Exploring the Boundaries

Report on a public dialogue into Animals Containing Human Material

September 2010

EXPLORING THE BOUNDARIES

public dialogue on animals containing human material

Ipsos MORI

Ipsos MORI

Ipsos MORI, part of the Ipsos Group, is a leading UK research company, specialising in social & political research. See www.ipsos-mori.com

The Academy of Medical Sciences

The independent Academy of Medical Sciences promotes advances in medical science and campaigns to ensure these are translated into benefits for patients. The Academy's Fellows are the United Kingdom's leading medical scientists and scholars from hospitals, academia, industry and the public service. See www.acmedsci.ac.uk

sciencewise
EXPERT RESOURCE CENTRE

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. This report has been prepared by Ipsos MORI to summarise the views of dialogue participants. The findings do not represent the views of the Academy of Medical Sciences.

Contents

Summary

Acknowledgements

This report was prepared by Sarah Castell and James Noble of Ipsos MORI.

We are also grateful to many others who have contributed to the dialogue process: Anna Pierce, Vicky Lane, Jo Ashun and Sir Robert M. Worcester (Ipsos MORI); Pippa Hyam, Helena Poldervaart, Remco Van De Stoep, Andrew Acland, Helen Fisher, James Martin-Jones, Hally Ingham (Dialogue by Design); and Alice Taylor Gee and Amy Lothian (British Science Association).

We are grateful to the members of the oversight group, working group and Office at the Academy of Medical Sciences who supported the dialogue process.

In addition, we would like to thank those stakeholders who contributed to the design of the materials and the scientists who supported the dialogue process through their knowledge and expertise.

Finally, we would like to express our gratitude to all the members of the public who took part in the dialogue and who contributed their views so enthusiastically.

Executive Summary

1. Background to study

This report sets out the findings from a public dialogue and nationally representative survey on attitudes to research involving Animals Containing Human Material (ACHM), which was conducted in May-August 2010 by a consortium led by Ipsos MORI.

The dialogue was commissioned by the Academy of Medical Sciences with support from the Sciencewise Expert Resource Centre (ERC) for public dialogue in science and innovation, funded by the Department for Business, Innovation and Skills.

The dialogue is part of the Academy's wider study on the use of Animals Containing Human Material in research, undertaken with support from the Department of Health, Medical Research Council and Wellcome Trust, to inform guidance and recommendations on future Government policy in this area.

2. Methodology

The dialogue comprised:

1. Literature review of previously existing public opinion research.
2. 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.
3. 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.
4. Follow-up in-depth interviews among 20 of the above participants.
5. Nationally representative survey of 1,046 members of the general public.

The findings in this summary come from the qualitative elements of the dialogue (2-4) unless stated. During the qualitative sessions participants were presented with examples of ACHM research and other stimulus materials which are shown in the appendices of this report.

3. Main findings

3.1) Awareness of ACHM research

At the beginning of the discussions participants had **little knowledge** of specific research involving Animals Containing Human Material. However, the majority were aware of research that they saw as similar and were therefore not greatly surprised that ACHM research is being undertaken at present.

3.2) Acceptability of ACHM research

Overall, participants in the dialogue **accepted and were supportive** of ACHM research, **in principle**.

- The majority of participants gave their support based on the assumption that the aims of this research would be to improve human health or cure human diseases. It was generally felt that where research had these aims it would be acceptable despite any concerns that they had.
- Quantitative findings from the nationally representative survey of the British population were consistent with this finding. When told that ACHM research was done to address human health problems, more respondents said that they found it acceptable than unacceptable (48% vs 31%). In contrast, where respondents were *not* told it was to study human health problems, the balance between acceptable and unacceptable was more even (40% vs 37%, which is not a statistically significant difference).

In both the qualitative and quantitative parts of the dialogue there were a minority of people who did not find ACHM research acceptable, even to address human health problems. Analysis of the quantitative data enables us to estimate that this group represent around 15% of the British population.

3.3) How participants came to conclusions – a trade off

The majority of participants decided on how acceptable they found ACHM research by trading off their view of the **purpose** of the research against concerns about the **process**.

The majority of participants were enthusiastic about medical research because of the perceived benefits to human health that it has delivered. Therefore, when the benefits of ACHM research were perceived in these terms it was regarded as a highly persuasive purpose for doing the research. This was strengthened further if the health problem being addressed was seen as serious (i.e. terminal, debilitating or intractable) and the potential benefit of the research more tangible or understood.

Traded-off against the perceived value or purpose of research were the following concerns:-

What kind of animal is created? In vitro experiments caused less concern than those on living creatures, such as transgenic or chimeric animals[1]. However participants were unconcerned about whether the experiment was done at the gene level or the cell level.

What tissue and organ types are involved? Working with external tissues, which change the appearance of the animal, was sometimes considered to be less acceptable than working with internal organs – in part because the results could be visualised.

Changing the brain of an animal was sometimes seen as outside the boundaries of acceptability – especially if the changes might alter an animal's cognition. However, participants appeared to adopt a dual conceptualisation of the brain, in which it was seen as both a purely physical organ, and also as the source of consciousness and thought. When thinking about the examples of ACHM research that were given to them, participants tended to see the brain primarily in its physiological sense and did not believe that it would alter the cognitive capacity of animal research subjects. Consequently, participants were often no more concerned about ACHM research involving the brain than they were for other internal organs.

Changes involving animal and human reproductive systems were felt to be furthest outside the boundaries of acceptability. Key concerns here included the fact that creatures produced in this way might genuinely cross the boundary between human and animal. Participants also saw both moral and practical difficulties in creating such beings.

Participants also focused on **risk**:

- Participants most often mentioned the risk of experiments which might cause cross-contamination or genetic mutations outside of the laboratory. They worried that these could threaten humans, animals, and the ecosystem as a whole.
- There were also worries that if they said they would sanction some experiments now, this would lead to more unacceptable research in future - a "slippery slope" argument.

Animal welfare was important for a large number of participants:

[1] The term **transgenic** animal refers to an animal in which there has been a deliberate modification of the genome. Foreign DNA is introduced into the animal which is transmitted through the germ line so that every cell, including germ cells, of the animal contains the same modified genetic material. A **chimera** is an animal with cells from two or more original embryos. Chimeric embryos are formed when one or more cells are injected and integrated into another animal of the same (intra-specific) or different (inter-specific) species.

- For many participants, animal suffering was weighed up against the purpose of research in exactly the same way as it would be for other examples of laboratory research involving animals (i.e. the fact that it was specifically ACHM research that was being discussed made no difference to their conclusions).
- However, on some occasions ACHM research was seen to have the potential to create new forms of animal suffering which would be seen as less acceptable. For example, if animals' limbs, or external organs, were modified to be more human, or if animals had their cognition enhanced, it was sometimes questioned whether it might suffer increased distress.
- For a minority, there were further ethical concerns around animal welfare; for example if an animal becomes human-like, at what point does it gain human rights? How should its remains be disposed of?

