

Exploring the Boundaries: A dialogue on Animals Containing Human Material

Evaluation Report

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Executive summary

Introduction

In 2009 the Academy of Medical Sciences began a study examining the use of animals containing human material (ACHM) in scientific research. The study had two parts:

1. An expert working group review due to be completed in early 2011;
2. A public dialogue delivered between May and September 2010, commissioned with support from the Sciencewise-ERC programme.

The public dialogue was delivered by a consortium led by Ipsos MORI involving Dialogue by Design and the British Science Association, and was independently evaluated by Laura Grant Associates. This report presents the findings of the dialogue evaluation.

The dialogue programme itself included reconvened public workshops in two locations (London and Newcastle) involving around 20 participants each, and three special interest focus groups with patients, those for whom animal welfare was important, and those for whom religious belief was important. Twenty follow-up interviews were conducted with workshop and focus group participants. The deliberative research was followed by a nationally representative survey with over 1000 participants.

Evaluation methodology

The evaluation aimed to provide an independent assessment of the dialogue programme's credibility, effectiveness and success against its deliverables and objectives, throughout the programme and at its conclusion; and to contribute to the overall Sciencewise-ERC aim of creating excellence in public dialogue to inspire and inform better policy in science and technology.

Our evaluation methodology had the following elements:

1. Structured observation and informal interviews during workshops and focus groups;
2. Exit questionnaires and telephone interviews with public participants;
3. Telephone and face-to-face interviews with expert participants;
4. Telephone interviews with stakeholders and dialogue contractors;
5. Cost-benefit analysis.

Findings: dialogue delivery

Opened my mind to science and what's going on. It's made me feel like I'd go again, no matter what was being talked about. It felt nice to be invited.

(Male participant, 35-44, London)

The atmosphere at the workshops was lively and relaxed. The science communication element was a strength that many participants commented on; they were brought up to speed on developments in ACHM research very quickly. A range of techniques were used to draw out opinions from all participants and a large majority were satisfied that everyone was able to contribute, although some discussions in Newcastle were dominated by the male participants.

In our follow-up interviews, participants most strongly recalled topics of discussion that had divided opinion. In particular, an activity in Workshop 2 where groups were asked to place

different examples of ACHM research on a spectrum of 'acceptability' was effective in drawing out a range of views. Overall, groups were very accepting of the use of ACHM in research, which surprised some of the scientists that attended discussions as experts. Especially at Workshop 1, it was sometimes difficult for dissenting voices to be heard in groups, but mixing the groups between workshops helped address this.

Participants were satisfied with the amount of time that was spent on each of the main topics, although discussions often became sidetracked onto the wider issue of animal research, rather than the specific case of animals containing human material which was of greatest interest to the Academy. This was reflected in the final task: groups were asked to present their ideas for what is important to be communicated and some focused on animal research without considering ACHM.

Findings: public participants

Sometimes I had not been aware of what I thought about a particular topic until I had been asked to consider and discuss it. (Male participant, 35-44, Newcastle)

Public participants enjoyed the workshops and described them as interesting, informative and thought-provoking. There was considerable evidence of views changing throughout the dialogue, especially during Workshop 1. The mechanisms for this change appeared to be the provision of new information and listening to each others' views.

Interactions with scientists were a highlight of the workshops for participants. Unfortunately scientists were not present at the focus groups, and some participants in these sessions suggested that more time for discussion may have been beneficial.

Findings: expert participants

I was surprised that they were so openly accepting of it to the point where I was sometimes are you really understanding what this means? But then some things they really were understanding and I mean like they were still accepting of it. (Scientist, London)

The expert participants (scientists who took part in dialogue discussions) were the most critical group surveyed in the evaluation. They were surprised at how accepting members of the public were of ACHM research if it was seen to be for medical benefit. They were concerned that they may have introduced bias into the groups by being present, and felt unsure about whether their contributions were appropriate, despite their briefings.

In follow up interviews the experts felt that they had been inspired to do more science communication after realising the level of public interest in science and the impact that it can have. The workshops were also an opportunity for reflection:

If you're not an ordinary person it is good to be reminded what ordinary people think. (Scientist, Newcastle)

Findings: stakeholders

I think it was credible, I think it's going to be very useful for the working group, I think they can draw on the results without having to temper what they say in any way. (Oversight Group/Government department)

The Oversight Group were surprised at how much of their time the dialogue had taken, and although they valued the involvement some had been unprepared for the level of commitment. Overall they were satisfied with the outcome of the process, which was felt to be useful and credible. The various sources of evidence that the dialogue had collected were seen as adding confidence to the conclusions. The dialogue report had led some stakeholder interviewees to reflect on their own opinions, and perhaps see the issue from a different perspective, while for others there was an opportunity for insight into a dialogue process.

Cost-benefit analysis

The cost-benefit analysis work indicated that the dialogue had been delivered efficiently. It was not possible to identify areas where savings could have been made, or alternative approaches that could have yielded a similar richness of evidence.

The dialogue forms part of the Academy's wider study on ACHM and as this work is ongoing it is too early to determine the full policy impact of the dialogue. However, stakeholders put forward aspirations for how the results would be used by the Academy, the influence the dialogue might have in framing future regulation, and as a starting point for continued dialogue.

Successes, challenges and learning points

Successes have been identified under four broad headings:

- The dialogue was meaningful in the context of the wider Working Group study;
- The dialogue was well timed to be influential in that study;
- There were a number of successes in the dialogue process including the level of science communication and the use of a mixed method approach;
- The dialogue outcome was seen as credible by stakeholders.

There were three main **challenges** with the dialogue:

- Managing the dialogue alongside the Working Group study;
- Challenges related to dialogue delivery such as overcoming group cultures, minimising bias due to the presence of scientists and maintaining focus on ACHM rather than more general animal research;
- Sharing learning from innovative methodologies.

The following **learning points** may be useful considerations for future public dialogues:

- Dialogue is an intense process that requires a great deal of time and commitment from Academy staff and the Oversight Group. Being as realistic as possible in allocating this time will help ensure the process runs smoothly and delivers a credible outcome.
- Despite comprehensive briefing, expert scientists found it difficult to know when to contribute and were concerned about introducing bias into groups. Clear roles in groups and direction from the facilitator are helpful; however it did seem that some were keen to do more preparation work than suggested, so a reading list, some FAQs or pointing to the Sciencewise-ERC website might help.
- It is important to carefully consider which experts to involve in both the dialogue workshops and the Oversight Group. It is valuable to build capacity in those with limited experience or understanding of public dialogue. It is also important to balance the seniority of those involved with their capacity to commit time to the dialogue.

- From this process, it would appear that two public workshops, reconvened twice, can provide a good outcome if the time is used effectively.
- The purpose of the dialogue could be explained more effectively at workshops. Public participants were very interested in the structure of the dialogue but could not confidently explain its purpose.
- It would be helpful to have a forum where contractors can share learning from innovative methods they have used, as it is not necessarily appropriate to discuss methods at length in the dialogue report itself. The Sciencewise-ERC wash-up meeting was one opportunity to capture this, although there were many issues on the table for discussion at that meeting so it was only mentioned briefly and it would be useful to explore other ways to share learning.

1 Introduction

In 2009 the Academy of Medical Sciences began a study examining the use of animals containing human material (ACHM) in scientific research, supported by the Department of Health, the Medical Research Council, the Wellcome Trust and the Department for Business, Innovation and Skills. The launch of the study also received endorsement from the Home Office. The scope of the work is to: examine the scientific, social, ethical, safety and regulatory aspects of research involving non-human embryos and animals containing human material. The study itself had two parts:

1. An expert working group review due to be completed in early 2011¹;
2. A public dialogue delivered between May and September 2010, commissioned with support from the Sciencewise-ERC programme².

This report concerns the second part of the study: the public dialogue. The dialogue was delivered by a consortium led by Ipsos MORI involving Dialogue by Design and the British Science Association. Laura Grant Associates was commissioned to conduct an independent evaluation of the dialogue, including assessment of its impact and success; and to provide information on developing best practice in public dialogue.

This report details the findings of the evaluation and summarises successes, challenges and learning points for future dialogues.

2 The dialogue

2.1 *Dialogue objectives*

The aim of the dialogue was: to engage members of the public in dialogue on current and future issues related to the use of animals containing human material. The following objectives were also set:

- Provide opportunities for members of the public to discuss and explore their aspirations and concerns about current and future issues related to the use of animals containing human material;
- Identify areas of consensus, disagreement or uncertainty on a broad range of issues raised by current and possible future developments and explore both initial views and changes in opinion;
- Inform the final conclusions and recommendations made by the Academy for public policy and research needs;
- Enable the Academy and wider science community to build on previous experience in public dialogue, and to develop knowledge and understanding of public dialogue and its potential for future applications.

2.2 *Dialogue structure*

The summary of the dialogue below is taken from Ipsos MORI's final report³.

¹ Further information on the Academy review is available at <http://www.acmedsci.ac.uk/index.php?pid=47&prid=77>

² Sciencewise-ERC is the UK's national centre for public dialogue in policy making involving science and technology issues. For further information see <http://www.sciencewise-erc.org.uk/>

³ Ipsos MORI (2010) *Exploring the Boundaries: public dialogue on animals containing human material*. <http://www.acmedsci.ac.uk/index.php?pid=209>

Background to study

The dialogue comprised:-

- Literature review of previously existing public opinion research;
- Two groups in London and Newcastle, of 21-22 members of the public, in two day-long dialogue sessions each; involving discussions with facilitators and scientists;
- Three additional groups with a) people with some experience of serious health problems, b) those for whom animal welfare was important, and c) those for whom religious belief was important;
- Follow-up depth interviews among 20 of the above participants;
- Nationally representative survey of 1,046 members of the general public.

The dialogue was part of the Academy's wider study on the use of animals containing human material in research, undertaken to inform guidance and recommendations on future government policy in this area.

An interesting element of the workshops was the work of an observational researcher who made notes without taking part in the facilitation, but moved between groups looking at body language, facial expressions and evidence of behaviours.

In addition to delivering the work involving the public detailed above, Ipsos MORI worked closely with the Academy to develop the stimulus materials for the dialogue. This involved discussions with the dialogue Oversight Group (members of the Working Group which had already been established to lead the wider ACHM study and others) throughout the programme, and a materials development workshop convened with a wider group of stakeholders where key questions and case studies for the dialogue were identified.

More detail on the structure of the dialogue is provided in Section 2 of the dialogue report, and an excerpt from that Section is appended to this report.

3 Evaluation methodology

3.1 Evaluation questions

The aims and objectives of the evaluation were:

Aims

- To provide an independent assessment of the dialogue programme's credibility, effectiveness and success against its deliverables and objectives, throughout the programme and at its conclusion;
- To contribute to the overall Sciencewise-ERC aim of creating excellence in public dialogue to inspire and inform better policy in science and technology.

Objectives

- Gather and present objective and robust evidence of activities, achievements and impacts to support Sciencewise-ERC work in increasing understanding and awareness of the value of public dialogue;
- Identify lessons from practice to support Sciencewise-ERC work in capacity building across Government, and the development of good practice in public dialogue.

Based on the original specification for the evaluation and discussions with the Academy and Sciencewise-ERC, the following evaluation questions were set:

1. Has the dialogue met its objectives?
2. Has the dialogue met standards of good practice (as outlined by Sciencewise-ERC principles)⁴?
3. Have those involved been satisfied with the dialogue?
4. What difference / impact has the dialogue made?
5. What was the overall cost / benefit of the dialogue?
6. What are the lessons for the future?
7. **Why** were the approaches used in this dialogue effective or not? What success factors can be identified and could these be transferred to other dialogues?
8. What **external factors** influenced the dialogue process and/or outcomes, and in what way? What mechanisms might be put in place to draw upon/mitigate these factors in future dialogues?

There were several elements of the process we were especially interested in exploring within the evaluation questions:

- How effectively the dialogue identified the ‘boundaries of acceptability’ for research or treatments involving animals containing human material, and to what extent these were affected by international boundaries, human aesthetics, the organs involved or a perceived hierarchy of species;
- How effectively the above ground was covered along with a philosophical consideration of what it means to be human and an understanding of how science is done;
- The impact of the dialogue outcomes on the questions used in the subsequent nationally representative survey;
- The effectiveness of the follow-up depth interviews conducted after the second workshops.

In the dialogue report, the contractors identified differences in attitudes between the regional groups and special interest groups, pointing towards areas of consensus and disagreement. In the evaluation we explored these aspects through the opinions of public and expert participants, the dialogue deliverers, Sciencewise-ERC and the Oversight Groups gained through evaluation interviews.

3.2 Evaluation framework

We used the Sciencewise-ERC principles for effective dialogue⁵ as a framework of success criteria to evaluate the process against. In summary, the principles are:

- That the conditions leading to the dialogue process are conducive to the best outcomes (Context);
- The range of issues and policy opinions covered in the dialogue reflects the participants’ interests (Scope);
- The dialogue process itself represents best practice in design and execution (Delivery);
- The outputs of dialogue can deliver the desired outcomes (Impact);
- The process is shown to be robust and contributes to learning (Evaluation).

⁴ Sciencewise-ERC (Accessed 2010) *The Government’s Approach to Public Dialogue on Science and Technology* available at www.sciencewise-erc.org.uk

⁵ as previous footnote

3.3 Methods

Our evaluation methodology had the following elements:

1. Structured observation and informal interviews during the workshops and focus groups;
2. Exit questionnaires and telephone interviews with public participants;
3. Telephone and face-to-face interviews with expert participants;
4. Telephone interviews with stakeholders and dialogue contractors;
5. Cost-benefit analysis.

Questionnaires are appended to this report (see Appendices pages 46-59). Some of the questionnaires were co-designed with the dialogue contractors to provide feedback for both the dialogue and the evaluation. This was the case with the questionnaires administered at the start and end of workshop 1, and after the focus groups. The exit questionnaires at workshop 2 were administered by the evaluators alone, and it was explained to participants that this feedback would only be shared anonymously with the contractors.

4 Metrics

4.1 Workshop attendances

Figure 1 summarises the participants that attended each of the dialogue workshops.

Figure 1 Workshop attendances

Session	Experts	Public		
		Male	Female	Total
Newcastle 1 (22 May 2010)	Expert A, Expert B	9	11	20
Newcastle 2 (5 June 2010)	Expert A, Expert C	9	11	20
London 1 (5 June 2010)	Expert X, Expert Y	12	13	25
London 2 (12 June 2010)	Expert X, Expert Z	9	13	22
Newcastle – patients (3 June 2010)	n/a	1	10	11
London – faith (9 June 2010)	n/a	2	5	7
London – animal welfare (10 June 2010)	n/a	2	5	7
Follow-up depth interviews	n/a	20		20

The experts were recruited through the British Science Association and paid for their input. They included a mental health researcher, a cancer researcher, a cell biologist, two geneticists and a science communicator with a background in genetics.

4.2 Evaluation samples

The evaluation collected data from various sources:

Observation and informal interviews

- All four dialogue workshops were observed;
- Thirty-eight snapshot interviews with public participants were conducted across the four workshops;
- Exit interviews with all six expert participants and one observer were conducted across the four workshops;
- The faith and animal welfare special interest focus groups were observed;

- Four brief exit interviews conducted with two public participants from each of the observed focus groups.

