving improved outcomes according to explicit best-practice guidelines.

However, in spite of the proliferation of public dialogue and engagement activities in recent decades, little rigorous evaluation has been undertaken. A recent review of academic literature revealed a tendency for papers in this area to focus almost exclusively on the findings and their impact (Rowe and Frewer 2004). Analysis related to the suitability or efficacy of the methodologies employed or to the challenges faced or to different criteria for evaluation was largely overlooked. This may be because evaluation has traditionally take place in an ad hoc fashion, often tagged onto the end of public engagement in response to public or political pressure to justify its cost and to assess whether 'it was worth doing'. Until recently efforts to embed evaluation processes into programmes of engagement from the beginning were met with financial or logistical rebuffs. Determining the benefits of engagement is, however, difficult without evaluating specific applied examples.

The need for evaluation is becoming more urgent as the conduct of public engagement activities is starting to be increasingly contested. A number of academics question the extent to which recent initiatives actually reflect the proclaimed shift from a conventional deficit-model approach of experts merely imparting information to publics, to the two-way dialogue between different parties envisaged in the House of Lords report. Some identify a tendency for dialogues to be framed in expert-led, technical terms at the outset (Rayner 2003), while others find lay participants tending to defer to expert perspectives (Kerr et al. 2007). In either case, the capacity for open discussion is compromised. Academics have also noted a tendency for engagement processes to become part of a process of justifying policy decisions and 'closing down' technology choices in the face of complex, conflicting societal responses (Stirling 2005). There has also been criticism of how some public engagement activities produce a static picture of the

views of ‘the public’, ignoring the diversity and fluidity of perspectives found in actual deliberations (Lezaun and Soneryd 2007). In this context, both public dialogue initiatives and their evaluators need to show greater reflexivity and awareness of the theoretical complexity and practical challenges involved.

## 2.2 Evaluation criteria

In determining the *quality* of a public engagement exercise and its outputs, its level of *success* or *effectiveness* needs to be systematically and comprehensively assessed. There exists, though, considerable disagreement as to what constitutes effective engagement (Rowe and Frewer 2000). Effectiveness is a subjective quality that is not easily defined, identified and measured as it may be understood differently by different people. To complicate matters further, effectiveness relies on the success of both the process and its outcomes (i.e. its wider acceptance by various publics) to ensure its continued implementation.

Consequently, to evaluate the quality of the *Stem Cell Public Dialogue* process, and to establish the benchmarks against which it will be evaluated, we begin with three different sets of criteria to provide a comprehensive and methodical assessment of its effectiveness: sponsors’ criteria, normative criteria and participants’ criteria.

### Sponsors’ criteria

The aims and objectives of the *Stem Cell Public Dialogue*, drawn from the project materials and from our in-depth interviews, provide an insight into the criteria by which the sponsors and the Oversight Group will measure the public dialogue’s success or effectiveness. The objectives for the public dialogue (see Box 2.1 below) were formulated by the BBSRC in consultation with the MRC and Sciencewise prior to the commissioning of the BMRB to undertake the dialogue. The Oversight Group also had a hand in fine-tuning the wording and the expected outcomes.

Let us briefly consider each of the objectives and how they will be used to evaluate the effectiveness of the public dialogue:

Objective 1: The objective to ‘identify the range of views and concerns about the science and ethics of stem cell research amongst the wider public and their societal context’ is ambiguous in the context of the *Stem Cell Public Dialogue*. The extent to which the views and concerns of a group of participants can be seen to be representative of wider publics is contentious and discussed under the heading of *representativeness* in Section 4. Other barriers to achieving a range of views and concerns are discussed under *structured dialogue* and *translation quality*. Data on the range of views and concerns was primarily sourced from participants’ responses to our questionnaires and substantiated by our observations (and those of the Oversight Group and organisers who attended the workshops) of their discussions during the workshops. The societal context in which these views and concerns emerged was identified from the literature and from responses to our participants’ questionnaires and interviews with the Oversight Group and stakeholders.

Objective 2: The objective to ‘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’, is also ambiguous and when read in conjunction with Objective 1, suggests that scientists and stakeholders participated in a two-way dialogue with participants about stem cell research and related social and ethical issues. Our observation of the workshops and responses to the questionnaires and interviews are discussed in the context of *representativeness*, *resource accessibility*, *task definition*, *structured dialogue* and *translation quality* highlights this ambiguity. The involvement of key organisations such as UK National Stem Cell Network and the UK Stem Cell Communications Coalition was confirmed via an analysis of the membership of the Oversight Group, some of whom are also members of these organisations and who also participated in the

stakeholder workshop and interviews, conducted by OPM and BMRB respectively, and as expert speakers.

**Box 2.1: Stem Cell Public Dialogue aims, objectives and anticipated outcomes\***

**Aims**

- Engage the diverse public about developments in stem cell research, in order that their views can be taken into account in policy development
- Help create an environment that will sustain dialogue on issues relating to developments in stem cell research and their clinical applications

**Objectives**

- 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

**Anticipated Outcomes**

The project will provide an understanding of views and concerns amongst diverse groups, including scientists themselves, that can feed into policy-makers' strategic decision-making and will provide a good foundation on which to build an ongoing plan of dialogue and communications activities. Outcomes of the project will include:

- Up-to-date, in-depth information for Research Councils, Government, the science community and other stakeholders on publics' views and concerns to inform strategic decision-making
- Increased public awareness of the challenges, opportunities and uncertainties of stem cell research, its clinical application and on-going social and ethical issues
- An improved environment for dialogue between scientists, science policy makers, other stakeholders and diverse publics
- The public feel their views and concerns around stem cell research have been heard by policy-makers
- Increased involvement of the stem cell scientists in public engagement and dialogue about their research, its social and ethical context and impact

\* [http://www.bbsrc.ac.uk/society/dialogue/activities/stem\\_cell\\_dialogue.html](http://www.bbsrc.ac.uk/society/dialogue/activities/stem_cell_dialogue.html)

Objective 3: The objective to 'raise public awareness about the potential opportunities, challenges and uncertainties of stem cell research' is also ambiguous in the context of the public dialogue. As we discuss under the heading of *representativeness*, the public dialogue was not widely known beyond those 200 members of the public who participated in its workshops. Furthermore, as the dissemination of the public participants' findings is largely limited to the research councils,

government ministers and departments and other institutional stakeholders, opportunities for raising awareness among wider publics are limited. Our analysis of the extent to which this objective was achieved was based on a documentary analysis of public dialogue materials, responses to our questionnaires and interviews and observation of the report launch. It is important to note that measuring the extent to which this objective, and the following two objectives, was achieved was not possible within the financial and time resources of this evaluation.

Objective 4: The objective to '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' is discussed under the headings of *early involvement* and *policy influence*. Early involvement and policy influence imply an interest and willingness by the scientific community, research councils and policy makers upstream take on board the views and concerns of publics early in their decision-making processes. Our analysis of this objective is based on responses to our questionnaires and interviews. We are not able to measure the actual impact of this objective as it is beyond the remit of this evaluation.

Objective 5: The objective to 'inform development of a plan for a longer-term project of public dialogue and engagement around stem cell research' infers that one output of the public dialogue will be a strategy for continued dialogue and public engagement on stem cell research. The extent to which this objective is likely to be achieved will depend on the perceived *transparency* of the process and a lack of hidden agendas. Perceptions of transparency or hidden agendas are drawn from our observations of the workshops, and from responses to the questionnaires and interviews. Again, we are not able to measure the actual impact of this objective as it is beyond the remit of this evaluation.

An overall assessment of the extent to which the objectives were achieved, or even achievable, is given under the heading of *task definition* where we discuss whether the tasks of each of the participants groups was sufficiently defined so as to enable them to contribute effectively to their achievement.

### **Normative criteria**

The literature relating to public engagement continues to amass in response to broader recognition of the value of such exercises to innovation and policy processes. Yet few studies provide useful frameworks for their effective evaluation. Normative criteria developed by Rowe and Frewer (2000, 2004) have previously been adapted and used to evaluate a deliberative conference (Rowe et al. 2004) and, more recently, the UK-wide *GM Nation?* public debate (Rowe et al. 2005, Horlick-Jones et al. 2006). The criteria have also been developed recently by Horlick-Jones et al (2007a) in the context of their usefulness in evaluating previous dialogues. Given that the utility of these criteria have been previously and successfully tested on a large-scale, nation-wide engagement process such as *GM Nation?*, they stand out as potentially adaptive to the *Stem Cell Public Dialogue* (see *literature review* above). We employed twenty-six closed-answer questions in our questionnaire (see Appendix) to assess the participants' evaluations of the success or effectiveness of the dialogue according to these criteria.

However, we want to provide a cautionary note about the limitations of this framework especially in light of emerging criticism about how it is based on an inadequate conceptualisation of 'the public' defined in terms of distance and previous disengagement from the technology under discussion (Reynolds and Szerszynski 2006). Other academics have also challenged a model of engagement that defines publics in terms of their lack of knowledge, arguing that the boundaries between science and publics are more blurred (Irwin and Michael 2003). In addition, we note that Horlick-Jones et al (2007b) appear to assume that public engagement is solely about eliciting value judgments about new technologies from members of the public, ignoring aspirations for a two-way (or multi-way) dialogue where experts are equally engaged in exploring their own underlying values in conjunction with publics.

In light of these caveats, we have modified eight useful normative criteria from this literature to fit the particular circumstances of the *Stem Cell Public Dialogue* and to partly address some of these criticisms. Horlick-Jones et al. (2007a, 2007b) have identified a key aspect of engagement processes that is not addressed by either the normative criteria drawn from the research literature, nor by the criteria generally set by the sponsors or inferred by the participants, all of which tend to focus on their effectiveness as organisational processes. This aspect is concerned with determining how effectively public dialogue processes utilise sources of knowledge (via texts and debate), including the ways in which conclusions drawn from one stage of the process form the basis for subsequent stages, informing and shaping them. They identified a hitherto disregarded need to evaluate the debate as an information system, according to a new (and ninth) criterion of *Translation quality*. Of particular interest to us is the capacity of translation quality to determine the level and effect of initial issue framing on both the breadth and depth of the publics' dialogue.

#### **Box 2.2: Normative criteria**

1. **Representativeness** – the public dialogue should be *inclusive* of the spectrum of relevant views and participants should be broadly representative of the wider public.
2. **Independence** – the process should be *independent* and *free from bias* by sponsors, organisers, stakeholders, etc.
3. **Early involvement** – public should be involved *upstream* of the innovation process before value positions become entrenched
4. **Policy influence** – the outputs of the dialogue should have a genuine *impact* on policy
5. **Transparency** – the process and its modus operandi (especially with regard to how decisions were taken) should be *transparent* to those both internal and external to the process
6. **Resource accessibility** – participants should have access to *sufficient resources* (human, financial and material) to achieve their aims
7. **Task definition** – the roles and responsibilities of each of the participant groups should be (organisers, stakeholders, public etc.) *unambiguous and well-defined*
8. **Structured dialogue** – the process should encourage and enable *effective* and *inclusive* dialogue
9. **Translation quality** – the process should utilise *sources* of knowledge effectively

In applying the criteria identified in the research literature (Box 2.2), we engage with key debates on how they are to be interpreted and on how appropriate they are in particular contexts. The most contentious criterion is the concept of representativeness and the value that can be placed on the opinions of an extremely small proportion of the population (Fixdal 1997, Campbell and Townsend 2003), though this in turn presumes that majority views are necessarily more valuable simply by virtue of being in the majority. One methodology often utilised by evaluators to 'test' the representativeness of the attitudes of the public dialogue participants is to survey public opinion on the issue at hand to assess the views of a broader representative sample and then compare the two (Rowe et al. 2005, Horlick-Jones et al. 2006). However, others (Brown 2006) argue that public engagement exercises should be evaluated in terms of their capacity to articulate diverse social and cultural perspectives rather than to provide a statistical sample of individual opinions in the population. Reynolds et al. (2007) note that the statistical approach provides an excessively abstract and static picture of 'general public opinion', ignoring the diversity of actual publics and the capacity of particular views to change through interaction with each other.

We propose to approach this with an open mind using survey data where feasible to determine whether the views of the public dialogue participants may be considered representative of the wider UK public and, if not, whether they reveal other valuable dimensions of public responses to stem cells. A number of recent surveys involve the exploration of UK public attitudes on a range of stem cell-related issues and topics, including a 2006 Eurobarometer survey, a 2005

YouGov/Daily Telegraph survey and a 2005 Human Fertilisation and Embryology Authority survey, as mentioned in the OPM desk research (OPM 2007).

### **Participants' criteria**

These criteria are derived from the public participants' own evaluations of the strengths and weaknesses of specific elements of the process (Rowe et al. 2004, Horlick-Jones et al. 2006). Participants' perspectives, based on their own experience of the dialogue process, are equally as important and valid to the evaluation of the *Stem Cell Public Dialogue* as the criteria elicited from the sponsors' objectives and from the scholarly literature on evaluating public engagement exercises. The participants, depending on their motives for, and experience of, participation are likely to have different perceptions of what the public dialogue aims to achieve and the manner in which it should be judged. To elicit participants' own criteria for *effectiveness*, the questionnaires included a number of open-answer questions, including two that asked them for their personal opinion of the 'least' and 'most successful aspects of the workshops'.