A further important dimension was **who benefits from the research?** In particular many participants wanted to see that the benefits would be distributed fairly and equitably. A minority of participants in one special interest group developed a critique of ACHM research in these terms, suggesting that the main beneficiaries would be 'big companies' and rich people who could afford the treatments. They doubted whether this was worth the harm to animals or associated risks.

Consistent with the above findings from the qualitative dialogue, the most important dimensions for respondents in the nationally representative survey were the clarity of the medical goal and the seriousness of the medical condition addressed, along with the welfare of the animals involved and the assurance that the research is only done in a controlled environment.

It is important to bear in mind that whilst the above discussion outlines some of the concerns or issues that participants raised, the majority of people were supportive of ACHM research that is seen to address human health problems.

3.4) Differences between groups

The two general public dialogue sessions in London and Newcastle reached broadly the same conclusions.

The specially convened 'patient group' and 'faith group' were both positive about ACHM research.

The animal welfare group were overall the most opposed to ACHM research. They had some of the same concerns as those in the general public dialogue but went further by questioning the underlying purpose or premises behind ACHM research.

Evidence from the nationally representative survey suggests that the perceived acceptability for ACHM research rises slightly with educational level and age. A higher number of women than men had concerns about animal welfare in general, which seems to translate into regarding ACHM research as less acceptable. However, at the conclusion of the qualitative dialogue process, the attitudes of men and women were similar.

3.5) Regulation of ACHM research

Participants felt inclined to trust that the regulation of research involving ACHM (in the UK) would be adequate and properly enforced. Forty-four percent of the general public in the quantitative survey also agreed that they would trust the regulation of ACHM research, compared to 29% who said they would distrust it (the remainder saying 'neither trust nor distrust' or 'don't know').

The two main factors that participants felt should be the focus for regulation were transparency and the independent supervision of research. The results of the dialogue also suggest that the public want to see regulation of ACHM that focuses on animal welfare, minimises risk and that reflects their views on the kind of animal that is created and the tissues and organ types involved (as outlined in section 3.3).

In discussing ACHM research with the public, communicators will need to be aware of how people trade off the purpose of the research with their concerns about the process. This dialogue also highlights other factors which may be important, such as how 'new' the research seems to people and whether there are apparent associations with other known examples of medical research.

4. Underlying values and knowledge

Participants' underlying values were revealed through their contributions to the discussion. These values may have influenced judgements about ACHM research.

Defining 'human': Ethically, human lives were seen as precious because they have the capacity and potential to *go beyond* other species. Therefore, there was a high level of support for research which sought to maximise human life and prevent death or suffering. Participants tended to discuss the respective natures and behaviours of humans and animals in terms of essential differences between different species rather than in biological terms, which it was felt would not be significantly altered through ACHM research.

Ethical concerns about animals appeared throughout the dialogue discussions. Participants made judgements about what might be acceptable by taking into account the type or order of animal, and the degree of suffering they might experience. Scientists causing a high degree of suffering was felt to be less acceptable than scientists killing animals. Overall, whilst it was perceived to be unpleasant to use animals in research, it was felt to be permissible and necessary to do so when there was sufficient reason.

Participants by and large did not profess an ordered world-view. A few participants were influenced by religion and strong political beliefs but the overwhelming majority of participants approached subjects from a pragmatic and secular perspective.

Participants had faith and trust in medicine in particular, because of the benefits it has been seen to deliver. However, some aspects of scientific research provoked concerns and uncertainties, such as the possible dangers of experiments going wrong and the links to profits/big business. A minority of individuals were particularly concerned about these risks and the belief that some scientists might proceed into new areas of ACHM without sanction. These participants were generally more wary about the potential of ACHM research.

There were some important issues related to ACHM research about which the majority of participants had little detailed knowledge[2]. Aside from the science behind ACHM research, these included:

- how medical research is structured and funded;
- what medical research involves on a day-to-day basis;
- how animal subjects are sourced and used;
- details about regulation such as what the rules are and how they are enforced.

The limits of participants' understanding sometimes influenced the attitudes they expressed. In particular, without knowledge of the scientific method or process it was more difficult for people to interpret the value of the research. This in-turn could affect the trade-off that is made when assessing the acceptability of ACHM research.

Learning more about issues associated with medical research was both informative and reassuring for participants, and was a positive aspect of the dialogue process for many of those who took part.

[2] It should be noted that the recruitment process excluded a small number of people who felt that they were 'very well-informed' about scientific and medical research.

5. Reflections on the dialogue process

We suggest that this dialogue process has been effective in understanding public attitudes towards ACHM research and then testing the extent of these attitudes through a nationally representative survey.

The findings from the qualitative public dialogue provide insight into the moral, ethical, practical and other issues that condition public opinions, and the underlying principles which are important to participants.

The results from the nationally representative survey provide statistically reliable evidence of views, although they reflect the views of a public who have not necessarily reflected on the issues, nor have they been exposed to the range of information and stimuli that was available to participants in the qualitative dialogue.

This report therefore provides two perspectives on public opinion, which, when taken together, can be of use to policymakers, scientific researchers and communicators.

1. Background & objectives

1. Background

1.1 Background to the Academy of Medical Sciences study on Animals Containing Human Material

The Academy of Medical Sciences' 2007 'Inter-species Embryos' report[3] examined the scientific, ethical and safety issues around research involving embryos containing both human and animal material. The report provided a key reference for debate around the Human Fertilisation and Embryology (HFE) Act (2008), which amended UK legislation to ensure that UK scientific and medical research on human and human admixed embryos continues to be conducted within a robust regulatory and ethical framework.[4]

Whilst 'Inter-species Embryos' focused on human embryos containing animal material (human admixed embryos), it also briefly addressed the creation and use of animals, and animal embryos, incorporating human material. This research may involve the:

- transfer of human cells, including adult or embryonic stem cells, into animals or animal embryos (to create chimeric constructs);or the
- transfer of human genetic material into animals, or animal embryos (to create transgenic constructs).

These techniques are already in widespread use in UK and international laboratories. However, as the Academy's report noted, the increasing sophistication of these research techniques is likely to present future significant regulatory and ethical challenges. Meanwhile, the strength of public opinion around the creation of mixed human/animal entities was evident throughout parliamentary debates on the HFE Bill, and in associated media coverage. Together with other studies[5], the Academy's report recognised the importance of public values and judgments in informing the development of law and policy around the use of non-human embryos and Animals Containing Human Material, but warned of an "apparent gulf between current and future scientific practices, and public awareness". The Academy report recommended that future policy work should include a programme of public engagement to describe and explore this gap.

