

Evaluation of the HFEA public consultation on hybrid and chimera embryos

Final report

Diane Warburton
November 2007



11 Clifton Street
Brighton BN1 3PH
+44 (0)1273 774557
www.sharedpractice.org.uk

CONTENTS

1. INTRODUCTION

2. THE EVALUATION STUDY

- 2.1 Introduction
- 2.2 Aims and objectives of the evaluation
- 2.3 Approach to the evaluation
- 2.4 Methodology for the evaluation
- 2.5 Background and context

3. AIMS, OBJECTIVES AND SUMMARY OF ACTIVITIES

- 3.1 Introduction
- 3.2 Aims and objectives of the public consultation process
- 3.3 The main activities of the public consultation

4. STAKEHOLDER ADVISORY GROUP

- 4.1 The purpose of the Group
- 4.2 The nature of the Group
- 4.3 The effectiveness and value of the Group

5. OPINION POLL

- 5.1 The purpose of the exercise
- 5.2 The nature of the exercise
- 5.3 The effectiveness and value of the exercise

6. DELIBERATIVE WORK PART 1: LOCAL DISCUSSION GROUPS

- 6.1 The purpose of the exercise
- 6.2 The nature of the exercise
- 6.3 The effectiveness and value of the exercise
- 6.4 Overall conclusions on the discussion groups

7. DELIBERATIVE WORK PART 2: RECONVENED PUBLIC MEETING

- 7.1 The purpose of the exercise
- 7.2 The nature of the exercise
- 7.3 The effectiveness and value of the exercise
- 7.4 Overall conclusions on the reconvened event

8. OPEN PUBLIC MEETING

- 8.1 The purpose of the open public meeting
- 8.2 The nature of the open public meeting
- 8.3 The effectiveness and value of the open public meeting
- 8.4 Overall conclusions on the open public meeting

9. ASSESSMENT OF ACTIVITIES AGAINST OBJECTIVES

- 9.1 Introduction
- 9.2 Assessment against objectives
- 9.3 Assessment against principles of good practice
- 9.4 Conclusions on achievement of objectives

10. LESSONS FOR THE FUTURE

- 10.1 Introduction
- 10.2 What worked well
- 10.3 What worked less well
- 10.4 Lessons for the future

11. OVERALL CONCLUSIONS

- 11.1 Introduction
- 11.2 Value for participants
- 11.3 Value for other stakeholders
- 11.4 Value for the HFEA
- 11.5 Final conclusions

APPENDICES

Appendix 1. Analysis of questionnaires from discussion groups

Appendix 2. Analysis of questionnaires from reconvened public meeting

Appendix 3. Analysis of questionnaires from open public meeting

Appendix 4. Government guidelines on public dialogue on science and technology

ACKNOWLEDGEMENTS

We would like to acknowledge the help of the HFEA staff responsible for this project (especially Helen Coath) and Opinion Leader (especially Liz Sparham), who helped enormously with the evaluation research; also Chris Allinson and Helen Fisher, who contributed extensively to the interview research for the evaluation. We are also extremely grateful to all those who gave their time to be interviewed for the evaluation research.

1. INTRODUCTION

In November 2006, the Human Fertilisation and Embryology Authority (HFEA) received two research licence applications to derive stem cells from embryos created by Somatic Cell Nuclear Transfer (SCNT or cloning) using animal eggs. At its meeting on 10 January 2007, the Authority concluded that, in the light of current scientific and legal opinion, the regulation of research using human-animal embryos is probably within its scope. In the light of the potential ethical and social implications of creating these embryos, the Authority decided that a full public consultation on the use of hybrid and chimera embryos for research should be held.

The consultation ran for three months, from 26 April to 20 July 2007. It examined a wide range of issues relating to the creation of human-animal embryos for research, covering both the scientific background and the social and ethical issues.

The findings from the various strands of the consultation were presented to the Authority at their meeting on 5 September 2007. The decision was taken that "cytoplasmic hybrid research should be allowed to move forward, with caution and careful scrutiny. Research teams wishing to pursue a licence for this type of research will have to demonstrate, to the satisfaction of an HFEA licence committee, that their planned research project is both necessary and desirable"¹. The final report on the consultation was published in October 2007.

The public consultation was the largest exercise of its type that the HFEA had undertaken. In order to capture the lessons from the experience, and assess its effectiveness and value, the HFEA commissioned an evaluation study, which started in April 2007.

This report presents an evaluation of the public consultation exercise. In particular, the evaluation focuses on the deliberative public engagement elements of the consultation: the discussion groups and the reconvened event for the public, and the open public meeting, as these were the elements of the process that potentially had the most lessons for future HFEA public engagement work. The other elements of the consultation, such as the consultation document and online consultation, the stakeholder consultation and literature review that provided the scientific background to the HFEA decision, are covered only briefly.

The report summarises the methodology of the evaluation, the purpose and objectives of the process, feedback on the main activities within the public consultation (and associated activities such as the Stakeholder Advisory Group that helped shape the process and materials used), considers the extent to which the objectives and principles of good practice have been achieved, identifies the elements of the process that worked particularly well and less well, and identifies some lessons for future practice in the light of these findings. The final section concludes the report by identifying the particular value the process provided for public participants, stakeholders and the HFEA.

¹ *Hybrids and Chimeras. A report on the findings of the consultation*. HFEA, London, October 2007.

2. THE EVALUATION STUDY

2.1 Introduction

The HFEA has undertaken many public consultations in the past, but this consultation was on a larger scale and used various methods that had not been used by the HFEA before, especially the deliberative work with the public. The HFEA was particularly interested in identifying lessons from this process to inform future consultations.

The evaluation was designed to focus on the public consultation exercise, making only brief reference to the stakeholder consultation and literature review that provided the scientific background to the HFEA decision. In particular, the evaluation focused on the deliberative public engagement elements of the consultation: the discussion groups and the reconvened event for a diverse sample of the public, and the open public meeting. The other elements of the public consultation, such as the consultation document and online consultation, are covered briefly.

The evaluation does not assess the policy outputs or implications from the initiative in any detail; it focuses on the engagement processes and assesses the extent to which the activities met the objectives set, and complied with principles of good practice. Policy issues are touched on throughout this report, but only where relevant to assessing the effectiveness of the engagement.

The evaluation was commissioned in April 2007, and was completed in November 2007. Details on the methodology are given in section 2.4 below.

2.2 Aims and objectives of the evaluation

There were no formally agreed objectives for the evaluation other than to assess the consultation process by considering the extent to which it met its objectives, met principles of good practice, and provided lessons for the future. More specifically, it was agreed that the evaluation should aim to achieve the following:

- To examine how well the whole process worked in order to identify clear lessons to feed into future HFEA work. This required examining how well individual events and processes have worked and have engaged with the participants (e.g. how well the information materials were received and used by participants), the quality of the information resulting from each part of the process, and how the data from the different sources was integrated.
- To examine the level of understanding among the public and the effectiveness of the information provided through this process in extending that understanding. This assessment needed to take into account the role of the media in moderating public views.

- To identify and assess how the different elements of the consultation interacted (e.g. issues from the initial public discussions feeding into the design of the open public meeting and the public opinion poll).
- To check the demographic mix among those attending events. The OSI guidelines suggest that dialogue can be 'narrow and deep' in early discussions on issues the public are not knowledgeable about, or wider if there is some knowledge, a wide-ranging impact or the issue is contentious. It was expected that, in this case, the consultation would cover both levels.
- To examine the impact of the results of the consultation on HFEA policy and decision-making.
- To examine the extent to which the whole process adheres to the OSI guiding principles for public dialogue². These include "principles of openness, honesty and fairness, designed to generate mutual understanding of views and underpinned by a willingness to take account of the outcomes of such dialogue in decision-making".

These questions are covered specifically in sections 9 and 10, which summarise achievement of the objectives, and the lessons on these issues for future work.

2.3 Approach to the evaluation

Evaluations of engagement can range in approach from a mechanistic 'audit' approach, focusing on quantitative assessment of achievement against formal targets or goals, to approaches that focus much more on 'learning' from the experience, focusing on qualitative description and interpretation of more 'subjective' data (e.g. from interviews, stories, observation etc) to explain why and how certain outcomes were achieved.

The audit approach can be summarised as asking questions such as:

- have we done what we said we were going to do?
- have we met our targets (e.g. numbers of participants; reaching a representative sample of the population)?

The learning approach is more likely to ask questions such as:

- were the objectives we set ourselves the right ones?
- what have the impacts been on the participants, policy outcomes, our decision-making processes, etc?
- what have we learnt for the future?

The approach to this evaluation has used elements of both approaches. It focuses on a learning approach, while ensuring that the quantitative and audit elements required are also delivered (e.g. objectives met).

² Office of Science and Innovation. *The Government's approach to public dialogue on science and technology*. OSI, September 2006.

Therefore both qualitative and quantitative data was collected and analysed against a range of frameworks (e.g. the stated objectives of the engagement process, agreed principles of good practice). In this way, clear lessons and advice can be distilled from the evaluation research as well as measuring the effectiveness and the overall achievements of the process.

The style Shared Practice adopts for evaluation is collaborative. However, the evaluator also has responsibility for ensuring the independence and rigour of the evaluation process, and to reporting findings openly and honestly to appropriate audiences at appropriate times.

2.4 Methodology for the evaluation

The evaluation methodology was made up of the following elements:

- **Detailed design and planning of the evaluation.** This involved work with the HFEA to agree the detailed parameters of the evaluation and the programme of work, especially the main themes and questions for the evaluation.
- **Evaluation research.** This included the following:
 - **Observation** of a sample of events, including informal interviews with a range of participants. Evaluators attended, observed and conducted informal interviews with the public at one discussion group, the reconvened event and the open public meeting. Evaluators also attended the final Authority decision-making meeting on 5 September 2007, to observe the final decision-making process.
 - **Development and use of questionnaires at all public events.** Questionnaires were distributed at all the discussion groups, the reconvened event and the open public meeting. Detailed analyses of all these questionnaires has been undertaken and can be found in the annexes to this report.
 - **Interviews.** Interviews were used to complement the data gained from questionnaires, and provide deeper and richer data on some of the key issues. Interviews were carried out with:
 - **Public participants.** This is particularly important to examine their learning from the exercise, as well as to test the quality of the process from their perspectives. Interviews were carried out with
 - 10 people from the reconvened workshop
 - 9 people from the open public meeting
 - **Other stakeholders.** This was to gain their perspective on the value and quality of the events they attended, and whether their involvement affected their views of public engagement. Interviews were carried out with:
 - 4 experts / speakers from the reconvened event and the public meeting;
 - 4 members of the HFEA Stakeholder Advisory Group, which commented and advised on the process and content of the public engagement.

- **Policy-makers** using the outputs of the process in their decision-making processes. Interviews were conducted with 3 of the Authority members who were involved in the final decision-making.
- **Those commissioning and delivering the process** (HFEA and Opinion Leader), to fully understand the approach to the design of the process, what happened in practice, and the lessons identified by those involved for future practice. Interviews were conducted with the one person from each organisation most heavily involved in commissioning, designing and delivering the process.
- **Analysis of data.** Quantitative and qualitative analysis of questionnaires and interview transcripts has been undertaken to provide statistics, overall qualitative feedback and some illustrative quotes from those involved. It was agreed that the final analysis for this report should focus on achievement of the agreed aims and objectives, and adherence to principles of good practice.
- **Final reports.** The final report was presented to the HFEA in draft form in November 2007, and finalised for publication that month. It is likely that the ScienceWise programme, that helped to fund the consultation, will produce a case study on the exercise.

2.5 Background and context

In November 2006, the Human Fertilisation and Embryology Authority (HFEA) received two research licence applications to derive stem cells from embryos created by Somatic Cell Nuclear Transfer (SCNT or cloning) using animal eggs. At its meeting on 10 January 2007, the Authority concluded that, in the light of current scientific and legal opinion, the regulation of research using human-animal embryos is probably within its scope. In the light of the potential ethical and social implications of creating these embryos, the Authority decided that a full public consultation on the use of hybrid and chimera embryos for research should be held.

However, the debate on these issues was already well underway before this public consultation was launched in April 2007. The HFEA final report on the consultation summarises all the main events leading to their final decision in principle in September 2007, including the detailed internal discussions within the HFEA. Some of the main events in the debate identified in that report (and elsewhere) are:

- 2000** Sir Liam Donaldson's report, *Stem Cell Research: Medical Progress with Responsibility*, recommended, among other things, that "mixing of human adult (somatic cells) with the live eggs of any animal species should not be permitted".
- 2002** The House of Lords Select Committee report on *Stem Cell Research*, took issue with the recommendation of Sir Liam Donaldson's expert group that there was a need for an outright ban on research involving inter-species embryos.

2004 In January, the Government announced a review of the Human Fertilisation and Embryology Act. They also announced that the HFEA and the Human Tissue Authority would be replaced by a single body: the Regulatory Authority for Tissue and Embryos. The legislation to allow this would be through the proposed changes to the HFE Act.

The HFEA were discussing the issue: the HFEA Scientific and Clinical Advances Group (SCAG) heard a presentation on chimeras and their role in stem cell biology, and considered a scoping paper on chimeras as part of their work on the definition of an embryo.

2005 The House of Commons Science & Technology Committee report on *Human Reproductive Technologies and the Law* recommended that new legislation was required to define the nature of inter-species embryos and make their creation legal for research purposes subject to the 14 day rule (that embryos would be destroyed within 14 days) and the prohibition on implantation in a woman.

The Government launched the public consultation on the Review of the HFE Act in August 2005, and it closed in November 2005. The Science & Technology Committee held a further inquiry on the specific issue of animal-human hybrid embryos for research.