Questionnaires

- London: 25 from Workshop 1 (100%) and 22 from WS2 (100%);
- Newcastle: 20 from Workshop 1 (100%) and 20 from WS2 (100%);
- Focus groups: 7 from faith (100%), none from the others (0%).

Unfortunately questionnaires were unintentionally omitted at patients' focus group, and could not be distributed at the animal welfare group as this overran.

Detailed follow-up interviews

- Ten telephone interviews with public participants from the dialogue workshops and two of the three focus groups. These were balanced between London and Newcastle, and between those who had/had not been included in the Ipsos MORI follow-up interviews);
- Three telephone or face-to-face interviews with the expert participants (Experts A, C, and X in the table above).

Due to coordination of timing with Ipsos MORI's follow-up interviews, the participant interviews took place around two months after the workshops. This made it problematic to contact participants and while we met our target, some interviews yielded greater depth than others. In discussion with Ipsos MORI at the end of the project we agreed we could have done more to coordinate this approach in order to ensure participants were clear about what might be asked of them.

Stakeholder interviews

- Telephone interviews with five stakeholders from the Oversight Group, Working Group and the stakeholder workshop convened to discuss the dialogue materials;
- Telephone interviews with representatives from Ipsos MORI and Dialogue by Design;
- A meeting with three members of Academy staff to discuss the cost-benefit analysis.

5 Dialogue design and delivery

5.1 Context of the dialogue

Motivations and pre-existing attitudes

Participants' motivations for being involved with the dialogue fell under three main themes: those who were interested in learning more about the subject; those who were motivated by citizen participation and the opportunity to hear others' views; those who were financially motivated. All participants who said that money was their primary motivation qualified this answer with a secondary reason for their involvement.

Two reasons - the money and it was an area that interests me. I work in education and I work with scientists. Also I enjoy doing market research.
(Male, 45-54, Newcastle)

When asked about their existing attitudes to science and medical research before participating in the dialogue, several of the participants focussed on their attitudes to research on animals. Those who referred specifically to animals felt that they had always

been conditionally accepting of scientific research. Some participants, particularly those with a scientific background, stated that they were supportive of science in general, while others felt that they had too little information to form an opinion of their own at that stage.

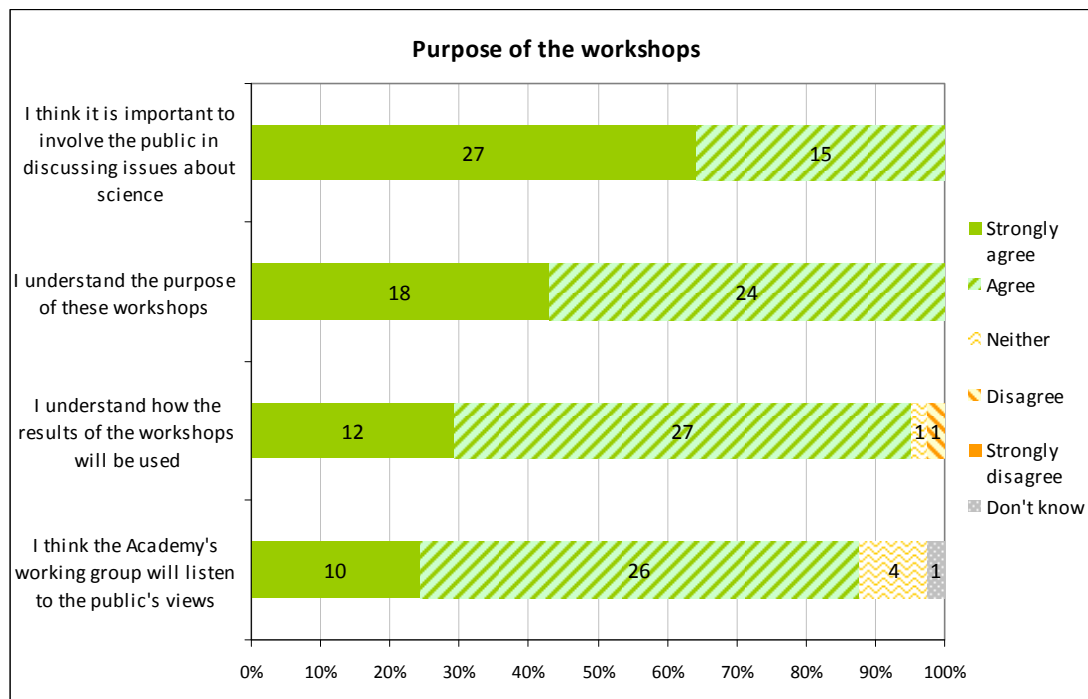
The participants felt that the pace of developments in medicine was often slow, and that scientific progress was important. Some of those interviewed felt that there was a disconnect between the pace of developments, public understanding of technology and the ability to regulate it, but none of those interviewed felt that scientific progress was too fast. Concerns were expressed over the motivations of industry and the interests of the regulators. Some of those interviewed referred to a lack of international regulation and were worried that science may not be conducted ethically in other countries. Most participants saw scientists as individuals with differing ethics and values, which meant that while scientists in general could be trusted, regulation was essential.

Only so far as I would trust any professional. I think they can sometimes miss things in pursuit of a goal.
(Male participant, 45-54, London)

Participants felt they received most of their information about science from television, particularly television news, newspapers and the internet. A few participants also took information from specialist science publications such as New Scientist, through formal education or through campaign leaflets. All of those interviewed felt that there should be more science coverage, but some felt that this should focus on more 'engaging' formats such as documentaries and discussion programmes, rather than news items. Views of science in the media were mixed, with some putting more trust into 'heavyweight' sources (e.g. New Scientist) but around half saying that they tend to trust science as it is reported.

Purpose of the workshops

Figure 2 Exit questionnaire: purpose of the workshops



Respondents agreed or agreed strongly with most of the statements that related to the purpose of the workshops. Most agreed strongly that public engagement is important, and this was reflected in the emergent themes from their open responses. Interestingly, there

was a slight difference in the focus of the comments between participants in the two cities. Participants in both locations, but slightly more in London, described the importance of **public engagement** or that public opinion on scientific issues should be listened to. However in Newcastle a number of respondents also stated the importance of **public education**. For some, education was linked to the idea of winning public support for ACHM and other animal experiments. This may have reflected the focus of the participants' closing presentations in Newcastle, which tended to present a case for the support of ACHM or animal experiments. Others described **benefits to society** (including scientists and the public) or expressed interest in **what would happen next** with the dialogue report. Comments included:

Think it is important that the public are engaged in discussions regarding medical science (Female participant, 25-34, London)

Public will support issues they know about (Participant, Newcastle)

The public opinion should be valued but after they are given information to inform choice and preferences (Female participant, 35-44, Newcastle)

Although they remembered the purpose of the dialogue being explained to them, and despite all agreeing they understood the purpose in their exit questionnaires, interviewees were only able to describe it in vague terms. Some felt that it was 'to get a public view' or to 'get an ethical view' whilst others felt that it was for dissemination of information about science to the public, or to allow them to talk about health and medical research issues. There was no mention of the Academy or the Working Group in the responses.

5.2 Scope of the dialogue

What does it mean to be human?

Most participants were satisfied with the extent to which this was covered during the workshops. A few pointed out how this was revisited throughout the sessions.

To be honest, that [discussing what it means to be human] could take your whole life. In the space we had it was covered to the right level.

(Male participant, 45-54, Newcastle)

Boundaries of acceptability

Compared to the group discussions and presentations, the exit questionnaires were an opportunity for participants to reflect on their individual opinions about ACHM. Respondents were invited to make a recommendation to the Academy's working group on the issue. The responses supported the findings in Section 3 of the dialogue report, which suggests that the workshops were effective in capturing the range of views.

In the follow-up interviews the London participants recalled aspects of research that they found acceptable or unacceptable strongly. Newcastle participants did not recall the boundaries as clearly. Overall, interviewees felt that the purpose of the research was the most important factor in determining whether an experiment in which animals contained human material was acceptable, although the organs and species involved and the regulation of the science were also seen as important. Not all participants were concerned about the appearance of the resulting animal, although some were. Participants felt that all of these factors and the idea of regulation were given adequate time in the dialogue discussions.

Standout points of the dialogue were different for different individuals, but interviewees tended to reflect on issues that had divided the discussion such as the development of

cosmetics, surgical implants of animal material and the use of ‘cute’ animals in research. One participant felt that the dialogue would have benefited from a clearer explanation about the current state of research, i.e. whether the scenarios related to things that were already happening, likely in the near future or possible in the far future. Other participants felt that there was too little discussion of blue sky research and its importance to scientific progress, while another felt that morality issues were not looked at in depth.

Perhaps a better explanation of how technologies are used. An explanation of what the research processes are like. People didn't understand the idea of blue sky.
(Male participant, 55-64, London)

Information about the processes of research was mainly introduced through the scientists' contributions to discussions, although a handout about regulation was provided.

5.3 *Dialogue delivery*

Workshop 1

Aims / desired outcomes (taken from Ipsos MORI topic guide)

1. Participants acquire enough of an understanding of the science to discuss and form a view
2. Indication of relative acceptability of various aspects
3. Indication of which aspects need further discussion at workshop 2

The workshop first took place in Newcastle on 22 May 2010, and was repeated in London on 5 June. The points below give an overview of the main elements in the workshop, put together from our observations, snapshot interviews and debrief at the end of the session. Each workshop involved plenary sessions with all participants, and two breakout groups each containing around ten participants. Each breakout group was joined by a scientist who was introduced as a source of information. The scientists moved between the groups throughout the day.

- The first session on ‘what is human’ was frequently referred to in later discussions. Participants at both workshops engaged well in this session.
- The science was introduced through a quiz, video and fact sheets. Only the most confident participants asked questions in plenary, but in the snapshot interviews all said that the science was well-explained.
- The late morning and afternoon sessions were spent moving through a series of ACHM case studies. The flow between these was effective and the time allocated appeared appropriate. In many instances groups had difficulty moving on from the debate about the use of animals in research and addressing the idea of mixing animal and human material, despite the work of the facilitators.
- In Newcastle, a key prompt in the last case study session was ‘what proportion of the monkey’s brain would need to be human for it to be human?’ Responses varied widely and it was at this point the debate opened up, with a diversity of views emerging from a group that had previously been mostly in agreement.
- At the end of the day participants were set ‘homework’ – a set of questions they were to think about, discuss with others and respond to, and a ‘DNA origami’ exercise.

Participants’ comments were recorded by note-takers on laptops during the sessions, as well as on flipcharts or whiteboards in some groups. The groups were also filmed on video.

Overall, the workshops ran effectively. Participants were engaged throughout and described the experience as interesting during the snapshot interviews. The atmosphere at both workshops was friendly and convivial. The energy level was good, even in one 90 minute breakout session participants remained engaged throughout; in fact for some the topics raised were emotive. Participants continued the conversations (between themselves and with scientists) informally over the breaks and lunch.

At some points in Newcastle, discussions were dominated by males, or male participants spoke over female participants. In London there were a number of strong, confident women in the group, and it did not seem to be either male or female dominated. A range of facilitation techniques were used to good effect, such as asking participants to discuss the case study with their neighbour. Asking each pair to feed back ensured everyone had a clear opportunity to input into the discussions, although the potential flow of the conversation was a little interrupted as a result.

In the snapshot interviews, Newcastle participants described feeling nervous that they would not know anything at the start of the day, but in later conversations (albeit with different participants) said they felt comfortable asking questions or for clarification. In London participants were more confident in their knowledge and described listening to others' opinions as interesting.

Experts felt they held back from giving their opinions, and some were unsure whether the amount they contributed was appropriate. In London some of the participants were 'pro science', and expressed stronger views than the scientists. At one point one of the scientists appeared to argue a point with a participant but this was quickly noted and addressed by the facilitator. Information from scientists on how medical research is done (e.g. that tests on animals are a requirement for the development of new treatments and medicines) was especially valuable.

The London group were very engaged and were happy to keep the discussion going for the full day. In Newcastle the day started late and finished early, partly because the venues were very hot and this was uncomfortable for some participants. There was a lot of moving between rooms planned that would have been unrealistic in the space available, but the facilitators adapted this and the programme worked well.

In their exit questionnaires, participants were asked to cite one good aspect and one poor aspect of the workshop. In terms of good aspects, the dialogic approach itself was popular, with many participants highlighting the good discussions or range of views included. A number also commented on their learning or the material being well explained. The handouts, case studies or general high quality of the materials were also commented on. Fewer poor aspects were mentioned. Several (especially in Newcastle) commented on the room being too hot or the food being served late. Others had comments about the workshop content or structure, which included suggestions that conversations should have had greater depth or been less repetitive. Some respondents cited a particular risk, application or ACHM case study that they had not liked.

All but two respondents felt that everyone in the group had a fair chance to get the information they needed and give their opinions. Supporting factors included the role of the facilitators, a respectful culture within the group and/or having plenty of time for discussion. Several also mentioned that the material was well explained and/or presented in 'plain English'. A small number of respondents acknowledged that some group members were more

vocal than others, and two felt that everyone did not have a fair chance to express their opinions. One felt that this was due to other dominant group members, and the other felt the facilitator should have done more. Comments included:

Yes, there was plenty of time and space to talk and ask questions. (Male participant, 35-44, Newcastle)

Yes, since the co-ordinator directed questions to others who had not spoken & encouraged them to say what they thought without making judgement about any comment (Female participant, Over 65, London)

On occasions, some of the group overtook the conversation, making it difficult for others to express their opinions (Female participant, 35-44, Newcastle)

Three strong themes emerged when participants were asked about the main thought or idea they would take away from the workshop. For some (especially in London), the message was about the benefits of medical research conducted using animals. For others (especially in Newcastle) the responses suggested a more critical approach. Some in this theme talked about needing more information, or mentioned moral and/or ethical dilemmas. A similar number in each city mentioned a greater level of awareness or understanding.

Well "they" really do say that knowledge is power! And I feel that I am more aware [of] how far science has moved on. (Male participant, 35-44, Newcastle)

That research is being done on animals for the greater good and sacrifices have to be made (Female participant, 25-34, London)

Issues around moral & ethical vs. needs to develop medical advances to help humans - where do we stop. (Female participant, 25-34, Newcastle)

Most respondents were unable to suggest improvements to the workshops beyond feedback on the venue (e.g. temperature) mentioned earlier. In Newcastle there were a few comments on the content or structure of the workshop. Of the seven that commented, two would have liked smaller groups, and two would have liked clearer or less similar questions. Two said that more visuals would have been helpful and one felt the group was dominated by a few participants.

Workshop 2

Aims / desired outcomes (taken from Ipsos MORI topic guide)

1. Deepen understanding of how participants come to decisions about the boundaries between human and animal
2. Deepen the understanding of participant perceptions of acceptability of animals containing human material; clarify any caveats they would put on the future of research
3. Understand the most motivating and clear way to communicate this subject to the public

The workshop took place in Newcastle on 5 June 2010, and was repeated in London on 12 June. The points below summarise the main activities in the workshop. Each session involved plenary sessions with all participants, and two breakout groups each containing around ten participants, which were mixed from the previous workshop so discussions happened between different participants. At the end of the day, the facilitators stepped away to allow smaller groups of participants to gather their thoughts and present these back to the wider

group. Again each breakout group was joined by a scientist and they moved between the groups throughout the day.