The Academy study examining the use of Animals Containing Human Material (ACHM) in scientific research was launched in November 2009, and is supported by the Department of Health, Medical Research Council, Wellcome Trust and Sciencewise-ERC.[6]

[3] Academy of Medical Sciences (2007). Inter-species embryos. http://www.acmedsci.ac.uk/download.php?file=/images/pressRelease/interspe.pdf

[4] Human Fertilisation and Embryology Act (2008) http://www.opsi.gov.uk/acts/acts2008/ukpga_20080022_en_1

[5] http://www.hfea.gov.uk/docs/Hybrids_Chimera_review.pdf : a public dialogue on hybrids and chimeras which assisted the decision-making process and provided evidence for the HFE Bill

[6] 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 scope of the study is to examine the scientific, social, ethical, safety and regulatory aspects of research involving non-human embryos and Animals Containing Human Material. The study is intended to inform policy on the part of Government, professional and regulatory bodies, research funders and the wider scientific research community. The study has two elements:

i. an expert working group review (including a stakeholder consultation) – see below;
ii. a commissioned programme of public dialogue – see next section.

The aim of the expert working group is to conduct a robust, independent review of the issues. Specifically to:

- agree definitions for animals, and animal embryos, containing human genetic or cellular material;
- describe the current use of Animals Containing Human Material in medical research, and to anticipate future research directions and challenges for this work;
- assess future applications of research involving Animals Containing Human Material – including potential requirements for preclinical (animal) studies of candidate human stem cell therapies;
- address safety concerns surrounding the generation and use of Animals Containing Human Material in research, and to consider welfare issues which apply specifically to Animals Containing Human Material;
- explore societal and ethical aspects of medical research involving the creation of animals that include significant amounts of human material, and to develop a constructive public dialogue in this area;
- explore the current and future regulation of the use of animals and embryos containing human material for research purposes, including primary legislation, regulations and guidelines;
- draw conclusions and make recommendations for action.

To focus the study, and to avoid replication of previous work and debates, the following areas are not considered in depth:

- scientific or ethical issues relating to the general use of animals in research;
- the use of human admixed embryos in research (and other issues addressed in the debates of the Human Fertilisation and Embryology Act (2008));
- broader issues relating to the genetic modification of animals or plants (e.g. the genetic modification of plants or animals for agricultural purposes).

The study will report in early 2011 and its conclusions will be designed to inform Government policy, professional and regulatory bodies, research funders and the wider scientific community.

1.2 Background to the dialogue on Animals Containing Human Material

This report describes the findings from the dialogue element of the study - which was commissioned to a consortium led by Ipsos MORI, including Dialogue by Design and the British Science Association, with support from the Sciencewise-ERC for public dialogue in science and innovation, funded by the Department for Business, Innovation and Skills. The findings from this dialogue will be integrated into the Academy study.

The **overall aims** of the dialogue have been to engage members of the public on the issues raised by the current and future use of Animals Containing Human Material (ACHM).

Specific objectives were:

- to provide opportunities for members of the public to discuss and explore their aspirations and concerns relating to the scientific, social, ethical, safety or regulatory aspects of research involving ACHM;
    - giving participants the accessible information they need to take an informed view;
    - facilitating open discussions where everyone is able and asked to contribute;
    - enabling representation from a wide diversity of population groups;
    - engaging with a range of different stakeholders to ensure that the content and focus of public discussion reflected the breadth of scientific and other opinion;
    - ensuring that stakeholders input into the design and process of the dialogue, including working group members, researchers, scientists, policymakers, faith groups and NGOs;

- to identify areas of consensus, disagreement or uncertainty on a broad range of issues raised by current and possible future scientific developments, and explore both initial views and changes in opinion;

- to inform the final recommendations made by the Academy for public policy and research needs.

A secondary objective has been to:

- enable the Academy and the wider science community to build on previous experience in public dialogue, to pioneer innovative approaches in public engagement where appropriate, and to develop knowledge and understanding of public dialogue and its potential for future applications.

A further objective was then to quantify findings in a nationally representative survey.

As with the scope of the working group (described in section 1.1) the dialogue focused specifically on ACHM research and sought to distinguish ACHM research from wider related issues, such as the general use of animals in research. With this aim in mind the key questions investigated by the dialogue were:

- What is the general level of awareness of ACHM research?
- What are the public aspirations?
- What are the public concerns?
- What is the level of approval?
- Where might members of the public set the boundaries of acceptability for such research?
- Where are particular sensitivities (e.g. around particular tissues - reproductive, or neural tissue; or species e.g. primates, domestic animals)?
- What are the specific concerns of different subgroups e.g. patients, religious representatives?
- What would the public need to know to reach a decision on whether ACHM research should be permitted?
- What language can be used to describe Animals Containing Human Material to help the general public understand the research?

The process of engaging the public on these issues entailed providing participants with appropriate background information. This included:

- what Animals Containing Human Material are and what they are not;
- how Animals Containing Human Material are currently used in research;
- what scientific knowledge and medical benefits have resulted from such research;
- how Animals Containing Human Material might be used in future research, and what knowledge or medical benefits are anticipated;
- what the possible risks from such research might be;
- how research involving Animals Containing Human Material is regulated, both in the UK and internationally.

The methodology used for developing and sharing this information and addressing the key research questions is outlined more fully in chapter 2.

An oversight group was formed to inform the work of the consortium. This group consisted of members from the working Group, the Department of Health, Sciencewise-ERC and the Academy Office. In addition, the dialogue has been independently evaluated by Laura Grant Associates. Overall, the dialogue adhered to the Sciencewise-ERC guidelines on effective public dialogue[7].

[7] The Government's Approach to Public Dialogue on Science and Technology available at: http://www.sciencewise-erc.org.uk/cms/assets/Uploads/Project-files/Sciencewise-ERC-Guiding-Principles.pdf

2. Methodology

The focus of this chapter is to provide a clear **description of the methodologies used**, whilst reflections on the **effectiveness of the process** are the focus of chapter 5.

2.1 Literature review

The dialogue process began with a review of previous opinion research on issues relevant to public views on ACHM research. It was structured across a number of themes which were developed in conjunction with the oversight group and wider stakeholders[8].

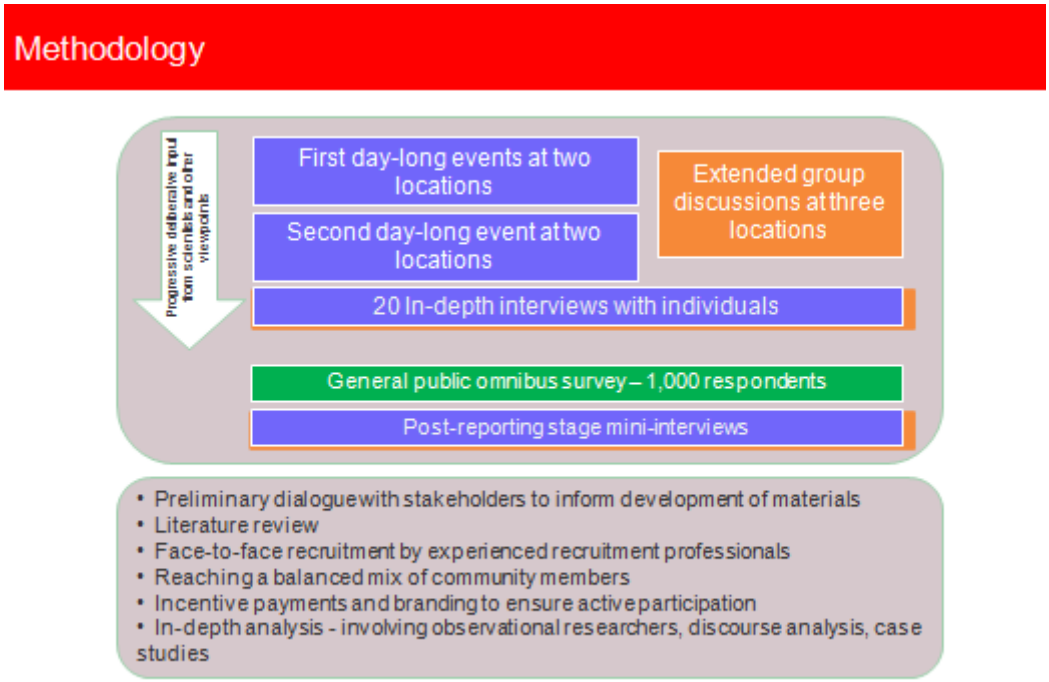
2.2 Stakeholder engagement & materials development