2006 In March, the Government issued a report of the results of the consultation on the Review of the HFE Act. In December the Department of Health published their Review of the HFE Act. This said that "The Government intends to put this matter to Parliament for further consideration. Revised legislation will clarify the extent to which the law and regulation applies to embryos combining human and animal material ... The Government will propose that the creation of hybrid and chimera embryos in vitro should not be allowed. However....the law will contain a power enabling regulations to set out the circumstances in which the creation of hybrid and chimera embryos in vitro may in future be allowed under licence for research purposes only".

The HFEA Ethics and Law Committee (ELC) and SCAG considered the issues of the creation and use of hybrid embryos in research. Scientists in the UK had publicly stated that they may wish to create hybrid embryos by fusing human cells with rabbit eggs.

In November 2006, the HFEA received two applications for research licenses for derivation of embryonic stem cells from hybrid embryos. The Authority received a briefing paper in preparation for a full discussion in January 2007.

2007 The HFEA sought an updated opinion from Counsel on whether hybrid embryos would fall under the remit of the HFEA. At its meeting on 10 January 2007 the Authority was advised that: "If the embryo contains a complete human genome and it cannot be shown definitively that the embryo does not have the normal potential to develop, it is most likely that the Court would find that this constitutes a live human embryo for the purposes of the Act. The Courts are likely to see the 'hybrid' embryo in this way to ensure that this type of research falls under the scope of regulation rather than to allow it to be

unregulated". Presented with this opinion the Authority concluded that hybrid embryos are probably within its scope and decided to hold a full consultation on human-animal embryos to gauge public opinion on the issue.

In March, the House of Commons Science & Technology Committee report on Government proposals for the regulation of hybrid and chimera embryos concluded that the Government's White Paper proposals were "too prohibitive and that the promise of future regulation was insufficient". Instead the Committee called for permissive legislation which would allow research using animal-human hybrid and chimera embryos through licensing.

In April, the HFEA launched its public consultation, which closed in July. In May, the Government published the Human Tissue and Embryos (Draft) Bill based on the Review announced in 2004 and the consultation in 2005. The Government issued a statement announcing its intention to accept in part the Science and Technology Committee's recommendation of March 2007 and allow in legislation, under licence, certain categories of inter-species embryo. However, 'true' hybrids would remain proscribed unless permitted by regulations made by the Secretary of State.

In August, the Joint Parliamentary Committee on the Bill recommended an alternative definition of inter-species embryos and proposed that authority should be given to the regulator: "To interpret and apply that definition to individual research applications, based on the principles set out in legislation".

On 5 September 2007, the Authority decided that "cytoplasmic hybrid research should be allowed to move forward, with caution and careful scrutiny. Research teams wishing to pursue a licence for this type of research will have to demonstrate, to the satisfaction of an HFEA licence committee, that their planned research project is both necessary and desirable"³. The final report on the consultation was published in October 2007 (see footnote).

All these developments resulted in significant publicity from April through to August 2007 around whether there would or would not be a ban on human-animal hybrid embryos for research, and then fairly extensive coverage of the HFEA decision in September. Publicity ranged from horror stories about 'mutants' to coverage of what was portrayed as a Government shift from banning to allowing human-animal hybrids to be created for research.

The publicity was certainly extensive and populist enough to have been seen even by uninterested members of the public, and the deliberative research and the evaluation therefore checked the extent to which this had influenced people's views on the issues.

³ *Hybrids and Chimeras. A report on the findings of the consultation*. HFEA, London, October 2007.

3. AIMS, OBJECTIVES AND SUMMARY OF ACTIVITIES

3.1 Introduction

This section provides a brief overview of the aims and objectives of the public consultation, and an overall picture of the activities that took place. Subsequent sections analyse each consultation activity in more detail.

3.2 Aims and objectives of the public consultation process

The aim of the consultation exercise overall was outlined in the original brief for the process:

The aim of the Authority's consultation exercise as a whole is to examine the ethical and social issues arising from the creation of hybrids and chimera embryos for research. ... the consultation is being designed to include a public dialogue process to explore these issues in detail and to gauge public opinion and to understand why people feel the way they do. A key element of the consultation as a whole, and to some degree the public dialogue process, will be the provision of good information, raising awareness both of the consultation itself and of the scientific, legal and ethical issues it addresses. The outcome of the whole consultation, including the public dialogue elements, will inform the Authority's policy-making in this area.

The key objectives for the work were:

- To engage stakeholders in the scoping and development of the dialogue process in collaboration with the Authority and in line with the wider written and web consultation process.
- To undertake a deliberative process with a diverse set of the public which accords with the Government's Guiding Principles for Public Dialogue on Science and Technology.
- To capture, analyse and report the results of the dialogue project so that they can be easily understood by policy makers and can inform the Authority's policy recommendations along with the results of the written and web consultation.

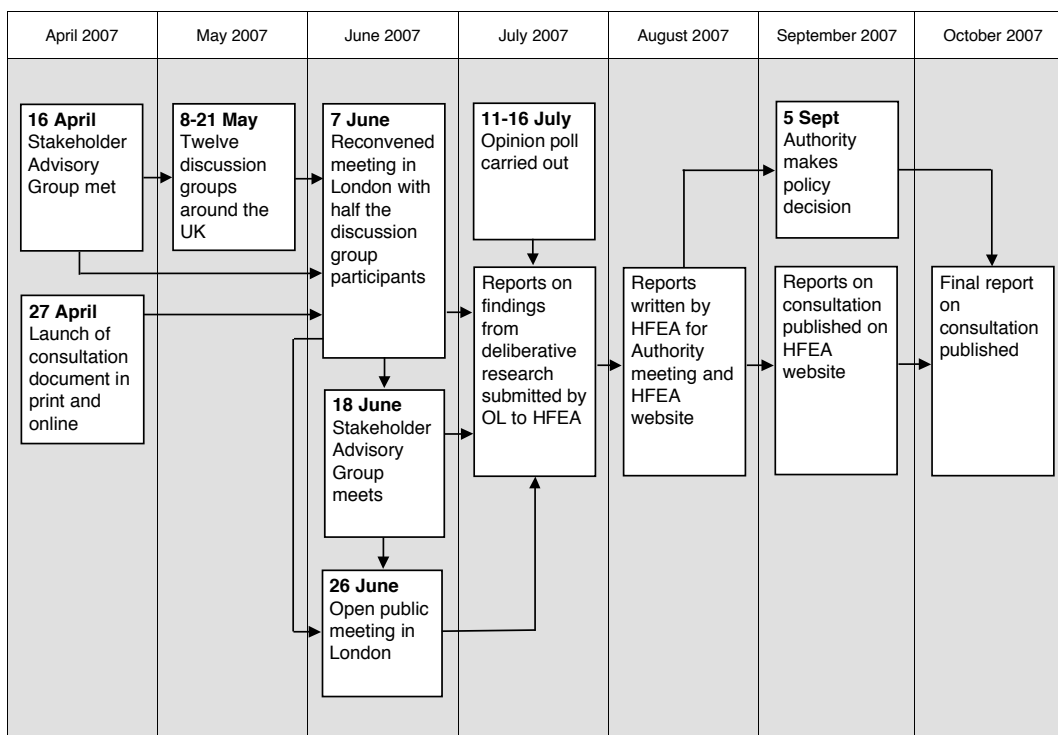
3.3 The main activities of the public consultation

The overall process was in two main parts:

- the public consultation
- a scientific review, including a literature review and a consultation on specific scientific issues.

3.3.1 The public consultation in summary

The public consultation activities were, in summary, as shown in the following diagram:



Overall, the scale of the process was as follows:

- Stakeholder Advisory Group: 16 stakeholder organisations took part.
- Consultation document and online consultation: 810 responses; 74 (9%) on behalf of an organisation; 736 (91%) as individuals.
- 12 discussion groups for the public, held around the UK with two groups each in Belfast, Glasgow, London, Manchester, Newcastle, Swansea: each group had between 6 - 10 participants, with a total of 106 participants.
- Reconvened meeting for the public, with half those participating in the discussion groups invited back: 44 participants
- Open public meeting, held in London: 153 participants
- * Opinion poll: target of 2000 responses; actual total 2,073.

This is an overall total of 3,142 participants in the public consultation, plus those involved in the internal scientific consultation.

3.3.2 Scientific consultation

The scientific consultation was carried out to gain a greater understanding of the scientific issues surrounding human-animal hybrid embryos, particularly whether or not they could be classed as live human embryos and thus if their creation falls within the remit of the HFEA. Within this there were two specific questions:

- whether the entities created would contain a complete human genome, and
- whether embryos would have the potential to develop if placed in a woman.

The scientific consultation involved:

- A scientific literature review.
- Feedback in writing from a number of key stakeholder organisations (scientific organisations, funding bodies and others). 15 organisations were invited to respond to these and a number of other scientific questions; and responses were received from 10, as follows:
 - Medical Research Council (MRC)
 - Wellcome Trust
 - The Royal Society
 - Association of Medical Research Charities
 - Motor Neurone Disease (MND) Association
 - Human Genetics Alert
 - Association for Clinical Embryologists (ACE)
 - Royal College of Obstetrics and Gynaecologists (RCOG)
 - British Fertility Society (BFS)
 - Scottish Stem Cell Network (SSCN).

The responses from the consultation were summarised and published (on the HFEA website) in the paper for the Authority's meeting on 5 September 2007.

4. STAKEHOLDER ADVISORY GROUP

4.1 The purpose of the Group

A Stakeholder Advisory Group with representatives from 16 stakeholder organisations was convened during the planning stages of the consultation process. The purpose of the Group was to contribute to the scoping and development of the dialogue process with the Authority, and in line with the wider written and web consultation process.

4.2 The nature of the Group

The Group met twice, and gave feedback on documents via email. The two meetings were:

- 16 April 2007, just before the launch of the consultation document in print and online on 27 April. The main focus of this meeting was to discuss the recruitment, information materials and process for the deliberative work with the public, starting with the discussion groups in May, and the open public meeting.
- 18 June 2007, after the main public deliberative events had been completed. The meeting briefly reviewed events to date, and the main part of the meeting was then spent considering the open public meeting to be held on 26 June and the public opinion poll to be conducted in July.

There was quite a drop in attendance between the two meetings, with 16 organisations represented at the April meeting, and only eight at the second meeting. However, others commented on documents via email.

The membership of the Group did reflect a broad range of opinions on the subject of embryo research, with a mix of research organisations, religious organisations and those concerned with the ethics of such work.

4.3 The effectiveness and value of the Group

The assessment that follows is based on a review of the minutes of the Group and other descriptions of their work, and interviews with four members of the Group as well as those in the HFEA and Opinion Leader responsible for the process.

It was important to the legitimacy and accountability of the public consultation exercise that both the consultation process, and the materials used, were seen to be fair and balanced, and not to promote any particular view. Involving stakeholders in discussing the design of the process and the drafting of the materials helped ensure that all viewpoints were taken into account before materials were used, so that any bias could be identified and removed and the materials could be seen by all participants (as well as stakeholders) as fair and balanced.

Partly as a result of these stakeholder comments, the written materials for the public provided only basic factual scientific information about the nature of the different types of embryos, rather than providing different perspectives on the issues. The materials that were finally produced worked very well both in the discussion groups and in the reconvened meeting.

4.3.1 Feedback overall

In interviews with four members of the Stakeholder Advisory Group, the following were the main points raised:

- **Positive feedback on deliberative processes.** There was generally very positive feedback about the design of the process, especially the mix of methods that was used (deliberative, polls, etc). The deliberative research work (the discussion groups and the reconvened groups) were seen as particularly valuable. For example:

"It was multi-faceted, the iterative process worked really well, they did a good job of reaching beyond the 'usual suspects' to people who are not part of the obvious interested groups."

"I think the iterative process, where you got people's thoughts first and then observed how their views changed with more information and context, was very important. Especially with these sorts of issues where people's responses are often their gut reactions, or influenced by how the media presents it."

"It is so difficult to provide balanced and unbiased information, to provide enough information for people to be able to discuss, but not too much so they can't take it all in. But in the end I was very impressed."

- **Less positive feedback on the open public meeting.** There was a sense that this had been done before, that it attracted only polarised and strongly held views, and that it did not add anything to the overall process. For example:

"I wasn't in favour of the public meeting ... I think that with such contentious issues you attract very specific constituencies, and it did ... So it is unclear to me what it achieved."

"I wasn't sure about the public meeting. I don't think it added anything."

- **Positive feedback on HFEA role.** There was positive feedback about the way the HFEA handled the whole consultation, and that the HFEA had actually listened to the input from the public. There was particular praise for the HFEA reports that summarised the findings from the consultation. For example:

"It demonstrated ... that the HFEA can listen ... And it was 100 times better than what they have done before"

"I was impressed with those papers, there was a lot of history, a good literature review, lots of cross referencing and lots of data from various parts of the consultation."

- **Mixed support for public engagement.** There was strong support for the need for public consultation among those interviewed, but it was pointed out that this was not the case for all members of the Stakeholder Advisory Group. For example:

"There was a certain amount of cynicism about engaging the public on this ... I just became aware of a much greater resistance to working with the public on these issues than I was aware of before".

4.3.2 What worked well

- **Relationships worked.** The relationship between the Stakeholder Advisory Group, Opinion Leader and HFEA staff worked very well in terms of developing certain parts of the process, refining the specific questions to be asked at different points and through different methods (e.g. the opinion poll, the open public meeting) and the briefing materials.
- **Value in helping draft materials.** The Group was particularly useful in drafting the briefing materials for the deliberative events. The variety of interests on the Group helped to ensure that any potential bias was identified that could otherwise have undermined the independence and balance of the materials, and thus helped ensure that the materials were fair.
- **Value in exercise overall.** The stakeholders saw real value in the public consultation exercise. For example:

"They're in a much more secure position now to carry decisions out. They will be able to back up their decisions with the findings of the consultation."