Responses to questions relating to participants' perceptions of the successes and failures of the workshop served to both confirm or question the utility of the normative criteria as well as to provide additional criteria against which the success of the dialogue process is measured by the participants' themselves. These responses were subject to qualitative analysis in the wider context of the quantitative results (closed-answer questions) and were also coded into categories to provide additional quantitative data. Understandably, the participants' criteria overlap to a certain extent with the normative criteria identified by the literature. However the participants' experience of this particular dialogue process enables a more nuanced analysis and reveals supplementary criteria not fully encapsulated by the normative criteria. Incentives such as personal or collective empowerment, participant learning, understanding of other people's points of view, and engaging with specialists on the topic, are critical to the perceived effectiveness of a dialogue process by its participants.

## **2.3 Methods used in our evaluation**

Using both qualitative and quantitative evaluation research methods, the evaluation utilised a multi-method approach combining participant questionnaires, ethnographic techniques including structured participant observation and in-depth interviews, media analysis, and documentary analysis of project materials and scoping documents commissioned by the BBSRC/MRC to inform the public dialogue. The evaluation's Internal Advisory Group was called upon regularly to reflect on both the conduct and the progress of the evaluation to ensure intellectual and methodological rigour.

### **Observation**

The evaluator and one member of the advisory group attended 11 of the 15 workshops to cover the range of locations and sequence of workshops. The workshops were observed by at least one person (see Table 2.1 below) and detailed observation notes were taken using an Observation Protocol that drew attention to the various activities and outputs and whether these could be considered successful against the normative criteria. Observers also recorded their broader impressions of different aspects of the events. The protocol (see Appendix), adapted from Horlick-Jones et al. (2007b), sought to augment the data collected for each of the normative criteria described above, while providing a uniform approach to data collection.

### **Participant questionnaires**

Questionnaires comprising both open- and closed-answer questions were handed out to participants at the close of each of the 15 workshops (see Appendix). A FREEPOST envelope was provided to enable participants to complete and return the questionnaire at their convenience within a two-week deadline. The open-answered questions aimed to determine the participants' opinions about the strengths and weaknesses of the public dialogue process to identify the

criteria by which they evaluate the event. The closed-answer questions explored participants' perceptions of the public dialogue process in terms of the normative criteria drawn from the literature. In total, 569 questionnaires were distributed resulting in 208 returned questionnaires; a response rate of over one-third (36.6%) (Table 2.2) and considered very good for this medium and field.

**Table 2.1: Workshops observed (highlighted) by the evaluators**

LOCATION	W1	W2	W3
London*	15 March	26 April	24 May
Bristol	29 March	3 May	31 May
Cardiff	29 March	3 May	31 May
Edinburgh	5 April	10 May	7 June
Newcastle	5 April	10 May	7 June

\*All three London workshops were observed by two evaluators.

Table 2.2 lists the responses to the questionnaires according to location and workshop number. The table details the total number of participants who attended each workshop and the number of completed questionnaires they returned. The response rate ranges from 24.5 percent in Cardiff, 34.2 percent in Newcastle, 37.9 percent in London, 39.8 percent in Bristol to 45.7 percent in Edinburgh.

All questionnaires were coded to enable identification of the workshop location and number to allow us to match responses from each of the workshops and locations across the three questionnaires. Our analysis considers the responses to all questionnaires and, where possible, we distinguish between particular workshops and locations. If significant differences in responses occur according to age and gender, these are also reported. Our analysis of the responses according to the socio-demographic data provided by both the participants and by BMRB in its sampling (see Table 2.3) will be discussed under the criteria of 'representativeness' in Section 4. Responses to the closed-answer questions will provide the basis for discussion under each of the normative criteria, also in Section 4. The responses to the open-answer questions will be used to identify further criteria by which the participants' themselves evaluate the dialogue process, and these are also reported in Section 4.



**Table 2.2: Questionnaire response rate by workshop location**

<b>Workshop location</b>	<b>Total participants according to BMRB*</b>	<b>Responses to questionnaire</b>	<b>Percent (%) of total participants</b>
London W1	41	13	31.7
London W2	39	17	43.6
London W3	36	14	41.7
<b>London (total)</b>	<b>116</b>	<b>44</b>	<b>37.9</b>
Bristol W1	38	12	31.6
Bristol W2	38	17	44.7
Bristol W3	37	16	43.2
<b>Bristol (total)</b>	<b>113</b>	<b>45</b>	<b>39.8</b>
Cardiff W1	40	10	25
Cardiff W2	36	9	25
Cardiff W3	34	8	23.5
<b>Cardiff (total)</b>	<b>110</b>	<b>27</b>	<b>24.5</b>
Edinburgh W1	39	20	51.3
Edinburgh W2	39	21	53.9
Edinburgh W3	38	12	31.6
<b>Edinburgh (total)</b>	<b>116</b>	<b>53</b>	<b>45.7</b>
Newcastle W1	42	16	38.1
Newcastle W2	36	14	38.9
Newcastle W3	36	9	25
<b>Newcastle (total)</b>	<b>114</b>	<b>39</b>	<b>34.2</b>
<b>TOTAL</b>	<b>569</b>	<b>208</b>	<b>36.6</b>

\*Data taken from BMRB (2008), Table 3: Achieved sample for the workshop, pp. 82-83.

**Table 2.3: Participant profile for each workshop\***

<b>Workshop location</b>	<b>Gender</b>	<b>Socio-economic status</b>	<b>Ethnicity</b>	<b>Total number</b>
<b>London W1</b>	M 19 F 22	ABC1 24 C2DE 17	White 27 Black 7 Asian 7	41
<b>London W2</b>	M 17 F 22	ABC1 23 C2DE 16	White 25 Black 7 Asian 7	39
<b>London W3</b>	M 15 F 21	ABC1 21 C2DE 15	White 24 Black 6 Asian 6	36
<b>Bristol W1</b>	M 18 F 20	ABC1 19 C2DE 19	White 35 Black 1 Asian 2	38
<b>Bristol W2</b>	M 18 F 20	ABC1 19 C2DE 19	White 35 Black 1 Asian 2	38
<b>Bristol W3</b>	M 18 F 19	ABC1 18 C2DE 19	White 34 Black 1 Asian 2	37
<b>Cardiff W1</b>	M 20 F 20	ABC1 23 C2DE 17	White 36 Black 3 Asian 1	40
<b>Cardiff W2</b>	M 18 F 18	ABC1 22 C2DE 14	White 32 Black 2 Asian 1 Other 1	36
<b>Cardiff W3</b>	M 17 F 17	ABC1 22 C2DE 12	White 30 Black 2 Asian 1 Other 1	34
<b>Edinburgh W1</b>	M 17 F 22	ABC1 18 C2DE 21	White 33 Black 0 Asian 6	39
<b>Edinburgh W2</b>	M 18 F 21	ABC1 19 C2DE 20	White 34 Black 0 Asian 5	39
<b>Edinburgh W3</b>	M 17 F 21	ABC1 18 C2DE 20	White 34 Black 0 Asian 4	38
<b>Newcastle W1</b>	M 20 F 22	ABC1 20 C2DE 22	White 37 Black 0 Asian 5	42
<b>Newcastle W2</b>	M 16 F 20	ABC1 19 C2DE 17	White 31 Black 0 Asian 5	36
<b>Newcastle W3</b>	M 16 F 20	ABC1 19 C2DE 17	White 31 Black 0	36

			Asian 5	
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\* Table adapted from BMRB (2008), *Stem Cell Dialogue*, pp. 82-83.

## Oversight Group and stakeholder interviews<sup>1</sup>

The evaluator and, where possible, a member of the advisory group attended the small number of Oversight Group meetings in London. **Interviews** with key members of the Oversight Group and the public dialogue contractors (including facilitators) were conducted. Additional interviews with key members of the stakeholder, scientific and policy-making communities to explore their particular perceptions of the public dialogue in the context of the normative criteria were also proposed, but not feasible in practice given that the public dialogue was not well known or attended beyond the members of the Oversight Group and the public dialogue contractors. All interviews were digitally recorded and transcribed to ensure accuracy in the attribution of opinions and comments.

## Supplementary methods

The evaluators undertook **documentary analysis** of all project materials produced over the course of public dialogue including meeting minutes, interim reports of both the organisers and the public dialogue contractors, and briefing and support materials for the participants. Scoping materials published by OPM and commissioned by the BBSRC/MRC to inform the framing and content of the public dialogue were also analysed. We had proposed to conduct a **media analysis** of reports released over the course of the public dialogue but this was not achievable within the time and resources provided.

Regular contact with the wider Internal Advisory Group provided opportunities for **reflexive discussion and analysis** on both the conduct and the progress of the evaluation, especially in the development of questions for the participant questionnaires and Oversight Group and stakeholder interviews, to ensure intellectual and methodological rigour throughout.

The findings discussed in this report are the result of a rigorous analysis of the range of data listed above. The **quantitative data** were analysed using statistical software (SPSS) and the **qualitative data** were analysed in accordance with the evaluation criteria discussed above. Reflexive discussion and analysis of the quantitative and qualitative data with the wider Internal Advisory Group ensured intellectual and methodological rigour related to both the conduct and the progress of the evaluation.

## 2.4 Constraints on the evaluation

The scope of our proposed evaluation of the *Stem Cell Public Dialogue* was constrained in a number of significant ways. First, the scale of the budget and the number of person days expected to be devoted to the evaluation precluded a highly detailed evaluation exercise of the extent that would seem appropriate to the objectives set by the BBSRC and the MRC, especially with regard to longer-term impact. A national project of the scale of the *Stem Cell Public Dialogue* demands considerable human and financial resources to evaluate its numerous activities, processes and outputs effectively, including: monitoring the planning and implementation of the dialogue process over a period of 10 months; attending and observing a range of public dialogue event across the UK over a period of 3 months; administering questionnaires to dialogue participants (569 questionnaires were distributed across 15 workshops).

Second, we encountered a number of practical constraints on the scope of the evaluation:

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<sup>1</sup> In the context of our interviews, the term 'stakeholder' encompasses the public dialogue contractors, BMRB and the facilitators, in the sense that they have a vested interest in the dialogue project.

- Even though we were awarded the contract to conduct the evaluation early in the dialogue process, we were unfortunately not consulted on our availability to attend the various public workshops. Consequently, we were unable to attend and observe all 15 workshops across the three locations due to prior commitments. Last-minute assistance offered by an ISS postgraduate research student working in this area enabled us to attend a total of 11 workshops across all of the locations.
- As we were not able to attend all of the workshops, we were reliant on the facilitators to distribute our questionnaires for us. This meant that we could not be sure that the importance of the evaluation, in particular the participants' feedback on their experience of the dialogue process, and our independence was effectively and enthusiastically communicated.
- Our brief, provided by BBSRC in consultation with Sciencewise, stipulated that we could have access to the public participants for interviews. In practice, this turned out not be feasible for two reasons. First, the budget and person days allocated by BBSRC precluded the possibility of interviewing an appropriate proportion of the public participants due to the time and costs associated with interviews (face-to-face in particular, but also over the telephone), their transcription and the collation and analysis of the data collected. Second, access to a small number of public participants from London to pilot the questionnaire and for reflexive feedback on the evaluation process was delayed due to the confidentiality/privacy agreements BMRB had with the participants. Eventually, due to the small number of respondents from the first workshop in London, we decided not to proceed as the data set would have been too small to be meaningful.

Nevertheless, within these financial, temporal and practical boundaries, we have conducted and delivered a rigorous evaluation that will make a valuable contribution to the growing literature in this area. We hope to address the constraints imposed on this evaluation, in particular access to the participants and wider stakeholders, and conduct a follow-on evaluation that will investigate the broader impact of the *Stem Cell Public Dialogue* process on stem cell research, related policies and regulatory oversight, and participants' attitudes towards these contexts. Such a proposal has been submitted to Sciencewise.

### **3. The Stem Cell Public Dialogue**

#### **3.1 The public dialogue process**

BMRB, in partnership with Demos and the University of East Anglia, developed a deliberative process that brought together members of the public with a range of experts including scientists, clinicians, social scientists and ethicists (see Table 3.1) to discuss the science, ethics and governance of stem cell research. A total of fifteen public dialogue workshops, three each in London, Bristol, Cardiff, Edinburgh and Newcastle, were held between mid-March and early June 2008. Venues were mainly large hotels central to the area, except in London where the workshops were held in a University building. The workshops ran from 10.30am in the morning through until 4pm in the afternoon. At the first workshop in each location, a representative from the BBSRC or MRC explained how the *Stem Cell Public Dialogue* had come about and what they hoped it would achieve. Workshops were a mixture of whole group and smaller break-out group sessions. Each workshop began with a welcome and introduction by the lead facilitator before an initial round of electronic voting on a range of attitudinal questions related to stem cell research. The workshops were highly structured, combining whole group plenary discussions and smaller break-out groups where key issues were discussed in greater depth. Presentations by a scientist or a clinician and a social scientist or ethicist highlighted the core issues of the day and provide some insight into the specific research of the expert speaker. The experts addressed the participants as a whole group before, though not in all cases, rotating around the smaller groups to answer questions. Each workshop concluded with the participants reflecting on the core messages of the day and undertaking a second round of electronic voting on the same set of attitudinal questions to see whether their views had changed over the course of the day.