A process of stakeholder engagement was undertaken to agree the detailed aims of the dialogue and to help develop materials. This began with a meeting held with a group of stakeholders on 22 April 2010[9], with subsequent engagement taking place remotely. This process included members of the dialogue oversight group as well as representatives from NGOs, industry, religious organisations and animal welfare organisations. Additional stakeholders who could not attend the face-to-face meeting were interviewed by phone.

This process was instrumental in helping to develop the stimulus materials for the dialogue and which themes and questions to cover with participants.

2.3 Qualitative elements of the dialogue

The primary elements of the research methodology are summarised in the chart below and this section below this describes how each of these qualitative elements were undertaken.



2.3.1 General public dialogue

[8] See associated literature review document
[9] See appendix A3.1

The most substantial element of the qualitative dialogue is referred to throughout the report as the 'general public dialogue'. This consisted of two meetings held in Newcastle and London in May and June 2010, each of which was split over two whole days. A total of 43 members of the public attended the meetings (21 in Newcastle and 22 in London), along with two scientists at each to provide professional expertise. Representatives from the Academy, facilitators and note-takers from the Ipsos MORI/Dialogue by Design were also present.

2.3.2 'Special Interest' groups

Targeted discussion groups were also held with specific interest groups whose views might be distinct from those of the wider public. These groups were also conducted in Newcastle and London and were about two hours in length (considerably shorter than the general public dialogue).

- The first group, in Newcastle, was a group of patients, plus those who were caring for people with serious illnesses. The aim was to talk with people who might be beneficiaries of medical advances, a fact which might affect their views.
- The second group, in London, included people with religious faith and who stated that their religious beliefs were directly and practically important to them every day.
- The third group, in London, were recruited because they attached importance to animal welfare issues or had participated in animal welfare activities in the past year.

There were several reasons for convening the special interest groups. The first was to speak to those whose opinions or life experiences might mean that they felt differently about ACHM. Having these opinions represented in distinct groups enabled us to explore these views more thoroughly.

Separating out special interest groups was also a good way to ensure that people with powerful, emotive or special experiences to recount did not exert too much influence over the general public dialogue. For example, a member of the public who felt that medical research was not beneficial may not have wanted to express those views when talking with someone who has personal experience of a particular disease.

This approach also meant that those with particular religious or animal welfare views (who might be in a minority in the dialogue as in the general public overall), would not be cast in the role of "witnesses" to their experiences or have to act as "apologists" for their views rather than reflecting upon or discussing them (which would also raise some ethical concerns).

2.3.3 Follow-up interviews

A sub-sample of twenty participants in both the general public dialogue and special interest groups were interviewed individually over the phone during July and August 2010. Interviewees for this stage were selected in part because the views they expressed during the day were distinct (for example we were seeking to follow up people with more oppositional views). This enabled issues raised by preliminary analysis of the qualitative data to be more thoroughly investigated.

2.3.4 Recruitment approach

All participants for the qualitative elements of the dialogue were recruited face-to-face by experienced recruitment professionals who approached people initially in their homes to establish their willingness and appropriateness to take part. Critically, there was **no opportunity for particularly interested or engaged members of the public to volunteer to be part of the dialogue**. In line with standard practice for recruiting qualitative research, participants were each paid a cash incentive £40 to £145, depending upon the amount of time that they gave up. The strong argument for paying incentives (aside from it being a courtesy for people's time), is that it encourages many different people to attend rather than just those who are interested in the subject matter.

Some screening of participants did take place at the recruitment stage in order to place those with absolute views on ACHM research or animal welfare into the special interest groups (see above) and to eliminate those who reported that they were a) 'not at all interested' in "issues to do with science and medical research"; or b) already 'very well informed' about *issues to do with scientific and medical research*. Limited quotas were also set by age, gender, parenthood and work-status to ensure that a mixed and broadly representative group of people attended each discussion[10]. The table below features a breakdown of these participants by gender, age, social class and ethnicity across both the general public dialogue and special interest groups.

		London	Newcastle[11]	Total
Sex	Male	16	10	26
	Female	23	21	44
Age	18-34	10	6	16
	35-54	18	15	23
	55+	13	10	23
Social class	AB	12	4	16
	C1	10	9	19
	C2	5	5	10
	DE	12	13	25
Ethnicity	White British	15	28	43
	White other	2		3
	African	5		5
	Caribbean	5		5
	Indian	5		5
	Bangladeshi	2	3	5
	Chinese	1		1
	Mixed	3		3
	Other	1		1
Total		**39**	**31**	**70**

[10] A copy of the recruitment questionnaire used is shown in Appendix A5.

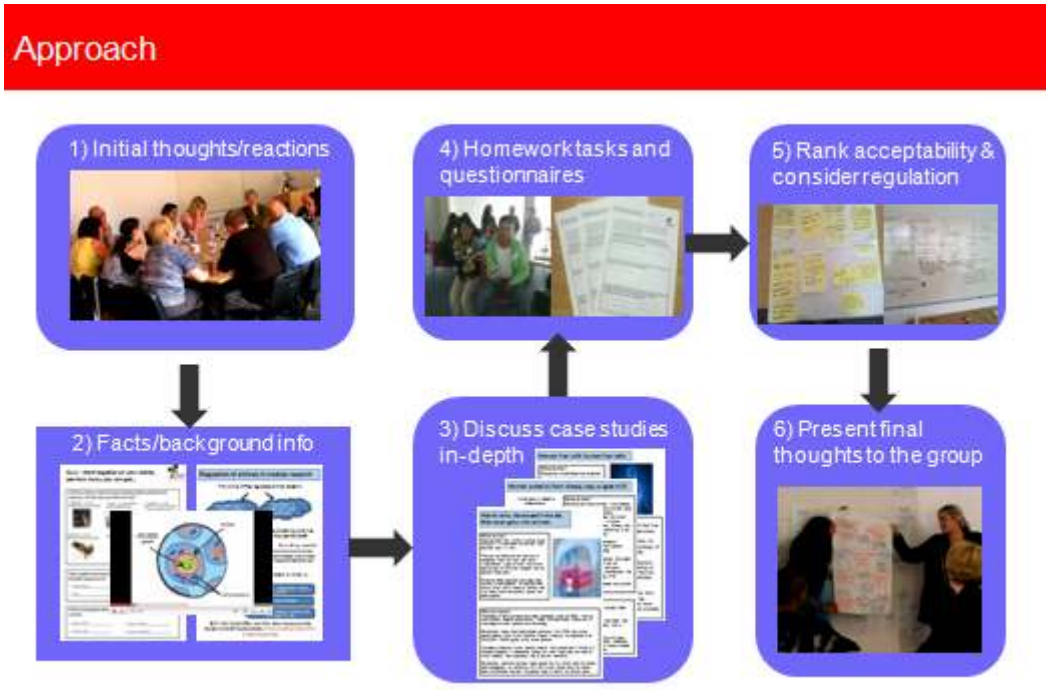
[11] The patient group - which was recruited in Newcastle – was predominantly older and female, which has skewed this profile on those directions.