"It should ensure wider input into decisions and it should allow you to harness views you don't normally get in these processes. So I personally think it is very valuable."

"Firstly, no organisation can survive without knowing what the public thinks ... Secondly, for those that want their voices to be heard it fulfils that purpose - you demonstrate that [you listen, that you can be trusted]."

"It if delivers results that give a picture of the range of people's informed opinion then I think you can say it is money well spent".

- **Value for the stakeholders.** The stakeholders themselves also clearly gained from being involved. Respondents suggested that it reinforced their commitment to engaging with people and stakeholders. They also said they learned a lot of practical lessons (seeing how it worked was important) about public engagement and would take lessons back to their own organisations from this experience. For example:

"It reinforced that [public engagement] is a good thing, and that we need to carry on with it against the odds and the opposition."

"The fact that other organisations are doing it makes it easier for us to get buy-in [for public engagement activities], both internally and externally."

"So actually this stuff works, and I don't mean to trivialise it, but it's not as scary or difficult as one might think ... This whole topic has been like a case study for how public engagement can work. Public opinion has come out completely in favour of something which it could have turned against. So if scientists get a chance to really explain what they're doing, they're not as scary. But at the same time it's important to respect that people have different views and give them a chance to discuss them."

"[We] are looking to do a longer consultation on the same type of issues, [so seeing how this was done helps]"

"I think it might influence how we design our website in the future, and that sort of thing."

- **Independent secretariat.** Opinion Leader provided the secretariat for the Group, which was important in maintaining its independent role in the process and worked well for the HFEA and Opinion Leader.

4.3.3 What worked less well

- **Clarity about Group role.** The terms of reference and role of the Group was not fully articulated and agreed, which led to a lack of clarity and poor sense of purpose among the Group members. This may have contributed to fewer stakeholders attending the second meeting, and generally a reduced level of interest from stakeholders as the process unfolded. Feedback from stakeholders included:

"I would probably have liked more say over the process. This would have involved getting the stakeholder panel set up quicker. Some people, including me, felt frustrated that we weren't able to input to the structure of the process ... although all this is understandable due to the constraints on time."

"Being able to have more time [would have helped the Group fulfil its role more effectively] - though I'm aware of the time constrictions they were working under. In these situation you can always feel as if [the Group] has been set up just to wave things through, and there was an element of that."

- **Additions to Group membership.** There was some feedback that the membership of the Group could have been improved. A couple of respondents suggested that the Group should have included more practising scientists, while recognising that scientists may also take a particular line on these issues.

- **Tight deadlines.** There were times when deadlines were very tight and there was not as much time to consult the Group as would have been ideal. However, the group members interviewed, and those consulting them, found it was very valuable to have this input even if it was not as full or detailed as it may have been if there had been more time.

5. OPINION POLL

5.1 The purpose of the exercise

The aim of the opinion poll was to provide quantitative data on the views of a fully demographically representative sample of the UK population. This provided a set of statistics which was valuable in their own right for the Authority members when it came to considering public opinion, and also to compare with the changes in attitudes that developed among those public participants who took part in the deliberative research meetings.

5.2 The nature of the exercise

The questions were put on an omnibus (general) survey run by ICM research from 11 - 16 July. A sample of 2073 residents of the UK was interviewed during this period. All participants were adults aged 18+. Quotas were set on age, gender, standard geographical regions and housing tenure, and the data was weighted against the profile of the UK to provide a representative sample. Random digit dialling was used to recruit participants for the interviews.

The answers to the questions were summarised and reported by Opinion Leader to the HFEA in July 2007.

The poll consisted of four questions which were formulated with input from the Stakeholder Advisory Group, and from the findings from the deliberative and public meetings. In particular, the Stakeholder Advisory Group advised on the sequential build up of the questions, starting with stem cells and building up to human-animal embryos.

There was a significant investment of time by all those involved in developing and refining the questions to ensure they worked in terms of getting the quite specific information required, and could still be understood easily by the general public.

It was agreed that only a small amount of information would be provided to the public to clarify terminology, but that generally the respondents would not be prepared in any way for the questions. At the end of the survey, respondents were directed to the main HFEA written and online consultations if they wanted to express their views in more detail.

The questions were:

Q1. Please can you tell me how much you feel you know about each of the following:

- Using human embryos for research
- Stem cell research
- The possibility of creating embryos that contain some human and some animal material for research

Prompts then explored where people's knowledge had come from (e.g. television / radio, newspapers, websites, a clinician etc).

Q2. Human embryos are currently used in the UK for fertility research, to study the development of embryos and to study potential treatments for some serious diseases. This research has some legal limits, for example, it is illegal for the embryo to be implanted into a woman or animal and the embryo must be destroyed within 14 days.

- To what extent do you agree or disagree with scientists using embryos for research which are donated by a couple after they have finished their fertility treatment?
- To what extent do you agree or disagree with scientists creating human embryos for research from sperm and eggs?
- To what extent do you agree or disagree with scientists using human embryos in research at all?

Q3. Human eggs, needed to create embryos for research, are in short supply. So some scientists want to use **animal** eggs instead of human eggs to create embryos for research. Most of the genetic material from the animal egg would be removed and replaced with the genetic material of a human cell, in order to create an embryo. Under regulation, the embryo would be destroyed within 14 days and it would be illegal for the embryo to be transferred to a woman or animal.

- To what extent do you agree or disagree with scientists creating an embryo which contains mostly human with a small amount of animal genetic material purely for research?

Q4. To what extent do you agree or disagree with the following statements:

- I agree with using human embryos in research if it may help to understand some diseases for example Parkinson's and Motor Neurone Disease
- I agree with creating embryos for research with mostly human and a small amount of animal genetic material in research if it may help to understand some diseases for example Parkinson's and Motor Neurone Disease
- Creating embryos for research with mostly human and a small amount of animal genetic material concerns me because it is meddling with nature
- Creating embryos for research with mostly human and a small amount of animal genetic material concerns me because of what scientists might want to do next in research
- Creating embryos for research with mostly human and a small amount of animal genetic material concerns me because I think they might be put in a woman or an animal even though it is against the law
- Creating embryos which contain half human and half animal genetic material for research should be allowed if scientists want to be able to do this and it is under the same regulatory controls.

5.3 The effectiveness and value of the exercise

The assessment that follows is based on a review of the findings of the opinion poll produced by Opinion Leader and HFEA, and interviews with the Stakeholder Advisory Group, Authority members as well as those in the HFEA and Opinion Leader responsible for the process.

The results of the exercise showed that agreement with the use of cytoplasmic embryos increased slightly when respondents had more knowledge of the subject (those with less knowledge were less keen). Agreement also increased if the respondent felt it would help understand certain diseases such as Parkinson's and Motor Neurone Disease.

This increase in willingness to accept the use of cytoplasmic embryos if respondents had increased knowledge, and/or a clear idea of the purpose of any such research, were similar to the findings from the deliberative research. This confirmed two things:

- that the general public clearly understood the questions, because the data was what you would have expected (given the findings from the deliberative work); and
- strengthened the findings of the deliberative research by showing similar findings using quantitative data on the views of a demographically representative sample of the UK population as a whole.

The Authority members found the poll valuable in providing an overall 'feel' of the general public instinct on these issues, and providing another method for gauging public opinion so that there was an overall sense that the Authority had *"invited, received and considered as full a range of views as possible. Without doing that, a decision would be incomplete"* (Authority member in interview).

It was also important to Authority members to have detailed statistically valid feedback on the views of a demographically representative sample of the UK population. They felt it was important to have a 'baseline' against which the findings of the deliberative research could be seen.

However, feedback from interviews with others points to the importance of the public having at least some basic information about the subject before being able to provide answers that had any value to the research process. For example:

"We need to face the fact that the general public don't give a hoot about these things ... The vast majority of the British public don't know anything about this." (Expert speaker at the reconvened and open public meetings).

"An opinion poll, by definition, requires an instant response and may not be appropriate for some issues." (Authority member).

6. DELIBERATIVE WORK PART 1: LOCAL DISCUSSION GROUPS

6.1 The purpose of the exercise

The first part of the deliberative work involved discussion groups which were designed to bring together a mix of participants from across the UK in small groups of 6 - 10 people, and then to gather 'top of mind' responses to the creation and use of the various types / origins of embryos in research.

6.2 The nature of the exercise

- **Overall scale.** 12 discussion groups were held during May 2007, with a total of 106 people. There were two groups in each of six locations, one group of men and one of women in each place. The groups were as follows:
 - Belfast: 19 participants overall (10 men and 9 women)
 - Glasgow: 18 participants (9 men and 9 women)
 - London: 14 participants (6 men and 8 women)
 - Manchester: 18 participants (9 men and 9 women)
 - Newcastle: 20 participants (10 men and 10 women)
 - Swansea: 17 participants (8 men and 9 women)
- **Recruitment.** The participants were recruited to provide around 16 participants in each location. The actual attendance was higher than the target overall (see above), and in each location other than London (which had 14 participants).

Participants were recruited to provide a mix of views from different perspectives including of:

- Social class (46 of social classes ABC1 attended, and 60 of social classes C2DE / socially excluded). Specific efforts were made to ensure that there was a good representation of those who would normally be excluded from these types of discussions, and that was successful.
- Religious views from different faiths, practising and non-practising, and those with no stated faith. Participants were as follows: 27 Catholics, 11 Church of England, 1 Hindu, 2 Humanist, 3 Jewish, 3 Muslim, 29 with no religion, 4 other, 1 Presbyterian and 25 Protestant. Of these, 34 were practising, and 66 were non-practising (no information was available on 6). They were asked to self-define themselves as practising - the question was "Would you consider yourself to be a practising [xx] e.g. attending a religious ceremony weekly?".
- Age groups and gender. Half the participants were men and half were women; and there was a good spread of participants from all age groups, over 18.
- Ethnic background: 97 participants were white, and 9 were from black and minority ethnic communities.

The aim in recruitment was to provide a diversity of views, not a rigorously representative demographic sample of the UK population. This diversity was achieved overall.

- **Incentives.** Participants were each paid £45 including travel expenses, to attend. This is normal practice in any form of deliberative research, and helps ensure that those who cannot afford to attend because of the costs of travelling etc can be encouraged to take part, thus ensuring a greater diversity of views at the event.
- **Process.** Each meeting lasted two hours, although they were held at different times of day in different places. The process worked through a set of carefully designed steps to:
 - introduce the research area and variety of different types / origins of embryos
 - enable participants to consider and give their views on the creation and usage of the various types / origins of embryos in research
 - briefly introduce the current legal position in the UK regarding the usage of these embryos in research.

The steps were:

- introduction and warm up
 - prompt and gather participants' views on medical science and research, to provide the context for later discussions
 - prompt and gather participants' unprompted beliefs and opinions, with information only given on the HFEA's role and their receipt of the applications for research on hybrid embryos; the group considered immediate responses in terms of what they thought and felt and had heard about the issue
 - introduction to embryonic stem cell research, and discussion, with glossary provided of key terms and handout
 - introduction to the different types and sources of embryos that could be used / created for research, with more handouts on embryos from normal fertilisation, cell nuclear replacement / cloned embryos, cytoplasmic hybrid embryos, human chimera embryos, transgenic human embryos and true hybrid embryos, including the legal position
 - summary of key responses from the group
 - next steps, including preparation for the reconvened event for those that will attend, and signposting of the HFEA website if they wanted to make an input there; each participant was given the full consultation document to take away.
- **Drafting materials to aid discussion.** A series of handouts was provided throughout the process, to introduce information to aid each element of the discussion. These materials were drafted jointly by Opinion Leader and HFEA, with input from the Stakeholder Advisory Group. A significant investment of time was made in ensuring that the materials were fair, balanced and understandable as it was recognised that this was vital to an effective engagement on these complex and very technical issues.

- **Reporting.** The findings from this research were presented in a single report by Opinion Leader to HFEA on the deliberative research element of the process. However, the results from the discussion groups are shown separately from the views of the public at the reconvened meeting (at the beginning and end of that meeting) so that the similarities and differences can be seen clearly.

These results show a clear general trend to greater agreement (and less disagreement) with the use of various types of human embryos as participants gain greater knowledge about the issues, with a majority agreeing to the use of cloned and cytoplasmic embryos; the use of chimera, transgenic and true hybrid embryos was supported by less than half the participants. Overall, agreement decreased as the mix of animal-human elements increased from the minimum to the maximum.

6.3 The effectiveness and value of the exercise

The assessment that follows is based on observation of one of the discussion groups, and analysis of a questionnaire that was circulated to all participants. Interviews were carried out with participants but covered their involvement in the reconvened meeting as well, so those findings are covered in the next section. The discussion groups were also covered specifically in interviews with those in the HFEA and Opinion Leader responsible for the process.

6.3.1 General feedback

Questionnaires were distributed to all participants in the discussion groups, and there was 100% return rate for all workshops. However, due to a clerical error, the questionnaires from the two Swansea groups were mislaid by the workshop organiser and so these are missing from the analysis.

A full analysis of the findings from each of the 10 discussion groups covered is given in Appendix 1, and the overall results are outlined in summary below.

This analysis shows remarkably positive feedback from participants, who clearly enjoyed and valued the experience, and were more likely to get involved in future such events as a result, which shows a very positive attitude to their involvement here. They clearly learnt a lot and the experience helped clarify their thinking. They could understand and use the information provided and found it fair and balanced.

Overall:

- 95% were satisfied with the event overall; 73% were **very satisfied**. No-one was dissatisfied at all.
- 96% were satisfied with the way the event was run on the day; 78% were very satisfied. Again, no-one was dissatisfied at all.
- 76% were satisfied with the information received before the event; 51% were very satisfied.

The feedback on this last question is less significant than it appears. The participants were purposely given very little information prior to the event, so that they would not have any preconceptions about what would happen.