A range of stimulus materials was used to inform the debate. BMRB, in partnership with the research councils and the Oversight Group, identified key issues and areas for discussion from the findings of the OPM desk research, the OPM stakeholder workshop and the BMRB stakeholder interviews. The BMRB conducted 49 telephone interviews with a range of stakeholders.<sup>2</sup> The structure of the interviews broadly mirrored that later used in the public workshops and explored the stakeholders' visions and their views on the sources and applications of stem cells. The generation of the stimulus materials was an iterative process to ensure that key areas were incorporated but not so restrictive as to limit the range of discussion. Insights from the stakeholder interviews were used to inform the content of the stimulus materials including the 'hypothetical' case studies of different stakeholders with differing perspectives of stem cell research.

Discussion in each of the public workshops was guided by a lead facilitator assisted by a small team of co-facilitators in the break-out sessions and prompted by a detailed topic guide. Workshop 1 provided an introduction to stem cells, and explored the participants' aspirations and concerns raised by the science and its clinical applications. Workshop 2 involved an in-depth discussion into the social and ethical issues related to the various sources of stem cells. Workshop 3 focused on the potential future applications of stem cells and the wider social implications of stem cell banks, therapies and clinical trials.

Two hundred public participants were recruited by BMRB to participate in the workshops (see Table 2.3 above). The demographic profile of the area in which each of the workshops was held was reflected by quotas set for age, socio-economic status and ethnicity. Attitudes to stem cells were also screened to ensure the sample was broadly reflective of the public attitudes profiled in the results of the BMRB omnibus survey, including those concerning the science more generally and the ethical acceptability of embryonic research more specifically. Participants received an

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<sup>2</sup> The stakeholders are categorised broadly by BMRB into nine groups, including research scientists, clinicians, social scientists and ethicists, commercial and pharmaceutical organisations, religious and faith groups, medical charities, pro-life groups, funders, and government and regulators.

incentive payment of £70 for attending each of the first two workshops, and a further £75 for workshop 3.

**Table 3.1: Scientists, clinicians, social scientists and ethicists who participated in the workshops\***

<b>Workshop/ Location</b>	<b>W1</b>	<b>W2</b>	<b>W3</b>
<b>London</b>	Stephen Minger (Kings College London)  Amanda Dickins (King's College London)	Robin Lovell-Badge (National Institute for Medical Research)  David Jones (St Mary's University College London)	Chris Mason (University College London)  Steven Wainwright (King's College London)
<b>Bristol</b>	Melanie Welham (University of Bath)  Susan Weber (University of Exeter)	Melanie Welham (University of Bath)  Christine Hauskeller (University of Exeter)	Neil Hanley (University of Southampton)  Ann Bruce (University of Edinburgh)
<b>Cardiff</b>	Charlie Archer (Cardiff University)  Jennie Gunning (Cardiff University)	Anthony Hollander (Bristol University)  Neil Stephens (Cardiff University)	Nazar Amso (Cardiff University)  Derek Morgan (Cardiff University)
<b>Edinburgh</b>	Tilo Kunath (University of Edinburgh)  Nicola Marks (University of Edinburgh)	Neville Cobbe (University of Edinburgh)  Sarah Cunningham Burley (University of Edinburgh)	Brendan Noble (University of Edinburgh)  Calum McKellar (Scottish Council on Human Bioethics)
<b>Newcastle</b>	Michael Whitaker (Newcastle University)  Dana Wilson-Kovacs (University of Exeter)	Jon Frampton (University of Birmingham)  Donald Bruce (Society, Religion and Technology Project)	Jaap van Laar (Newcastle University)  Jan Deckers (Newcastle University)

\* Table adapted from BMRB (2008), *Stem Cell Dialogue*, p. 84.

### 3.2 Chronology of key events and outputs

**Table 3.2: Chronology of key events and outputs**

Date	Event / Output
<p><b>2005</b></p> <p>March</p> <p>November</p>	<p>The UK Stem Cell Initiative (UKSCI), chaired by Sir John Pattison, is established to ensure that the UK remains one of the global leaders in stem cell research</p> <p>UKSCI publishes a report and recommendations for a ten year vision and strategy for UK stem cell research</p>
<p><b>2007</b></p> <p>1 March</p>	<p>Press release announcing Sciencewise funding and that the UK's two major public funders of stem cell research will run a national public discussion about this cutting-edge area of science.</p>
<p><b>2007</b></p> <p>July</p> <p>5 July</p> <p>August</p> <p>12 October</p> <p>26 November</p>	<p>OPM publishes its desk research, commissioned by the BBSRC/MRC, of past and ongoing projects, events and information which have engaged the public in discussion or communicated with them about stem cell research*</p> <p>OPM conducts a stakeholder workshop in London on 5 July, as the second stage of a project commissioned by the BBSRC/MRC to inform the public dialogue*</p> <p>The BBSRC/MRC commissions BMRB and ISS to conduct the public dialogue and its independent evaluation respectively</p> <p>First meeting of the Oversight Group held at the MRC in London</p> <p>Launch of the Stem Cell Dialogue project at a press event at the Science Media Centre</p>
<p><b>2008</b></p> <p>January-October</p> <p>5 April-7 June</p> <p>19 September</p> <p>28 November</p> <p>December</p> <p>17 December</p>	<p>BMRB conducts telephone interviews with 49 stakeholders</p> <p>Public dialogue workshops staged across five locations: London, Bristol, Cardiff, Edinburgh, Newcastle</p> <p>Policy workshop to discuss dialogue findings with BBSRC, MRC and Department of Health policy-makers</p> <p>Final Oversight Group meeting to discuss BMRB report, conclusions and recommendations</p> <p>ISS conducts face-to-face and telephone interviews with 10 Oversight Group members and stakeholders</p> <p>Event to launch BMRB report*</p>
<p><b>2009</b></p> <p>May</p>	<p>Evaluation report is published</p>

\* OPM documents and BMRB final report available on the BBSRC website [http://www.bbsrc.ac.uk/society/dialogue/activities/stem\\_cell\\_dialogue.html](http://www.bbsrc.ac.uk/society/dialogue/activities/stem_cell_dialogue.html)

## 4. Evaluation against the criteria

For each criterion, a brief definition suited to its use in this stem cell dialogue is provided followed by a broader discussion of its conceptualisation in the public engagement literature and its application in previous evaluations of public engagement exercises. The remaining discussion and analysis related to each criterion is based upon workshop observation data, and responses to our participant questionnaires and Oversight Group and stakeholder interviews.

### 4.1 Representativeness

The criterion of 'representativeness' is subject to differing interpretations. Different types of representation (such as geographic, political and socio-demographic) are often emphasised differently depending on the nature of the participation process (Abelson et al. 2003). However, it is widely agreed that public engagement exercises should include a wide range of views, and that participants should as far as possible represent the full range of publics and interests potentially affected by the decisions made (Petts and Leach 2000). It is also widely accepted that the process of selecting participants should be objective and transparent, and that potential barriers to participation are removed or minimised.

Nonetheless, a significant tension remains in how the shared norm of representation is operationalised in recruitment or evaluations. A dominant approach is to look for a statistically representative sample of the population. For example, Horlick Jones et al. (Horlick-Jones et al. 2006, Horlick-Jones et al. 2007b) tested the representativeness of the attitudes in the *GM Nation?* public debate by comparing the results to wider polling, assessing what they called 'attitudinal distribution'. They also looked at socio-demographic representativeness by testing samples of participants with the socio-demographic profile of the UK population, and found that a disproportionately high number of participants had higher degrees. Carr and Halvorsen (2001) have also measured socio-demographic representativeness by comparing attendance to demographic data. This statistical approach can be misleading especially where public dialogue outputs are assessed against findings from attitudinal surveys, suggesting that the engagement exercise is simply yet another method of gathering data on public attitudes. This is contrary to the very meaning of public *dialogue* which is, after all, inspired by the philosophy of different parties reflecting or deliberating on matters of common relevance in interaction with each other.

A number of scholars have tried to clarify the above misunderstanding in relation to public engagement around science including Brown (2006) and Burgess and Chilvers (2006), arguing that public engagement activities should be evaluated in terms of their capacity to *articulate* diverse social and cultural perspectives rather than to provide a statistical sample of individual opinions in the population. Indeed, this is also reflected in the stated sponsors' aims for this stem cell dialogue. Particular perspectives may not represent population beliefs at a point in time, but they are valuable for precisely that reason, i.e., the ability to highlight issues not widely considered. Here, representation is understood in terms of diversity and complexity in the substantive content of a dialogue, reflecting different social experiences and therefore, different ways of framing the wider context of the science in question. Socio-demographic variation in attendance (dialogue input) may be important and necessary, but may not in itself be sufficient for producing diversity of perspectives (dialogue output), as the latter depends on the success of the process in eliciting differences.

In the case of the *Stem Cell Public Dialogue*, attitudes to stem cells were screened by BMRB to ensure that participants' attitudes were broadly representative of wider publics, as profiled in the results of the BMRB omnibus survey comprising a nationally representative panel of 1013 people aged 16 and over. Among those surveyed, the phrase 'stem cell research' mostly brought to mind nothing (29%) or medical treatments/treating disease (23%), and almost half (49%) claimed to have some awareness of stem cell research. The majority (73%) of those surveyed approved of stem cell research with a slightly higher majority (76%) approving of the use of embryos in such research. However, desk research conducted by OPM (2007) that systematically analysed British



public opinion in relation to stem cell research based on previous public dialogues, engagement exercises and polls, noted that the majority of the public 'feel they do not have enough information to make judgements regarding stem cell research'.

The socio-demographic profile of the respondents to our questionnaires is as follows. Of the respondents (N=208), more than half (52.9%) were female and over a third (37%) were male, while the remainder (10.1%) did not indicate a gender. Less than one-fifth (18.3%) were aged between 16-34, more than two-fifths (40.9%) between 35-54 and a third (33.7%) over 55, while a small minority (7.2%) declined to indicate an age category. The gender balance of the questionnaire respondents is fairly consistent with the gender balance of the total participants, of whom 53.6 percent were female and 46.4 percent were male (see Table 2.3 above). We do not have the age sample achieved by BMRB to compare this data with our own.

Turning now to our questionnaire data. When asked to reflect on whether 'there was a wide range of different attitudes towards stem cell research among the participants' (N=208), nearly four-fifths (79.8%) of respondents agreed with this statement and less than one-fifth (18.8%) disagreed, while a small number (1.4%) were unsure whether this was an accurate reflection. Yet, our observation data (see *structured dialogue* below) suggest that in many workshops there was very little disagreement among the participants on most issues. A few respondents directly raised the issue of representativeness in response to the open-ended questions. One commenting, for example, 'I suspect the people in the workshop are not really representative of the population as a whole', while another was heard to remark in a break-out group, 'I don't feel it is a realistic representation of how people feel'. Our observations and the participants' responses suggest that the perceived representativeness of the participants was not incontrovertible. Although the first comment appears to reflect the kind of statistical representativeness that we have queried above, it can be interpreted in context to mean a concern for the lack of diversity in societal perspectives articulated at the workshops.

Similar observations emerged from our interviews with the Oversight Group and Stakeholders. Bhattachary noted that the participants in the London workshops held fairly different views on the issues surrounding stem cell research but that unfortunately some of the more contrary views dropped out after the first and second workshops resulting in more homogenised views (Interview with Darren Bhattachary 16 December 2008).

## 4.2 Independence

'Independence' is often conjoined with credibility, as the former is generally seen to confer the latter, especially in the context of public engagement. The dialogue process should be free from any signs of bias, and conducted in a way that ensures maximum independence from the sponsors and their agendas (Rowe and Frewer 2000). The process should be seen to be independent because a perception of bias, even if mistaken, can be damaging to its credibility for publics, stakeholders and policy-makers. A number of procedural elements are often suggested to facilitate independence in a dialogue process. The appointment of a steering body or group comprised of diverse members who represent a broad range of interests, as well as full disclosure of its links to the sponsoring body, can reinforce the independence of a process (Rowe and Frewer 2000). Moreover, the appointment of an independent evaluator from the early planning stages, who is granted extensive access to the various elements of the process, ensures a comprehensive, impartial appraisal of the process' effectiveness that can further enhance its credibility for wider audiences.

An Oversight Group, comprising nineteen members (see Table 1.1 above), was convened by to oversee the public dialogue. Its composition was clearly designed to reflect a broad range of interests relating to stem cell research, with an emphasis on independent voices from universities, charities and public interest groups. One notable absence in this mix is that of a clinician; and while this was recognised by the Oversight Group in its meeting of 12 October 2007, it was never rectified. The potential significance of this omission is underlined by a recent

review of the barriers to regenerative medicine, which emphasised the need for multidisciplinary collaboration between academia, industry and clinicians and widespread cultural, institutional and behavioural change in the NHS to facilitate the adoption of novel cell therapies (Rowley and Martin 2009).