- Near the start of the sessions participants were asked to reflect on the dialogue so far. In Newcastle they were also questioned on the level of acceptance in their views and they were very aware that their views had changed: *'my view at 10 o'clock was different to my view at 3 o'clock' (Newcastle)*. Factors in changing views seemed to be: being informed; progression of information (i.e. that case studies became more extreme gradually); and the fact that humans share so much DNA with animals.
- At both workshops the facilitators explained the design of the dialogue (including that those with particular views would be consulted in sub groups) which participants found useful and interesting.
- Quite a few people in Newcastle said they had tried the DNA origami, but nobody had brought it with them. A few people in London (four or so) had brought their DNA origami.
- Some different levels of acceptance emerged within the groups. This was revealed by the homework, which was a successful way to get people to write down their own views and not be influenced by the group.
- In the late morning, groups were given a number of ACHM scenarios with the purpose of the research, the type of animal and amount of human material involved. They were asked to place these on a spectrum of acceptability. This sorting activity was very effective at drawing out different views, as pairs of participants were asked to give reasons for ranking a particular scenario as more or less acceptable than another.
- After lunch, groups recapped on the human qualities discussed in workshop 1 (e.g. the potential to lead richer lives than animals, mental capacity, language, complexity), and discussions explored whether it was acceptable to give these qualities to animals and how this should be regulated.
- Each group then split into smaller groups and were asked to prepare a poster and 2 minute presentation to help other members of the public understand the issues covered in the workshop. The facilitators stepped away at this point. In Newcastle a few groups were unclear on the task, but it seemed better understood in London. Several groups produced what seemed like an advertisement for ACHM research, especially in Newcastle. In some groups the human material aspect was overlooked and the presentation focused on animal research more broadly. It was also sometimes the case that the presenter gave a one-sided view of the whole group's opinions, or presented as if the group had reached consensus when this was not always the case.
- The day finished with some plenary discussion about science communication and a discussion of the next steps for the dialogue.

Overall participants seemed positive about the day, which was again lively and relaxed. Groups approached the new tasks with enthusiasm, although there were spells in the middle of the day (during some of the longer breakout sessions) where the energy levels dropped.

The facilitators felt that the discussions had gone over some 'old ground' again, but that this had brought an opportunity to unpack views and assumptions. Specifically, the discussions frequently returned to issues around animal research in general, rather than ACHM. It was felt that discussions were more nuanced than in the previous workshops.

Mixing the groups after the first workshop was effective and appeared to contribute to a greater range of opinions being expressed away from any group cultures that had been

established previously. However in some groups we observed considerable self-moderation and group moderation from participants when a negative opinion was discussed, usually done by pointing out benefits. Interestingly, when one of the cards in the sorting activity indicated research 'for interest' rather than for a specific application, one group projected an application (to help accident victims) onto the example to make it '100% acceptable'. In this group people seemed to be placing scenarios onto the scale before developing a justification, rather than applying criteria to a case to determine its position. It is fair to say however, that this group's spectrum of acceptability was the least diverse, with many of the scenarios grouped at a similar position on the scale. A much wider spread was observed in the outputs from other groups.

Groups in London seemed more comfortable expressing a range of views than groups in Newcastle, and a number of individuals stood their ground in the face of opposition from the group. Some started to express more extreme views to balance arguments made by the group as the session went on.

In Newcastle there was a late start and some sessions ran over. There was considerable deviation from the topic guide, which meant that the two groups did not necessarily cover the same material. However this did allow them to explore issues that were important to them as they arose. There was some anxiety/confusion because timings weren't explained at the start of the day, but this was addressed by facilitators as soon as it was pointed out.

The Workshop 2 exit questionnaires mostly asked about the process overall. However participants were asked to comment briefly on the second workshop. The strongest theme that emerged can be described as 'drawing out a range of views'. Here, participants commented on the value of hearing each others' views and the extent to which they agreed or disagreed. Also coded in this theme were responses that picked up on particular activities in the workshop (the sorting activity in particular) that facilitated this. Others talked about becoming more informed, and there being some good discussion (references to specific activities that described understanding or discussion as the outcome were coded under these themes). One participant felt the quality of debate was better than that at Workshop 1.

The different ideas people brought to the table (Male participant, 35-44, London)

The different statements do we agree 0-100% yes/no. It was good to [see] what people agreed to and why (Female participant, 25-34, Newcastle)

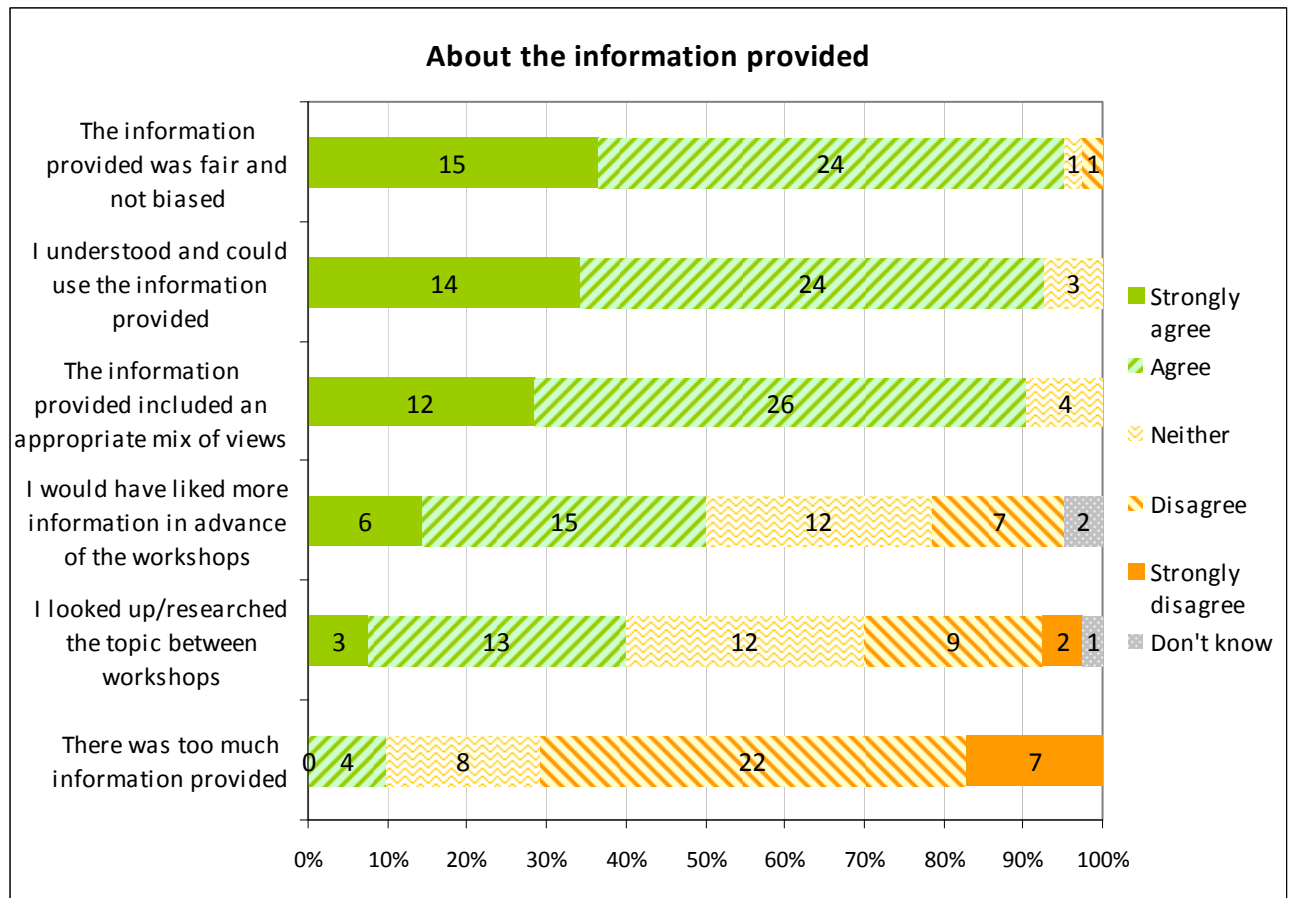
It was all good because I learn [sic] a lot more (Male participant, 18-24, London)

Less fragmented than last week. Stronger discussion (Female participant, 45-54, London)

In terms of poor aspects, the main comments were about the venue, catering or logistics.

Information provided

Figure 3 Exit questionnaire: information provided



A large majority of questionnaire respondents felt that the **information provided was good and at an appropriate level**. A few made comments on other aspects of the information, but overall it appears that this aspect of the workshops was handled successfully. Comments from the questionnaire respondents included:

It was vey basic but enough to enable further independent research if interested (Female participant, 45-54, London)

The information was clear and concise made simple in laymans terms with professionals on hand to answer any questions we had (Male participant, over 65, Newcastle)

If we had more information before the workshop we would not have been able to input what we have (Female participant, 25-34, Newcastle)

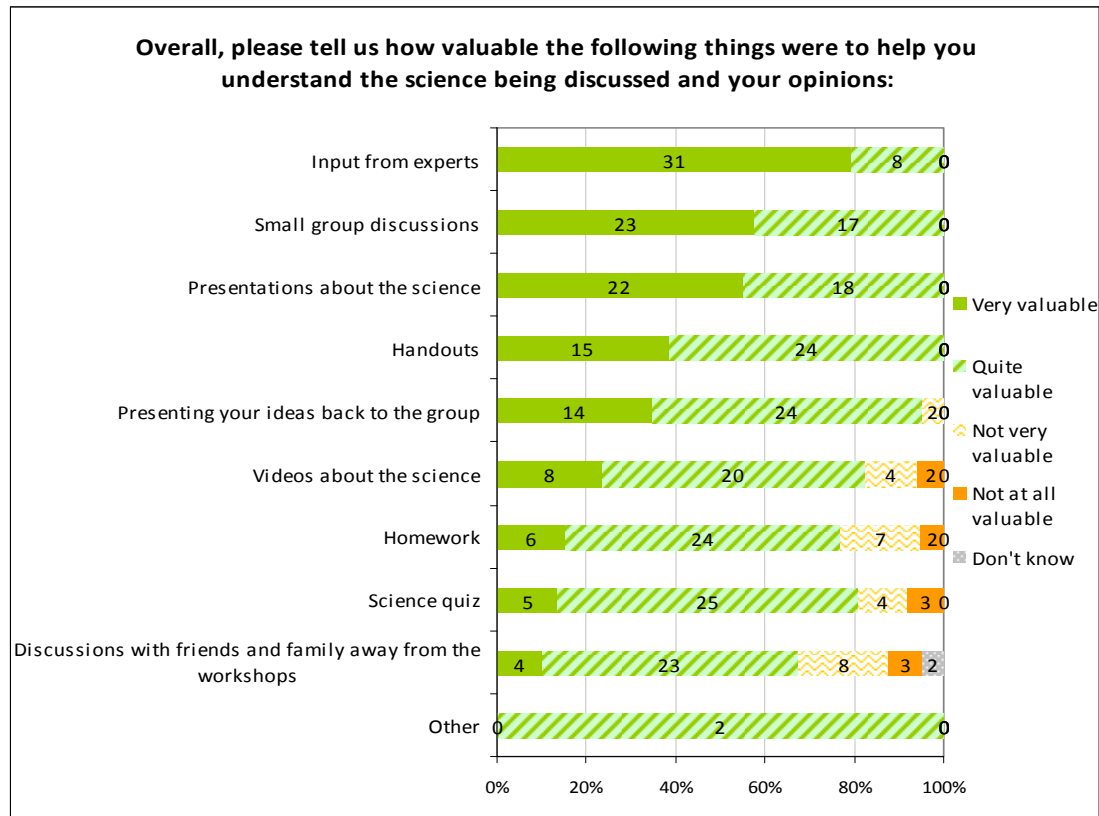
There was a lot of issues and not enough time to take it all in (Male participant, 35-44, London)

All interviewees thought that the descriptions of the experiments were good, and that these enabled them to understand the science. They seemed to meet all levels of scientific literacy adequately: those whose science was stronger felt that the point was sometimes laboured, while those with less experience of science found the descriptions of experiments difficult to grasp at first, but felt more comfortable by the end of the first workshop.

It wasn't clear at first, but as the day went on I had a good understanding, everybody did. That's what made it good. Everyone started off with the unknown. As it got more interesting we got more depth and more opinions. I said to the missus it was brilliant to be part of it, not for the money. (Male participant, 35-44, Newcastle)

Activities within the workshops

Figure 4 Exit questionnaire: activities within the workshops



As is often the case in dialogues, the interaction with experts was seen as especially valuable. Small group discussions and presentations were also highly rated. Videos, homework and the quiz were less highly rated, but still seen as at least 'quite valuable' by most. For some, the homework and quizzes were not popular. Two respondents felt there was an 'other' aspect that was useful, but they did not state what this was.

In the open questionnaire responses several commented on the **learning from the workshop overall**, so it appears that participants valued the **combination of activities** in helping inform their opinions. Their comments included:

Sometimes I had not been aware of what I thought about a particular topic until I had been asked to consider and discuss it (Male participant, 35-44, Newcastle)

Overall everything [listed in the questionnaire question] was needed for the group to progress (Female participant, 55-64, London)

It is hard to explain to people without them being here to realise (Male participant, 35-44, London)

The most useful aspect in exploring issues related to ACHM varied for the interviewees. Some felt that they gained the most through watching other people and their reactions, and for

some it was being able to ask the scientists direct questions. Some recalled specific discussions which had led them to a realisation.

Talking about things like Huntington's ...What sticks out for me was no cure being there and research just being done to see if they can find something. I was in limbo about whether I did or didn't agree. I realised I had more of an attachment to primates than rodents... It was sensitive to me to know that a monkey had been given Huntington's and had all that pain, but we all discussed that they need to research to find something. (Female participant, 25-34, London)

Those who had completed the homework had enjoyed it; the video was seen as the least useful resource, although some found it useful. In general the workshop resources were well received by participants.

I've kept all the handouts so I can look at them again. (Female participant, 45-54, Newcastle)

Participants' views on the final presentation exercise varied. Some really enjoyed being able to summarise the day in a creative way, but some could not see the point and felt that the views of the group were not adequately captured.

I did not enjoy that at all. No-one really knew what to do. Everyone was not doing a lot. It seemed a waste of time. (Female participant, 18-24, Newcastle)

That was fantastic. One of our team, a man, got up and when he gave his presentation it was lovely to know they wanted to keep his presentation. It was brilliant everyone said what they thought. (Female participant, 45-54, Newcastle)

Role and influence of experts

Interviewees particularly valued the input of the scientists because they were able to answer specific questions in depth. The participants did not feel that the scientists allowed their personal views to influence the dialogue, and were careful to give only factual information. When asked, participants recognised that the influence of the experts could be problematic in this type of study, but most felt that the scientists were aware of this and had taken care when giving information.