In more detail:

- 97% of participants agreed that all participants were treated equally and respectfully, and that no single view was allowed to dominate (63% strongly agreed)
- 96% agreed that they had enjoyed taking part (60% strongly agreed)
- 96% agreed that they had learnt something they did not know before (65% strongly agreed)
- 96% agreed that they understood the purpose of the consultation (39% strongly agreed)
- 95% agreed that attending the discussion group had helped them think more clearly about the issues (53% strongly agreed)
- 90% agreed that the information provided was fair and balanced (38% strongly agreed)
- 90% agreed that they were more likely to get involved in these sorts of events in future (46% strongly agreed)
- 84% agreed they understood and could use the information provided (37% strongly agreed)
- 80% agreed that they were able to discuss the issues that concerned them (35% strongly agreed).

From observation, these findings certainly reflected the enthusiasm and energy that participants invested in the discussions. There was no sense that they were going through the motions for their incentive fee and expenses. There was a high quality of discussion, questioning and engagement with the issues as participants worked hard to understand and discuss the issues, and to come to a considered view that they felt comfortable expressing.

Again from observation, the handouts worked extremely well. They were short, clear, with plenty of illustrations. The information was often very complex and technical, but the participants understood it relatively quickly and seemed to have no difficulty in asking questions if there was anything they did not understand. The speed at which they seemed to be absorbing the information demonstrated the quality and effectiveness of the materials.

There was slightly less positive feedback on there being enough time and on the extent to which they understood how the results of the consultation would be used, although this was still largely seen as working well:

- 76% agreed there was enough time to discuss the issues properly (only 27% strongly agreed, and 13% disagreed)
- 76% agreed that they understood how the results of the consultation would be used (only 25% strongly agreed, 19% were uncertain, and 4% disagreed).

From observation, it would not have been effective to have extended the discussion time. At the meeting observed, participants were clearly getting tired towards the end. It was a demanding subject and they had engaged very fully. The demand for more time could, therefore, be seen as a sign of enthusiasm rather than criticism.

In terms of lack of understanding of how the results of the consultation were going to be used, there could possibly have been a little more explanation about how the results would be used, but there was a generally good level of understanding (76% agreed they understood). In future, it may be worth considering providing, for public participants, a simple explanation of how results will be collated and analysed and turned into a final report that will inform decision-making.

6.3.2 Impact of participation on people's views

The majority of participants (55%) agreed that attending the discussion group had changed their views on these issues:

- 26% agreed strongly
- 29% agreed that it had changed their views
- 27% were uncertain / didn't know
- 19% said it had not changed their views.

This is an indication only of the extent to which people's views were actually affected, as people's views are likely to have been shifted but may not actually have changed in substance. Nonetheless, more than a quarter of participants agreed strongly that their views had been changed as a result, and another 29% agreed, which means that over half agreed that their views had been changed.

This is higher than is normal for these processes; research processes of this type usually find it hard to show real shifts in views (and participants are often quite reluctant to say they have changed their views). It is therefore likely that this represents quite a significant shift for it to be shown so clearly.

6.3.3 Impact of the media

While 40% of participants said they had seen media coverage of the issues, only 16% agreed that this had made any difference to their views. This is clearly only an impression, as people are not always fully aware of the difference that media coverage has made, but it suggests quite a lot of awareness of the general issues, but also quite a strong resistance to being influenced by that media coverage.

The findings were:

- 40% said they had seen media coverage of the issues; 51% said they had not
- 16% said that media coverage had affected their views; 21% said it had not.

From observation, it was not clear that there was enormous awareness in that group of the issues prior to the information provided during this process. There was certainly no sense of detailed prior knowledge of the issues. The points raised in discussion seemed to be coming much more from people's personal experience, general sense of the morality of the issues, science fiction etc than from prior knowledge, including from the media.

6.3.4 What worked best

The elements of the process that the participants valued most were:

- **Learning**, especially about the specific issues of embryo research: 46% mentioned this overall, within which 12% said specifically they valued the information about embryo research, 8% mentioned good explanations and 6% the information sheets
- **Hearing different views** from other participants (22%). Other valued elements were that everyone joined in, and that there was a good facilitator.

From observation, the discussion groups worked extremely well. The timing of discussion on each topic worked well, it did not feel rushed so that when people veered off the subject there was time for them to remember what the meeting was about and get back on track without the need for heavy handed facilitation. The facilitation was excellent - encouraging and engaging without being patronising, and efficient without being unfriendly.

In terms of the research output, it was clearly valuable to the HFEA staff and Authority members, and stakeholders, that views from all these different groups could be seen separately and then overall, to get a sense of public opinion from a diverse set of publics. The recording and reporting of participants' views worked well.

The payment of incentives is always a difficult issue, but is seen generally as being essential to ensure a diversity of views, including those that may otherwise not be able to afford to attend. As one public participant said: *"If you asked people to volunteer you'd miss out on those who can't afford it. So yes, it's public money well spent."*

6.3.5 What worked least well

Here the biggest comment was 'none' (38%). Otherwise people's main concerns were with the implications of the discussion (animals mixed with humans - 7%), and not enough time (6%) - this is confirmed by the 18% of respondents who identified that more time would have improved the event.

Other suggestions for improvement were requests for more information (10%), including before the meeting (3%), and having a wider range of people involved (9%).

From observation, and consideration of other engagement processes, there can be disadvantages to using groups that are segregated in this way. Firstly, participants like to be in mixed groups having discussions with people they do not normally meet (9% of participants suggested this would be an improvement, as above). Secondly, there is a danger that when everyone in the group has a similar background (even just age and gender), that can reinforce cultural prejudice, rather than allowing views to be challenged.

6.4 Overall conclusions on the discussion groups

Overall, there is no question that the discussion groups worked very well - they were well facilitated, the materials were carefully drafted and were fair and balanced and the groups found them understandable and usable. The way the information was introduced worked very well, with enough time for the participants to grasp the basics and then discuss the implications. Participants clearly enjoyed the experience and learnt a lot from it, and left the event more enthusiastic to participate again in such events in future.

One indication of the participants' enthusiasm is that 80% of them said it is **very important** to involve the public in discussing these sorts of issues, plus another 6% said it is important. No-one said it was not important.

For the research exercise, this was an important first step in a deliberative process but was also valuable in its own right, providing information on the views of a diverse group of people from across the UK in ways that directly addressed the questions being posed by the consultation.

7. DELIBERATIVE WORK PART 2: RECONVENED PUBLIC MEETING

7.1 The purpose of the exercise

The second part of the deliberative work consisted of a reconvened meeting, designed to bring back together a mix of participants from across the UK who had already participated in the local discussion groups. The aim was to continue and deepen the discussion, and provide further input and opportunities for questions and discussion amongst participants themselves, with the resulting public views being more informed and considered than those from the initial local discussion groups.

7.2 The nature of the exercise

- **Overall scale.** This was a full day meeting in London, with 44 participants. The aim was to bring back together about half of those who had participated in the local discussion groups.
- **Recruitment.** The aim was, as in the local discussion groups, to provide a diversity of views, not a rigorously representative demographic sample of the UK population. This diversity was achieved overall, and the individual tables / groups for discussion were also mixed to ensure diversity.
- **Incentives.** Participants from London were each paid £75 to attend. Participants from outside London were each paid £100, plus travel expenses. This is normal practice in any form of deliberative research, and helps ensure that those who cannot afford to attend because of the costs of travelling etc can be encouraged to take part, thus ensuring a greater diversity of views at the event. For those travelling longer distances, a night in a hotel was also provided, and train travel was organised for them.
- **Process.** Prior to the meeting, from the discussion groups, participants had been given the full consultation document, and the purpose of the reconvened event had been explained at that stage. In their invitation letter, and final letter with details, there was only further information on the logistics of the event.

The meeting lasted a whole day, from 9.30am (start at 10am) to 4.30pm. The main elements of the event were:

- Introduction from Opinion Leader and HFEA, and then warm up exercise
- Presentation from platform from external expert to recap on the scientific information they had been given about the different types of embryos
- Group discussions about what they had thought since previous meeting, anything they had seen in the media, and overall arguments for and against creating human-animal embryos; plus initial data collection on views (at start of the day)
- Presentation from platform by external expert on why scientists want to be able to do this research
- Table discussions in response to presentation
- Presentation from platform by external expert on ethical arguments for and against human-animal embryos

- Table discussions in response to presentation
- After lunch, a panel presentation from four external experts with different views (10 minutes each)
- Table discussions in response to presentations
- Table discussion to develop questions for the panel
- Question and answer session with the panel
- Final table discussions on previous session, plus final data collection on views (at end of the day)
- Summing up and response by HFEA, and close by Opinion Leader.

Participants were seated in tables of 8 -10, each with a table facilitator and young scientists who was there to answer any scientific and technical questions. The people on the tables were mixed to ensure a diversity of views.

- **Materials to aid discussion.** A series of handouts was used to support the points made by the experts from the platform. These materials were drafted jointly by the experts and Opinion Leader with the HFEA. Again, a significant investment of time was made to ensure that the materials were fair, balanced and understandable as it was recognised that this was vital to an effective engagement on these complex and very technical issues.
- **Recording and reporting.** The comments from participants were collected by table facilitators on laptops, and on flipcharts when capturing e.g. the three most important points, or to agree questions for the panel. This worked well as a mix of capturing what people said and ensuring that all agreed with the key points.

The findings from this research were presented in a single report by Opinion Leader to HFEA on the deliberative research element of the process, with the results from the discussion groups. However, the results from the discussion groups were shown separately from the views of the public at the reconvened meeting (at the beginning and end of the meeting) so that the similarities and differences can be seen clearly.

Overall, the results show a clear general trend to greater agreement (and less disagreement) with the use of various types of human embryos as participants gain greater knowledge about the issues, with a majority agreeing to the use of cloned and cytoplasmic embryos; the use of chimera, transgenic and true hybrid embryos was supported by less than half the participants. Overall, agreement decreased as the mix of animal-human elements increased from the minimum to the maximum.

7.3 The effectiveness and value of the exercise

The assessment that follows is based on observation of the reconvened event, informal interviews with participants, and analysis of a questionnaire that was circulated to all participants. Interviews were carried out with 10 participants, and interviews with those in the HFEA and Opinion Leader responsible for the process also covered this event. Interviews with stakeholders and Authority members fed into this analysis as they provided feedback on the legitimacy of the findings based on the value of the deliberative process.

7.3.1 General feedback

Questionnaires were distributed to all participants at the reconvened event, and there was 100% return rate (44 questionnaires from 44 participants).

A full analysis of the findings is given in Appendix 2, but the overall results in summary are outlined below.

This analysis shows similarly remarkably positive feedback from participants to that from the discussion groups - the response after the reconvened event was even slightly more positive on some issues. The participants also clearly enjoyed and valued this experience, and were more likely to get involved in future such events as a result, which shows a very positive attitude to their involvement here. They clearly learnt a lot and the experience helped clarify their thinking. They could understand and use the information provided and found it fair and balanced.

Overall:

- 100% were satisfied with the event overall; 77% were **very satisfied**. No-one at all was dissatisfied.
- 98% were satisfied with the way the event was run on the day; 82% were **very satisfied**. Again, no-one at all was dissatisfied.
- 95% were satisfied with the information provided; 77% were **very satisfied**.
- 95% said they were more likely to get involved in these sorts of events as a result of attending this one; 55% strongly agreed this was the case.

These results are even more positive than at the discussion groups, which were themselves very positive. They are remarkably positive results for this type of engagement.

In more detail, the findings were:

- 100% agreed that they were able to say everything that they wanted to (50% strongly agreed)
- 98% of participants agreed that no single view was allowed to dominate unfairly (50% strongly agreed)
- 98% agreed that they had learnt something they did not know before (55% strongly agreed)
- 97% agreed that they had enjoyed taking part (61% strongly agreed)
- 95% of participants agreed that all participants were treated equally and respectfully (55% strongly agreed)
- 95% agreed there was a good mix of people (59% strongly agreed)

- 93% agreed that attending the discussion group had helped them think more clearly about the issues (52% strongly agreed)
- 86% agreed there was enough time to discuss the issues properly (52% strongly agreed)

From observation, these findings certainly reflected the enthusiasm and energy that participants invested in the discussions. There was no sense that they were going through the motions for their incentive fee and expenses. There was a high quality of discussion, questioning and engagement with the issues as participants worked hard to understand and discuss the issues, and to come to a considered view that they felt comfortable expressing. There was also a fairly high level of disagreement at the tables, but all discussions were polite, people listened to each other's opinions and were able to respect those while disagreeing, sometimes on a very fundamental basis and with some strong feelings. The professionalism of the facilitation contributed to managing what could have been quite a difficult situation. As some interviewees put it:

"We weren't stifled and everyone was polite enough not to talk over each other. And if it got heated we all got a chance to have our say at some stage ... it certainly wasn't intimidating and everyone was encouraged to have their say."

"Some of us agreed with each other and some didn't, but I guess that was the point, wasn't it?"

"Even when there were quiet ones, there were people asking them questions and prompting them to speak. So everyone had the chance to have their say ... There were plenty of arguments that went on, when people had different views. I felt that all views were covered, definitely. Absolutely."

"I felt quite relaxed to be honest with you. You could say what you wanted to say. Even though not everyone always agreed around the table, it was never intimidating."

Again from observation, the handouts worked well to complement the input from the experts. The participants understood the information relatively quickly and had no difficulty in asking questions if there was anything they did not understand.

Not everyone interviewed agreed that the event was worthwhile; one respondent was quite cynical about the whole process:

"I honestly believe that those agendas are set anyway ... a small focus group in Centrepoint is not going to stop them, if they can make millions out of this research"

But this was very much the exception to the general tone of the feedback from participants, which was generally remarkably positive.