Another omission is that of a legal perspective. An Oversight Group member noted that a lawyer, to explain the status of the embryo in law, was also not represented among the many stakeholders who were invited to participate in various capacities (Interview with Josephine Quintavalle 12 December 2008). The Oversight Group, in consultation with BMRB, the BBSRC and the MRC, was instrumental in reviewing the methodology of the dialogue process, in selecting appropriate expert speakers, in finalising the contents of the background information for the participants, and in finalising the recommendations incorporated in BMRB's final report. Oversight by a multi-institutional and multi-disciplinary group was important for projecting the independence of the dialogue process. A MRC representative claimed that there were numerous email exchanges between the members of the Oversight Group about different aspects of the stimulus material to ensure that none of the content could be viewed as leading (Interview with Simon Wilde 15 December 2008). In response to a question about how the dialogue could have been improved, a BBSRC representative mentioned that in relation to engagement activity around synthetic biology they were considering a wider range of views of the groups doing the commissioning, for example by including the ESRC, but recognised that this might raise issues about clarity of purpose (Interview with Monica Winstanley 5 December 2008).

The appointment of BMRB and its affiliates, Demos and the University of East Anglia, to conduct the public dialogue can be seen as a strategic move by the research councils to elevate both the processes' perceived independence from government and its chances of success by appointing organisations with considerable experience in conducting public engagement processes. The extended facilitation team was drawn from these and similar organisations. BMRB conducted a series of stakeholder interviews from which a diverse range of views on stem cell research were gathered and used to construct a collection of case studies to prompt discussions by the participants. These fictional case-studies tried to reflect the broad spectrum of views on stem cell research held both within and across the stakeholder categories and aimed to reinforce the independence of the process from any particular point of view.

In our questionnaire data, the way in which the public dialogue was run was largely perceived by the participants to be independent from the organisers' and sponsors' views and agendas. A significant majority (86.5%) agreed that 'The people running the workshop did not promote a specific view on the issues around stem cell research' (N=208), with almost half of these in strong agreement with the statement. Only one in ten (10.1%) disputed the dialogue's independence from its sponsors and organisers. Some of those who called into question the dialogue's independence (3.6%), stated that this perceived bias was for them one of the 'least successful aspects' (N=169) of the workshops. The dominant view that the public dialogue was an independent process is corroborated by a majority (84.5%) who also thought that 'the information handouts provided were unbiased' (N=207). Of interest, is that around 10 percent (10.1%) of participants were unsure whether the handouts were biased or not, possibly reflecting a sustained low level of understanding of the issues among this group. Likewise, the selection of expert speakers to reflect a diversity of expertise and opinions on the topic so as not to promote a particular view or agenda over other possibilities is another important determinant for independence. Practicably, this was not achievable in the individual workshops as only two experts were accommodated: one scientist or clinician and one social scientist or ethicist. Rather, the experts were invited to speak about their own work in lay terms and, where relevant, discuss the science behind their work and its regulatory, social, cultural, economic and ethical context. Nevertheless the participants were in high agreement (94.2%) that 'the specialists' presented a balanced range of views on the issues' (N=208), while disagreement with and uncertainty about this statement were evenly divided (2.9%).

Our observation data reveal a slightly different picture, offering the context and nuance that are difficult to capture with questionnaires alone. At the beginning of the workshops, the lead facilitator introduced the facilitation team and the organisations they worked for. Their specific role as facilitators was not detailed beyond that they would each be 'facilitating' a break-out group. BMRB's independence to the sponsors was not always made clear to the participants. Although the lead facilitator in the first London workshop explained that BMRB was contracted by the sponsors to design and run the workshops, a participant in one of the break-out groups later mistook him for a research council representative. Confusion about the relationship between BMRB and the sponsors was further compounded by participants' uncertainty regarding how the agenda for the public dialogue was set and by whom. The sponsors' representatives who spoke at the first round of workshops demonstrated ownership of the process by stating that the BBSRC/MRC had set the overall agenda to which BMRB was working to. It was apparent that some participants understood this to mean that while BMRB was running the workshops the sponsors were behind the scenes pulling the strings.

### 4.3 Early Involvement

A clear role must be assigned to the deliberative process before it is possible to define what early involvement is. There is a general consensus in the literature on public engagement that public participation in the governance of new scientific research that raises ethical questions should occur 'as soon as it is reasonably practicable' (Rowe and Frewer 2000). Involvement of publics is desirable as soon as the key issues become salient and before value judgements become entrenched. Early involvement enhances the credibility of the dialogue process and the sponsors' motives and signals that the process can have genuine influence on technical and policy decision-making processes. Late or 'downstream' engagement with the innovation process may have the reverse effect and be viewed merely as an exercise in communication or legitimisation rather than deliberation.

The timing of public dialogue 'upstream' of the research and development process is a particularly important consideration for the BBSRC's promotion of basic research. It has a particular interest in the publics' perception of the direction and emphasis of the research which it views as vital to securing public trust and projecting openness (Interview with Monica Winstanley 5 December 2008). The intended link between the *Stem Cell Public Dialogue* process and government policy was not clearly defined (see *policy influence* below) either in the dialogue's objectives or in the welcome speech to participants, thus it is difficult to evaluate the dialogue's effectiveness in terms of early involvement as the results of the report have not yet had sufficient time to feed into the policy process.

The responses to our questionnaires indicate that a significant number of participants were sceptical of the appropriateness of the timing of the public dialogue for it to influence policy and future research in this area. Across all three workshops, just over half (55.8%) of all respondents thought 'this public dialogue is taking place early enough in the policy-making process to be influential' (N=208), while almost a third (32.7%) did not know whether or not they would be able to influence the direction of policy in this area. The dialogue's potential impact on future research was even more equivocal. Fewer respondents (45.7%) were confident that 'the results of our discussions will influence the future of stem cell research in the UK' (N=208), while almost as many (46.6%) were unsure of the level of influence the results would have.

This scepticism could have been due in part to the fact that the Human Fertilisation and Embryology (HFE) Bill had its second reading in the Commons (12 May 2008) in between the second and third workshops of the *Stem Cell Public Dialogue* and was debated over eight sittings of the Commons Committee (19 May-12 June 2008) throughout the third round of workshops, and was widely publicised. Yet, responses to our questionnaires before and after the second reading on 12 May show little evidence of changes to participants' perceptions of the appropriateness of the timing of the public dialogue. This suggests that the significant proportion

of respondents who were doubtful of the dialogues timing and potential influence did not base their opinion on the Commons debate of the HFE Bill alone, if at all.

#### 4.4 Policy influence

Policy influence is a significant factor in evaluating a public dialogue. Not only should the results of the dialogue have a genuine impact on public policy, but that impact should be transparent and clear to participants and broader publics (see *transparency* below). Warburton et al. (2007: 5) claim that the 'overall objective of any public engagement exercise is to get effective public engagement that makes a difference to policy'. Rowe and Frewer (2000) point out that the most common criticism of participation processes is that they are seemingly ineffectual, often being seen to legitimate decisions made elsewhere or to give an appearance of consultation whilst lacking serious intent to act on the recommendations. They suggest that a 'clear acceptance beforehand as to how the output will be used' could be most effective in fulfilling this criterion (Rowe and Frewer 2000: 15).

In the workshops, policy influence was generally discussed in terms of how the public dialogue would enable research councils to understand the publics' views on which areas of stem cell research to prioritise. The ways in which government policy-makers and the scientific community might also use the results of the public dialogue (Objective 4) received less attention. Participants at some workshops did express scepticism about the potential influence of the public dialogue stating, for instance, 'We can vote or say whatever we like, it won't make any difference. It'll happen behind closed doors'.

The extent to which a public engagement exercise is able to exert influence upon policy is largely determined (as we discussed above in *early involvement*), by its timing 'upstream' of the policy-making process. While just over half of the respondents agreed that the *Stem Cell Public Dialogue* took place early enough to influence policy, they were sceptical that 'government policy-makers will take the results of our discussions into account in making their decisions' (N=208). Just over one-third (35.6%) of respondents believed this to be the case while more than half (54.3%) were unsure of the government's commitment to acting on the results of the dialogue. Given that twice as many respondents (60.1%) indicated 'I understand how the results of this public dialogue will be used' (N=208) than those who expressed uncertainty (31.3%), it could be assumed either that influencing government policy was not seen as an explicit objective of the public dialogue or that faith in the dialogue process to achieve such an objective was not particularly high. While the respondents were largely sceptical of the government's commitment to translating the results of the public dialogue into policy, the commitment of the sponsors to act on the views and recommendations of the participants (N=207) was seen as more reliable, but not significantly so. More than half of the respondents (56%) agreed that 'the sponsors of this public dialogue will act on the views and recommendations of the participants', while just under two-fifths (39.1%) continued to be unsure about the dialogue's potential influence on decision-making processes. As the public dialogue progressed participants became increasingly uncertain about the sponsors' intentions and by the third workshop the proportion of respondents who thought the sponsors would act on their recommendations dropped to just 42 percent. This uncertainty was, for a small minority (0.6%) who did not believe the public dialogue would make a difference, one of the 'least successful aspects' (N=169) of the workshops.

While Bhattachary admitted that there was no precise decision context for the public dialogue to feed into, he felt there was always an openness from the research councils to take the findings very seriously (Interview with Darren Bhattachary 16 December 2008). The MRC and the BBSRC hosted a workshop for policy decision-makers from their own organisations and from the Department of Health on 19 September 2008. The workshop provided an 'opportunity not only to gain an understanding of the top line results of the dialogue, but also for policymakers in the field of stem cell research to discuss how their plans and strategies match up to the findings from the study' (email from Simon Wilde 15 September 2008). The aim was to have an open and constructive discussion about how funders' planned activities play into public and stakeholder

expectations for the science and its potential applications. Feedback provided during the policy workshop was used by the Department of Health to inform its study of cord blood banking policy and practice in the UK. Participants' feedback regarding cord blood stem cells was specifically discussed in response to questions by the Department's representatives. However, there is no specific mention of the dialogue and the participant's views on cord blood stem cells in the Department's report published on 12 January 2009 (Technopolis Ltd for Department of Health 2009).

A BBSRC representative was confident that the BBSRC has developed a culture and the appropriate structures with which to feed the findings of the public dialogue into its decision-making processes (Interview with Monica Winstanley 5 December 2008). She recognised that it is sometimes difficult for the BBSRC to respond practicably, citing the calls for labelling that emerged from the *GM Nation?* debate, but felt sure that the participation of the BBSRC and the MRC Chief Executives in the BMRB report launch signalled a high-level commitment to taking the findings on board. The report launch event on 17 December 2008 provided a further opportunity to disseminate the dialogue's findings to a broader policy and general audience. An MRC representative thought the range of views and concerns, the language used, the levels of understanding and the information needed by the participants regarding stem cells was going to be very important in terms of the way the MRC communicates with publics in the future (Interview with Simon Wilde 15 December 2008). He indicated that the dialogue report would be discussed by the MRC Council at its next meeting, and from there it would be fed into its relevant Boards, and that any concrete policy action in response to the report's findings would probably occur on a case-by-case basis rather than as wholesale changes.

While influence on policy is seen as the substantive objective of most public engagement activities, these types of events have a broader, normative utility as a rich source of 'social intelligence' that underlines the public value of science. Bhattachary sees the public dialogue as playing both a moral and practical role in the social shaping of stem cell science alongside funders and other institutional actors (Interview with Darren Bhattachary 16 December 2008). Alongside its stated objectives, he envisaged the dialogue's purpose more broadly to involve a democratic approach to 'doing science'.

It is of course difficult to evaluate the extent of influence of the public dialogue as policy decision-making processes are notoriously prolonged and convoluted, and most often occur behind closed doors. However, it is clear that the participants themselves were unsure whether their findings would be used – that 'government policy-makers will take the results our discussions into account in making their decisions' was the most contested statement in the questionnaire – suggesting that the mechanisms by which the results would be fed into government decision-making processes was unclear. Exploring ways of involving publics in decisions about science and technology, including decisions about funding, continues apace. The Engineering and Physical Sciences Research Council's (EPSRC) 2008 dialogue on nanotechnology for healthcare was part of a wider consultation to decide how to frame a call for funding in the area of nanotechnology for medicine and healthcare. The connection to a policy decision was clear. The EPSRC would be deciding to support one or two sub-themes of nanomedicine, and the decision on which areas to concentrate on would be informed by the results of the public dialogue, together with other inputs from the research community, industry representatives and clinicians (Jones 2008). The measurable influence of the nanotechnology for healthcare dialogue encourages public confidence in dialogue projects to affect influence on policy in the future.

#### **4.5 Transparency**

The criterion of 'transparency' stipulates that the process and its modus operandi should be transparent to those both internal and external to the process. This emphasises the open and clear nature of the participation process to both the participants and to wider audiences. It is especially important that the participants can see how decisions are being made, and that they are given access to the information and documents they need to make a valuable contribution to

the discussions. Withholding information from participants should take place only exceptionally, and the reasons for doing so should be explained (Rowe and Frewer 2000). Petts and Leach (2000) emphasise that transparency must be maintained from the inception of the process, throughout its operation and in the communication of its outcomes, such that the diverse range of views expressed during the dialogue are acknowledged in the outcome.