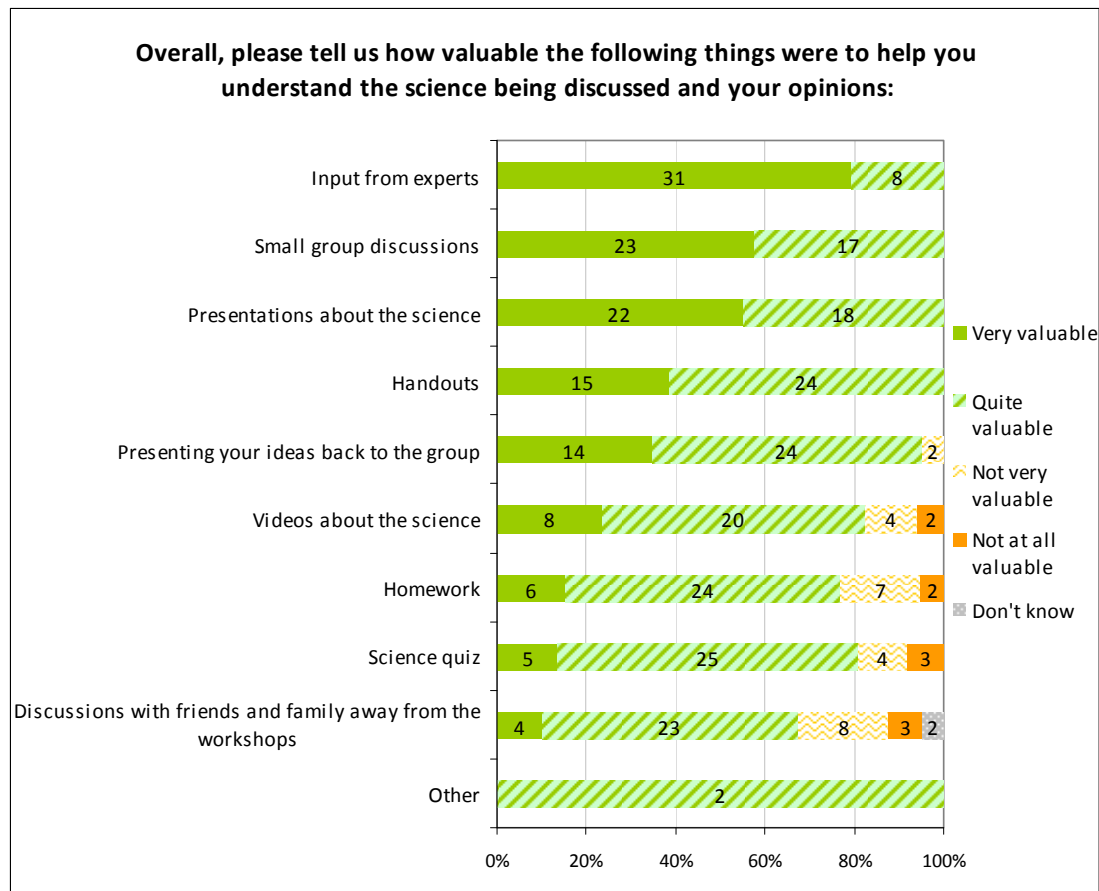
When you talk... they [the scientists] give their view and it seems more acceptable than ours. They let it run though. They didn't give too much... A few times we debated and when asked a question again views had changed. (Female participant, 25-34, London)

It was notable that in this dialogue, experts were briefed to act as neutral sources of information. This is in contrast to other approaches, where a range of positive and negative perspectives are provided. Neither approach is able to completely eliminate bias and in this case some found it easier than others to hold back from providing their personal views.

A useful check for the effects of bias in the dialogue sample for this project was the nationally representative survey, where members of the public were asked about the issue with no scientists present. The fact that the survey findings supported those from the workshops suggests that the presence or comments of the scientists did not strongly skew the results.

Group interactions

Figure 5 Exit questionnaire: interactions



Participants were very positive about their interactions within the workshops. Three main strengths of the workshops were highlighted in the open responses. Firstly, respondents (especially in London) were positive about the **open discussions**, where people with different views were enabled to come together to listen and share ideas. Many of the comments about how **well-organised** the workshop was indicated that the workshop was well structured to facilitate such discussions, so these themes appeared to be linked (especially in London). Thirdly, several respondents at both workshops commented on what they had **learned** from the workshops. This included learning about the science itself, the benefits and their own views. A few participants would have liked **more information**.

People from diverse backgrounds discussing openly (Female participant, 45-54, London)

The workshop was consistent allowing each person the time to articulate their points of views (Male participant, 45-54, London)

Made me think more about animal testing and why it is carried out and think about the benefits to humans (Female participant, 25-34, Newcastle)

The follow-up interviews provided an opportunity to explore the group interactions in greater depth. Some interviewees described 'holding back' on their views to allow others to speak. Those with scientific knowledge in particular, talked about not wanting to influence the discussion too far, and the need to give everyone space to express their views.

I think I'm quite opinionated and there was mix of opinions in the room and I found that I'm quite a strong personality and opinions were quite strong but I had to rein myself in, but not say too much. (Female participant, 25-34, London)

This was not necessarily seen as a good or bad thing to do, but simply part of the experience of both talking and listening during the dialogue.

Everyone could comment and it was nice to sit back and listen to what they had to say. (Female participant, 45-54, Newcastle)

Other participants felt that they had strong views and were confident in debate, but found it more interesting to allow others to contribute to the discussion. They felt that the facilitators played a key role in ensuring that everyone spoke and guiding the group through the topic.

They [the facilitators] were good - letting the discussion flow and then steering it back to the topic. (Male participant, 45-54, London)

Focus groups

The focus groups were a valuable addition to the dialogue overall, as they enabled the inclusion of groups that may have had stronger or different views than those in the public workshops.

The sessions themselves had a very different atmosphere to the public workshops; they were considerably shorter and did not include scientists' input. This meant that they felt less like dialogues and more like research exercises with the participants giving their views and perhaps receiving less new information or insight through exchange than those at the public workshops. Largely this was an issue of time, as the discussions were two hours rather than two days. The contractors felt that had the budget allowed, extending the involvement of these groups to encourage engagement with scientists and allow more lengthy deliberations could have yielded even more interesting findings.

The time wasn't enough. Needed at least half an hour extra to get more people's views. (Faith focus group participant)

The contractors felt that the timing of the focus groups (they took place between the first and second workshops) was effective as it informed some of the questioning for the second stage workshops.

The health and religious special interest groups expressed views similar to those captured through the public workshops, but the animal welfare group highlighted a more critical perspective, which the contractors felt 'greatly added to the results'⁶. In the report, the findings from the different strands of the dialogue were presented clearly, and attitudes and findings from the different groups compared and contrasted.

Disaggregated follow-up

The follow-up interviews ('disaggregated follow up') were evaluated through interviews with participants two months after the workshops. We conducted interviews with two male and two female participants from each of the venues, ensuring that one male and one female participant were selected from those who had taken part in the disaggregated follow up.

⁶ Ipsos MORI (2010) *Exploring the Boundaries: public dialogue on animals containing human material*. <http://www.acmedsci.ac.uk/index.php?pid=209> p59

The four interviewees who had participated in the follow-up phase said that they had received a phone-call a short time after the second workshop and that the questions had been similar to those at the beginning of the evaluation interview. There was some confusion among the participants about the role of the contractors and the role of the evaluators, and those who had taken part in the disaggregated follow up were unsure why they had been contacted again for the evaluation interviews. We agreed with the contractors that, in hindsight, we could have done more to coordinate our various interviews and clearly communicate this to participants.

Those participants who had taken part in the disaggregated follow-up did not remember specific details, however they recognised that it was an opportunity to give their personal views away from the group. In this instance, interviewees felt that they had adequately expressed their views at the workshops. None of those we interviewed felt that their views had changed since the second workshop. However this was not possible to predict, and while the interviews did not yield much new intelligence, their outcome meant that the contractors could report the findings from the workshops with greater confidence, adding to the robustness of the report. Two of those we interviewed felt that they would have benefited from a third workshop, but others felt that two workshops were sufficient to draw on participants' views.

[A third workshop] would have been good to refresh our memory on what has been discussed but in terms of representing our views I don't think it would have changed. It would have been more effective but the interview was practical.

(Female participant, 55-64, London)

6 Satisfaction with the dialogue process

6.1 Public participants' experiences

Participants were asked to summarise their experience of the dialogue overall in three words. The responses were used to create a word cloud⁷ and are presented below.

Figure 6 Exit questionnaire: three words about the workshops



The larger words represent those that were cited most frequently. So it appears that many participants found the workshops interesting, informative and thought-provoking. Removing these three most common responses from the data set reveals the range of other descriptors that participants used.

⁷ See www.wordle.net

I think I had an effect just by being there though. Sometimes the participants would be talking and they would look over to me for confirmation of their ideas and views, so I made them feel more comfortable in speculating, so they didn't feel that they were wrong.
(Scientist, Newcastle)

The scientist quoted above went on to say that it might have been useful for the scientists to explain and be open about their position, rather than feeling they were holding back from giving opinions and have participants make assumptions.

They did make assumptions about me. I was labelled 'scientist' and I thought it was important to say 'I don't do this'. At the beginning they assumed I was for everything, and it was not my place to say that I didn't do it. Maybe I should have been introduced more, so they knew more about who I was and what I worked on.
(Scientist, Newcastle)

One of the experts felt it was helpful when the facilitator was more direct in asking them to contribute at particular points.

So I liked it in the first week when I was more directed to when I should be offering an opinion, answers or whatever and when I shouldn't be, so I wasn't just getting involved and going you know, well I think this. So I liked being more directed.
(Scientist, London)

The experts all noted that people were more accepting than they had thought they would be, but some felt that the high levels of acceptance indicated that the participants had not fully grasped the complex ethics involved. There was a mixture of perceptions of the public participants among experts.

Can we get to people's hidden depths? The problem with the people who were there was that there were no hidden depths. A lack of understanding coupled with their disinterest was disappointing.
(Scientist, Newcastle)

Everyone was given the opportunity for involvement and although it was obvious that some people were only there for the money, some were really interested and actively engaged.
(Scientist, Newcastle)

The experts felt that the default position of the public seemed to be that 'everything was OK'. For some, this led to the question about whether participants had reached a level of understanding that allowed them to be critical of the issue over the two days.

People had a strong default setting that everything was permissible if it was for medical benefit.
(Scientist, Newcastle)

I was surprised that they were so openly accepting of it to the point where I was sometimes are you really understanding what this means? But then some things they really were understanding and I mean like they were still accepting of it.
(Scientist, London)

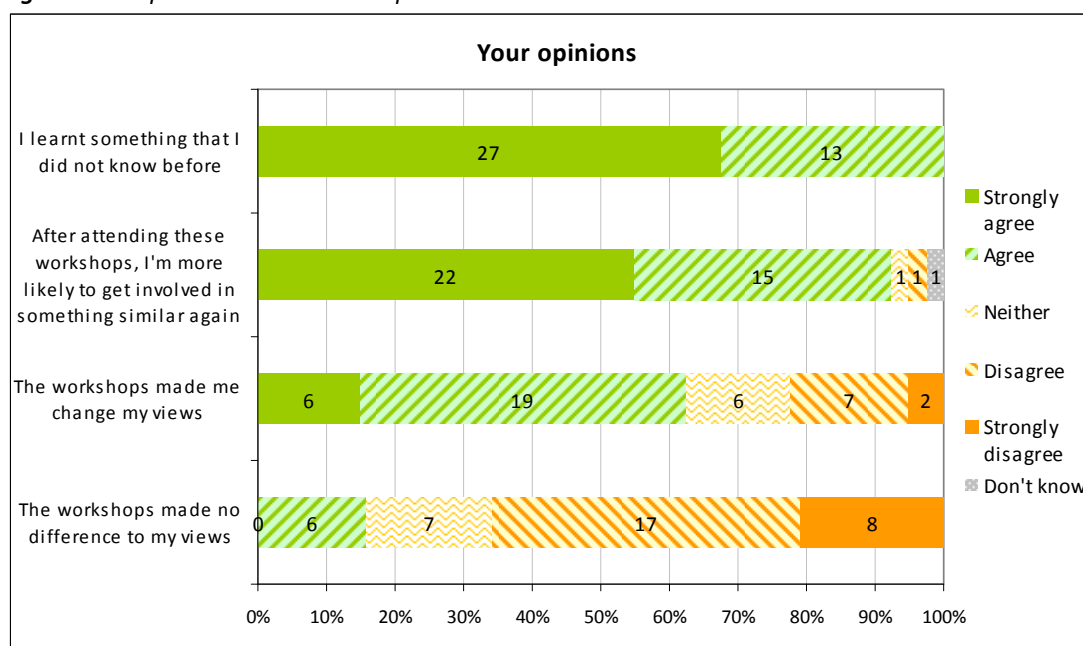
It was suggested by one expert that their role in the dialogue, which did not necessarily require high-level technical expertise, may be better suited to early career scientists.

I probably wouldn't do this again unless it was very important to me. A student could have done this and not being able to tell them anything was frustrating.
(Scientist, Newcastle)

7 What was the impact of the dialogue?

7.1 Outcomes for participants

Figure 8 Exit questionnaire: workshop outcomes



All of the participants said that they had learned something new as a result of their involvement in the dialogue. Most were also enthusiastic about being involved in something similar again. A smaller proportion (but still over half) said that the workshop had made them change their views, with a similar proportion rejecting the notion that the workshop made no difference to their views.

Respondents described either a cognitive or affective impact from their participation at the end of the second workshop. Comments included:

Some of what was discussed was very interesting, I feel I have learned so much (Female participant, 45-54, London)

From being ignorant of science to gaining a little knowledge (Male participant, over 65, Newcastle)

Having to question my own position in relation to the animal tested products medicines I currently use (Female participant, 45-54, London)

Some of my strong opinions have been changed simply because of the knowledge gained (Female participant, 45-54, London)

I am a bit more balanced in my views, having listened to others with different views. I found it interesting which surprised me (Male participant, 35-44, Newcastle)

Interestingly, some of the comments hint at the mechanisms behind attitudinal change, namely gaining knowledge and discussions with others who have different perspectives.

The **value of hearing others' perspectives** was the strongest theme in responses to the question about other outcomes from the workshops. As well as **seeing different views** (both from other participants and scientists), participants reiterated their **learning** from the

workshops. Some also described the **social aspects** of the dialogue experience. Comments included:

It was good to meet living and breathing scientists, and I will be looking to get involved in similar discussions again (Male participant, 35-44, Newcastle)

I feel that attending both days I am more aware of what is happening and [will] not rely upon the media for all information (Female participant, 25-34, Newcastle)

The connection of the group (Male participant, 45-54, London)

The interviewees felt that they had found out more about a subject they had little prior knowledge of. Some said that they would now take notice if they saw something related to this subject in the media, whereas before they would have been unlikely to give it their attention. Despite over half of questionnaire respondents agreeing their views had changed, most interviewees did not feel that their views had changed, but they framed this as learning rather than a change in attitude.