The feedback from interviews with expert speakers and Authority members was also very positive about the quality of discussion among the public participants. For example:

"I was actually surprised by how well informed they were. Of course, this wasn't the first event they went to so they weren't just plucked off the street. They were very keen to be involved and they asked some very pertinent questions. They were really down to earth about it. They were pragmatic, not off the rails in one direction or another. So from that point of view it was an extremely satisfactory process to be involved in - it reinforced my faith in the general public. I had expected it to be more polarised than it was." (Expert speaker at reconvened event)

"[want] to say how impressed I continue to be by the way ordinary members of the public can say in a few words what an academic says in a paragraph." (Authority member).

7.3.2 Feedback on understanding of the process

There was slightly less overwhelmingly positive feedback on the extent to which people understood the purpose and process of the consultation, although the results from the questionnaires still show a very good level of understanding and trust in HFEA. For example:

- 82% agreed that they understood the purpose of the consultation (34% strongly agreed)
- 82% agreed that they understood how the results of the consultation would be used (30% strongly agreed, 52% agreed, 16% were uncertain, and 2% disagreed)
- 84% thought that the HFEA would take the results of the discussions at the event into account in making their decisions (34% strongly agreed, 50% agreed, 16% were not sure but no-one thought this would not happen)

From observation, the purpose of the consultation was explained clearly and, from informal interviews at the event, there was clearly trust among the participants that the HFEA would listen and take account of views from the public. No-one expected the decision to be made by the public, but they did expect that what they said would be listened to.

There was also, among participants on the day, something of a sense of responsibility that they should work hard to come to sensible conclusions, as this was an important issue, and they could influence what happens in future.

The feedback from the interviews was similar. There was a sense that the interviewees were not entirely clear about how the whole process worked in terms of how their views would be used, and most had not heard about the final HFEA decision apart from a few who knew only what had been on the news. Almost all the interviewees did want to know more about the final HFEA decision and how their views had been used in reaching that decision. For example:

"[had heard] nothing officially. It would have been good to have received some form of follow up notification with the outcome and decisions made."

There was, however, still a considerable degree of trust in the HFEA, with half of respondents believing that the HFEA would take notice of what the public said, and quite a few others saying they would like to think this would happen. Only one interviewee (out of 10) felt the HFEA would not take any notice. Comments from interviewees included:

"To have been involved in the process reassures me and enables me to reassure others that our opinions can make a difference and that public bodies such as HFEA are interested in public opinion and do react to it. They are not autonomous megalomaniacs who make up rules and regulations for the hell of it. They are responsible and accountable."

"It felt genuine, a genuine attempt to talk to the public, and it felt that it was for the public good."

"It was very professional and they clearly took into consideration what we had to say."

"I was impressed by the thoroughness of it - that they made sure they had public consensus on their side before doing anything."

7.3.3 Feedback on the information provided

The information provided was generally very favourably received by the public participants, both in relation to the written information and information from the speakers. The feedback from the questionnaires was:

- 82% agreed they understood and could use the information provided (32% strongly agreed)
- 88% agreed that the information provided was helpful and unbiased (27% strongly agreed)
- Only 2% felt there was information missing; 68% said there was nothing missing.
- The participants said that the most useful information provided was:
 - information provided by experts on the day (68% identified this as the most useful)
 - information sheets provided on the day (55%)
 - information sent out in advance of the event (30%)
 - only 5% had found the information on the website useful.

This was confirmed by the interviews with participants after the event, who specifically mentioned the value of the information sheets with diagrams, and the mix of written information and having it explained to make it clear, as well as highly valuing the input from experts. They particularly remembered the examples of stories of individuals suffering from illnesses presented by speakers. They felt overall that there had been plenty of information and it was understandable.

Overall, this was a remarkable piece of public education on a highly complex and technical subject. People were not overwhelmed by the complexity and while they did not understand everything immediately, they were not afraid to ask questions. As interviewees put it:

"We had a student scientist on the table and any technical questions that we had we could put to her. We also asked questions of the speakers, we put all the questions together and that worked very well ... Most of the written information was useful in that you had an explanation of the terminology and so on before you went there. And obviously the speakers' presentations were very informative."

"There were technical terms but anything you didn't understand was explained when you asked. And it was explained quite well, you know."

There was also feedback that it was the mix of hearing expert views, having written information and talking to each other that worked. For example:

"It was good to hear other people's views, and the professionals' views. Also talking to people in the teabreaks, I liked that. The scientists and other professionals would walk around and talk to us and you could have a little chat and ask questions."

A further indication of the level of interest generated by the process among the participants, and their confidence to discuss the issue, is that almost all the participants interviewed (9 out of 10) said that they had discussed the issues outside the event with friends, family, at work etc.

7.3.4 Impact of participation on people's views

70% of participants said that the event had made a difference to what they thought about these issues; of those, 43% said it had made 'a lot' of difference; 27% said it had made a little difference. 16% were uncertain and 16% felt it had not really made any difference.

This suggests that this event had an even greater impact on people than the discussion groups - of which 55% said that attending had changed their views (26% strongly agreed; 29% agreed), 27% were uncertain or didn't know, and 19% said it had not changed their views.

This difference could possibly be explained by the different wording of the questions for the two events: the first focused on 'changed views' and the second asked whether the event had 'made a difference to what they thought'. As stated above, research processes of this type usually find it hard to show real changes in views (and participants are often quite reluctant to say they have changed their views). Asking whether the process has made a difference is easier for participants to identify, without having to accept that their views had been changed.

When asked what made the difference, the main points raised were greater clarity and clearer understanding, and having more facts and information. For example, participants said the following in questionnaire responses:

"Having information explained in more depth. Reasons for using embryos that aren't 100% human and having my concerns diminished" (female, 25 - 39 years)

"Made me think about the different views of others" (male, 25 - 39 years)

"Having the facts" (female, 16 - 24 years)

The interviews with public participants followed up on the issue of the impact of the event on people's views and at least half of respondents said quite clearly that the event had made them feel more positive about the use of hybrid embryos than they had been before. For example:

"It gave me a more positive outlook. I think I was more unsure before, but I became more positive."

"Yes, I did change my mind, yes. Before, I was probably against it but when I learned all the facts and why [they do it] I was in agreement."

"Hearing their personal stories [when I first heard about it I thought I'd never approve of that, but then I heard the other speakers and I could understand their point of view] it helped me think in a clearer way."

"It was towards the end of the day that we all started to change our minds ... it was when people stood up to speak that we changed our minds ... I was against it ... but when they explained it I thought they should do it ... I think when they gave a more humanist perspective rather than just black and white on a piece of paper [we could relate to it better]. ... I was more for it at the end"

The shifts in the views of the public throughout the process were of particular interest to Authority members, particularly when the issues that arose from the public deliberations were those that were expected. For example:

"I think the results showing changes in individual views were the most interesting to us. There were no surprises, but there were reassurances that the issues as we saw them were also in the public mind." (Authority member)

"[The information gained from the public engagement process improved the quality and value of the HFEA decision] because of two aspects. It shows that public opinion can be educated by appropriate presentation of the issues and, second, it gives us the reassurance that we are on the right track, and in touch with the real world." (Authority member)

7.3.5 Impact of media coverage

Given the media coverage of this issue in the weeks prior to the reconvened event, it was not surprising that participants were aware of this coverage:

- 57% had heard about the issues discussed at this event in the media; 39% had not. This is higher than the overall feedback from the discussion groups - at which point 40% said they had seen media coverage of the issues; 51% had not.

- When asked what affected people's views, there was not extensive feedback and what there was tended to focus on the issue rather than how it had affected them: 3 people mentioned having seen something on stem cells from skin, 2 mentioned something treating blindness / macular degeneration, and 2 people mentioned cloning.

As mentioned in the previous section, these types of figures can only provide a partial picture of media awareness, as people are not always fully aware of the difference that media coverage has made. However, it does suggest quite a lot of awareness of the general issues, and that the awareness had grown since the previous discussion groups that people had attended. From observation, it was clear that participants were drawing on a range of sources, including what they had picked up in the media, to develop their thinking during the day, as they discussed the various topics.

7.3.6 What worked best

The elements of the process that the participants valued most were:

- **Listening to the experts / panel:** 21 of the 44 questionnaire respondents said this was the best / most successful aspect of the event. For example:

"The different points of view from the speakers" (female, 16 - 24 years)

"The different views from the speakers. This made the whole discussion more realistic" (female, 16 - 24 years)

"The opportunity to question the speakers and listen to their presentations. The amount of information and the level at which it was pitched was just right" (female, 40 - 54 years)

- **Gaining understanding, information and knowledge:** 8 respondents identified this as the best part. For example:

"Getting the right information from the right people" (female, 16 - 24 years)

"It covered any query anyone might have" (female, over 65 years)

- **Group discussions:** 5 respondents
- **Opportunity to question the experts:** 5 respondents
- Other elements identified as the most successful were the table facilitator (3), hearing the views of other participants (2) and 'everything' (2).

Participants were also asked what the greatest benefit to them had been, from their involvement in the process. The findings here were:

- **Learning, information, knowledge etc about the issue:** 19 respondents
- Other benefits were the chance to put their own views forward (3), taking part in an important topic (3), the mental challenge of thinking about the issues (2), and hearing different views. A couple of people (2) mentioned that the money had also been a benefit.

Some specific benefits mentioned were:

"To be aware of how our government values the public view. To experience a balanced argument from the experts" (woman, 40 - 54 years)

"Receiving the information first hand" (female, 25 - 39 years)

"Information / mental challenge - enjoyed thinking about the subjects and related issues" (male, 16 - 24 years)

"Taking part in something that may change medical science (and the overnight stay and money!)" (female, 40 - 54 years)

"Taking part and hopefully making a difference" (male, 16 - 24 years)

Feedback from interviewees was similar. For example:

"Having the opportunity to listen to the speakers on the day ... Having the opportunity to give my opinion, whether they took it on board or not. You know, it's a life experience you wouldn't normally have."

"Well, I felt part of it. I felt part of the process ... of giving my opinion. Before, I've never been part of giving my opinion - not on something as important at least."

This feedback clearly shows not only that real learning had taken place among the public participants on these complex technical and ethical issues, but that the participants recognised and strongly valued the opportunity to develop this learning. It also shows the links between learning and being taken seriously - from observation there was a real sense that the learning resulted because people felt the need to understand (and in some cases struggled to understand) the information in order to make their contribution, and fulfil their responsibilities to the process and to society.

The elements of learning among public participants were also important for the expert speakers at the main events, and Authority members. For example:

"[there are] problems with misinformation about these issues ... I think it is important to put out a clear message about what's really being done ... it is educational, and there is a trickle down effect [with the people attending then going to tell other people about it]. ... I think the people who were there certainly felt empowered. And I think there would have some dissemination through the participants [telling others about it], though there was such a small number of people involved it's difficult to say." (Speaker at reconvened event).

"It's very important for any publicly regulated and funded science to be publicly understood. We're not doing this just because it's interesting science - although it is - we're doing it for the public good. So I was always very positive about public engagement ... it explains to the general public why it's so important to do these things. ... Apart from anything else, there are lay members on grant giving committees ... so we want them to understand what we do. And also, transparency is always a good thing." (Speaker at open public meeting).

"I think the whole debate was an educational process for most people involved. It certainly was for me as a non-scientist. [It was] a reinforcement of the importance of this type of open public consultation, as a sort of educational process, and at the same time a process of accountability, when dealing with contentious issues."(Authority member).

"We have a role in educating people about the issues, and we can do this through public engagement."(Authority member)

There was also some feedback about the process being an advance on previous HFEA engagement work, and the benefits that has had for those involved in thinking about the public face of their own work. For example:

"[It was] a more open consultation process [than the HFEA has done in the past] so I saw it as a step forward in the HFEA's engagement with the public. It also got me to do some more thinking in terms of how we market our interests."(Speaker at both the reconvened and open public meetings).

On more practical issues, from observation, the balance of input from the platform from the introduction to the consultation, to the presentations in the morning followed by discussion, and then the panel with questions and answers, worked extremely well. The timing of discussion on each topic worked very well, allowing time for people to discuss issues in a relaxed but efficient manner, without feeling too tight for time. The table facilitation was largely very good, ensuring that all participants were encouraged to take part and keeping the discussion moving. This professionalism contributed to the sense for the participants of a high quality event that had real status.

It was also particularly valuable to have a variety of viewpoints among the speakers. This helped ensure that participants did not feel manipulated towards a particular conclusion, and also helped them feel there was no 'right' answer, which in turn made them feel more comfortable about expressing their own views. In addition, it was clear that the speakers / experts were there to contribute to the process of the public coming to their own conclusions - there was no sense that there were speakers and an 'audience' but rather that the speakers were there to provide input to contribute to and stimulate discussions among the public themselves.

More generally, in feedback from interviews with HFEA staff and Authority members, the outputs from this meeting were clearly of a quality and value that contributed significantly to the Authority's confidence in their final decision (see some of the quotes above).

Most of the influence of the deliberative work was through the reports prepared by the HFEA based on summaries of findings from Opinion Leader. However, attending the actual public events was also important. The HFEA staff who drew up the papers for the Authority based on the consultation attended the event, and felt that attendance gave them a feel for the quality and seriousness of the public debate that was vital in presenting the findings appropriately to the Authority.

7.3.7 What worked least well

Here (as with the discussion groups) the biggest comment was 'none' (12 out of 44 respondents). Otherwise people's main concerns were:

- **Disagreed with the experts:** 5 questionnaire respondents (out of 44) mentioned this, and it tended to be a disagreement with the content of the expert input rather than the quality of their presentation.
- Other points were that there were some logistical problems (acoustics, temperature of room etc). This suggests that the actual design and content of the process were quite satisfactory.