2.4 The dialogue process

The dialogue process that participants experienced drew upon some of the traditions of research, in that it was designed to identify how participants would respond to information about ACHM research. 'Focus group'-style sessions were therefore used, in which participants could share their views, first spontaneously, and then at other times after reflection. Group members were asked not to talk over each other and, while the facilitator drew everyone into the discussion, it was accepted that some would talk more than others.

However, the dialogue was not simply a longer set of research focus groups, but also included periods of dialogue between the participants and the scientists and facilitators present. When the aim is for citizens to influence the agenda, there is a greater to create space and time to think about what they would recommend. The emphasis is on analysing what they eventually conclude, rather than on capturing every phrase as they say it for later analysis. So, exercises where participants worked in smaller groups and wrote their own feedback were also included. This also helped ensure that quieter participants could talk to one another or ask the science experts specific questions, and then feed back as a group.

The actual process that participants experienced during the general public dialogue is summarised in the chart below. It should be noted that the process for the special interest groups was similar in terms of content, but truncated because of the shorter amount of time available (these groups only experienced stages 1, 3 and 5).



At the outset (**stage 1**), discussions focussed on underlying attitudes/values towards human and animal life and gauged preliminary awareness and reactions to ACHM research.

Stage 2 provided participants with background information, including definitions of genes, cells and chromosomes. This was done through fact sheets and a quiz[12], as well as showing a short video[13].

[12] See Appendix A1
[13] http://www.youtube.com/watch?v=eOvMNOMRRm8

Stage 3 was a critical part of the process. Participants were given examples of a variety of current and potential uses of ACHM research, each of which explained the process and the reasons why it might be carried out. The core set of examples were:

- hybrid cells made by fusing animal and human cells together in a lab;
- transgenic sheep producing a human protein in their milk;
- mouse liver with human liver cells;
- the human Huntington's disease gene in monkeys;
- Down's Syndrome in mice carrying human chromosome ;
- Human stem cells in rats and monkeys[14].

These examples were used as the foundation for discussions which covered the acceptability of various forms of ACHM research, and then went into some detail on the principles underlying responses and the importance of different factors. Facilitators and expert participants took care to stress that the examples used were general cases rather than specific.

Homework tasks at **stage 4** included speaking with friends and family, answering a series of questions[15] and making models of 'origami DNA'[16].

Stage 5 (morning of day 2) began by discussing the homework task and recollections from the week before. Participants were then asked to focus on the boundaries for ACHM research and what was acceptable or unacceptable? A technique used for exploring this was a 'card sort' exercise in which various types of ACHM research were presented (some real, some hypothetical) and participants were asked to say what they liked/disliked about them, and to rank them in terms of acceptability. These discussions also covered the various conditions that might be applied to ACHM research and how it should be regulated.

At **stage 6** (at the end of day 2), participants worked in smaller groups to discuss their overall impression of the two days and present their final thoughts to the wider group.

Each of the sessions in the general public dialogue included a mix of plenary and smaller moderated groups of about 8-10. Particular exercises were done in still smaller groups (or even individually), while presentations were generally delivered to the whole group. Scientists were available to provide expert knowledge and engage with participants throughout the general public dialogue but not the special interest groups, as time was not available in these sessions for this level of engagement.

2.5 Quantitative Methodology

The **quantitative findings** in the report provide an indication of the **views of the public overall**. The survey worked followed the dialogue process and the questions developed were informed by analysis of the dialogue findings. However the results only indicate what the general public, who have not been through the dialogue process, might think about the issues.

The survey findings were collected through the Ipsos MORI "Capibus"[17], which is a weekly survey of approximately 1,000 individuals aged 15+ in Great Britain. The sample is cross-sectional, so different individuals are interviewed each week, which avoids conditioning effects. It is based on a random location sampling design across 177 different sampling points each week. This ensures that interviewing is spread over a large geographical area, rather than clustered around just a few centres. Specific quota controls are set for each interviewer location, ensuring a representative sample at both local and national levels.

[14] All of which can be found in Appendix A1
[15] See Appendix A1
[16] http://www.yourgenome.org/downloads/activities.shtml
[17] http://www.ipsos-mori.com/omnibusservices/capibus.aspx

All interviewing for Capibus is carried out in-home by Ipsos interviewers using CAPI (Computer Assisted Personal Interviewing). Strict quality control procedures are applied; all interviewers are trained to a recognised standard and one in ten interviews are back-checked by telephone. Furthermore, CAPI software is used to monitor both the overall length of each interview (the average interview length does not exceed 26 minutes) and the time taken over individual questions in the questionnaire[18].

When interpreting the nationally representative survey data, it is important to be aware of the levels of statistical confidence that are relevant. For example, for findings based on the whole sample of 1,046, confidence intervals of ± 3 percentage points are applicable. In other words, for a finding of 50%, we can be 95% certain that the true figure for the British population would be between 47% and 53%. For comparisons of sub-groups, larger confidence intervals should be applied[19]. In this report, sub-group differences are not discussed unless they are significant.

2.6 Analysis of data

Detailed notes were taken throughout each dialogue session, and these stated whether the information came directly from participants (e.g. homework tasks, posters) or from transcribed notes (near-verbatim comments) or from facilitators' notes or flip charts. The insights that each facilitator gained were then shared during analysis meetings at the end of each day and at the end of the dialogue process as a whole.. The different types of event in the process were also accorded different status in the analysis. Facilitators were aware that the special interest groups had had less time for reflection so this was balanced against the more considered views of participants in the main dialogue.

For the general public dialogue, an **observational researcher** also made notes without taking part in the facilitation. These researchers moved between groups looking at body language, facial expressions, and evidence of behaviours. The researchers also carried-out ad hoc interviews with individuals, to check on their thoughts and feelings. The purpose of this was to understand more subtle and unspoken reactions alongside the main discussions, and to help build hypotheses as to participants' thoughts and feelings throughout the process as their views developed.