I wouldn't say change. But now I know more. I would say learned. (Faith focus group)

The interviews strongly support the questionnaire findings about cognitive impacts. Because the workshops were more distant, some of the other outcomes measured in the exit questionnaires appeared to have faded. However the idea about seeing and hearing the views of others was still memorable for some.

Surprised at the range of people's beliefs. I find it hard to think people would rather die than allow this to happen or allow their children to die. That was quite a surprise. (Male participant, 55-64, London)

Some of the interviewees had spoken about the issue with friends and family. For a few this was a source of interesting discussion, but for others the conversation was somewhat one-sided with only the dialogue participant really understanding the topic. This gap in knowledge appeared to have prevented others from talking about their experiences.

The homework was also interesting because I'd never talked about it with people before and I started to talk to my mates about it. (Female participant, 18-24, Newcastle)

Family and friends wouldn't have a clue what I was talking about. (Male participant, 45-54, Newcastle)

The interviewees hoped that the dialogue outcomes would be listened to by the regulators and government, although some were uncertain about the intended audience of the report. Most of those interviewed also hoped that scientists and other members of the public would listen to their views.

All of those interviewed said that they would like to be involved in dialogue again. For some this was because they enjoyed the process of learning and debating, while for others it was important to be 'making a difference'.

Opened my mind to science and what's going on. It's made me feel like I'd go again, no matter what was being talked about. It felt nice to be invited. (Male participant, 35-44, London)

7.2 Outcomes for experts

Most of the experts were surprised by how relaxed the public were about animals containing human material, and how interested they were by the science. The experts in Newcastle found that the group were very permissive, often going further than the scientists would in order to benefit human health.

*It's quite remarkable how supportive people are, and today's reinforced that it's actually difficult to find any work that caused people great anxiety
(Scientist, Newcastle)*

In London the participants had probed experts heavily on the regulations, and this had allowed them to consider their own roles and the purpose of the regulations that govern them.

When you're doing the actual experiments in a lab Home Office regulations – you have to abide by them but they're a bit of a pain, but then you realise in a meeting like this how important it is that they are regulated. (Scientist, London)

Experts' attitudes towards the permissive view of the public participants varied. In Newcastle the experts responded differently to the level of acceptance shown by the participants. One felt that it was an indication of public support for science, and that it showed that current regulations are restrictive of research, while another found the level of trust placed in science by the participants disconcerting, feeling that it showed a lack of understanding or full knowledge of the topic. Also, perhaps because of their role slightly outside the groups' conversations, they observed the way that group interactions affected the opinions that were expressed. The quote below expresses this, but also suggests that perhaps the scientists had unrealistic expectations about how objective members of the public could be:

*I think that the participants were genuinely more accepting than I believed they would be, but the group interactions exaggerated this. In the first session one lady talked about her mother who had died from cancer. Another man opposed her view, talking about the science not about her, but she said he made her feel uncomfortable.
(Scientist, Newcastle)*

In London experts highlighted the enthusiasm of the participants, and the way that they responded to the information that they received. They also commented on the role of the facilitators, and how difficult it was to keep the public from discussing the issue of research on animals, in order to discuss the more complex ethics around mixing animal and human material. All experts felt that they learned something about how to communicate science, and how people think about and discuss science between themselves. Each of the London experts felt that the experience would directly improve their science communication practice, and had got them thinking about reaching different audiences.

*More science communication stuff could be done that's actually reaching people that don't realise they want to know about it until they're told about it. I think it's difficult but I think that was a good aspect of it that came out that wasn't even part of the whole project I don't think, that people want to know more.
(Scientist, London)*

The less senior scientists felt that the day also gave them a broad overview of issues which they often miss in the context of their own projects. Those who had prepared for the workshop by reading around the topic felt it had allowed them to review their subject, and

that this learning would have an impact on their work. They felt that despite being briefed that extra reading was unnecessary, it had actually helped considerably during discussions.

Everyone was going like you don't need to look anything up and you don't need to look at anything, but I did anyway and it definitely kind of helped me to just read around the subject a bit and if I hadn't I would have felt a bit more out of my depth. So I'm glad that I did that so maybe I don't know, next time just give them a few ideas to have a small read around or something like that, to just sort of feel prepared. Because you've got these people firing stuff at you and you don't know what it's going to be.
(Scientist, London)

In follow up interviews most experts felt that they had been inspired to do more science communication after realising the level of public interest in science and the impact that it can have.

If you're not an ordinary person it is good to be reminded what ordinary people think.
(Scientist, Newcastle)

7.3 Dialogue findings launch event

The dialogue findings were launched at the British Science Festival at an event titled *Beyond the yuck factor: just how 'human' should laboratory animals become?* on Wednesday 15 September 2010. A press conference was also held on the same day, prior to the event.

The two-hour event involved five speakers (four from the Working Group and one from Ipsos MORI) and was chaired by the chair of the Academy's Communications Group. Over 50 people attended the event and the audience was made up of sixth form students, medical undergraduates, members of the general public and Academy and Sciencewise-ERC representatives.

Four presentations focused on the science of ACHM, and the final one summarised the findings of the dialogue. This was followed by an interesting discussion, with a range of questions about both the science and public attitudes towards it.

At the end of the event, an informal group interview was conducted with four science and medical undergraduate students that attended. They described listening with interest to the findings of the dialogue, and reflecting on their own role as future scientists and clinicians. Specifically, hearing how strongly the public were concerned about the purpose of medical research left them feeling a responsibility to ensure this is effectively communicated.

Maybe this event has opened my eyes to the fact that we really do have a responsibility to make people aware of what we do, because we do tend to do it all behind closed doors and not talk about it and that's probably quite a bad thing. If we provided more things like this with more info to the public about what we do do, we've proven that people are going to be quite accepting of it. So maybe it's not just the fault of the animal rights activists giving incorrect information.
(Biochemistry student, launch event)

This suggests that the dialogue could have further impacts on scientists who read the report, but who were not necessarily involved in the process.

Following the event, the report received coverage in the Financial Times⁸ and the Daily Telegraph⁹ as well as one specialist print article (Research Fortnight), one radio feature and eleven online articles at the time of writing this report.

8 Findings: stakeholders

Five stakeholders were interviewed in relation to the dialogue. Four were members of the dialogue Oversight Group and one was a member of the wider stakeholder group involved in the workshop near the start of the process. Three of the stakeholders had not been involved in a Sciencewise-ERC funded dialogue before. A further two interviews were conducted with representatives from the Ipsos MORI consortium that delivered the project. Their comments have informed some of the discussions about dialogue delivery.

8.1 Dialogue rationale

In describing the scope and context of the dialogue, interviewees recounted the history of the wider study and how the issues were highlighted in the earlier report on Interspecies Embryos¹⁰. The dialogue was described as an important source of evidence in the Academy study on animals containing human material.

We felt that it was important to have a public dialogue and partly because we wanted to gather information, find out what level of understanding people had, but also to find out where were the barriers in terms of how the public thought, what things would they find hard to justify and what things were easy to justify, what were they worried about and really whether they felt they should ever be able to put a complete ban on something or whether as it turned out, essentially if you can justify it they seemed to be relatively ok towards almost anything being done.

(Oversight Group)

The lack of public awareness and debate on the issue was also put forward as a reason for doing the dialogue.

One of the major questions in going into this is what would be the level of public resistance and although we all had our own views, the reality is that it just hasn't been in the papers, it's not an issue that's been formulated in quite this way and we really didn't know.

(Oversight Group)

8.2 Dialogue delivery

Dialogue workshops and structure

Only one of the interviewees had attended part of one of the public workshops, so most were unable to comment on this aspect of the process. However, all felt satisfied with the way the dialogue was structured and conducted.

I was only there for half a day but I have to say I thought it was conducted extremely well, the moderators were very good at trying to get people to say what they thought without leading them and I thought that was excellent. I thought unfortunately I wasn't there for the more contentious issues, when they were discussed, but I thought it was a good idea to take people through gradually because I felt that gave them a

⁸ *Public accepts research on human-animal hybrids* Financial Times, 16 September 2010

⁹ *'Human' animals could be justified* The Daily Telegraph, 16 September 2010

¹⁰ Academy of Medical Sciences (2007) *Inter-species embryos*
<http://www.acmedsci.ac.uk/p99puid105.html>

*much better understanding of the sorts of issues and what the concerns might be.
(Oversight Group)*

Particular strengths of the process were seen as the way the science was explained, the methods (particularly the combination of workshops and survey) and the way that the process was organised by the Academy and the deliverers.

*I thought the team understood the nature of the science that they were looking at, I think they seemed to work quite well with the Working Group itself in framing the questions and the structure of the dialogue, their methods seemed to me as good as others that I've seen in this area and certainly much better than some and I thought they did a rather good job given the rather inescapable limitations of a kind of dialogue process of this form.
(Oversight Group)*

The contractors that were interviewed as part of the evaluation were also largely satisfied with the process. They described how they approached the dialogue from different perspectives – Dialogue by Design had a greater focus on participants and their experiences and Ipsos MORI focused slightly more on the project and its outcomes. This led to useful discussions that prompted deeper consideration of both perspectives. Collaboration throughout the process was seen as a strength by both, rather than a more compartmental approach where organisations deliver different parts alone.

Limitations

Although the stakeholders were largely satisfied with the dialogue, they did point out some limitations. It is fair to say that most of these were limitations that relate to dialogue generally, rather than this specific process.

An issue raised by most was with the number of groups and participants. Interviewees recognised that this was limited by budget, but several would have liked to have seen groups from a more diverse range of towns and countries.

*I think maybe it would have been better in hindsight to have done dialogues in a number of different regions as well, but obviously time is a constraint and financial constraints, but maybe other than London and Newcastle would have been interesting to see and obviously it didn't capture the devolved [nations] either.
(Stakeholder)*

Interestingly, two interviewees identified the potential for scientists present to introduce bias in discussions. In contrast to one of the expert participants, one felt that involving more experienced researchers would be preferable; this may refer to experience in dialogue as well as experience in scientific research.

*I was slightly concerned that they [expert participants] were tending to give their personal views a little bit rather than that there is a spectrum of views in certain cases... ...I mean I don't think it was terrible, I think it just needs to be emphasised a little bit more, I mean it's hard I know to get more experienced people to devote their Saturdays to these things.
(Oversight Group)*

In addition, some acknowledged the difficulty in helping groups reach a point where they could draw out answers to some of the more subtle questions from the Working Group.

The issue of animals containing human material is difficult in many people's minds to separate from the more general issue of animal experimentation. And my impression

is that some of the contributors in the dialogue process found it difficult to make the distinctions that those who had set up the study in the Academy of Medical Sciences felt was so crucial.
(Oversight Group)

The dialogue contractors suggested improvements that could have been made had extra resource been available for the dialogue. For one, the relatively large size of the groups was an issue. She felt that with smaller groups participants would have found it easier to express views that challenged others in the group. Another suggestion was to extend the engagement with the special interest groups.

The contractors also reflected on the structure of the dialogue, in particular the different sources of evidence that were drawn together. Disaggregated follow-up interviews were included to give participants an opportunity to share their views away from the group, which was felt to be important for a potentially controversial issue such as ACHM. In reality, only a small amount of 'new' evidence was gained from these, as participants appeared to have been happy to put their points across during the group sessions. One of the contractors pointed out that with hindsight it may appear that this time was not the best investment, although they felt that without the interviews the level of confidence in the findings from the workshops would have been undermined.

The contractors felt that holding two workshops was appropriate for the dialogue, and that reconvening participants for a third time would not necessarily have given the findings any greater depth.

Stakeholder involvement

The involvement of stakeholders in the dialogue was seen as positive by both the stakeholder interviewees and contractors. The initial workshop was critical in shaping the materials and ensuring that appropriate case studies were included. It also provided an opportunity for a wider group to learn about the dialogue, and helped manage expectations about the outcomes of the process.

That was a good meeting actually, I think it got on the table all of the kind of issues that we – that kind of people felt should be broached, and allowed some groups to I think, kind of better understand the direction that the Academy wanted to go. So if you come from a basis that animal testing in general is acceptable, does this kind of research go beyond that and I think that was quite clearly put across there, which was very good in terms of managing the expectations of those involved.

(Oversight Group/Government department)

Oversight of the dialogue

Some interviewees found that the oversight element of the dialogue required a higher level of commitment than they had anticipated. The contractors were also aware of this to some extent, and described how after the initial Oversight Group meeting they had used phone conferences and email to gather feedback in the most time-efficient way possible.

I'd rather naively thought that they would all go away leaving us to write a report and come back and we could then integrate what they had done with what we had done. And the reality is that they – it took an awful lot of time from the group of us who were involved in the working party and other scientists. So that was – it was somewhat unexpected, on the other hand I'd have to say that I never felt that they were wasting my time, I thought they were simply trying to make sure that keeping it on track involved them understanding how the questions they were formulating

integrated with the issues we were trying to address. So I'm not sure that I would want it differently, but I would have had different expectations if I'd known that from the beginning.
(Oversight Group)

The implication of this extra involvement was in delaying the reporting of the Working Group's wider study.

The Oversight Group had many members with considerable pressures on their time. For one interviewee in particular, this meant he was unable to devote as much time as he would have liked to the process. He questioned whether it would have been beneficial to involve others with fewer such pressures.

Maybe there's a general tension in groups like this between getting people who are senior in their field and therefore appear to have the authority and the weight to make such weighty decisions but the downside of that is just what we've been talking about, these tend to be the people who are very, very committed... .. maybe some people at a rather more junior level in their career might be good to bring into these kinds of working groups because they'd have more time and because they'd not be split up between multiple, multiple things and they're not necessarily less wise because they're less old.
(Oversight Group)

Both the stakeholders and the contractors mentioned the important role of the Academy in project managing the dialogue effectively. From the point of view of the contractors, the Academy was a client that understood the dialogue process and helped manage it professionally. From the point of view of the stakeholders, the Academy role facilitated their engagement in the process and represented the most efficient use of their time in contributing. For organisations outside the Oversight Group, the Academy was seen as uniquely placed to take the lead on the project.

One of the things that [the Academy is] particularly well known for is their voice in the regulatory ethical issues. And that's an area where we're happy to work alongside them, but for them to take the leading role on it really.
(Stakeholder)

Credibility

Stakeholder interviewees were pleased with the quality of the outcome of the dialogue. The various sources of evidence that the dialogue had collected were seen as adding confidence to the conclusions.

I was impressed by its thoroughness. I thought that it was consistent, there were several different grouplets of evidence that were brought in and they seemed to be reasonably consistent. The story overall seemed coherent and it seemed to fit with the sorts of messages that came out of less formalised discussions.
(Oversight Group)

There were no strong surprises in the outcomes, but there were some differences to what stakeholders had expected. Firstly, the public were more accepting of research with ACHM (when justified) than had been expected. Additionally, some had not anticipated the order of the species in the hierarchy or that reproductive and aesthetic aspects would be as unacceptable as experiments with the brain for some.

Overall, interviewees felt that the dialogue was credible.