As noted above, the objectives of the dialogue and the role and composition of the Oversight Group were not explicitly mentioned in the workshop, although the objectives were publicly available on the BBSRC website. However, it was not always made clear how the findings of any particular workshop would relate to the overall objectives of the dialogue. In some cases (such as in the second workshop in Cardiff) how the findings will be used was not discussed; other times (such as the first workshop in London) it was explained that BMRB would take the key messages from the dialogues and spend a few months communicating these to the research councils, by spending time with their decision-makers. It was regularly mentioned that the results of the workshops would influence which aspects of stem cell research the research councils would prioritise in the future. In the final round of workshops, participants were told that there might be an opportunity for them to get involved in the launch of the public dialogue report. The majority of participants in the workshops appeared generally keen to engage in subsequent dialogues and in some workshops, such as the first Edinburgh workshop, the final launch event in London was mentioned as an opportunity to continue to engage in a dialogue on these issues. The report launch, held in London in December 2008, however provided limited opportunity for participants' to continue to engage in a dialogue as few participants were invited to attend because of funding constraints (see *resource accessibility* below).

What the public dialogue aimed to achieve was transparent to the participants, the great majority (94.7%) of whom agreed, 'I understand the purpose of this public dialogue' (N=208). Very few participants disagreed (2.9%) with this statement or answered 'don't know' (2.4%). However, participants' understanding of how the results of the public dialogue would be used suggests that this important stage of the dialogue process was not explained as clearly by the organisers or sponsors. While the majority (60.1%) agreed 'I understand how the results of this public dialogue will be used' (N=208) almost a third (31.3%) of respondents expressed uncertainty but less than one in ten (8.7%) disagreed. Responses to our questionnaires indicate that by the third workshop, participants had a much clearer understanding of how the results of the dialogue would be used (75% compared to 60.1% overall) compared to earlier workshops. Better conveyed to the participants was how they could take the debate forward after the public dialogue had come to an end. Nearly four-fifths (79.7%) of the respondents agreed that they 'understood how they could continue to be involved in a dialogue on these issues' (N=207), while few (5.3%) disagreed and fifteen percent (15%) were unsure.

In our interviews with the Oversight Group and stakeholders, we asked whether public engagement can be considered meaningful in the context of the clear mandate for stem cell research expressed in the UKSCI's terms of reference.<sup>3</sup> At the core of this question is a concern about transparency and whether the *Stem Cell Public Dialogue* is viewed internally and externally as a legitimate or legitimising process of public engagement. The MRC representative acknowledged that public engagement is a question of balance. It's about asking the public what they think, but on the issues where they defer to the experts, it's about acting responsibly on the public's behalf and, most importantly, it's about encouraging trust in the process of public engagement (Interview with Simon Wilde 15 December 2008). He explained,

'one thing we have learned from our ongoing activities on stem cell research is that . . . the way in which you become a leader in stem cell research is by being responsive to

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<sup>3</sup> The UKSCI was charged with developing a ten year vision for UK stem cell research which seeks to make the UK the most scientifically and commercially productive locations for this activity over the coming decade and which commands the support of public and private research funders, practitioners and commercial partners.

public opinion and by making sure that the things that encourage trust in the process of doing stem cell research are things like regulation and . . . trust in the scientists . . . and the ethical probity of what you are doing' (Interview with Simon Wilde 15 December 2008).

Wilde was confident that the dialogue will influence the ways in which the joint Stem Cell Communications Coalition<sup>4</sup>, established by the MRC, will engage with publics in the future. A BBSRC representative was not aware of a mapped out trajectory of a sustained program of public dialogue and engagement around stem cell research and their clinical applications (Interview with Monica Winstanley 5 December 2008). She was however confident that as the field progressed and clinical applications increased that dialogue would be initiated around these developments.

Bhattachary concurred that the public dialogue had a meaningful role to play. His view is that 'it was part and parcel of the wider [social and cultural] support for regulation and legislation, particularly for stem cell science to develop and flourish in the UK' (Interview with Darren Bhattachary 16 December 2008). However, he warned that if you only look at the top line message from the dialogue and see it as a green light for innovation, you will miss the point. There are caveats; conditions that need to be met that are fundamental to the participants' vision of stem cell research. An example is their vision of the commercialisation of the products of stem cell research, the current structures and cultures of the institutions' involved in that process and how public views sit in that space as well. Bhattachary believes the social and ethical issues raised by stem cell research have yet to be properly tested and that the issue of commercialisation may prove to be the watershed. He views the results of the public dialogue as fundamental to understanding these wider factors and to building resilient institutions that can overcome crises of public trust.

Our analysis suggests that, as with *policy influence* above, while the dialogue process was transparent in itself and participants were relatively happy with the way it was run, there was a lack of definition, particularly in the early stages of the public dialogue, regarding the ways in which the results of the dialogue would be used by decision-makers. Hence, the great majority of participants said they broadly understood the purpose of the dialogue, but far fewer said that they knew how the results would be used. These results suggest that more could have been done from the outset to clearly explain the process by which the results of the dialogue, and of individual workshops, would be used.

#### **4.6 Resource accessibility**

The success of any public engagement exercise is dependent on its participants having the appropriate resources to enable them to undertake their duties to the best of their abilities. This requires that participants receive the utmost human, financial and material resources that can be provided to them. Restrictions on or deficiencies in the provision of any of these resources could compromise the process and its results (Rowe and Frewer 2000). Facilitators and experts should also have suitable communication skills and, if necessary, be given the appropriate training (Petts and Leach 2000). A common resource constraint when deliberating complex issues is time. Insufficient time to present and deliberate the range of relevant issues can lead to frustration and, ultimately, dissatisfaction with the process. Crucially, time constraints may also lead to nebulous and unsophisticated results that have little or no utility for decision-makers (Mohr 2003).

Our observations revealed that participants' generally responded positively to the materials introduced to the workshops to stimulate dialogue. The handouts used to guide the discussions in the break-out sessions were either read aloud by the facilitators, or read quietly by the participants and then opened up for discussion. On the more complex topics related to the

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<sup>4</sup> The MRC has created a joint Stem Cells Communications Coalition, composed of the research councils, charities, health departments, and regulatory authorities, so that all the agencies speak with one voice and explain to the public the work being done.

technical and regulatory science base, participants found it more helpful to read the text in small sections, stopping to discuss salient points before moving on to the next. The discussions prompted by the topic guides were generally lively and participants' often drew on anecdotes of their own experiences or those of their family or friends to frame their discussions. Two facilitators thought that some of the text in the topic guides was a lot for some participants to take in, while another commented that the 'visions' in the handouts used to illustrate different perspectives on stem cell research worked particularly well and brought the sessions alive.

Each workshop was attended by two experts: one with a scientific or clinical research background to discuss the basics of stem cell science and one with a social science or ethical perspective to address the social, ethical and regulatory aspects of the research. The Oversight Group and BMRB targeted experts who were considered eminent in their field and who had experience in communicating with publics who don't necessarily have the technical knowledge of the issues being discussed (Interview with Sharon Fortune 5 December 2008, Interview with Simon Wilde 15 December 2008). The experts' brief was to provide, in ten minutes, an overview of stem cell science or its social, ethical and regulatory dimensions interspersed with a small number of specific examples from their own work.

The vast majority of expert speakers (see Table 3.1 above) were university researchers, with the remaining few drawn from civil society organisations – industry was not represented at all. Industry and a range of broader perspectives were included in the fictional case studies of the topic guides, but it is curious that their views were not considered among the expert speakers. While we are aware that only Higher Education Institutions (HEIs) and Research Council Institutes (RCIs) are eligible for funding by the research councils, industrial perspectives are nonetheless an integral part of the stem cell research community and their exclusion served to enforce participants' scepticism about their motives for stem cell research. We observed considerable homogeneity among the general views and attitudes of the scientists and clinicians, save for the inclusion of embryonic stem cell scientists and adult stem cell scientists. Likewise, the interspersing of social scientists with ethicists served to conflate the two disciplines so that ethical questions tended to dominate the expert presentations and subsequent dialogue by the participants; and this is borne out by the final report. Questions about social science, such as the meaning of different types of policy cultures, what translational medicine means in practice, and how clinical take-up is shaped by a range of different processes could have been given greater emphasis (Interview with Andrew Webster 23 December 2008). Engagement with a broader range of stakeholders in a genuine two-way discussion with the public participants was suggested as one way to improve the process (Interview with Jack Stilgoe 18 December 2008).

The relative influence of the scientists and clinicians compared to the social scientists and ethicists on the opinions of the participants emerged both from our observations and from our interviews with the Oversight Group and stakeholders. One facilitator noted that the participants tended to be fairly sceptical and critical of the presentations by the ethical and social experts whereas they appeared more favourable towards the scientists (Interview with Peter Simmons 16 December 2008). Bhattachary observed that the social scientists weren't as forceful in their arguments while the ethicists tended to pose open questions rather than coming out with a definitive position (Interview with Darren Bhattachary 16 December 2008). We observed that the scientists/clinicians were typically in favour of stem cell science and the ethicists/social scientists were generally reluctant to criticise it. There was an absence of industrial, clinical or social science experts willing to discuss the problems that have already been encountered with stem cell research and regenerative medicine (e.g. the fact that we are still at the early stages of development for cell therapies for many diseases) and other novel therapeutics (e.g. gene therapies, xenotransplantation) and the potential problems we are likely to encounter in the future (e.g. the logistical and procedural difficulties that will be involved in translating stem cell science into the clinic). These points should not have dominated the discussion but they should at least have been made so that participants could base their discussions on all the available information.



The positive framing of stem cell research – via the generally favourable perspectives of academics (clinicians/scientists and ethicists/social scientists) compared to alternative or more critical/sceptical perspectives (e.g. advocacy/pro-life group, religious group, journalistic or NHS viewpoints) – limited the range of participants' discussion and increased the potential creation of hyperbolic public expectations, and the potential for obtaining positively-biased indications of public approval and acceptance. Even if representatives of such organisations were not actually invited to speak, alternative/critical voices around stem cell research could have been given greater emphasis in the handouts.

The participants responded more enthusiastically to animated and articulate speakers who did not attempt to cover too much information, who kept to their allocated time limit, who did not use complex terminology and spoke at a pace that made the talk easy to follow and whose visual presentations were dominated by images rather than dense text. Furthermore, those speakers who responded to participants' questions with candour and humour were also well received. One particularly enthusiastic expert who was clearly experienced in communicating with lay audiences was the only speaker to receive a round of applause that we observed. These attributes were influential in changing participants' views on certain issues. For example, after engaging with one expert (whose presentation was especially well received) in a Q&A session about the government's regulation of human embryonic stem cells (hESC) research and the procurement of embryos, we observed that the mood among the participants had changed from one of distrust in the government to act ethically or in the interests of the public, to one of trust in the government and a reluctance for industry to lead the research. Where expert speakers failed to enthuse with their presentations, we noticed that participants' were less keen to question them in the break-out sessions and were therefore managing only to discuss the issues on a more superficial level. During particularly technical or jargonistic presentations participants' were overheard remarking, 'what is heterogeneous?', 'people won't know what that is' and 'I fell asleep during through that one'. In some of these situations the lead facilitators politely interrupted the speakers to ask for clarification.

Where expert speakers tried to cover too much ground in their presentations or relied too heavily upon technical language or acronyms, participants often felt overwhelmed by the information. In spite of this, participants generally seemed eager to take on board the information provided to them and when prompted about whether they felt they needed more information to discuss the issues in more detail they responded affirmatively. The level and depth of their questioning suggests that they grasped the social and ethical dimensions of the research with some ease, but excessive scientific and technical details did prove more difficult to grasp. For example, the 14-day rule governing the use of embryos discussed by one expert in his presentation needed to be re-explained later in a break-out session as the participants were not sure whether this was considered unnecessarily restrictive by stem cell scientists. During the lunch break, three participants were heard to state that they would have liked to have been given copies of the expert's presentation to help them to better understand the scientific and technical details it covered. Timing the distribution of information to the participants is also important to avoid any unanticipated disruptions. During some expert presentations, we observed a small number of participants reading the topic guide rather paying attention to the experts.

The information provided both in the topic guides and by the expert speakers in their presentations was deemed sufficient by the participants, the majority (85%) of whom agreed with the statement, 'I had access to all of the information I needed to fully engage in the discussions' (N=207). Less than one in ten (8.2%) was unsure whether they had sufficient access, while fewer (6.8%) again disagreed. The comprehensible way in which the expert speakers communicated their information was seen as one of the 'most successful aspect of the workshops' (N=199) by almost a quarter of the respondents (23.6%). However, for one in five (20.1%) respondents, problems with information delivery were seen as one of the 'least successful aspects of the workshops' (N=169). A significant number of these participants thought that some of the presentations were 'too technical', that they 'went over [people's] head[s]', or that they were 'confusing'. Others commented that they were 'still not clear' on some issues, and that they would

have liked more varied information delivery, for example, using 'video footage'. More time to talk with the expert speakers would also have been appreciated.