This report presents the synthesis of all these data sources and the nationally representative quantitative survey.

[18] A copy of the questionnaire is shown in appendix A2.1
[19] Appendix A2.2 provides an indicator to different degrees of confidence

3. Main findings

3. Main findings

3.1 Current awareness of ACHM research

The majority of participants at the start of the dialogue generally knew little about current ACHM research or what might be possible in the future. This included knowledge of what was involved, what it was for, or who was doing it.

However, when participants heard about examples of ACHM research, they could relate it to other research which they had already heard about. For example, participants mentioned:

- use of pigs - insulin and valves transplanted into human hearts;
- cloning (most frequently 'Dolly the sheep' but also other examples), which was felt to be vaguely related, even though participants could not say exactly how;
- the mouse with the human ear shape on its back (this had a resonance because of its visual impact) - few people seemed to be aware of how or why it was produced;
- work with chimpanzees and dolphins to investigate communication and intelligence.

All participants had at least some knowledge of these examples, and it meant that when the details of ACHM research were introduced few seemed particularly surprised by them. Indeed, participants sometimes seemed more surprised by the suggestion that they might find the research controversial (particularly case study 1). The majority saw this as a continuation of the kind of research that they had already heard of. This can be seen as consistent with the earlier HFEA consultation which found that the majority of people had at least heard of related issues, such as stem cell research and the possibility of creating embryos that contain some human and some animal material for research[20].

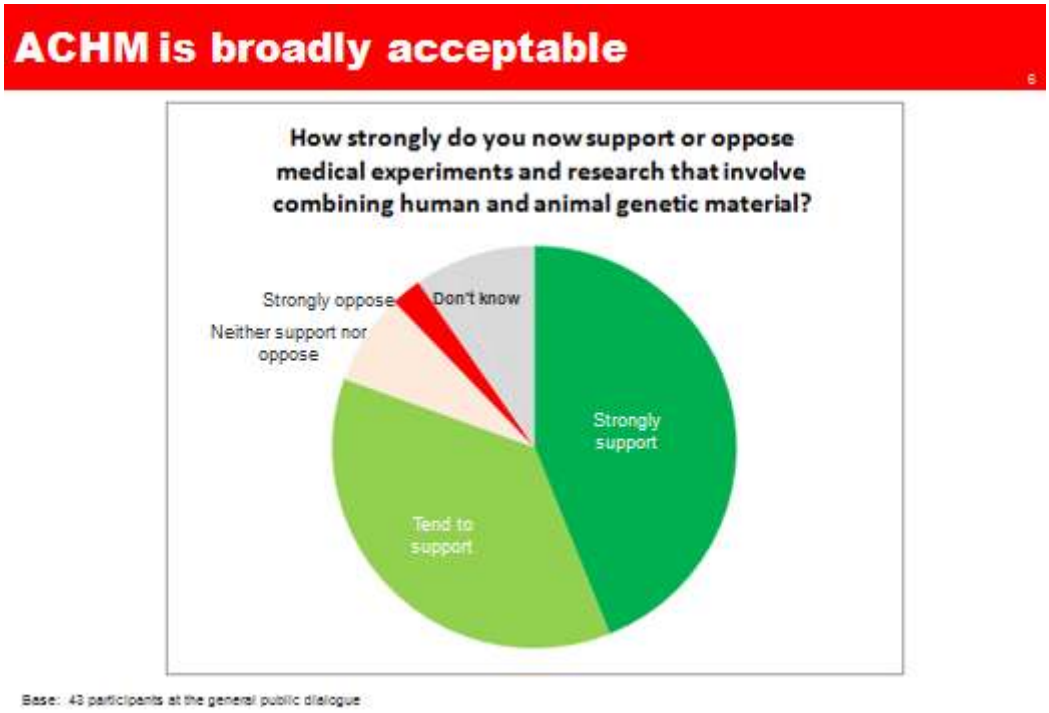
3.2 Acceptability

3.2.1 Overview: ACHM research largely acceptable in principle

On hearing about the ideas behind ACHM research and discussing the issues in more detail, participants in the public dialogue were mostly **accepting or supportive** of it. This majority of this support was for ACHM research in **principle**.

This was the case both at the beginning of the sessions, and throughout the first day. Participants at the end of the first session remained supportive (the chart below shows responses to a questionnaire administered at this stage).

[20] See http://www.hfea.gov.uk/docs/Hybrids_Report.pdf page 77



During the second day, the implications of ACHM research were explored in detail and more concerns tended to be raised. However, while different views were expressed and alternative trade-offs made, the **overall view remained the same** – that in principle, participants were accepting and supportive of ACHM.

Across all the 70 people consulted during the qualitative dialogue, only a very small minority objected to the most 'basic' mixing of human and animal material (these were objections on animal welfare and religious grounds). Moreover, there were very few obvious or immediate boundaries or limits on research set by participants *spontaneously*. Only after further probing did issues and concerns emerge, and these are discussed below in section 3.3.

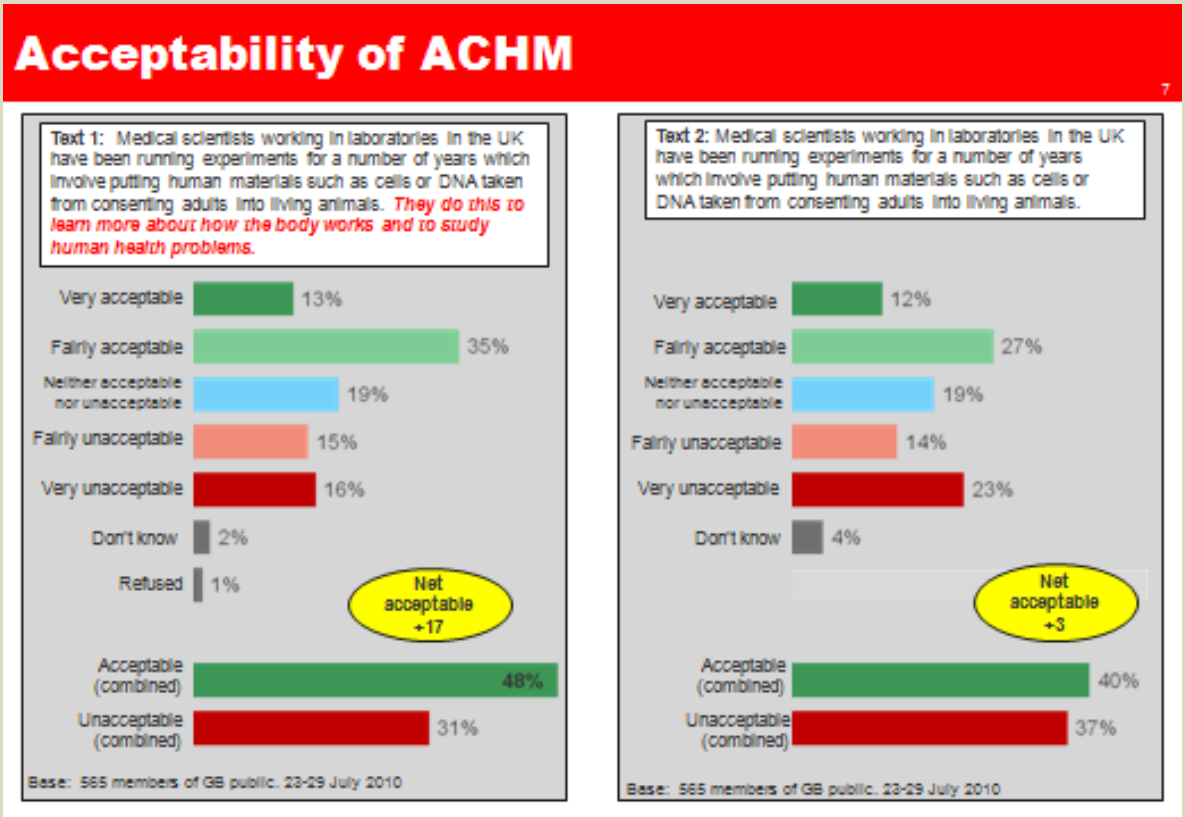
A notable feature of the generally positive response was the fact that the majority of participants appeared to **trade off the purpose of the research against concerns about the process**, and usually concluded by **supporting ACHM research *when they believed it would benefit human health*.** We discuss this further in 3.2.2 below.