From interviews, there were again almost no negative remarks other than some sense that they would have liked to know what the final decision had been, and had not been entirely clear how their views had contributed to that decision.

From observation and informal interviews on the day, there were a few practical issues that were identified:

- **Difficult to reflect strength of feeling on issues.** Where three key issues were identified by the groups, there was no way for the group to distinguish (and thus for the notes taken by facilitators to distinguish) if, for example, there was one vital issue and a couple of not very important issues. It would be useful to find mechanisms for capturing the strength of feeling on certain issues so this sort of prioritisation could be reflected in final reports.
- **Neutrality of speakers.** It is always difficult to entirely predict what external speakers or experts will say on the day and, although here the speakers were generally excellent, and generally invited because they did have a particular perspective rather than being neutral - where speakers were expected to provide neutral information and failed to do so, this was very quickly recognised by the public participants who identified these inputs as least useful.
- **Balance of science and ethical input.** It was noted that all the scientists speaking were in favour of the use of hybrid embryos for research, and all the speakers against were non-scientists. As it was, a slight sense emerged that arguments against were emotive or spiritual or moral rather than technical or scientific, which may not necessarily be entirely the case. Although it is understood that perfect balance among speakers is never possible, it may have been useful to have had some scientific input to the arguments against to provide greater balance.

- **Feedback after the event.** While the information provided during the events was clearly exemplary, there was no information provided to participants afterwards (until news of the final report was circulated to participants in November 2007). This was noted as a particular concern among interviewees. For example:

"Keep people informed before, during and most importantly (which is where this event has fallen short for me) after the event."

"It would have been nice to find out what happened afterwards."

7.4 Overall conclusions on the reconvened event

Overall, this was a highly successful event. The table discussions were well facilitated, the materials were carefully drafted and were fair and balanced and the groups found them understandable and usable.

The way the information was introduced worked very well, with enough time for the participants to grasp the basics and then discuss the implications. The balance between printed information and input from speakers worked very well indeed, as did the balance between input and discussions among participants in their small groups. The note-taking at tables was smooth and did not disrupt the flow of the discussions, and the quality of the final reports shows that much of the richness of the debates was captured well.

Participants clearly enjoyed the experience and learnt a lot from it, and left more enthusiastic to participate again in such events in future. One indication of the participants' enthusiasm is that 93% of them said it is **very important** to involve the public in discussing these sorts of issues, plus another 7% said it is important - so **100% thought it was important**. This is even higher than from the discussion groups, when 80% said it was very important. This sort of feedback shows that the participants had a strong sense of the importance of the exercise.

For the research exercise, this completed a very good and balanced deliberative research exercise, which provided a quality and quantity of information that was useful to the Authority in their decision making, providing information on the views of a diverse group of people from across the UK in ways that directly addressed the questions being posed by the consultation.

8. OPEN PUBLIC MEETING

8.1 The purpose of the open public meeting

The aim of the open public meeting was to provide an event at which anyone could attend and express their views. It was also expected that this event would gain a higher level of media coverage than the deliberative work and thus stimulate wider awareness and debate of the issues.

8.2 The nature of the open public meeting

The meeting was held at a central London hotel from 6pm to 8pm on a weekday evening. It was chaired by a well-known host (television presenter Nick Ross) and was structured overall using the model of the BBC Question Time programme: with a panel representing different views taking questions from the floor and the Chair linking and prioritising questions and issues.

The format was essentially as follows:

- Introduction by the Chair and HFEA
- Introduction to the consultation overall, including a DVD with footage of the reconvened public event to show that deliberative public consultations had already taken place and how that worked
- A series of polling questions, using handheld electronic devices (similar to those used in TV quiz shows)
- Introductions by the Chair to the five Panel members
- Questions and answers from the floor. This was the core of the meeting and was allocated almost one hour.
- Further polling questions
- Closing remarks - thanks and next steps for HFEA
- Drinks and canapes.

The panel was as follows:

- Dr Lyle Armstrong - Lecturer in Stem Cell Biology, University of Newcastle
- Rev. Dr. Stephen Bellamy - The Mission and Public Affairs Council of the Church of England
- Josephine Quintavalle - Co-founder and Director of Comment on Reproductive Ethics (CORE)
- Christine Young - Carer and patient representative, Special Parkinson's Research Interest Group
- John Cornwell - Director of the Science and Human Dimension Project at Jesus College, Cambridge and regular writer for the Tablet

All participants had been asked to register online before attending, although it had been agreed that no-one would be turned away at the door unless the room was full.

Attendees were sent the glossary and link to the full consultation document before attending.

Participants were also asked to pre-register questions, so they could be identified at the event. However, further questions and points were taken from the floor during the meeting.

220 people registered and a total of 153 people attended. The meeting had been widely advertised including with HFEA stakeholder organisations, universities, the Metro (free London newspaper), The Tablet, and internet sites and networks.

This was a very different audience from the other public events for the consultation. An initial polling question was designed to assess the levels of knowledge among the audience, and the results were that:

- 30% knew a lot about the issues
- 45% knew a bit
- 16% knew a little
- only 9% knew very little.

Even allowing for the vagaries of self-assessment of knowledge, the participants clearly had quite a significant level of knowledge about the issues. Further polling showed that 36% of the audience said they were from an organisation with an interest in the issue, 27% were academics / scientists and 37% described themselves as members of the public.

The evaluation questionnaire completed by 49% of participants provided another perspective on the make-up of this audience. There was a relatively high level of young people and older people (with 12% each of respondents being either 16 - 24 or over 65), and a relatively high proportion of people from different cultural backgrounds - with only 69% of respondents being White British and others being white other (9%), Asian or Asian British (8%) or Black British (7%). This is a larger proportion particularly of younger people and people from black and minority ethnic communities than at the deliberative public meetings and thus adds to the diversity of views that formed part of this consultation overall. There were also slightly more women than men (57% of respondents were women, 43% men).

The meeting room was very full, and there was a general atmosphere of strong interest and excitement throughout. There was also a much higher level of passion about the issues than had been apparent at the public meetings, with heckling and shouting from the floor at various points.

An audio recording of the event was made and published on the HFEA website shortly after the meeting.

This meeting was not intended to be part of the main research process for the consultation, and the results of the polling were not included as part of that report. These polling results were, however, published in the final report from the HFEA on the consultation in October 2007.

The polling results from this meeting on the key questions fell between the responses to the consultation document and online consultation (which had a large majority against the proposal to create and use hybrid embryos for research), and the deliberative work (which had a small majority in favour of the research if a clear benefit

was stated and the research was subject to strict regulatory controls). The views from this meeting were that more participants were against using animal eggs to create human embryos for research, and felt that the potential benefits did not outweigh the ethical concerns.

Polling feedback also showed that 75% of participants at the open public meeting had already (13%) or were planning to (62%) respond to the online consultation.

8.3 The effectiveness and value of the open public meeting

The assessment that follows is based on observation of the meeting, informal interviews with participants, and analysis of a questionnaire that was circulated to all participants. Interviews were carried out with nine participants, and interviews with those in the HFEA and Opinion Leader responsible for the process also covered this event. Interviews with stakeholders and Authority members fed into the analysis that follows as they provided feedback on the legitimacy of the findings based on the value of the deliberative process.

8.3.1 General feedback

75 questionnaires were returned from the 153 participants; a return rate of 49% which is generally considered a good return for research purposes. A full analysis of the questionnaire responses is given in Appendix 3, but the overall results are outlined below in summary.

Although this was a very different audience, and the meeting had a very different purpose from the deliberative public events, the feedback from this event is also largely positive.

Overall:

- 92% were satisfied with the event (40% were very satisfied; 52% were fairly satisfied. 4% were not very satisfied but no-one was not at all satisfied).
- 91% said they enjoyed the debate, although one respondent qualified this by saying the debate was 'worthwhile' rather than 'enjoyable' (52% strongly agreed that it was enjoyable and 39% agreed). Only 2 respondents disagreed.
- 91% agreed that it is important to consult the public on these issues; **71% agreed strongly** and 20% agreed. This closely matches the polling result at the event, which found that 90% thought it was important.

This does show a high level of satisfaction with the process, and with such processes of public engagement generally.

Some of the additional comments on the questionnaires were:

"Complex issues like these need a lot of debate. Discussions like this should be encouraged"

"I appreciated the prepared materials and Nick [Ross's] skilful mediation"

"The discussion went off topic a fair bit, its important for debate but the issue was quite specific and we ended up discussing very broad issues - not really up for discussion - a tricky task though, on the whole well done!"

The main criticisms of the meeting from questionnaire respondents were that some issues were not explored fully enough - particularly alternative sources of stem cells (9 out of 75 respondents raised this issue of needing more in depth discussion), that the panel should have included more scientists and ethicists (mentioned by 7 respondents), and that there was too much shouting and heckling (6 respondents). There was also some criticism that these issues were too complex and emotive for the public, who need more information before being consulted (4 respondents), and that some voting questions were poorly phrased. For example:

"Vox pop is not a satisfactory methodology for deciding ethical issues on complicated matters"

"I do agree with public consultation but on such an emotive issue I think issues can become confused through lack of understanding by many people of the general public."

"The phrasing of the questions was confusing and amateur. For example the question on receiving therapies 'from' human / animal embryos did not make it clear if it included therapies derived from knowledge derived from this area, and the question on the benefits outweighing 'any' ethical issues is confusing since the pursuit of benefits is itself an ethical one (so the question could be read as 'ethical concerns' vs 'benefits', which is a false dichotomy."

This criticism of the questions was echoed by an expert speaker at the event, who said in interview"

"Some of the [polling] questions were quite ambiguous ... They were not phrased in a helpful way."

As can be seen from the proportion of negative comments, this is relatively minimal criticism overall.

The feedback from the interviews with public participants generally reflects this sense of satisfaction. Almost all interviewees said they were more likely to get involved in this sort of consultation again as a result of taking part in this one, and there was a general sense that this had been a good, well-organised event and that it had been worthwhile. Not everyone agreed:

"I personally think the HFEA should have been more confident in its legal powers in making these decisions. They don't actually need to consult but I think they felt the need to because of pressure from the government that this kind of research might be banned in the future. The consultation shouldn't really have happened in my view; it was unnecessary." (participant interviewee).

Several interviewees (and questionnaire respondents) expressed the view that the decision had already been made by the HFEA, and that the consultation was only going through the motions. However, these views were a minority.

8.3.2 Feedback on fairness and balance

Although it was always expected that this meeting would be more polarised than the other public consultation processes, there was nevertheless a fairly positive view on the fairness and balance of the meeting:

- 78% felt that the panel represented a balanced range of views on the issues; 31% agreed strongly that this was the case, 47% agreed, and only 9% disagreed
- 74% agreed that no single view was allowed to dominate the discussion unfairly; 25% agreed strongly, 49% agreed, and 11% disagreed.

Given the passionate views that the meeting revealed among participants, this is very positive response to the fairness of the process.

There was some criticism that there should have been more scientific arguments against the research. For example:

"I feel that the panel should also have had on it a medical scientist engaged in adult stem cell technology and/or cord blood cell work. The assumption in the debate was that only embryonic stem cells can be used for research around treatment of degenerative diseases."

The overall respect for the fairness and balance of the process was reflected in the feedback from the public participants that were interviewed. They felt that the consultation document was good and covered the issues fairly, that the meeting was run fairly and that there was enough time for discussion.

The main criticism of the balance in the meeting was that there should have been more scientists on the panel, particularly scientists who were against the research or who came from a different perspective. For example:

"There weren't people on both sides of the argument - there was no scientific case against." (participant interviewee).

Several interviewees mentioned that Nick Ross's chairing had been very good and helped make the meeting work well. However, several mentioned a potential bias which was more important to some than others. For example:

"Nick Ross ... although a layperson, had a conflict of interest: he is the executive chair of a pro-stem cell research group so has a clear bias." (participant interviewee).

"Having a chair that is well known but with clear interest and knowledge of the subject was good." (participant interviewee).

8.3.3 Feedback on understanding of the process

There was a high level of understanding of the purpose of the overall consultation, with 94% agreeing that they understood, 49% agreeing strongly. None of the respondents felt they did not understand.

8.3.4 Impact of participation on people's views

Here, there is a marked difference from the findings from the deliberative public processes. Only 15% agreed that attending the meeting had changed their views, and no-one agreed strongly. 64% disagreed, of which 37% disagreed strongly, and 17% were unsure. This shows that this meeting did not really impact to any real degree on participants' views. That was not the purpose of the meeting, and probably reflects the strength of feeling about a particular position on the issues that participants arrived and left with.

8.3.5 What worked best

- **Hearing the views of others.** Interviewees mentioned the benefits of the open debate and having the chance to hear other's views. For example:

"[There] was not much new information, but a good chance to hear different views put by those who hold them ... I don't think my position really changed but I gained a more realistic appreciation of some other people's opinions." (participant interviewee).

"[The main benefit was] the opportunity for me to learn more, to listen to differing opinions and hopefully having a voice in policy making ... This was the first sort of event of this kind I have participated in. I enjoyed it more than I thought I would - I thought it was well organised and very enjoyable." (participant interviewee).

- **This was an important opportunity to debate an important issue.** Interviewees mentioned the value that they placed on the opportunity to express their views and for there to be a public debate at all. For example:

"If democracy means much at all then people need to have involvement with contentious issues like this." (participant interviewee).

"I thought myself privileged - it was very useful." (participant interviewee).

- **The meeting was well done.** The professionalism of the design and organisation of the meeting was praised. For example:

"I must say having been to many meetings, this one was very well organised and attended. I was very impressed with the organisation and conduct of the meeting itself." (participant interviewee).