Our interviews with the Oversight Group and stakeholders revealed a number of problems related to the recruitment of expert speakers for the public dialogue. The majority of speakers, some of whom had also participated in the stakeholder interviews conducted by BMRB, were recruited well in advance of the public workshops, but a few proved difficult to contact. The organisers acknowledged that asking these busy people to give up their Saturday, without the incentive of an honorarium, was a lot to ask of the speakers (Interview with Darren Bhattachary 16 December 2008). Recruiting social scientists whose research is traditionally not funded by the BBSRC or the MRC, and who therefore do not have a relationship with these research councils, was especially difficult in some cases. To make sure the three to four key messages the experts speakers were asked to focus on in their presentations were communicated clearly, the lead facilitator followed each presentation with a slide summarising the key points that would then guide the discussions in the break-out groups. In spite of these attempts at clarification, Bhattachary admitted that some of the handouts were slightly text heavy and that some areas of stem cell research, such as the use of induced pluripotent stem cells (IPS), were conceptually difficult for the participants to understand (Interview with Darren Bhattachary 16 December 2008).

Time limits are a necessary device for focussing discussions and, for the most part, sufficient time appeared to have been given across the workshops. In the closing stages of some of the workshops, we observed that participants were still raising new points for discussion even though the facilitators were trying to wrap things up. This suggests that the time management of some sessions could have been handled better to ensure the introduction and discussion of all relevant issues. On occasion there were also problems with the scheduled visits of experts to break-out groups – sometimes an expert would spend an entire session with one group, while other groups had no experts visit at all.

A large majority (91.7%) of respondents agreed that 'all the important issues were covered in our discussions' (N=206), leaving few who were uncertain (5.8%) or who disagreed (2.4%). This would seem to suggest that participants were given sufficient time to engage in comprehensive discussions. This conclusion also emerged from the electronic voting in the workshops where, overall, the participants agreed, 'I had enough time to fully discuss the issues'. For the minority who did not agree with the above statement, a key resource constraint preventing a successful exercise was that of time. More than ten percent (13%) of respondents listed poor use of time resources as one of the 'least successful aspects of the workshops' (N=169). These participants were mostly concerned with the lack of time allocated to the experts for their presentations. Some felt the experts were 'rushed when presenting their information' and that 'more time should have been given to them'. A few respondents (2%) thought that some of the workshops sessions were too long.

Finally, the provision of suitable workshop accommodation and refreshments is important for guaranteeing participants' comfort during long and demanding days, which in turn is vital for their sustained concentration. It is clear from participants' comments, however, that some of them thought that these basic resources were not adequate. Of the 'least successful aspects of the workshops' (N=169) noted, one in ten (10.7%) respondents mentioned resources such as 'venue', 'rooms' and 'food'. Common complaints focused on unsuitable room layouts for the break-out sessions and on the poor quality and limited dietary choice of the refreshments. In some locations, such as Cardiff, the rooms were not ideally shaped for the break-out groups, resulting in more fractured dialogue. The third London workshop was also held in an unsuitable venue, due to a mix-up in its booking, which did not allow for small groups, instead imposing large, unmanageable groups which hampered effective discussion.

## 4.7 Task definition

The roles and responsibilities of each of the participant groups (sponsors, organisers, public participants, experts) should be unambiguous and clearly defined so that each group is aware of not only its particular role but how the roles of the other groups links in with theirs, thus 'task definition'. The nature and scope of the entire process, its outcomes and impact should also be clear to all involved from the outset. Task definition can have a significant bearing on the effectiveness of a process, as well as its credibility (Rowe and Frewer 2000). The objectives of the process should be clear to those both internal and external to the process so that expectations about what the process is able to achieve are realistic.

Our observations revealed mixed results when it came to defining the roles of the participant groups in the context of the dialogue's objectives. In the first round of workshops, the lead facilitator gave a brief introduction to the dialogue process and its importance for helping decision-makers. The nature and scope of their role was described to the participants' by one facilitator as 'you are all part of a big experiment'. An overview of the day and how it would progress was also provided. A representative from either the BBSRC or MRC, the dialogue sponsors, also welcomed participants and reiterated the importance of the dialogue to the decision-making processes of the research councils, particularly in helping them to identify key areas for funding. These presentations were delivered with varying degrees of success and enthusiasm, with infrequent PR overtones. On occasion, the facilitators reminded the participants in their break-out groups that their opinions will inform future research and funding priorities.

The briefing of some expert speakers about their roles and responsibilities appears to have been haphazard, occurring at the eleventh-hour (especially those who attended the workshops in Cardiff). We observed that a small number of the experts had not been properly briefed about the specific information they should aim to convey and the level at which to pitch their presentation – leading to talks that were far too complex or covered issues that were off-topic, confusion and boredom among participants and poor engagement with key issues. Some also seemed unaware of the importance or value of their attendance beyond their actual presentation, arriving just prior to their talk and leaving immediately after. Some were also unaware that the workshop they were taking part in was one of many in an extended national dialogue.

Even though we observed little explanation of the dialogue's objectives and sometimes vague descriptions of their roles and responsibilities, responses to the questionnaires confirm that the participants were clear about the nature of the public dialogue and the role they were expected to play. The great majority (97.1%) of respondents agreed that they 'were given a clear indication of what this workshop would involve' (N=208). A similarly high proportion (95.7%) responded that they 'understood at all times what they had to do' (N=208). Their responses indicate a high level of satisfaction with the way in which their particular role in the public dialogue was defined and that of the purpose and structure of the process itself.

How the sponsors' objectives for the public dialogue were derived was not made clear in any of the workshops we observed. Nor were the processes by which the results of the public dialogue would be fed back into policy-making processes. While the dialogue's fourth objective to enable participants' views and concerns to be taken into account in policy development was discussed in relation to the research councils, little mention was made of the dialogue's potential input into policy development by the scientific community and government policy-makers, also contained within the same aim.

In our interviews with the Oversight Group and stakeholders, we asked them to reflect on the public dialogue's success or effectiveness against the stated 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', and 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', were considered, for the

most part, to have been successfully achieved. 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', was considered less successful. It was felt that 'we probably didn't network enough' (Interview with Darren Bhattachary 16 December 2008), and instead involved 'the usual suspects' (Interview with Andrew Webster 23 December 2008). The extent to which objective 3, 'Raise public awareness about the potential opportunities, challenges and uncertainties of stem cell research' was achievable, or even realistic, came up in our interviews a number of times (Interview with Peter Simmons 16 December 2008, Interview with Jack Stilgoe 18 December 2008). Their view was consistent with Fixdal (1997) and Campbell and Townsend (2003) who question the representativeness of the opinions of a small proportion of the 'wider public'. Objective 5, 'Inform development of a plan for a longer-term project of public dialogue and engagement around stem cell research', was considered too vague to be able to measure its effectiveness (Interview with Josephine Quintavalle 12 December 2008, Interview with Andrew Webster 23 December 2008). A pitfall of engagement activities is that they can come to an abrupt halt once their results have been published. Dissemination of the findings can be ineffectual resulting in months of effort by both the organisers and the participants being wasted. Such a pitfall is obviously a significant concern for Sciencewise as a prominent funder of these events. At the BMRB report launch in December, Alison Crowther, the Sciencewise representative on the Oversight Group, pleaded for feedback from those in attendance on how to avoid such pitfalls re-occurring.

#### **4.8 Structured dialogue**

A successful public engagement process is one that enables and encourages effective and inclusive dialogue. Thus the particular methods chosen by the organisers to create convivial spaces for dialogue, and their management by experienced facilitators, are key factors in establishing and maintaining 'structured dialogue'. A novel component of the *Stem Cell Public Dialogue* process was the use of interactive voting by the participants to register their opinions on certain issues at the beginning and end of each of the workshops. The electronic voting provided 'real-time' feedback on what the participants' views were regarding a range of stem cell issues. This information was used by the organisers to structure discussion around issues of particular significance.

The plenary sessions were largely controlled by the lead facilitator for organisational purposes. The break-out sessions were less controlled and participants were arranged in a circle to facilitate group discussion. The balance of male and female input was fairly equal, with perhaps slightly more input from men in the smaller groups (except in the Newcastle workshops). Participants were regularly encouraged by the facilitators to contribute to the discussions. Discussions were generally allowed to flow freely with interventions from the facilitators only when one participant interrupted another, to follow up an unclear statement or to encourage a participant to elaborate on a particularly interesting remark. If participants were quiet or were thought to have an interesting or different viewpoint they were invited to share it with the group. Minority views were welcomed by the facilitators who often took time to explore why such views were held. In spite of this encouragement, one participant in London, who believed her opinion to be a minority view that was contrary to the other views presented in the public dialogue, did not feel that she had the power or authority to be heard. Likewise, a Cardiff participant was reluctant, until repeatedly pressed by the moderator, to express her opinion that hESC research was morally wrong. Although a few participants repeatedly interrupted or challenged the perspectives of others in the London workshops, disagreements were rare and generally amicable for such an ethically-complex topic. Such disagreements, when they did occur, often centred on differing religious convictions or personal experiences with family members or friends. We observed little disruptive behaviour by the participants who seemed satisfied rather than frustrated with the process, although one or two participants in some workshops did leave during the workshop for unknown reasons.

Voting sessions using electronic IML audience engagement technology were held in each workshop to record participants' views on a range of issues before and after their discussions. This process proved particularly engaging for the participants who registered their votes anonymously using individual hand held devices during a ticking count down. Results, in graph format, were projected onto a screen at the front of the room. The voting sessions held at the close of the workshops displayed both before and after responses so that participants were able to immediately gauge whether their views had changed on each of the issues. Results were often greeted with laughter and comments between the participants. The voting process however did not always run smoothly. In the first Edinburgh workshop the technology failed and participants had to improvise by raising their hands to indicate their answer. However, the lack of anonymity did not seem to prevent participants from responding without hesitation. Mix-ups with pin numbers and broken devices meant that occasionally some participants were unable to cast a vote.

While providing a clear structure to guide dialogue ensures that discussions do not become unwieldy, the structure cannot be so rigid as to prevent participants from introducing new topics that they think are important or relevant to the discussion at hand. To draw a boundary around permissible topics may also lead to claims of pre-framing by the sponsors and organisers, calling into question both the processes' independence and transparency. From the participants' point of view, the *Stem Cell Public Dialogue* process managed to achieve a workable balance between both structured and flexible dialogue. Over four-fifths (82.7%) of respondents agreed that 'the format of the workshop enabled new topics to be introduced' (N=208), while around one in ten (11.1%) was unsure about this statement. Participants obviously felt unfettered in being able to discuss the issues that were important to them as a significant majority (94.7%) responded that they were 'able to say everything they wanted to' (N=208). Yet it seems that this unfettered discourse was deftly handled by the facilitators as the same percentage (94.7%) of respondents also agreed that 'no one person was allowed to dominate discussions unfairly' (N=207). Only in the London workshops was there a clear sense that some participants dominated discussions, with around one in ten (11%) respondents disagreeing with this statement.

One facilitator thought the balance achieved between organised, top-down control of the discussion and the bottom-up generation of public opinion was less successful. His view was that some participants felt they had been excluded from the discussion or were not encouraged to talk about certain things (Interview with Jack Stilgoe 18 December 2008).

#### **4.9 Translation quality**

This criterion, identified by Horlick-Jones et al. (2007a, 2007b), emerged from their evaluation of the *GM Nation?* public dialogue process. Examining 'translation quality' emphasises the role of the engagement process as an information system, rather than just an organisational process. Translation quality seeks to evaluate how effectively the many sources of knowledge are utilised, how effectively information is provided to the relevant groups, and how issues are framed in discussions. As a newly-developed criterion, Horlick-Jones et al. emphasise that 'considerable work is needed to develop specific instruments and procedures in order to assess translation quality' in systematic ways. The inclusion of translation quality in this evaluation will contribute to the study of engagement processes as information systems and in examining how translation quality can best be evaluated.

Although participants regularly drew on personal experiences in the anecdotes they used to contextualise their arguments, their dialogue was largely framed by the topic guides and the workshop handouts. The general agenda as set by the BBSRC/MRC was made clear but the question of how specific topics and views were initially framed was not explained to the participants. Framing played a significant role in bounding their discussions as participants also showed a strong tendency to follow and explore the key issues raised in the experts' presentations. These presentations most often reiterated the key points and boundaries of the discussions established by the topic guides, but the experts who were inadequately briefed had

more freedom to pursue their own interests and this left open some room for manoeuvre in terms of what was discussed. The experts' presentations were particularly effective in opening up discussions around particular aspects of stem cell research in which they were expert. For example, the use of cord blood stem cells and induced pluripotent stem cells (IPS) as alternatives to hESCs proved to be one of the most revelatory discussions of the public dialogue. As discussed above in *resource accessibility*, the experts' presentations were influential in shaping participants' opinions. Although the technicality of some of the scientific presentations, some of which did not seem to have been developed for a non-scientific audience, impeded good understanding and were less influential.

Discussions in some workshops were occasionally contextualised by the facilitators with reference to participants' previous points of view to determine whether their views would change given certain circumstances. Occasionally participants tried to extend the range of debate by introducing new topics (e.g. Newcastle W1), but the discussions were generally steered by the facilitators back to the issues raised in the topic guides. It is difficult to measure the extent to which each subsequent workshop was informed and shaped by conclusions drawn from previous workshops. Conclusions, able to be used as a platform for subsequent discussions, were not always drawn at the end of each workshop nor were the findings from previous workshops always recapitulated. When the list of the three key points to be presented to the research councils was made at end of a workshop it was unclear whether these would also be used to shape subsequent dialogue. While recapitulation of the formal conclusions drawn from previous workshops was less obvious, the informal reiteration of participants' comments and points of view was common.