Many participants took a long time to think through the implications, some until well into the second day. There were a minority, even by the end of the sessions, who did not appear to have engaged fully with the potential implications of different types of ACHM research. For example, towards the end of the second day, one participant in London brought up the idea of a 'slippery slope' of acceptability – ie. if one research project is accepted, it could be then used to justify more unacceptable activities. Many others in this group seemed uninterested in this, apparently either rejecting the notion that this was a serious risk or in some cases appearing not to follow the argument.

There was also very little immediate 'emotional recoil' or 'yuk factor' relating to the *principles* of ACHM research. Rather, participants were quite matter-of-fact and pragmatic about it as they learned more about it. Some were even enthusiastic about what they saw as the capabilities of science. However, it should be noted that ideas were introduced very slowly and more provocative ideas were not discussed until later in the sessions. Further discussion of the significance of this can be found in chapter 5.

Quantitative Findings

Findings from the nationally representative survey provide further evidence that the balance of opinion is accepting of ACHM research. The chart below shows that more respondents said they found the experiments acceptable than unacceptable. Moreover, by using a split sample in which half the respondents received a lengthier introduction (text 1) it is possible to measure the difference made by being told that ACHM research is "done to learn more about how the body works and to study human health problems". Where this explanation is given, 44% were accepting and 29% not accepting, whilst without the additional sentence a much more closely balanced result is found (40% acceptable vs 37% unacceptable, which is not a statistically significant difference). The conclusion here is that more people feel ACHM research is acceptable than unacceptable, especially if a reason is provided[21], but that also a large minority also find ACHM research unacceptable (this group are discussed in more detail in section 3.4.3). The other notable point about these findings is the high proportion (22-24%) who did not state an opinion either way. Elsewhere in this report (see section 3.5.2) we suggest that knowledge about ACHM research is limited and there is not yet a developed public discourse about the subject. These figures would appear to support this hypothesis.



3.2.2 How people decide: trading off benefits to human health against concerns about the research process

Before looking at the content of the discussions and the issues that participants found important, it is first necessary to outline the logic that participants deployed to decide upon the acceptability of ACHM research. Almost no participants applied absolute ethical positions to the questions posed, so there was very little that was described as being in-

[21] Similar findings were recorded in the earlier HFEA study into inter species embryos. See http://www.hfea.gov.uk/docs/Hybrids_Report.pdf Appendix F, figure 4

principle ‘right’ or ‘wrong’. Rather a very pragmatic equation was applied, which was to weigh up two opposing considerations.

a) The first consideration was the **perceived value** of the research’s objective or outcome – ideally a tangible benefit to human health (discussed in detail below in 3.3.2),

which was set against;

b) **Concerns about what the research process involves** (discussed in 3.3.3 onwards).

Participants engaged in this trade-off every time they made a judgement about the acceptability of research. Where the purpose of the research was seen and believed to be persuasive, it would nearly always override concerns about the process, such that the boundaries for the research might be extended considerably. Indeed, participants’ aspirations for the future of ACHM research were generally that it should continue, and that it should aim to make discoveries which can cure serious human illnesses.

Of course, these judgements had an inherently ethical dimension to them, but the ethics used were particular to individuals, tacit and applied flexibly (even in some cases inconsistently). For example, some of the more accepting participants felt that a legitimate purpose for ACHM research might include helping ameliorate skin conditions or migraines, whilst for others the only justification for the research was that it helped cure life-threatening, severely debilitating or intractable diseases. Similarly, some participants felt very disturbed about where scientists might take this, whilst others seemed wholly unconcerned. The important feature was that whatever the weight placed on different concerns or objectives, this trade-off was made.

Why was this ‘benefit to human health’ argument so strong?
Whilst the most notable feature of the discussions was **pragmatism**, the underlying ethical approach was that of valuing human life and one’s own health above other considerations.

> *“As an individual you would only want to know, does it work, would it make me feel better?”*
> Newcastle, day 1

Participants in the general public dialogue found it easy to express a simple and persuasive argument that it is important to solve human health problems. They drew on well known ideas that others were familiar with and found hard to dispute. This may reflect the fact that there is a strong pre-existing cultural discourse around the value of human life and health; perhaps participants found it easy to tap into and use this discourse.

In contrast, discourses around the disadvantages of ACHM research did not seem to be particularly developed. It was observed that in the sessions, those who seemed to want to oppose ACHM research had fewer really persuasive arguments. Rather, objections to ACHM research were voiced hesitantly and presented as ‘personal’, or even idiosyncratic. Often, individuals with concerns would conclude by agreeing with the rest of the group.

It seems plausible that in the future, more extensive media coverage or relevant news stories might change this dynamic, by giving people more time to consider their views or feelings, or for people to hear stronger arguments either for or against ACHM research.

3.2.3 Other conditions that are applied before the trade-off can happen

The trade-off between process and outcomes was central, but there were also some prior questions or conditions posed for this trade-off to be legitimate. These questions/conditions were around the context of the research and included:

- Has everything else has been tried? Is it essential to do the experiment this way?
- Can we be assured that the approach outlined is not just the cheapest way to do things, the most interesting way to do things or an attempt to save time/money?
- Is the motive behind the experiment genuine? Or are profits and big business involved?
- Who will be the beneficiaries? Will it be everyone or will there be restrictions?
- How will the research be restricted, controlled or supervised?
- Will it really deliver the benefits you think it will?