Even those who were not happy with the outcomes valued the opportunity to take part. For example:

"I am desperately disappointed with the HFEA. I don't think they are interested in engaging the public in a deep way. They are going through the motions. You can persuade the public to agree with anything if you say it's going to cure Alzheimer's. The HFEA are going down the route of 'what will the public wear' rather than 'what is morally proper'. ... Having said that, it was good to be involved and consulted." (participant interviewee).

One expert speaker particularly praised the polling at the meeting, as a way of gauging the mood of the meeting when there are a lot of passionate views being strongly expressed:

"The most informative tool that was used was the hand held voting device. Being a scientist, I like to see statistical data being produced that reflects what I am saying [especially when the audience includes noisy hecklers] - it makes it difficult to gauge where the audience's opinion is going".

8.3.6 What worked least well

- **Lack of feedback on what happened next.** As with the feedback from the deliberative events, there were complaints that participants had heard nothing since the meeting about either the conclusions of the consultation, or what the HFEA had decided to do. For example:

"If they [HFEA] did listen they ought to publish a paper or a booklet justifying how they came to the decision they did given what was said at the meeting." (participant interviewee)

"I'm not really clear how they [HFEA] weighed the findings of the different groups up. It would have been good to be sent something in the post to explain the outcomes and the weighting. It would have been good to have a summary of the questions, the answers our group [the open public meeting] gave and the national average, and on the basis of this how did the HFEA make its decisions." (participant interviewee).

"I'm not really sure about the follow-up - it would be nice to have feedback on how it was all used." (participant interviewee).

"I was disappointed by how little time they gave to the conclusions of the public consultation [deliberative work] at the event. They almost skated over that. I'm not quite sure at the end what role they were intending to give to the public views ... A fuller discussion of the results of the consultation by the HFEA. I think that was missing." (expert speaker interviewee).

- **Lack of balance.** There were two main issues here raised by a few respondents:
 - There were not enough scientists on the panel, especially scientists who were against the research but also those investigating alternative research routes for stem cells;

- The suggestion that the research would lead to 'cures' for terrible diseases such as motor neurone disease and Alzheimer's created problems. One expert speaker interviewee said *"I can understand that if you wave a carrot in front of people [e.g. the possibility to treat disease] they will respond in favour, but in my view it was not an honest carrot."*

Although these views were strongly voiced, the overall feedback on the process was that there was generally a good balance at the meeting both between different perspectives and, in process terms, between input from speakers and discussions and questions from the floor.

8.4 Overall conclusions on the open public meeting

Overall, this was a successful event. Although it was seen as separate from the deliberative research elements of the consultation with the public, it clearly played an important part in the overall process, particularly by:

- Providing an opportunity for those with strong existing views to air their opinions and be listened to as part of the process. Even when participants felt that the HFEA had made up its mind, and would not listen to views against the research, they were glad to have the opportunity to take part and give their views. The expert speakers also valued the opportunity to take part in the debate.
- Providing an opportunity for the HFEA to hear strong views. As one Authority member said in interview:

"It helped to hear people articulate strong views. It is right that we should listen to these views and that we should be seen to be listening to these views. It's part of our accountability." (Authority member)

The HFEA may have felt it knew the views of the 'usual suspects', those who always respond to consultations and have strong existing views, but Authority members still saw it as useful to actually hear these views expressed from different perspectives on this specific topic.

- The opportunity for participants and the HFEA to listen to a range of different views. Several public participants felt that it was useful for them to hear views that were different from their own.

The feedback from questionnaire respondents was very positive, with high satisfaction levels on the event, including on its fairness and balance overall - both in terms of a variety of views expressed, and in terms of the mix of input from the panel and questions and points from the floor. There was generally very positive feedback about the design and organisation of the event, and participants clearly enjoyed and valued taking part.

In terms of the research exercise, the conclusions of this meeting were not incorporated into the summary of views from the public as this was a self-selecting audience and could not be shown to provide the diversity of views that the careful recruitment for the deliberative work had achieved. The overall summary report by

Opinion Leader on the whole process did however summarise the conclusions from this meeting alongside findings from other activities within the consultation.

Overall, this meeting provided another very useful strand of input to the consultation overall, and filled what may otherwise have seemed to be a gap between the written / online consultation of largely interested parties and the more representative views from the deliberative work.

9. ASSESSMENT OF ACTIVITIES AGAINST OBJECTIVES

9.1 Introduction

The objectives for the overall consultation process were as follows:

- To engage stakeholders in the scoping and development of the dialogue process in collaboration with the Authority and in line with the wider written and web consultation process.
- To undertake a deliberative process with a diverse set of the public which accords with the Government's Guiding Principles for Public Dialogue on Science and Technology.
- To capture, analyse and report the results of the dialogue project so that they can be easily understood by policy makers and can inform the Authority's policy recommendations along with the results of the written and web consultation.

9.2 Assessment against objectives

Objectives:	Indicators of success	How each objective has been met
<p>Objective 1: To engage stakeholders in the scoping and development of the dialogue process in collaboration with the Authority and in line with the wider written and web consultation process.</p>	<ul style="list-style-type: none"> • Stakeholders engaged • Clarity of their role • Satisfaction of stakeholders with their role • Links to written and web consultation 	<ul style="list-style-type: none"> • Stakeholders engaged through the Stakeholder Advisory Group • There was some lack of clarity about the role of the Group, but it did operate quite effectively • The stakeholders interviewed for the evaluation were largely positive in their feedback on the process and their role in it. Some did have some criticisms (about short deadlines, their engagement coming too late in the design of the dialogue process and a desire for deeper involvement). • The questions developed for the dialogue process were closely linked to the questions in the wider written and web consultation process

<p>Objective 2: To undertake a deliberative process with a diverse set of the public which accords with the Government's Guiding Principles for Public Dialogue on Science and Technology⁴.</p>	<ul style="list-style-type: none"> • Whether a deliberative process has taken place • Whether a diverse set of the public has taken part • Whether the process accords with the Principles of good practice 	<ul style="list-style-type: none"> • A detailed two stage deliberative process has been undertaken, with 12 discussion groups at regional level followed by a national level reconvened meeting of half the original participants (44). • The participants for the deliberative process were recruited to provide a diverse set of the public based on age, sex, social class, white or black and minority ethnic background, and religious views. This was not a demographically representative sample of the UK population but was, both in recruitment and attendance, a diverse set of the public. • See separate analysis below.
<p>Objective 3: To capture, analyse and report the results of the dialogue project so that they can be easily understood by policy makers and can inform the Authority's policy recommendations along with the results of the written and web consultation.</p>	<ul style="list-style-type: none"> • Whether and how the results of the dialogue project have been captured, analysed and reported • Feedback from the Authority members on ease of use of the results 	<ul style="list-style-type: none"> • The results of the dialogue project were captured in detail at the meetings, analysed and reported by Opinion Leader to HFEA in a single report for the local discussion groups and the reconvened event as this was an iterative process. Separate reports were presented on the opinion poll and the open public meeting, which were separate from the deliberative research element of the consultation, to allow for separate analysis of the findings from the different strands. • The HFEA prepared reports for the Authority members, based on the Opinion Leader reports. The feedback from the interviews with Authority members were that the reports were very useful and easy to use in considering and coming to their decision.

⁴ Office of Science and Innovation. The Government's Approach to Public Dialogue on Science and Technology. *Guiding Principles for Public Dialogue*. September 2006.

	<ul style="list-style-type: none"> • Links to the findings from the written and web consultation 	<ul style="list-style-type: none"> • Opinion Leader prepared an overall summary report that drew together the findings from the deliberative research, the opinion poll and the open public meeting. This was found to be very useful for the HFEA staff in preparing the final reports for the Authority as it brought all the findings together.
--	---	---

9.3 Assessment against principles of good practice

It was part of the objectives of the consultation that it should meet the Government's Guiding Principles for Public Dialogue on Science and Technology⁵. The full set of principles is given in Appendix 4. The following analysis is based on the key principles outlined in the guidance.

Key principles of good practice	Indicators of success	How each principle has been met
1. CONTEXT The conditions leading to the dialogue process are conducive to the best outcomes	<ul style="list-style-type: none"> • Be clear in the purposes and objectives from the outset • Be well-timed in relation to public and political concerns, and start as early as possible in the policy decision process • Feed into public policy, with commitment and buy-in from policy actors 	<ul style="list-style-type: none"> • The objectives were agreed and explained to all those involved at the beginning and throughout the process. The evaluation research shows that public participants and others involved were clear about the objectives of the process. • The context is described in section 2.5; this dialogue fitted in with a range of other activities on these issues, and was designed to meet an appropriate timescale both for the HFEA decision and wider Government decisions. • The main focus for the consultation was the HFEA's own policy decision, and the HFEA was committed to the consultation and to taking account of its results.

⁵ Office of Science and Innovation. The Government's Approach to Public Dialogue on Science and Technology. *Guiding Principles for Public Dialogue*. September 2006.

	<ul style="list-style-type: none"> • Takes place within a culture of openness, transparency and participation with sufficient account taken of hard to reach groups where necessary. • Have sufficient resources in terms of time, skills and funding • Be governed in a way appropriate to the context and objectives. 	<ul style="list-style-type: none"> • The entire consultation was fully transparent, with reports being published on the website as the activity was concluded. In addition, the final meeting at which the Authority took the policy decision (in September 2007) was open to the public. • The exercise was well-resourced, while taking care to design and deliver the process economically. • The governance arrangements were with the HFEA Authority members, and the Stakeholder Advisory Group; both operated throughout the process to oversee design and delivery.
<p>2. SCOPE The range of issues covered in the dialogue are relevant to participants' interests</p>	<ul style="list-style-type: none"> • Cover both the aspirations and concerns held by the public, scientists in the public and private sector, and policy-makers. • Be focussed on specific issues, with clarity about the scope of the dialogue. • Be clear about the extent to which participants will be able to influence outcomes. Dialogue will be focussed on informing, rather than determining policy and decisions. • Involve a number and demographic of the population that is appropriate to the task to give robustness to the eventual outcomes 	<ul style="list-style-type: none"> • Stakeholders were consulted on the range of issues to be discussed. Evaluation research shows that public participants felt able to say what they wanted, raise issues and ask questions at all stages of the process. • It was one of the major strengths of the process that the focus of the consultation was very clearly on specific research techniques, and the consultation was focused on gaining public views on the ethical implications of those techniques. • It was clear throughout that this was a consultation, and that public views would be taken into account, but that the responsibility for the final decision lay with the Authority. • As outlined in sections 6 and 7, a diverse set of the public was involved, recruited to provide a mix of backgrounds. The number and mix was entirely appropriate to the task.

<p>3. DELIVERY Ensuring that the dialogue process itself represents best practice in design and execution</p>	<ul style="list-style-type: none"> • Ensure that policy-makers and experts promoting and/or participating in the dialogue process are competent in their own areas of specialisation and in the techniques and requirements of dialogue. • Employ techniques and processes appropriate to the objectives. Multiple techniques and methods may be used within a dialogue process, where the objectives require it. • Be organised and delivered by competent bodies • Include specific aims and objectives for each element of the process • Take place between the general public and scientists (including publicly and privately funded experts) and other specialists as necessary. Policy-makers will also be involved where necessary. • Be accessible to all who wish to take part – with special measures to access hard to reach groups 	<ul style="list-style-type: none"> • All the policy makers and experts involved were recognised as senior authorities in their field, and/or as well known advocates for particular viewpoints. • A range of processes were used including deliberative research, an opinion poll, an open public meeting and an open written and online consultation - this latter expected to attract those with existing views, while the deliberative work and opinion poll were designed to investigate the general public perspectives. • An independent organisation, highly skilled and experienced in deliberative research techniques, was commissioned to deliver the process • Each part of the deliberative work had specific objectives. • The local discussion groups were for the public only, supported by written information (produced with input from stakeholders) and guidance from the facilitator. The reconvened meeting and open public meeting allowed direct dialogue between the public and experts / specialists. • Some parts of the process were open to whoever wanted to take part (the open public meeting and the written and online consultation). The deliberative research was designed to gain a diversity of views from the general public; special efforts were made to recruit people from 'socially excluded' groups.
--	---	---

	<ul style="list-style-type: none"> • Be conducted fairly - with no in-built bias; non-confrontational, with no faction allowed to dominate; all participants treated respectfully; and all participants enabled to understand and question experts' claims and knowledge. • Be informed - This will include providing participants with information and views from a range of perspectives, and access information from other sources. • Be deliberative – allowing time for participants to become informed in the area; be able to reflect on their own and others' views; and explore issues in depth with other participants. • Be appropriately 'representative' – the range of participants may need to reflect both the range of relevant interests, and pertinent socio-demographic characteristics (including geographical coverage). 	<ul style="list-style-type: none"> • Evaluation observation, questionnaire and interview research (including with participants and stakeholders) all concluded that, overall, the process was very fair and balanced, that no faction was allowed to dominate, that all participants were treated respectfully, and were able to question the experts. In spite of the controversial nature of the issues, the atmosphere in the deliberative processes was entirely non-confrontational. • Briefing information was provided for the public participants (in consultation with the Stakeholder Advisory Group); the evaluation showed that the information was clear, useful and understood by participants. The participants also felt they had enough information to contribute fully to the consultation. • There was a two stage iterative process, with a reconvened meeting following initial discussion groups, with increasingly sophisticated information being introduced. There was space and time within each event and between events for reflection alone and with others to develop people's individual views, and to explore issues in some depth with other participants in the deliberative meetings. • As mentioned above, a diverse set of the public was involved. The discussion meetings were held regionally in 6 locations across the UK. Overall, the process was entirely 'appropriately representative'.
--	--	---