Little evidence was presented by the facilitators that the *Stem Cell Public Dialogue* was learning from and building upon previous consultations and dialogue projects. The lead facilitator of the London workshops did introduce the public dialogue as one of a growing number of public engagement activities that aimed to elicit public opinion and feedback on controversial technologies, making specific mention of the *GM Nation?* public debate. That BMRB was also conducting a parallel public dialogue on the issue of nanotechnology for healthcare for the EPSRC was not mentioned, that we observed. Likewise, that the public dialogue was informed by a stakeholder consultation that helped to frame the topics for discussion was also not made explicit.

The *translation quality* of issues for discussion in the stimulus materials such as the topic guides and the expert presentations was considered highly effective in stimulating dialogue among the participants. A significant majority (97.6%) agreed that 'issues were presented in such a way that I felt able to ask questions and discuss my own views' (N=207). The subsequent management by the facilitators of the essence of the participants' discussions was also viewed extremely positively, with the majority (96.6%) of participants agreeing that 'the substance of our group discussions was effectively and fairly captured by the facilitator/s in their summings-up' (N=207). Furthermore, there was a general perception that conclusions drawn from these discussions were used to inform and contextualise subsequent deliberations. More than three-quarters (78.7%) of participants agreed that 'conclusions drawn from earlier sessions of this workshop were used to inform subsequent sessions' (N=207), while almost one in five (17.9%) was unsure whether this was the case.

When reflecting on the public dialogue as an information system, some of our Oversight Group and stakeholder interviewees noted its success in this area. Bhattachary asserts that the facilitators were responsive to how effectively the sources of knowledge were being utilised, how effectively information was being provided, and how issues were being framed in discussions. For instance, he recognised that there were issues around participants' understanding of the distinction between a blastocyst and an embryo and the purpose served by the 14-day rule and, in response, created some slides on the Carnegie Stages of embryo development to clarify these points (Interview with Darren Bhattachary 16 December 2008). His method of moderation is, he maintains, to frame emergent topics on the basis of what is being discussed by the participants.

There was a debriefing by the facilitators between each phase of the workshops which led to some changes to the design of subsequent workshops and to the rewriting of some of the stimulus materials to reframe content in response to, for example, participants' increasing interest in foetal and cord blood cells (Interview with Darren Bhattachary 16 December 2008).

The integration of stakeholder and public voices and opinions was considered one of the main strengths of the *Stem Cell Public Dialogue's* methodology. Summarising the breadth of this opinion however presented certain challenges for BMRB and the Oversight Group when it came to drafting the conclusions and a set of recommendations for the report. In the Oversight Group meeting of 28 November 2008 to discuss the draft of the final report and the outputs of the dialogue, we observed certain members imposing their own opinions on the content of the recommendations, particularly with regard to the issue of regulation and the number of authorities involved in that process. Furthermore, it was not clear to us how feedback from the public participants that differed or conflicted with that of the stakeholders would be distinguishable in the recommendations. Rather what we observed was an amalgamation of opinions including, in some cases, those of some members of the Oversight Group. In our interviews before the final report was launched, we queried the handling of the recommendations and the representation of different voices, including minority voices. Bhattachary acknowledged there is a danger in simplifying a message to the point where it sends out the wrong message (Interview with Darren Bhattachary 16 December 2008). In finalising the recommendations, he stated that he purposely tried to reflect that tension and ambiguity between different voices while still trying to convey the overall view. The final list of recommendations is more nuanced in terms of projecting the ambiguity of opinions; however when read in isolation to the broader conclusions, any tension among the views within and between the participant and stakeholders group is indiscernible. This is a view shared by a couple of Oversight Group members (Interview with Josephine Quintavalle 12 December 2008, Interview with Andrew Webster 23 December 2008).

A final consideration in measuring the *translation quality* of the public dialogue to determine its effectiveness as an information system is whether its findings are communicated in a way that is compatible with the decision-making processes it aims to inform. One Oversight Group member was of the opinion that the recommendations formulated by BMRB and the Oversight Group were reflections on the outcome rather than points for action, and therefore questioned their utility for decision-makers (Interview with Andrew Webster 23 December 2008).

#### **4.10 Additional criteria**

This section outlines any additional criteria identified from our various data sets, but mostly from participants' responses to the open-answer questions in our questionnaires. Understandably, the participants' criteria overlap to a certain extent with the normative criteria identified by the literature. However the participants' experience of this particular dialogue process enables a more nuanced analysis and reveals supplementary criteria not fully encapsulated by the normative criteria.

##### **Participant learning**

Public engagement initiatives strive to demonstrate that policy-making is capable of blending elements of representative democracy with participatory democratic criteria (participant learning and empowerment) to accommodate a broader range of interests, values and worldviews (Mohr 2003). While *participant learning* is commonly associated with 'lay' or 'public' participants, what is often overlooked is that public engagement activities also serve to 'socialise the expert speakers into lay discourse and alert them to the range of presuppositions embedded in the views held outside the expert community' (Mohr 2003: 288). On a personal level, this was the case for Chris Mason (Oversight Group member and expert speaker) who commented:

'I gained a lot from listening to the views of a very diverse range of members of the public who, by and large, were very supportive of us but had a few areas where they weren't

certain. I think it has allowed me to sort of set my barometer at a more appropriate point' (Interview with Chris Mason 9 December 2008).

However, another Oversight Group member noted the absence of 'great two-way dialogue where the scientists' also learn' (Interview with Alison Crowther 10 December 2008). In a genuine two-way dialogue between experts and public participants, one would also expect experts to engage with the participants' as well as their own ethical assumptions rather than just play the role of providing 'information'. Due to the constraints on our evaluation, we were not able to pursue this aspect more fully, though our observations suggest that the *Stem Cell Public Dialogue* was primarily focused on generating learning through discussion amongst public participants (rather than amongst experts as well).

We asked the public participants a couple of questions to determine whether participation had made a difference to their views on the issues discussed in the workshops, and in what ways. Participants were asked, 'has participating in this workshop made a difference to what you think about these issues?' (N=208), to which the majority (81.3%) responded that it had, while fewer than fifteen percent (14.8%) responded that it hadn't. When asked, 'how were your views affected by the workshop?' (N=161), most respondents (59%) stated that the dialogue process had increased their knowledge and understanding of the issues surrounding stem cell research. 'It gave me a greater understanding of the different areas of stem cell research and all the complexities involved' was typical of the responses. This particular characteristic of participant learning was, for the majority (48.2%) of respondents, one of 'the most successful aspects' (N=199) of the workshops. As a result of their participation, a quarter (25.5%) of respondents admitted they had become more in favour of, or had increased confidence in, stem cell research. Likewise, fewer than ten percent (9.9%) had developed a greater awareness of the benefits and practical applications of stem cell research. A small minority (5.6%) denied that their views had been affected; claiming that they remain opposed to, or were still unsure about, some aspects of stem cell research.

These answers reveal that a significant proportion of participants found the dialogue process educative. A view supported by the fact that many of the participants mentioned that they possessed little knowledge of stem cell research prior to attending the workshops. However the extent to which other participants, such as the expert speakers or even the Oversight Group, learned from the public participants is not as measurable. This aspect of participant learning is often overlooked in evaluations of engagement activities, as it was in this one, and this is one lesson to take forward for future evaluation exercises.

### **Hearing other people's views**

Participant learning can have many dimensions, as we discussed above, but one dimension we are yet to consider is participant learning as a result of listening to other participants' points of view. According to the participants who responded to the question, 'what aspects of the workshop made a difference to what you think about these issues' (N=21), other people's views was ranked second (23.8%) behind expert or scientific opinion (61.9%) and ahead of the stimulus materials (14.3%) provided by the organisers. These avenues of influence are considered by the participants to be among the 'most successful aspects' (N=199) of the workshops. The participation of experts, especially the ways in which they delivered their information (23.6%), was considered by participants as a marginally more successful aspect of the workshop than that of hearing other people's views and engaging in a dialogue with them (17.1%). Nevertheless, other participants' views and experiences were considerably influential in informing and changing participants' own opinions on certain issues.

For participants, interaction with others in a collaborative and communicative atmosphere was a significant factor in their judgement of the success of the workshops. These responses also indicate a measure of success in this area, taking into account the relatively large proportion of people who named this factor as the most successful part of the workshop. This demonstrates



that a significant proportion of participants were happy with the dialogue environment in terms of its ability to prompt meaningful discussion.

### **Engagement with experts**

Observation of the workshops showed that participants were eager to discuss the issues with the expert speakers and welcomed the opportunities to engage with them. The experts were often questioned extensively especially as participants increasingly understood the technical processes behind stem cell research. Often, participants mentioned that they would have liked to have more time with experts, or more time to be able to ask them questions (see *time management* below).

In the questionnaires, when asked what the 'most successful aspect of the workshop' (N=199) had been for them personally, almost a quarter of respondents (23.6%) said that it had been the participation of experts and the way in which they delivered their information. Four-fifths (81%) of respondents said the 'workshops had made a difference to what they thought about the issues', and of the 21 people who explained which specific aspects had made a difference, 13 cited engagement with experts.

However, it was striking that there was little opportunity for the different experts at any workshop to interact with each other, for example, for the purpose of questioning or rebutting each other's claims.

### **Opportunity to participate**

The opportunity to participate emerged as a valued criterion for the participants' evaluation of the effectiveness of the public dialogue. A significant majority (90.4%) of participants responded that it is 'very important to involve the public in discussing these sorts of issues' (N=208). Fewer than one in ten (8.6%) were of the opinion that it was 'fairly important', while a small minority (1%) were of the view that it was 'not very important' at all. Being given the opportunity to express your own views was considered one of the 'most successful aspects' (N=199) of the workshops by a small percentage (4%) of respondents. Even fewer (0.6%) found that one of the 'least successful aspects' (N=169) of the workshops was that the opportunity to participate failed to provide any stimulus for them, thus they lacked interest in the process. The 'opportunity to participate' was clearly a significant criterion against which the respondents evaluated the success of the workshop, as evident in the first Edinburgh workshop where the participants agreed that the public should have a say about scientific issues – 'it should not be left to politics' one participant commented.

Another criterion to evaluate the success of a public engagement exercise is the participants' willingness to get involved in further engagement exercises. In this case, the *Stem Cell Public Dialogue* can be deemed a success as the majority (92.3%) of respondents agreed, 'I am more likely to get involved in these sorts of events as a result of participating in this one' (N=208). A small minority of respondents were unsure (6.2%) about the likelihood of their participation in future events, while even fewer (1.4%) disagreed that it was a possibility. It is worth noting that no one strongly disagreed with this statement.

### **Media as an information source**

Twice as many (65.9%) respondents were 'aware of any media (TV, radio, newspapers, magazines, electronic etc) coverage of the issues discussed at the workshops' (N=208), than those who were not (30.3%). In our interviews with the Oversight Group and stakeholders, some of those who attended the workshops observed that the media coverage of the HFE Bill, that was being debated in the Commons at the time, influenced the range of discussion as some participants were prompted by the coverage to ask questions about hybrid embryos (Interview with Sharon Fortune 5 December 2008, Interview with Darren Bhattachary 16 December 2008). After the first workshop, it was apparent that the participants had become far more sensitised to

media coverage and reported having picked up stories either in the press or on TV and the radio (Interview with Peter Simmons 16 December 2008). However, it was noted that while the media coverage had brought a number of issues to the attention of the participants, their questions suggested that they had engaged with the media reports in a critical way and they had not influenced their views (Interview with Simon Wilde 15 December 2008, Interview with Darren Bhattachary 16 December 2008).

## 5. Conclusions

The *Stem Cell Public Dialogue* was clearly a challenging exercise to plan, stage and report, given the range of stakeholder interests and conflicting positions in this area of research and the ambitious scope of the sponsors' stated aims and objectives. Evaluating the exercise posed its own challenges in light of resource constraints, the lack of established models of high-quality evaluation in this area and the wider critical interrogation that is emerging of the diverse political meanings and purposes of public engagement activities around science. In light of this, our multi-method approach was crucial for helping us develop a more nuanced and in-depth perspective on the dialogue than would have been possible with questionnaires alone. In conclusion, we reflect on the key messages and outcomes of the dialogue in the broader context of methodological and philosophical expectations of public engagement. We then consider aspects specific to the process of conducting the workshops. We then conclude with an outline of lessons and emerging themes for future dialogues and their evaluation.

### Outcomes

Beginning with the dialogue report (BMRB 2008), we found that, read as a whole, it conveyed a significant level of complexity in its picture of the wider scientific, social, policy and ethical issues at stake in stem cell research. This is an impressive achievement especially since it can be difficult to capture the range and depth of arguments around controversial topics where opinions, at first, appear polarized and predictable. The range of perspectives added nuance and specificity to the overall finding of high levels of support for stem cell research. Having said this, the diversity of perspectives found in the report did not quite match the level of discussion that we found at the public workshops.