I think it was credible, I think it's going to be very useful for the working group, I think they can draw on the results without having to temper what they say in any way. I think they can accurately take that report and use it and that's really what it was there for, it's good as a stand alone piece of work but from our perspective we want the Academy to have the best information and be able to draw upon accurate and reliable information to come up with their report and I think that report will do that.
(Oversight Group/Government department)

8.3 Impacts on stakeholders

Learning

It appeared that the dialogue report had led some interviewees to reflect on their own opinions about the issue, and perhaps see it from a different perspective.

The areas that people had reacted to or reacted cautiously to were pretty much the areas that I suppose we had considered in advance were likely to be sensitive. The order in which those things came was not quite the order in which I'd thought they would come and the sorts of emphases were interesting and different and I thought rather thoughtful actually and I slightly changed my – well not changed my mind but I had no difficulty understanding where people came from. (Oversight Group)

For others, there was an opportunity to have an insight into a dialogue process.

I think it was interesting to see the process, I think to properly learn about public dialogue I'd probably have to witness a few more going on if you know what I mean, see different ways of approaching it and different ways of doing it. But certainly I think I'd happily be involved again in that kind of work.
(Oversight Group/Government department)

Policy impacts

Because the dialogue is part of the Academy's wider study on ACHM, which has been ongoing at the time of the evaluation research and reporting, most interviewees felt it was too early to comment on the nature or extent of the dialogue's influence on the Working Group report or subsequent policy decisions.

However there was considerable discussion about the important role of the public voice in preparing the report.

I think it's allowed the working group to focus clearly on issues of communication and public acceptability not that those wouldn't have been on the agenda, they obviously would have been but I think that there's now something hard to chew on which now that we've got it done is going to allow us to move much more confidently on policy areas and to spend much less time trying to imagine what we think people think.
(Oversight Group)

There was also some discussion in the interviews of how the public dialogue findings would be weighed up with the other sources of evidence collected through the study.

So it's I guess one pillar of the work really because if you talk about the ethics or talk about the philosophy of it those views are – well the arguments made around that are generally going to be quite intellectual and the public argument is much more based around gut response around the yuk factor and that is, it's an important element because even if you can make the most highbrow argument that a piece of science is

justifiable, if the public look at it and decide it's wrong for whatever reason then that's an important factor. (Oversight Group/Government department)

While it is clearly too soon to say what the eventual policy impact might look like, some expressed aspirations for the type of influence the dialogue might have, and that it might be a starting point for continued dialogue.

I'm hoping a dialogue will help eventually frame the regulation, any changes in regulation in a better way. So I think as I already said, in terms of understanding the concerns this group of people had, [it] will certainly help to mitigate backlashes if we can incorporate that into a wider public dialogue or continuing public dialogue which inevitably there will be as these sorts of examples of research come up, whether it's in this country or abroad. (Oversight Group)

Next steps

The dialogue was always designed to feed in to the deliberations of the Academy Working Group on ACHM. Their report will be finalised in early 2011. The audience for that report is a range of interested parties including: policy makers in Government, regulatory bodies, research funders, academics, professional organisations, and international equivalents. It is particularly aimed at the Government bodies who regulate ACHM in the UK (Department of Health and the Home Office) and the groups who provide guidance to researchers under that broader regulatory framework (e.g. the Medical Research Council).

8.4 Cost benefit analysis

The cost benefit analysis is based on the approach described by Sciencewise-ERC¹¹. Evidence for this was collected through the stakeholder and contractor interviews and from a discussion with three members of Academy staff, including the dialogue project manager.

This cost benefit analysis does not aim to give a price for the costs and benefits of the dialogue, rather to use a set of questions related to costs to indicate whether the dialogue itself offered 'value for money'. The starting point for the analysis was identifying the difference the dialogue made, followed by different questions related to the costs and benefits, in order to draw conclusions.

What difference did the dialogue make?

Stakeholders felt that the dialogue had provided evidence of informed public views, which meant that the Working Group would not make assumptions about what these views were. This was seen as very important.

I guess it reinforced views that we hoped the public might have, but actually it was even better in a way so it – I think it was definitely worth doing, put it that way... Well it's actually a diverse group on the working party and as I say it's not just being reassured, I think it also helps us – it will help us quite a lot in terms of writing the report and in making our recommendations if we make any recommendations in how this topic needs to be presented when it's presented to the public at large and to politicians. I think I would rate it as very important. (Oversight Group)

¹¹ Warburton (2010) *Evidence counts: Understanding the value of public dialogue*

From the perspective of the Academy, the timing of the dialogue in relation to the wider study was important. It enabled the dialogue to influence the working group's considerations whilst the Academy's report was itself in a draft stage. This was balanced against the potential for the wider work to lose momentum whilst the dialogue programme was underway. This was mitigated through the tight timescale of the dialogue. The main outcome that the Academy noticed was the confidence with which the working group were able to take public views into account.

Costs

In financial terms, the total cost of the dialogue and its evaluation was £129,250 (inclusive of VAT). Without the VAT, this represents around half of the budget for the study overall, and without Sciencewise-ERC funding there would have been a very much smaller scale public engagement element to the study, or none at all. We were interested in comparing the proportion of the budget spent on the dialogue with the level of influence of the findings. However stakeholders were keen to point out that it is not possible to weight different types of evidence in a study like the Academy's against each other:

It's a very substantial part of that but I just can't weigh it against the evidence on the science itself, they're just on different – they're in different dimensions of space.

(Oversight Group)

However some felt that the public opinion should be given as much weight as other sources of evidence.

I think from the perception of a publically funded organisation, [public views should be] fairly heavily weighted because at the end of the day it's tax payers' money that we're spending. So whilst it has to be balanced alongside a scientific peer review process where you're getting the perspective of people that are doing it all the time and have the bigger perspective of the research they're involved in and how ultimately it's going to benefit the public in the long term through health care anyway. It's got to be balanced but it's difficult to put a percentage on it, but equally as important if – not knowing who the others are, but I would say pretty equal.

(Stakeholder)

The Academy also input considerable staff time to the dialogue; more than anticipated. This went towards dialogue oversight, organising contracts and financial arrangements which took longer due to the number of parties involved in the negotiations. This time was needed to mitigate a number of risks: that the findings of the dialogue would not be relevant or useful to the Working Group, sensationalist media coverage meaning that public debate became dominated by anti-vivisectionist groups, that the contractor did not deliver and that the Working Group would become sidetracked from the main study by the dialogue. The Academy felt that these risks were avoided, but that it cost extra time to ensure this.

In addition to central staff time, Academy Working Group members and members of the wider medical sciences community gave up varying amounts of their time to support the dialogue. The cost-benefit analysis was a useful way to recognise the value of this time.

Benefits

The Academy felt that the most important benefit of the dialogue was its input to the ACHM study. The credibility of the process was a key factor here: had it not been credible, the value of the process (and the wider study) would have been seriously compromised.

As well as this central benefit, the Academy noted several others. These included the nationwide survey acting as a baseline for understanding public views and surveying future trends in public opinion, meeting the Academy's own goals in public engagement including direct interaction between scientists and citizens, and the publicity for the study generated by the launch event. Benefits to public and expert participants are explored earlier in this report. However the Academy staff described the journey that the Working Group had undertaken with the dialogue as a useful outcome of the process. It was felt that the combination of deliberative and survey elements in this dialogue had allowed group members to see the benefits and drawbacks of both quantitative and qualitative approaches to exploring public views. In the end the combination of the two was powerful and the report has been well-received by the Working Group. Another factor here was the Academy's organisational learning from the 2007 Sciencewise-funded *Drugsfutures* dialogue¹². Although a different contractor was used and a different member of staff from within the Academy was involved, staff described approaching the ACHM dialogue with confidence based on their previous experience of commissioning dialogue.

For the Academy and stakeholders, benefits were also framed as costs that could be saved in future. An important saving was in creation of effective regulation with public opinion in mind, although predicting how necessary the dialogue would be in this was seen as problematic:

I suppose the only real answer to that is that if you compare the cost of an exercise of this sort against the possibility of reaching the wrong policy decisions and creating another GM uproar where billions disappear, it's a no brainer. The weakness of the argument is of course we may have reached - not just the working party but the country, may have reached perfectly good decisions without it and we can't quantify that.
(Oversight Group)

Other costs of not doing the engagement were leaving the study report open to critique for not including publics' views (or not including them in a credible way).

Finally, beyond the Academy study, a suite of benefits to science communication were identified. The dialogue was seen to have pinpointed key areas of public concern on which to focus future communication efforts. There has also been interest in some of the approaches to communication used, for example avoiding images of animal research to promote a less emotionally-charged debate. A level of ongoing dialogue following the project was also seen as a benefit in this regard:

I suspect [it] will serve rather more to ensure that we keep a level of engagement from newspapers and television and the rest of it, which keeps it in the public eye a bit longer and that helps in a process of dialogue, that is it helps keep the public interested which means that one day when some day someone probably in some other country does a slightly eye watering experiment, people at least remember that they have read somewhere sometime about some people thinking about this, rather than it suddenly coming out of the blue.
(Oversight Group)

The Academy staff felt that it might be possible to use some of the materials developed for the dialogue in other public engagement activities, such as science festivals or public events. Whilst there was insufficient time during the dialogue delivery period to do this, Academy staff felt that these could present good opportunities for further public discussion of the dialogue findings.

¹² OPM (2007) *Drugsfutures: Public engagement on the future of brain science, addiction and drugs*

Cost effectiveness

The Academy acknowledged that deliberative approaches are not cheap, but noted that this project was modest in comparison to some other dialogues. Overall, it was felt that the contractors offered good value for money. One of the interviewees who was involved in the commissioning process commented:

We felt on the basis of our assessment of the bids in front of us that this one delivered the maximum information to us for the kind of overall envelope of costs in which we were working.
(Oversight Group)

Stakeholders also discussed alternative approaches, and most felt that while the dialogue could have been replaced with an opinion poll or series of town hall meetings, this would have sacrificed the credibility and robustness of the process.

Just simply doing an opinion poll is not going to give you the same sort of answers, it'll give you an answer as was gained within (some) aspects of the report, but it's not going to give you I think, the right sort of – the sort of qualitative answer that you need to know, rather than a quantitative answer. So what information do people need to have to be able to make appropriately informed decisions? I think that's why this sort of dialogue is very important.
(Oversight Group)

There were no areas where a small increase in budget could have delivered a large additional benefit (although some identified areas where a larger investment could have extended the findings, for example by running events in more locations). Conversely, all felt that each element of the dialogue was necessary to support a high quality process and report. Academy staff suggested that it might be helpful to clarify how the observational work (described in more detail in the Appendix) had informed the findings overall. This element was valued by the contractors, and because it was a new and interesting approach it would be useful to share some of the insights gained more widely.

Cost Benefit Analysis summary

Overall, it was felt that the dialogue itself was efficient and that the contractors delivered a high quality, credible process and report that offered useful insights for the investment. The cost of mitigating risks in the process came at the expense of Academy staff time, but this was seen as a good investment as it helped keep the larger project on track.

However, stakeholders felt it was too soon to say whether the dialogue was 'money well spent', as this is strongly dependent on exactly how the findings are reflected in the Working Group report.

9 Successes, challenges and learning points

This section summarises the evaluation findings and learning points for future dialogues.

9.1 Successes

Successes have been identified under four broad headings:

- The dialogue was meaningful in the context of the wider Working Group study;
- The dialogue was well timed to be influential in that study;
- There were a number of successes in the dialogue process including the level of science communication and the use of a mixed method approach;

- The dialogue outcome was seen as credible by stakeholders.

The fact that the dialogue was **part of a wider study into the use of ACHM in research** gave it a clear purpose and route to decision-making. This created an arena in which public views could be taken on board alongside scientific and other evidence. Before the Working Group reports it is not possible to be sure of exactly how much influence the dialogue will have, but its inclusion as part of the wider study is conducive to the best outcome. The challenge of running these two elements concurrently is discussed in the next section, but effective management (helped by the experience of having managed a dialogue before) from the Academy was a clear success factor. Another success factor was the Oversight Group, which included some members who had already been working together on the wider study and had established trust and working patterns that could transfer easily to oversight of this process. Eliciting feedback using email and phone conferences made efficient use of Oversight Group's time.

The **timing** of the dialogue at about the mid-point of the Working Group's deliberations meant that it reported before the structure of the final report was agreed, bringing the potential for greater influence. The alternative was commissioning the dialogue later, when there was a smaller risk of the Working Group study losing momentum as a result, but meaning that the dialogue would report at a less influential time in the study. Delivering the dialogue to a very tight timescale was necessary due to the timing, and having the launch event at the British Science Festival was a challenging but useful deadline.

The **dialogue delivery** had many strengths. The consortium of contractors brought different approaches which helped lead to a high quality process. They worked effectively with stakeholders to ensure that the focus of the workshops was appropriate. Specifically for this dialogue, the range of ways in which the science was communicated was excellent, and this was frequently commented on by participants who felt that the material was accessible but never patronising. Crucially, this allowed most participants to make informed contributions to discussions. It is also interesting that the dialogue involved two workshops, rather than three workshops as in some other processes. Participants, stakeholders and contractors were happy with this approach, and did not feel that another workshop would have added much to the outcome. This probably reflects that the participants spent little time on ice breakers at the first workshop, and started straight away with the discussion about 'what is human?' This made efficient use of participants' and contractors' time.

The dialogue **outcome** was seen as credible by stakeholders, and a way that the important public voice could be included in the Working Group study. In addition, the mix of methods employed by the contractors (specifically the combination of the survey and public workshops) was seen to bring confidence in the findings through triangulation, as well as allowing stakeholders to see the value and limitations of the different types of evidence.

9.2 Challenges

There were three main challenges with the dialogue:

- Managing the dialogue alongside the Working Group study;
- Challenges related to dialogue delivery such as overcoming group cultures, minimising bias due to the presence of scientists and maintaining focus on ACHM rather than more general animal research;
- Sharing learning from innovative methodologies.

Commissioning the dialogue at the mid-point of the Working Group study gave the report maximum influence, but risked diverting the group's focus away from the larger task.

Managing both processes at the same time took greater commitment from Academy staff, Oversight Group members and stakeholders. This extra commitment meant that the study as a whole has been slightly delayed, although the Academy felt that this was acceptable given the useful outcome from the dialogue. The Oversight Group had not expected that such a high level of commitment would be required, so they may be more realistic if they are involved in dialogue again in future.

There were some limitations with the **dialogue delivery**. As with all dialogues or focus group methodologies, overcoming group cultures to reveal diverse views in the workshops was a challenge. The public participants were satisfied that they had opportunities in the workshops and interviews to put forward their views, but the scientists at the workshops were concerned that they may have introduced bias. In fact of all the groups that contributed to the evaluation, the scientists that attended the workshops were the most critical of the process, perhaps because at the time they were interviewed they had not been able to see how the group conversations would be translated into the report. It appears that they found it difficult to withhold their views, especially while public participants made assumptions about them or their work. An alternative approach is to allow scientists to give their views in a controlled way (such as a presentation that has been checked by dialogue contractors beforehand) and to explain the bias that they may have. This approach was not taken in this dialogue, so it is not possible to say whether it would have been more effective. Certainly having more structured input from the scientists is likely to have taken more time, and may have meant that discussions were unable to progress as far as they did.