<p>4. IMPACT The outputs of dialogue can deliver the desired outcomes</p>	<ul style="list-style-type: none"> • Ensure that participants, the scientific community and policy-makers and the wider public can easily understand the outputs across the full range of issues considered. • Ensure that participants' views are taken into account, with clear and transparent mechanisms to show how these views have been taken into account in policy and decision-making. • Influence the knowledge and attitudes of the public, policy-makers and the scientific community towards the issue at hand. • Influence the knowledge and attitudes of the public, policy-makers and the scientific community towards the use of public dialogue in informing policy and decision-making. • Encourage collaboration, networking, broader participation and co-operation in relation to public engagement in science and technology. 	<ul style="list-style-type: none"> • The reports produced on the findings from the consultation were highly valued by stakeholders and HFEA policy makers. The separate reports on the different strands of the process allowed readers to see the sources of the various viewpoints. • The evaluation has identified a clear correlation between the conclusions in the reports of the consultation, and the final decision of the Authority. The Authority explicitly took account of the results of the public consultation when making their decision (at a meeting open to the public). Interviews have corroborated that Authority members took notice of the results of the consultation. • The whole process led to significant public education on the subject, and many respondents to the evaluation identified the learning from the process as extensive and very valuable (including stakeholders and Authority members). • The public respondents to the evaluation were more likely to want to get involved in public consultation as a result of being involved in this process, and were strongly supportive of future public engagement on these types of issues. Other stakeholders and Authority members said that the process had confirmed their belief in the value of public engagement in policy making. • This was not a major objective of the process, although there has been some collaboration and networking within the ScienceWise programme.
--	--	--

	<ul style="list-style-type: none"> • Be directed towards those best placed to act upon its outputs 	<ul style="list-style-type: none"> • The HFEA Authority members were the ultimate targets of the outputs, and the outputs were very specifically designed to meet their needs.
<p>5. EVALUATION The process is shown to be robust and contributes to learning</p>	<ul style="list-style-type: none"> • 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 in the process • Ensure that evaluation addresses the objectives and expectations of all participants in the process • Be evaluated by independent parties (where appropriate) 	<ul style="list-style-type: none"> • This evaluation has covered processes and outcomes, and identified learning for the future. • The evaluation started at the beginning of the process, and continued until after the final decision had been made, so that the entire process could be considered. • The evaluation has considered the extent to which the process has met the objectives and the needs of participants. • The evaluation was carried out by an independent contractor, separate from the HFEA and the contractor delivering the process.

9.4 Conclusion on achievement of objectives

This process has met all the objectives fully, and has fully met all the criteria identified in the Government's Guiding Principles for Public Dialogue on Science and Technology.

10. LESSONS FOR THE FUTURE

10.1 Introduction

This section summarises some of the main lessons from the evaluation, across the whole consultation process. Each of the preceding questions also identifies lessons from the specific activity covered in that section. This section also identifies other findings from the evaluation that fall outside the assessment of the individual consultation activities (such as drafting the final policy papers for the Authority).

This section also aims to cover the main questions about the process identified by the HFEA at the beginning of the evaluation (see section 2.2) that have not been covered elsewhere in this report.

10.2 What worked well

- **Mix of methods.** Various respondents to the evaluation praised particularly the mix and range of methods used throughout the consultation process: the iterative two-stage deliberative process, the written and online consultation, the opinion poll, and the open public meeting. Each was seen to have its own value and each helped the other activities to be seen in context, particularly how the different processes elicited different views from different constituencies (e.g. stakeholders with strongly held views, the general public, the general public having been given additional information).

In particular, there was clear iteration of planning and information provision between the initial 12 regional discussion groups and the reconvened public meeting, and between the findings from that deliberative research and the questions for the opinion poll (which followed in July) and the open public meeting. The Stakeholder Advisory Group fed into the development of these questions. The flow of the process is shown in the summary diagram in section 3.3.1.

All the activities worked very well, and participants were very satisfied with the organisation, fairness and approach overall. Even the open public meeting, which was not expected to deliver any specific research findings, provided a valuable opportunity for stakeholders and the public to express their views, listen to other views and input to the HFEA. The HFEA Authority members found that it was valuable to hear the strongly held views articulated, even though they were already aware of most of the points raised.

The mix of methods, delivered very effectively, provided a particularly valuable process that brought together iterative public engagement, with time for public participants to learn new information, discuss it together and come to a considered view, with other methods to gain a wide range of other public views from a variety of sources, for the HFEA to consider.

Comments from respondents included:

"I was very impressed by how they had put the different processes together. That was quite groundbreaking I thought. And the evening public event, though [the audience] was self-selecting ... it was still very important I think. ... I think the quality [of the conclusions] is high because it was done in so many different ways. It was very thorough. I only wish this pattern could be replicated. It gives good conclusions about public opinion. ... This was a unique example of using so many avenues [of engagement]. It was done very comprehensively and I think it was a very good model for doing public engagement on these sorts of issues" (Expert speaker at open public event).

"The process worked very well, thanks to the high level of consonance of the findings. Different data fitted together well."(Authority member).

- **High quality design and delivery.** The process was well designed and delivered by skilled and experienced people. The consultation methods were appropriate to the specific objectives and target groups of each activity, the organisation and management of all the activities were efficient and effective, the recruitment was appropriate, recording and reporting by internal and external staff worked well to provide the outputs that the HFEA needed and could use easily to feed into their final decision-making. There was good collaboration and communications between internal and external staff, and with stakeholders. All these factors resulted in an appropriate process that was delivered very effectively.
- **The development of good quality information materials.** Specially produced briefing information was provided for the public participants, which increased in detail as the process continued. The evaluation showed that the information was clear, useful and understood by the public participants in spite of the highly complex and technical nature of the subject.

The advice from the Stakeholder Advisory Group led to the separation of the basic factual information, provided in written briefing materials, and the different views and perspectives given in person by a range of experts (at the reconvened event and the open meeting), worked very well in allowing the participants to understand the basic science and assess the diverse views being presented without becoming confused between facts and opinions.

Overall, this was a particularly effective approach to public education for engagement on a highly scientific and technical subject.

- **Openness and transparency.** The whole process was very transparent throughout, with specific elements of the process (the open public meeting and the written and online consultation) being open to anyone who wanted to take part.

More specifically, all research reports on the consultation were published prior to the Authority's decision, including full details of all the processes of consultation, who had responded, the questions they considered and a summary of their responses. All this was very clearly and fully documented, and published widely. In addition, the meeting at which the Authority actually took the final decision was open to the public.

The open and transparent approach, with public participants and stakeholders being able to access relevant information, is likely to have helped to reduce cynicism and distrust of a consultation on a highly contentious issue.

- **Impact on the final decision.** It is rare to be able to show a clear line from the beginning of a consultation, through deliberative activities with the public, to a final decision by the policy maker that actually reflects the conclusions of the public.

In this case, the final HFEA policy decision does reflect the conclusions of the public in the deliberative events - including the caveat that the research should go ahead only "with caution and careful scrutiny" and that any specific applications for licenses to carry out such research has to demonstrate that their research project is "both necessary and desirable". This reflects the caution of the public, and also the conclusion of the majority of public participants at the reconvened event that such research on cytoplasmic hybrid embryos should be allowed to go ahead in those circumstances.

The Authority members interviewed suggested that the consultation had not necessarily changed the decision but had still been very valuable in increasing the confidence with which they could take their decision (as it was based on sound evidence about public opinion), and in creating a higher degree of legitimacy, accountability and credibility.

- **The outputs and outcomes of the process fully met the objectives of the consultation, and agreed principles of good practice.** The evaluation assessed the overall process and showed in detail how the activities and outcomes fully met the objectives and principles of good practice according to the Government's Guiding Principles for Public Dialogue on Science and Technology⁶.

10.3 What worked less well

- **Clarity about the role of the Stakeholder Advisory Group.** Although the Stakeholder Advisory Group did operate to review and input to the design of various parts of the process, and the materials, there was a lack of clarity about the Group's role and tasks. It was also felt that it started operation too late in the process to have any significant impact on the overall process, which created frustration among some stakeholders involved.
- **Feedback to public participants after the consultation activities.** The biggest single missing aspect of the process was any feedback to participants after the reconvened event, or after the open public meeting, or to tell those people who had been involved what the final decision was. Although all participants were being contacted as this report was being written, this was a long time after the event for most of them and many respondents said they would have liked feedback before.

⁶ Office of Science and Innovation. The Government's Approach to Public Dialogue on Science and Technology. *Guiding Principles for Public Dialogue*. September 2006.

10.4 Lessons for the future

From the points above, the HFEA consultation provides some overall lessons for the future which can be summarised as:

- A mix of methods can be particularly valuable in gaining the maximum diversity of views from different constituencies.
- Deliberative public engagement can deliver particular value in terms of public education through engagement even on a complex, highly technical and highly controversial scientific topic, as well as outputs that are of great value to decision-makers.
- It is essential that the team delivering the process has the skills and experience to create consultation activities that are appropriate to the objectives, and to the participants being sought. This requires intense collaboration and constant communication both between internal and external staff, and with stakeholders.
- There are significant advantages in being as open and transparent about the process, and keeping as much information as possible in the public domain, to help reduce cynicism and distrust of the process.
- Effective involvement of stakeholders in providing advice on the process and materials requires clarity about their exact role and tasks, and should start as early as possible in the planning process.
- Feedback to participants should take place as soon as possible after their involvement. Ideally, feedback should provide a summary of the conclusions that resulted from their involvement, what was provided to the decision makers based on their input, and what the final decision is - when that happens.
- There should be a clear line from the outputs from the public events to the final decision being made, so that the influence of public views can easily be shown. This influence is vital to the public assessment of the value of the exercise and to trust in public engagement generally.

11. OVERALL CONCLUSIONS

11.1 Introduction

This section summarises the conclusions of the evaluation in terms of the value of the process to the various parties in the consultation (public participants, stakeholders and the Authority), and suggests some overarching conclusions.

11.2 Value for public participants

The two main benefits identified by public participants as having arisen from their involvement in the consultation were learning and influence:

- **Learning.** Public participants identified learning as a major benefits from the process, particularly listening to the experts and gaining other information, sharing their own views and listening to each others' views. They clearly enjoyed taking part and gained a lot from it, as can be seen from their overwhelmingly positive feedback (sections 6 and 7).
- **Influence.** The other key benefit that participants felt the process had given them was the opportunity to express their views and influence an important decision. The evaluation has shown that there was a clear line from the outputs from the public consultation process to the final decision, and the feedback from public participants shows that they clearly believed that the HFEA was indeed listening to their views, and would take them into account. It is likely that this was an important factor in the level of satisfaction public participants expressed about the process overall.

For example, public participant respondents to the evaluation said:

"I was impressed with the thoroughness of it - that they made sure they had public consensus on their side before doing anything."

"If it actually made a difference, I would think it was money well spent."

11.3 Value for other stakeholders

The feedback from stakeholders was that there were four specific areas where the consultation process had been valuable to stakeholders (on the Stakeholder Advisory Group and involved in other ways):

- Confirmation that public engagement in policy can be done effectively, that it was not too daunting and that it provided outputs of real value in scientific and policy decision making.
- Providing an opportunity for stakeholders to participate in the preparation of information materials for the public consultation activities through the Stakeholder Advisory Group.

- Showing the value of public engagement in extending public understanding of scientific issues, including the trickle-down effect of people talking to others about what they had learnt.
- Showing that the public could engage in complex technical scientific debates, and could take on significant levels of complex information, and come to conclusions that took account of the learning they had achieved. Stakeholders saw this as a good example of increasing public understanding of science in this field, as well as of how science develops and proceeds in general.

11.4 Value for the HFEA

The particular value of the consultation process for the Authority members was in providing evidence of public opinion from diverse sources that they could take account of in coming to their decision. This provided two specific benefits for the quality of their decision:

- **Confidence.** The consultation process and its outputs increased the confidence with which Authority members felt they could take their decision, as they were reassured that it was based on sound evidence that public opinion was in favour of the research in certain circumstances, which the decision clearly spelled out.
- **Legitimacy, accountability and credibility.** The consultation also provided a level of accountability and legitimacy for the final decision when it was made, as the issue had been openly and extensively tested with the public, and the final decision reflected the views of the public after the deliberative processes. Authority members also felt that on major controversial decisions of this sort, there has to be public consultation, without which the credibility of the Authority could have been damaged.

The responses to the evaluation from Authority members included:

"This was the most successful consultation that I have been involved in during my five years as a member of the HFEA. I felt that it successfully dissected the strands of opinion, highlighting the differences between informed opinion and instinctive responses in the general public. It also highlighted the dangers of reliance on public meetings and responses to consultation documents - by definition these target those with a specific interest in the topic - with a reduced chance of an unbiased opinion."

"It was reassuring that informed public opinion was supportive."

"There was nothing new or surprising but the important thing ... was about the process of accountability - showing that we were listening even when the views were well known ... being seen listening directly to public views in public, and to acknowledge those views, is important ... on big decisions like this there has to be public consultation ... Not to have done it could have been damaging to the credibility of the HFEA."

"I think the results showing changes in individual views were the most interesting to us. There were no surprises, but there were reassurances that the issues as we saw them were also those in the public mind."

"It made a difference in that we needed to be sure we were not just taking a step in the dark. This consultation showed that we were not."

"The nature and importance of the issues meant that the exercise was very visible and involved a lot of people. Our decision will always be met with howls of protest from some quarters, but this type of consultation helps reassure us that we have gone about making decisions in as open a way as possible."

11.5 Final conclusions

This exercise has been a remarkably successful public consultation, and has met all the objectives set and all the agreed standards of good practice identified by Government for these sorts of dialogue processes on science and technology.

It has provided significant value to the public participants involved, the stakeholders involved, and the HFEA themselves. It has also been a significant success as a public education project on a complex scientific issue. As one expert speaker said in interview for the evaluation: *" it was a very good model for doing public engagement on these sorts of issues"*. It is hoped that future public engagement exercises of this sort can build on the success of this initiative.