One of our most surprising findings was that there was remarkably little disagreement amongst participants in the public workshops given that they were discussing an ethically fraught topic. BMRB acknowledged that this was unfortunate, noting that there were some contrary views in the first workshops which had subsequently dropped out. In retrospect, the relative complexity of the written report was achieved by the amalgamation of public voices at the workshops with stakeholder views gathered from a prior set of interviews. This raises some methodological questions that deserve to be explored further.

The integration of stakeholder and public voices was considered to be one of the strengths of public dialogue's methodology. In principle, such a framework could help elicit the implicit ethical assumptions of *all* positions, scientific and non-scientific, and provide a symmetrical footing for all parties to engage in dialogue with each other. Otherwise, a questionable boundary is constructed between experts as bearers of purely 'scientific' information and publics as bearers of purely 'value' commitments, creating a hierarchy that hinders genuine deliberation. Where experts claim to represent the domain of ethics as opposed to science, the hierarchy persists in the form of an expert/lay divide, only over values rather than facts. In practice, the stakeholder/public distinction was only partly bridged in the public dialogue creating new problems in the process.

Stakeholder views were gathered separately through interviews and used to inform stimulus materials for the public dialogue. In practice, this meant that a rich variety of perspectives found their way into the final report, but unfortunately, many of them were not explored at the public workshops. Rather than a symmetrical deliberation of different value commitments, the workshop discussions tended to be led more by the presentations from experts (we say more on this below). On the other hand, stakeholder impact on the dialogue was rather more problematic in one respect as we observed some members of the Oversight Group imposing their own opinions on the drafting of the final report. Where feedback from stakeholders and publics differed, the distinctions and conflicts with minority views were not evident insofar as a single set of shared conclusions and recommendations were presented in BMRB's report.

This brings us to a curious feature of many public dialogue exercises around science including this one. Although they are billed as ‘dialogues’ rather than research studies, many exercises eventually become understood and described in terms of a snapshot of ‘findings’ about public attitudes. In this instance, the dialogue report (BMRB 2008) observed that a striking finding of their work was the very high level of support amongst workshop participants and stakeholders for stem cell research. Although, as we have said above, the report goes on to nuance this finding by outlining various ways in which support is conditional, subsequent press releases from BBSRC and MRC focused on high public support as the headline message from the dialogue. In the course of this, the broader objectives stated for this exercise – creating an environment for sustaining dialogue on the subject, raising awareness amongst both scientists and members of the public of different views and uncertainties – appear to have been sidelined.

## Process

In general, a significant majority of public participants responding to our questionnaires were very positive about the nature and organisation of the dialogue workshops. Most felt that they had been exposed to a wide range of perspectives on stem cell research, that the dialogue was run independently of the sponsors, that its purposes were made clear, that they had access to sufficient information to engage fully in the discussions, and that the format allowed them to ask questions and express their views including those not previously considered. A large majority welcomed the opportunity to participate and to engage with experts, and agreed that participating in the workshops had made a difference to their views on the issues discussed.

However, as we have noted, our multi-method approach was crucial for putting these statements in context and for giving due space to the minority views. For example, our observations of the workshops challenge the assumption that many diverse perspectives had been articulated as we found remarkably few disagreements expressed or explored. A few respondents did doubt whether they were getting a sufficiently broad picture that was a realistic picture of how different people felt about the issues.

One point on which a significant number of respondents expressed scepticism about the dialogue concerned the link with policy and future research on stem cells. Many did not think that policy-makers would take the results of the discussions into account in making their decisions. The lack of a clear link to a decision context was also noticeable. (Here, it is worth noting that an alternative approach was adopted in the EPSRC’s 2008 dialogue on nanotechnology for healthcare which was part of the wider consultation to help decide how to frame a call for funding). Indeed, a clear mandate for stem cell research had already been expressed in the UKSCI’s terms of reference, making the relevance of public engagement a moot one. As the dialogue progressed, participants became increasingly uncertain about the sponsors’ intentions and by the third workshop, the proportion of respondents who thought that their recommendations would be acted upon had dropped from 56% to 42%. Given these ambiguities, BMRB could have perhaps made their own role and independence from the sponsors and decision context clearer to the participants as this was not always evident in the introduction to the workshops. We also observed little actual explanation of the dialogue’s objectives and the expectations from it.

At the core of this issue of transparency of dialogue aims and uses is a concern that the *Stem Cell Public Dialogue* may be viewed both by the sponsors and by publics as a way of legitimising decisions rather than a legitimate social process with an open outcome. Research council representativeness acknowledged this concern and expressed confidence that a culture had been created that would help initiate further public engagements as clinical applications started to emerge.

Though there were few disagreements explored at the workshops, we would stress that this was not an outcome of any facilitation problems. Participants were regularly encouraged by the facilitators to contribute to discussions which were generally allowed to flow freely. The quieter or potentially contrary participants were often invited to share their views, and minority views, when

expressed, were welcomed by the facilitators. In retrospect, the homogeneity of responses appears to have been shaped by the role played by experts in framing the discussion. Framing played a significant role in bounding the discussions as participants showed a strong tendency to follow and explore the main issues raised in the most influential experts' presentations. We noted big variations in the responsiveness of participants to particular experts who were more effective communicators. A number of our interviewees also noted that scientific experts were relatively more influential than social scientists and ethicists in shaping participant responses.

Scholars (e.g., Kerr et al 2007) have remarked on the tendency of some engagement exercises to reproduce patterns of lay deference to experts even in a situation where they are encouraged to speak their own minds. Clearly, this is an area that requires further work if more democratic deliberations are to take place. As we have suggested, symmetrical dialogue can only be expected to happen if it is structured in a way that minimises the tendency for experts to slip into the 'deficit model' role of providing information as we observed at the workshops.

### **Lessons and emerging themes**

We have suggested that the high levels of support for stem cell research noted in the dialogue report and the low levels of disagreement found at the workshops need to be interpreted with some caution. The structuring of expert roles in the dialogue process, and the ambiguity of this particular dialogue in relation to the wider research policy context for stem cells had some impact on the quality of the dialogue especially in terms of the reproduction of a deficit model and the tendency for participants to defer to particular experts. In this context, we would also warn against the common tendency to treat public dialogue as an exercise in gathering data on public attitudes which can then be used to justify policy decisions.

Public engagement exercises are starting to generate more critical evaluation as represented by a few articles discussed in our literature review and the new ESRC Seminar Series on critical perspectives on public engagement. Amongst the challenging new suggestions emerging from this work, we would like to mention two. Lezaun and Soneryd (2007) suggest that engagement exercises should be evaluated not only in terms of the dialogue organisers' work and its impact on public participants, but also in terms of their impact on the sponsors themselves and their capacity to respond. A related criterion raised in this context is the capacity of dialogues to help articulate *new* positions on the issues (a sign that some genuine dialogue has taken place). This is an area that we have not been able to explore given resource constraints, but it deserves further attention if public engagement is to fulfil more of its democratic potential.

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## Appendix 1

### BBSRC/MRC STEM CELL DIALOGUE PARTICIPANT QUESTIONNAIRE

#### Stem Cells Workshop # Location, Date

I am:	Male	<input type="checkbox"/>	Female	<input type="checkbox"/>		
	16-34	<input type="checkbox"/>	35-54	<input type="checkbox"/>	55+	<input type="checkbox"/>

#### Q1.

How far do you agree with the following statements?	Strongly agree	Agree	Don't know	Disagree	Strongly disagree
There was a wide range of different attitudes towards stem cell research among the participants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
All the important issues were covered in our discussions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The participants were given a clear indication of what this workshop would involve	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information handouts provided were unbiased	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand the purpose of this public dialogue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
This public dialogue is taking place early enough in the policy-making process to be influential	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The format of the workshop enabled new topics to be introduced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The people running the workshop did not promote a specific view on the issues around stem cell research	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The results of our discussions will influence the future of stem cell research in the UK	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The substance of our group discussions was effectively and fairly captured by the facilitator/s in their summings-up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had access to all of the information I needed to fully engage in the discussions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Issues were presented in such a way that I felt able to ask questions and discuss my own views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I understand how the results of this public dialogue will be used	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I believe that government policy-makers will take the results of our discussion into account in making their decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understood at all times what I had to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The specialists presented a balanced range of views on the issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No one person was allowed to dominate discussions unfairly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Conclusions drawn from earlier sessions of this workshop were used to inform subsequent sessions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how I can continue to be involved in a dialogue on these issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The sponsors of this public dialogue will act on the views and recommendations of the participants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was able to say everything I wanted to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am more likely to get involved in these sorts of events as a result of participating in this one	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q2.**

Yes      No      Don't know

Are you aware of any media (TV, radio, newspapers, magazines, electronic etc) coverage of the issues discussed at this workshop?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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If yes, please state the nature of that media coverage and how it affected your own views

.....

.....

.....

**Q3.**

Why did you choose to participate in this public dialogue?

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.....  
.....

**Q4.**

What do you think the sponsors of this public dialogue on stem cell research hope to get out of it?

.....  
.....  
.....

**Q5.**

Yes, a lot      Yes, a little      Uncertain      No, not really      No, not at all

Has participating in this workshop made any difference to what you think about these issues?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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If yes, please state what aspects made a difference and how they affected your own views

.....  
.....  
.....

**Q6.**

What were the most successful aspects of this workshop for you personally?

.....  
.....  
.....

**Q7.**

What were the least successful aspects of this workshop for you personally?

.....  
.....  
.....

**Q8.**

How might future workshops be improved?

.....  
.....  
.....  
.....

**Q9.**

Very important      Fairly important      Not very important      Not at all important

How important do you think it is to involve the public in discussing these sorts of issues?

                

**Q10.**

Yes      No      Don't know

Has any major topic been omitted from this questionnaire?

          

If yes, please state which topics have been omitted and why you think they should be investigated?

.....  
.....  
.....  
.....

Thank you for taking the time to complete this questionnaire. Your responses will contribute to the final report to be produced at the end of the evaluation and presented to the BBSRC/MRC

If you would like to be entered into the prize draw to win a case of wine or a half-case of champagne from *The Wine Society* please enter your contact details below:

Name: .....

Telephone and/or email: .....

NB. These details will only be used for the purpose of the prize draw and will not be linked to your responses.

## Appendix 2

### OBSERVATION PROTOCOL

Observer descriptions should provide as much detail as possible, including verbatim quotations of group exchanges and their dynamics. We'll have access to recordings, so timing of reported events will help with subsequent analysis. Observers may speak informally with participants if suitable opportunities arise during the breaks, subject to the conventions of observer behaviour (see below).

#### Task definition

- Is the nature and scope of the activity clearly defined?
- Are the overall objectives of the exercise clearly set out (both for the event itself, and its wider impacts)?
- Is it clear how these objectives have been derived?

#### Independence

- How do facilitators describe themselves and their role in the workshop?
- How do they describe their sponsor and their relationship with them?
- How was the agenda set and by whom? Is this made clear?
- What reasons are given, if at all, for selecting workshop participants?

#### Resource accessibility

- Does the style of facilitation allow participants to fully take part in the workshop?
- How do participants seem to be responding to the stimulus material? Did they find it useful as an educative tool? Which mediums were used?
- Are participants overwhelmed by the information?
- Is there sufficient time for issues to be discussed in depth and conclusions to be drawn? Is the discussion constrained by time limits?

#### Nature of the discourse

- What form do disagreements take, and how are they resolved?
- How does the facilitator arrive at consensus, if at all?
- What arguments are used by the participants to make sense of the issues?
- What mediums (TV, radio, books etc) are referred to as sources of information? What percentage of contributions, roughly, is informed by such information?
- How much reference is made to scientific views?

#### Structured decision-making

- Are all participants able to contribute and shape the discussion?
- Do some participants dominate the discussion?
- Are minority views allowed to be heard?
- How well did the use of IML voting work?
- Is there evidence of non-participation or disruptive behaviour?
- To what extent is the workshop dominated by facilitator intervention compared to uninterrupted talk among the participants? Does this change during the course of the workshop?

## **Transparency**

- Is there scope for future involvement of the participants in a sustained dialogue on stem cell issues?
- Is it made clear how participants can follow the course of the public dialogue?
- Will participants be provided with any feedback on the findings of the workshop? If so, what form will this take?
- Is it made clear how these findings will be used, and who will be involved in determining these issues?
- Is it made clear how the findings of the workshop relate to the overall objectives of the exercise?

## **Translation quality**

- Did initial issue framing (text/debate) affect the breadth and depth of the dialogue?
- Were conclusions drawn from one stage of the process used as a source for subsequent stages (informing and shaping them)?
- Was there any evidence (verbal, printed) that the dialogue project is learning from and building upon recent consultations and dialogue projects?

## **Views and experiences of participants**

Is it possible to find evidence of:

- Satisfaction or disappointment felt by participants about any aspects of the workshop?
- The extent to which participants understood the workshop process and issues raised for discussion?
- Support for, or scepticism towards, the BBSRC/MRC stem cell dialogue, or, more generally, about the idea of public dialogue about such issues?

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## **Convention on observer behaviour**

- Be unobtrusive without appearing detached.
- Be careful not to inadvertently send out non-verbal signals.
- Do not make any audio or visual recordings.
- Take discreet notes by hand - do not use a laptop computer.
- Do not interact verbally with participants during the sessions unless directly addressed. When interacting with participants informally during the breaks, do not ask leading or framing questions.
- Do not take photographs.