The science is undoubtedly difficult, and distinguishing between the ethics of ACHM experiments and animal experiments generally was problematic. Some of the participants did make this distinction, while others did not – despite the very good science communication work. This meant that contributions from some were limited. Also, participants did not seem clear about the purpose of the dialogue. There were no misconceptions about what it was for, just a lack of confidence in participants' ideas about its purpose. This may reflect that for most people, the concept of dialogue is unfamiliar (unlike, for example, a public survey). While the contractors and the Academy did explain this at workshops, it could have been communicated more effectively.

The final point on delivery is about **sharing learning from innovative methodologies**. The follow-up interviews and observational research were relatively new approaches, and it was a challenge to feed back on these fully within the dialogue report, which needed to focus on public views. It would be helpful to have an alternative way to share learning from these methods, especially the observational work which the contractors found valuable.

9.3 Learning points

The following points may be useful considerations for others looking to work with public dialogue:

- Dialogue is an intense process that requires a great deal of time and commitment from Academy staff and the Oversight Group. Being as realistic as possible in allocating this time will help ensure the process runs smoothly and delivers a credible outcome.
- Despite comprehensive briefing, expert scientists found it difficult to know when to contribute and were concerned about introducing bias into groups. Clear roles in groups and direction from the facilitator are helpful; however it did seem that some

were keen to do more preparation work than suggested, so a reading list, some FAQs or pointing to the Sciencewise-ERC website might help.

- It is important to carefully consider which experts to involve in both the dialogue workshops and the Oversight Group. It is valuable to build capacity in those with limited experience or understanding of public dialogue. It is also important to balance the seniority of those involved with their capacity to commit time to the dialogue.
- From this process, it would appear that two public workshops, reconvened twice, can provide a good outcome if the time is used effectively.
- The purpose of the dialogue could be explained more effectively at workshops. Public participants were very interested in the structure of the dialogue but could not confidently explain its purpose.
- It would be helpful to have a forum where contractors can share learning from innovative methods they have used, as it is not necessarily appropriate to discuss methods at length in the dialogue report itself. The Sciencewise-ERC wash-up meeting was one opportunity to capture this, although there were many issues on the table for discussion at that meeting so it was only mentioned briefly and it would be useful to explore other ways to share learning.

Appendices

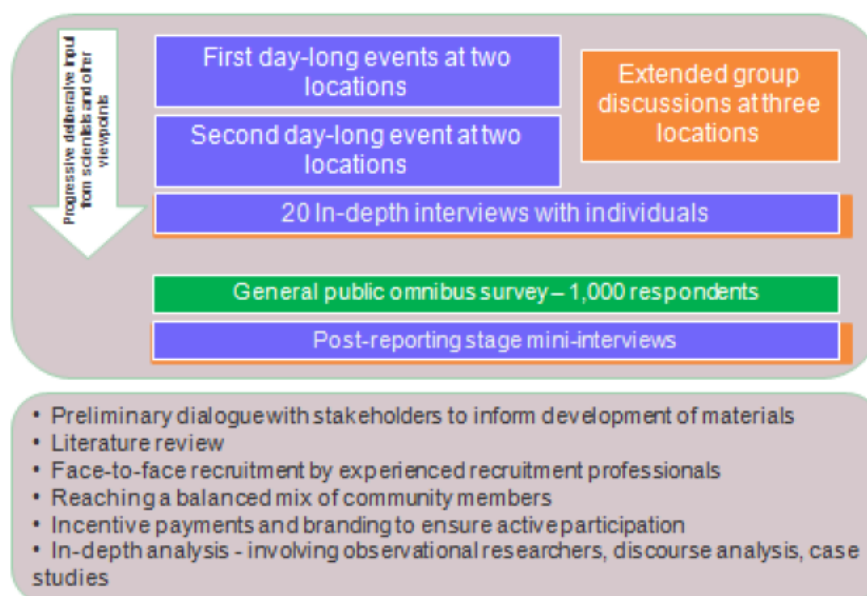
- Further detail on dialogue structure
- Evaluation questionnaires

Further detail on dialogue structure

Adapted from the Ipsos MORI report, the main elements of the process are summarised here.

- 1 **Literature review** of previous public opinion research, based on themes developed in conjunction with stakeholders
- 2 **Stakeholder engagement and materials development** involved a stakeholder workshop on 22 April 2010 to agree detailed aims for the dialogue and develop materials. It was attended by the Oversight Group and representatives from NGOs, industry, religious organisations and animal welfare organisations, followed by work over email and by teleconference.
- 3 **Qualitative elements of the dialogue**, as summarised in the diagram below.

Methodology



Taken from Ipsos MORI (2010)

- 4 The **dialogue process** included six stages:
 - 4.1 At the outset discussions covered underlying attitudes and values to animal and human life, and gauged awareness of ACHM research.
 - 4.2 The second stage provided participants with background scientific information in a range of formats
 - 4.3 Stage 3 involved a series of case studies of potential uses of ACHM research. These were:
 - Hybrid cells created in a lab
 - Transgenic sheep producing a human protein in their milk
 - Mouse liver with human liver cells
 - Human Huntington's disease gene in monkeys
 - Down's Syndrome in mice carrying human chromosomes
 - Human stem cells in rats and monkeys

- 4.4 Stage 4 was a homework task between workshops that involved discussion with friends and family and personal reflection
 - 4.5 Stage 5 involved exploring the boundaries of acceptability using a card sort exercise, where participants were invited to rank various ACHM scenarios in terms of acceptability. Applications and regulation of ACHM research were also discussed.
 - 4.6 Participants worked in smaller groups in stage 6 to discuss their overall impressions and present back to the larger group.
- 5 **Follow-up interviews** were conducted with a sub-sample of twenty participants from the public workshops and special interest groups. Interviewees were selected because the views they expressed during the group sessions were distinct. This enabled issues raised in the preliminary qualitative analysis to be further explored.
 - 6 The **quantitative methodology** centred on a large public survey
 - 7 **Data analysis** was conducted using feedback that was collected in various ways:
 - 7.1 Direct feedback from participants e.g. homework tasks, posters
 - 7.2 Transcribed notes (near-verbatim comments)
 - 7.3 Facilitators' notes or flipcharts
 - 7.4 Findings from an observational researcher who made notes without taking part in the facilitation, but moved between groups looking at body language, facial expressions and evidence of behaviours. Ad-hoc interviews were also conducted with participants to check on

Public dialogue on research involving animals containing human material – Session 1

Start of event questions

Before the event begins, we would like to hear a little about you, your views , and your expectations about the events.

This questionnaire is being carried out by Ipsos MORI, who are organising today's event.

The responses you give will be shared with our colleagues, Laura Grant Associates. They are independent researchers whose job it is to review how the event is run and make recommendations on potential improvements for future events like this one.

Your **answers will be completely confidential**. Both Ipsos MORI and Laura Grant Associates will only report the results as summaries in which no names will be mentioned.

Please could you answer the questions by ticking the box that best describes you or writing in the information requested. Then **hand to a member of Ipsos MORI team**.
Thank you!

Your name: (Please Print)

Today's event

Q1 What were the main reasons that you decided to take part in today's event?

TICK ALL THAT APPLY

- To learn more about medical research
 - Interest in science issues
 - To express my views
 - To influence decisions about scientific and medical research
 - Because of the financial incentive
 - To meet people
-

Q2 How much would you say you currently know about medical research that involves mixing human and animal material?

TICK ONE BOX ONLY

- A great deal about it
- A fair amount about it
- Not very much about it
- Very little about it
- Don't know

Q3 Based on your initial thoughts how strongly do you now support or oppose medical experiments and research that involve combining human and animal genetic material?

TICK ONE BOX ONLY

- Strongly support
- Tend to support
- Neither support or oppose
- Tend to oppose
- Strongly oppose
- Don't know

About you

Q4 Which of the following qualifications do you have?

TICK ALL THAT APPLY

O levels, CSEs, GCSEs, NVQ 1, School Certificate or similar

A levels, AS levels, NVQ 2 or 3, Higher School Certificate, Advanced Senior Certificate or similar

BA, BSc, MA, MSc, PhD, PGCE, NVQ 4 or 5 or similar

Other qualification

Q5 Did you vote at the last general election?

TICK ONE BOX

Yes

No

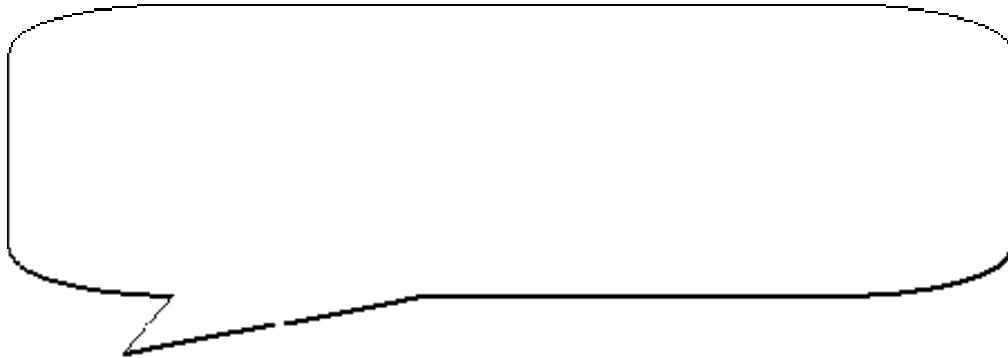
Thank you very much for your help

Workshop 1 – Post Questionnaire

This short questionnaire is designed to gather your impressions from today’s event. Your feedback will be used to help evaluate the dialogue.

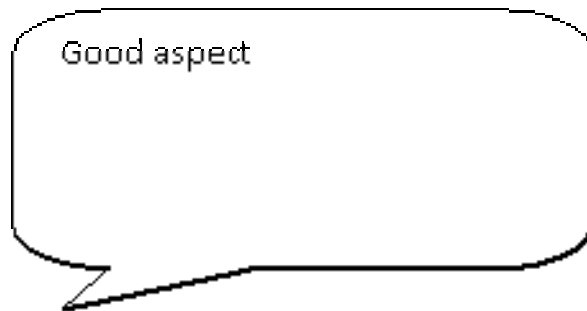
Your name: (Please Print)

1) Had you heard about medical research and experiments that involve mixing human and animal material before today? If so, where?

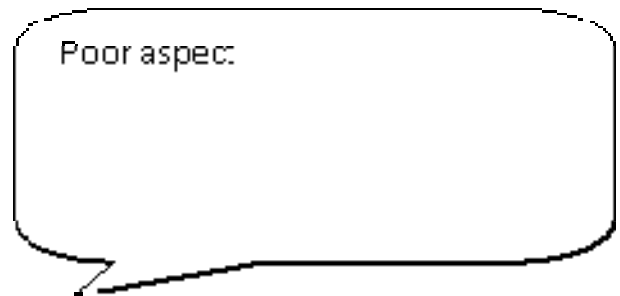


2) What aspect/s of the day stood out and why? (please tell us one aspect that was good and one that was poor)

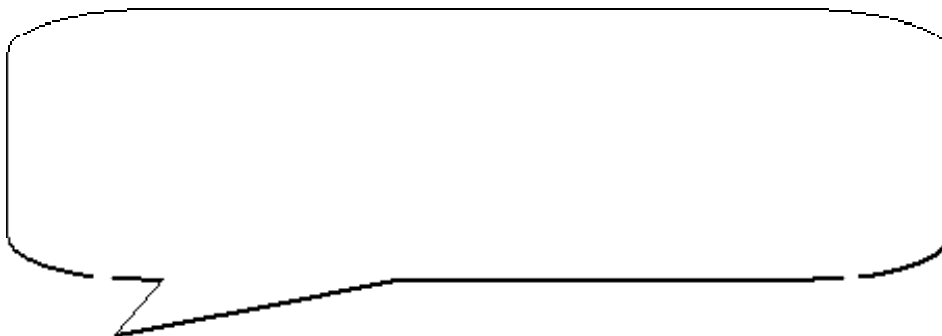
Good aspect



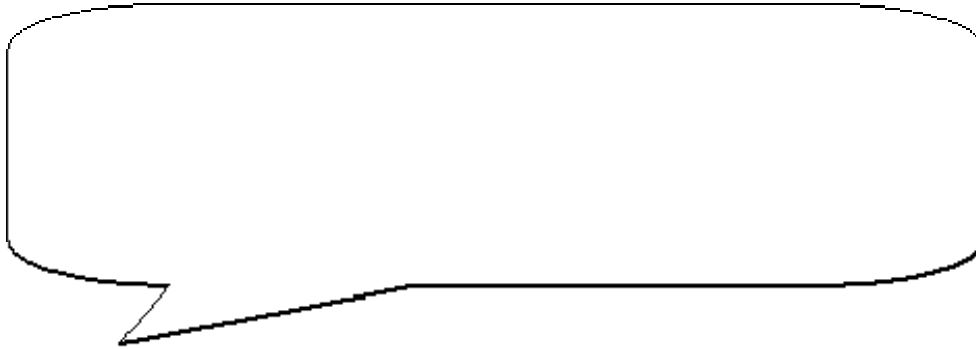
Poor aspect:



3) Did you feel that everyone in the group had a fair chance to get the information they needed and give their opinions? Why or why not?



4) What is the main thought or idea you will take from today?

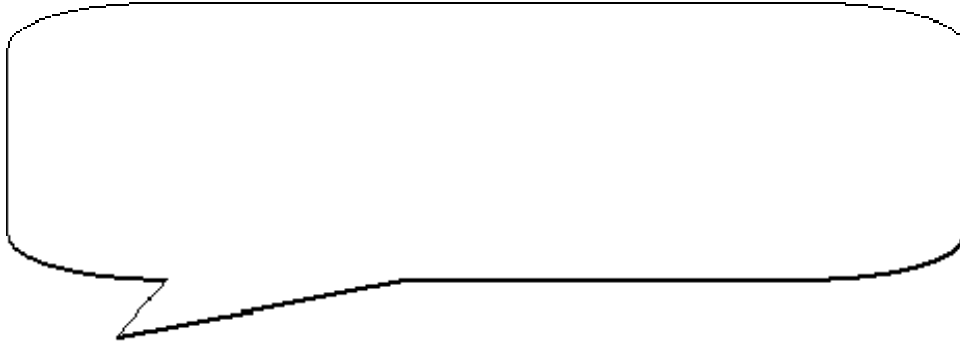


5) Based on what you have heard today, how much would you say you now know about medical research that involves mixing human and animal material? TICK ONE BOX ONLY			
		A great deal about it	<input type="checkbox"/>
		A fair amount about it	<input type="checkbox"/>
		Not very much about it	<input type="checkbox"/>
		Very little about it	<input type="checkbox"/>
		Don't know	<input type="checkbox"/>

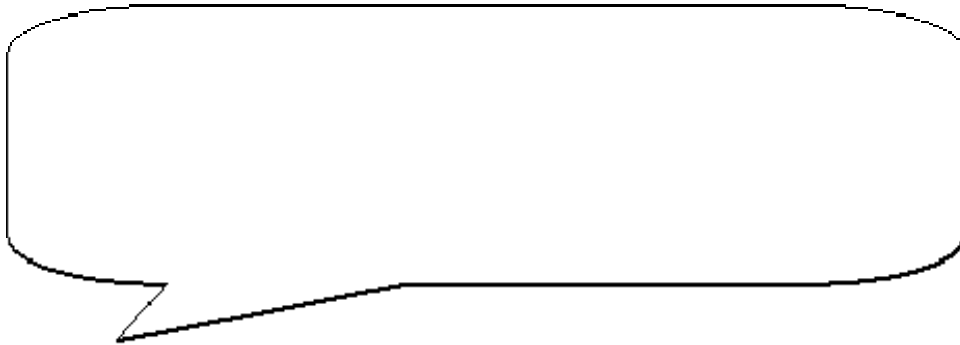
6) Thinking about the different research and experiments we have discussed today, how important have each of the following been to you? TICK ONE BOX IN EACH ROW					
	Extremely important	Very important	Fairly important	Less important	Don't know
What the research is for? (eg. to learn more about human body; or to test new drugs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The amount of suffering that is felt by animal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Which type of animal is being used (eg monkey or mouse)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How 'natural' the research seems to you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concern about whether the research might lead to unforeseen problems such as new viruses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Whether the scientists involved can be trusted to conduct experiments according to the rules	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Whether or not the experiments agree with your religious or personal views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The extent to which the animal is a creature that could live outside the laboratory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The type of animal or human tissue being used in the experiment (eg skin, liver, brain)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Whether the animal involved develops new characteristics or looks different.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7) How strongly do you now support or oppose medical experiments and research that involve combining human and animal material? TICK ONE BOX ONLY			
	Strongly support	<input type="checkbox"/>	
	Tend to support	<input type="checkbox"/>	
	Neither support or oppose	<input type="checkbox"/>	
	Tend to oppose	<input type="checkbox"/>	
	Strongly oppose	<input type="checkbox"/>	
	Don't know	<input type="checkbox"/>	

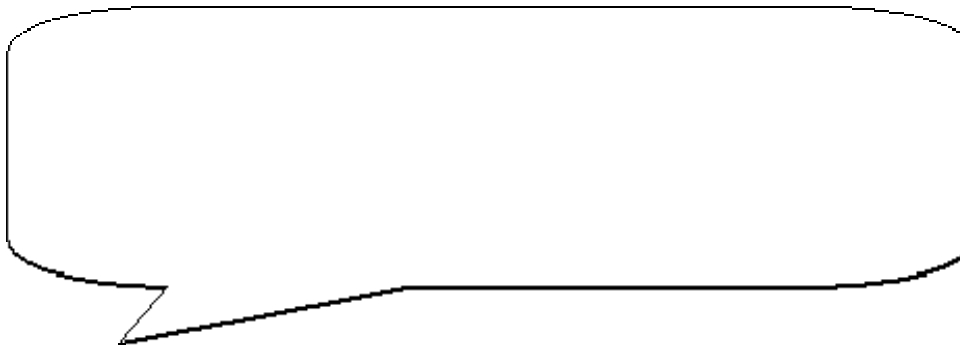
8) How if at all do you think the meeting could have been improved?



9) Is there anything in particular that you would like to discuss further in the next session?



10) Is there anything else you would like to add?



Thanks!

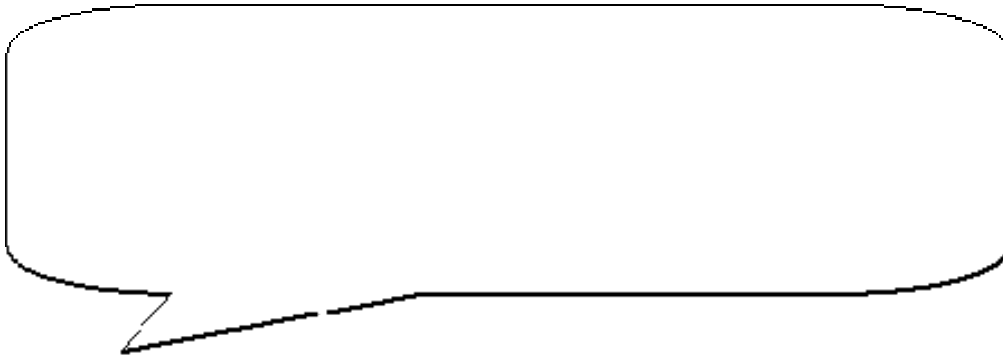
Please hand the questionnaire back to an Ipsos MORI team member.

Questionnaire (focus group)

This short questionnaire is designed to gather your impressions from today's event. Your feedback will be used to help evaluate the dialogue.

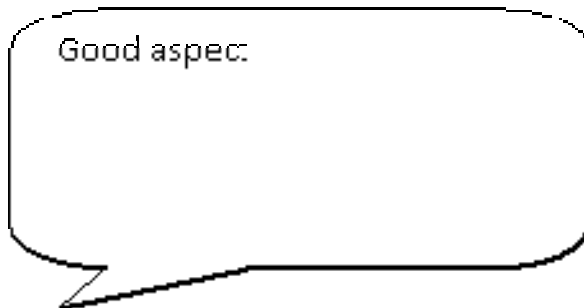
Your name: (Please Print)

1) Had you heard about medical research and experiments that involve mixing human and animal genetic material today? If so, where?

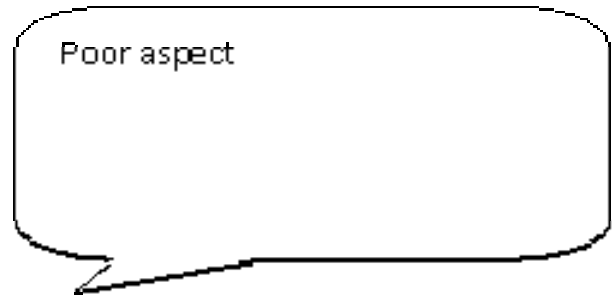


2) What aspect/s of the discussion stood out and why? (please tell us one aspect that was good and one that was poor)

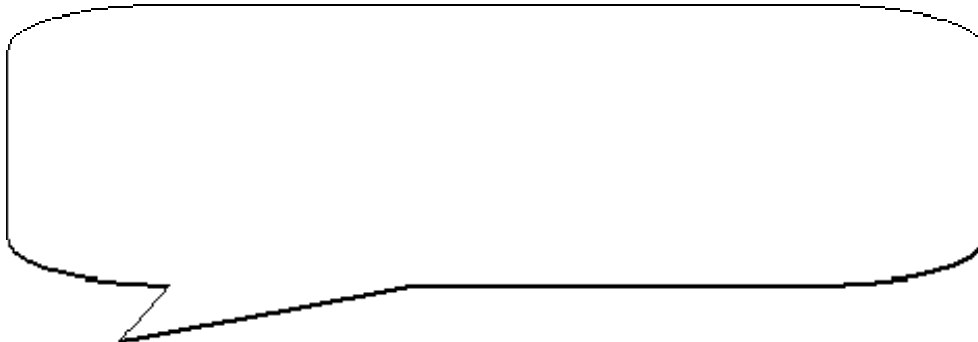
Good aspect:



Poor aspect



4) What is the main thought or idea you will take from this discussion?



5) Based on what you have heard today, how much would you say you now know about medical research that involves mixing human and animal genetic material? **TICK ONE BOX ONLY**

		A great deal about it	<input type="checkbox"/>	
		A fair amount about it	<input type="checkbox"/>	
		Not very much about it	<input type="checkbox"/>	
		Very little about it	<input type="checkbox"/>	
		Don't know	<input type="checkbox"/>	

6) Thinking about the different research and experiments we have discussed how important have each of the following been to you? **TICK ONE BOX IN EACH ROW**

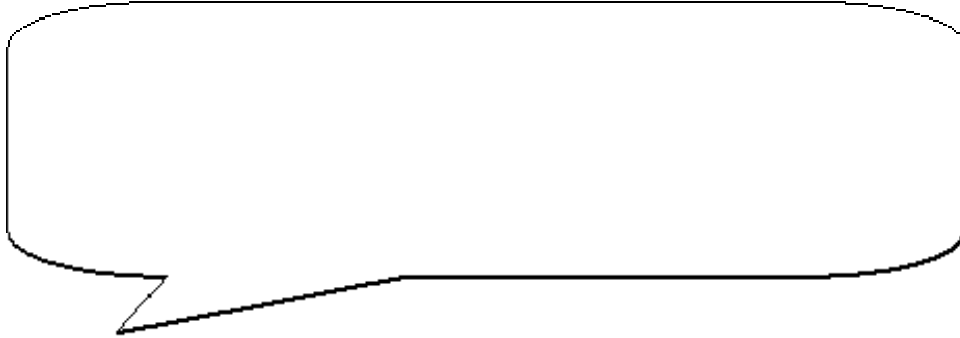
	Extremely important	Very important	Fairly important	Less important	Don't know
What the research is for? (eg. to test new drugs or just to find out more about the issue)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The amount of suffering that is felt by animal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Which type of animal is being used (eg monkey or mouse)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How 'natural' the research seems to you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concern about whether the research might lead to unforeseen problems such as new viruses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Whether the scientists involved can be trusted to conduct experiments according to the rules	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Whether or not the experiments seem to be against your religious or personal views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The extent to which the animal is a new creature that could live outside the laboratory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The type of animal or human tissue being used in the experiment (eg skin, liver, brain)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Whether the animal involved develops new characteristics or looks different.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7) How strongly do you now support or oppose medical experiments and research that involve combining human and animal genetic material? **TICK ONE BOX ONLY**

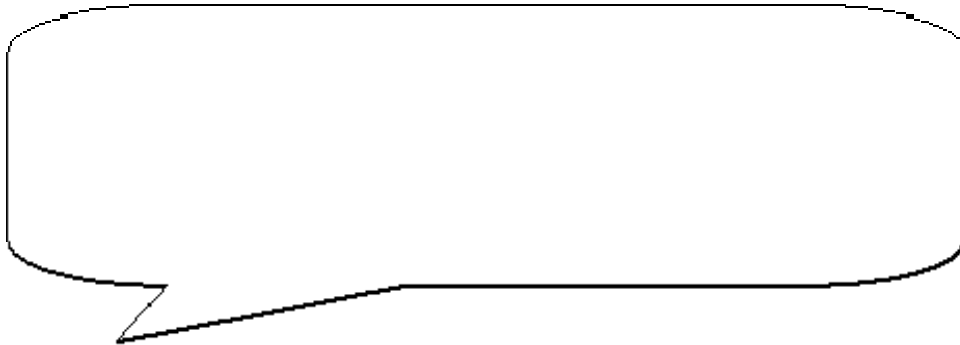
		Strongly support	<input type="checkbox"/>	
		Tend to support	<input type="checkbox"/>	
		Neither support or oppose	<input type="checkbox"/>	
		Tend to oppose	<input type="checkbox"/>	

		Strongly oppose	<input type="checkbox"/>	
		Don't know	<input type="checkbox"/>	

8) How if at all do you think the meeting could have been improved?



10) Is there anything else you would like to add?



Thanks!

Please hand the questionnaire back to an Ipsos MORI team member.

Workshop 2 Questionnaire

Please take a few minutes to complete this questionnaire. Your feedback will be used to help us understand how effective the workshops were and to plan future events.



These questions are about today

What aspect/s of the day stood out and why? (please tell us one aspect that was good and one that was poor)

Good aspect:

Why?

Poor aspect:

Why?

These questions are about the two workshops overall

Thinking about your individual opinion, what one thing would you recommend to the Academy's working group about animals containing human material?

What three words would you use to describe the workshops overall?

Please tell us whether you agree with the following statements **about the workshops**:

	Strongly agree	Agree	Neither	Disagree	Strongly disagree	Don't know
The workshops were well organised	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There was enough time to fully discuss the issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Everyone had a fair chance to give their opinion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There was a good mix of people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had a say in which topics or issues we discussed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The facilitator encourages everyone to contribute	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
This was a worthwhile experience	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please tell us why you think this:

Please tell us whether you agree with the following statements **about the information**:

	Strongly agree	Agree	Neither	Disagree	Strongly disagree	Don't know
I would have liked more information in advance of the workshops	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I looked up/researched the topic between workshops	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information provided was fair and not biased	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The information provided included an appropriate mix of views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understood and could use the information provided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There was too much information provided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please tell us why you think this:

Do you agree with the following statements about the **purpose of the workshops**?

	Strongly agree	Agree	Neither	Disagree	Strongly disagree	Don't know
I understand the purpose of these workshops	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how the results of the workshops will be used	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think the Academy's working group will listen to the public's views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is important to involve the public in discussing issues about science	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please tell us why you think this:

Do you agree with the following statements about **your opinions**?

	Strongly agree	Agree	Neither	Disagree	Strongly disagree	Don't know
I learnt something I did not know before	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The workshops made no difference to my views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The workshops made me change my views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
After attending these workshops, I'm more likely to get involved in something similar again	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please tell us what, if anything, changed:

Overall, please tell us how valuable the following things were to help you understand the science being discussed and inform your opinions:

	Very valuable	Quite valuable	Not very valuable	Not at all valuable	Don't know
Presentations about the science	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Videos about the science	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Science quiz	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Homework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Handouts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Small group discussions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Input from experts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Discussions with friends and family away from the workshops	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Presenting your ideas back to the group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please tell us:)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please tell us why you think this:

What else, if anything, did you get out of being involved?

What do you think should have been done differently? How would you change it?

A few questions about you:

These questions are only used to monitor the response rate to our questionnaire.

- Are you... Male Female
- Your age: 18-24 25 - 34 35-44
 45-54 55-64 Over 65
- Your ethnic group: Asian or Asian British
 White British Black or Black British
 White other Mixed/dual/multi heritage
 Chinese Other

- Do you consider yourself to be Disabled?
 Yes No

And finally...

As part of our independent evaluation, we might like to contact you later to see what you thought about the workshops, the results and the issues raised. This would involve either an interview over the telephone or completing a questionnaire electronically or on paper.

Would you be willing to be contacted again?

Yes I'd be happy to be contacted

If so, please leave your name

And your email/phone number

No thank you

Please note that your contact details will only be used for the purposes of this evaluation. The evaluation is independent from the workshop organisers and the Academy of Medical Sciences which is why we ask for your contact details separately.

THANK YOU. Your feedback is really valuable to help us understand and improve these types of workshops 😊



Laura Grant Associates is an independent public engagement consultancy that specialises in research and evaluation.



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The Sciencewise Expert Resource Centre (ERC) is the UK's national centre for public dialogue in policy- making involving science and technology issues and is funded by the Department for Business, Innovation and Skills. See www.sciencewise-erc.org.uk

The '*Exploring the boundaries*' dialogue was commissioned by the Academy of Medical Sciences with support from the Sciencewise-ERC, and delivered by a consortium led by Ipsos MORI. It was independently evaluated by Laura Grant Associates. This report presents the findings of the dialogue evaluation, and does not represent the views of the Academy of Medical Sciences.

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