3.3 Setting the boundaries – the critical dimensions of acceptability

3.3.1 Overview

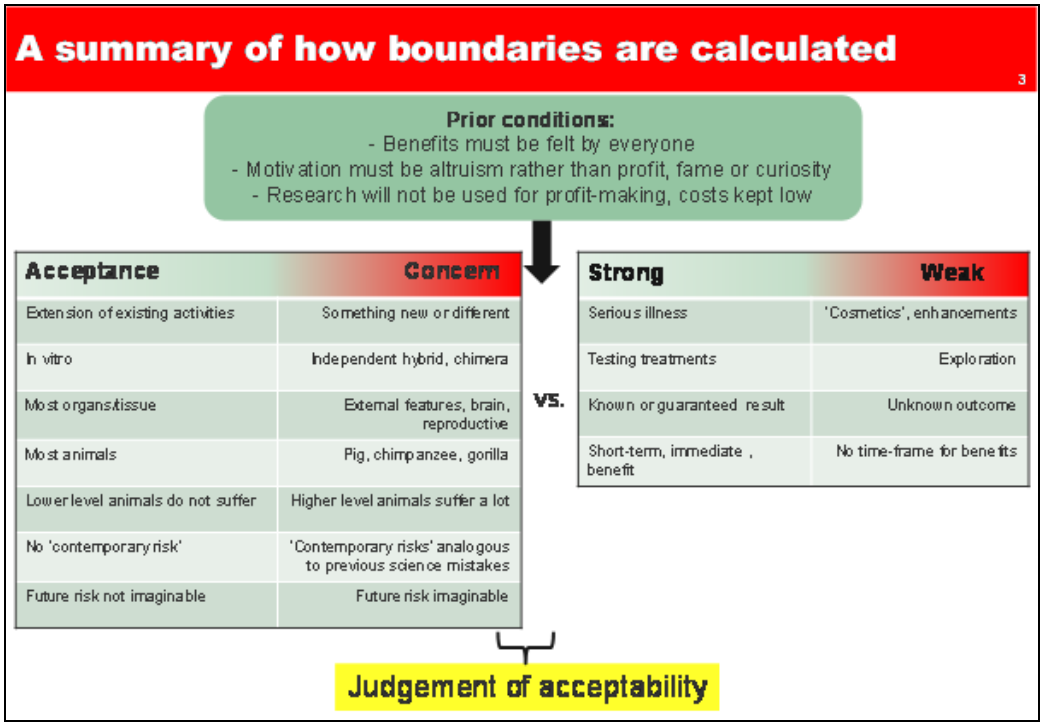
While overall ACHM research was seen as acceptable in principle, some things were seen to be towards or beyond the boundaries of acceptability. As described in the previous section, participants traded off the following dimension:

- What is the purpose or outcome of the research - how intelligible and likely is the benefit, and how much does it help human health?

against other concerns about the research:

- The perceived 'newness' or novelty of the research;
- What kind of animal is created? (test tube cells or living creature, transgenic vs chimeric?) Crucially, what does the animal look like and what capacities does it have?
- What tissue and organ types are involved?
- What species of animals are involved?
- What is the risk of cross-contamination into other species? How far can the created animal exist outside the laboratory?
- Animal welfare - how much does the animal suffer and what kind of suffering is it?
- Who benefits - how fairly and equitably are benefits distributed?

The chart below summarises this process and the following section then looks at each dimension in turn:



3.3.2 Purpose or outcome of the research

What makes the outcome so important?

The perceived purpose of the research is absolutely critical in determining whether or not research involving ACHM is viewed as acceptable[22]. Indeed, without information about the purpose of the research, participants would often refuse to be drawn on its acceptability.

Participants judged the purpose or outcome of the research in two ways – tangibility of findings, and the seriousness of the health problem being addressed.

i) Tangibility

Participants supported ACHM research where the purpose was perceived as more tangible and immediate, or if it is known in advance (e.g. a new drug, harvesting a protein, researching a specific process). Participants became less confident if they felt that the purpose of the research was:

- more unknown (i.e. exploratory);
- further away (in time);
- less certain (some went as far as to say that the research should be guaranteed to deliver a cure);
- potentially unsuccessful.

By way of illustration, this issue emerged around the case study concerning producing monkeys with Huntington's disease[23]. In this case study the following text was used:

*"These monkeys will be used to investigate how Huntington's disease develops and progresses, and **may in the long-term** help to support the development of new treatments".*

The purpose of the research was considerably weakened by the phrase 'may in the long term help'. This led to some people deciding that the research should not be permitted, as the lack of certainty, and the length of time, affected the trade-off they were making[24].

---

[22] This echoes the earlier study conducted by the HFEA on animal and human hybrid embryos. The findings from this work suggested that it was the potential benefits of the research that had a significant impact on opinion, the key issue being whether there is a clear rationale for the research. See, for example, http://www.hfea.gov.uk/docs/Hybrids_Report.pdf Appendix F, point 10.

[23] See Appendix A1

One might interpret this as a lack of understanding about the way science progresses through exploration. There was certainly an element of this, for example, people would often change their views after hearing the scientists discuss the value of exploratory research. However, some were suspicious that scientists might simply opt for radical experiments, not because they are the only way to study these problems or even the most effective way, but because they are the most interesting way.

When the objective was seen as less clear, acceptance of research tended to be more tentative and conditional and participants tended to want to discuss the limits and controls that ought to be imposed. These limits could sometimes be quite quantitative, for example suggesting that you could only try the experiment a fixed number of times before it had to be stopped, or to say that it must be explicitly incremental or modest in what it hoped to do.

> *"By putting stem cells into the brain you can regenerate it and make the brain go back to normal, it's a good thing. You can lose a whole person through a stroke. Therefore, this one [stroke case study] has more of the end result. The other two [case studies] look more towards research. I'm therefore more comfortable with the stroke one."*
> London, Day 1

ii) Severity of health issue

The other dynamic that influenced how people felt about the purpose of the research was the type of health benefit that it was aimed at addressing. Unsurprisingly, the most resonant health issues are the common terminal or debilitating illnesses that can affect people throughout the course of their lives (for example, cancer, Parkinson's disease, strokes). The particularly significant aspects of these diseases were:

- death, particularly early death;
- pain and suffering;
- loss of faculties, which could be seen as degradation of those factors which make us human (as discussed in the section on values);
- and, for a minority, disfigurement.

Research that could cite a benefit in terms of these conditions would most often find acceptance, regardless of any process concerns people had. However, a number of other health conditions might be investigated by research involving ACHM and these are discussed progressively in this section.

One level down in terms of persuasiveness were those illnesses or conditions that did not lead to death or pain. The most frequently discussed example was Downs Syndrome because it was the subject of one of the case studies. Participants found this research purpose somewhat less compelling because people with Downs Syndrome were generally believed to live fairly happy lives (although the case study described treatments for the consequences of the condition rather than the condition itself such as early onset Alzheimer's). Similar views were expressed around other conditions such as autism or physical disabilities. It is not that participants did not wish to see these conditions addressed or improved, just that in terms of the persuasiveness of the research objectives these are slightly less resonant.

To explore this idea further a range of alternative research purposes were explored during the follow-up one-to-one interviews, such as treatments for illnesses that affect peoples'

---

[24] This finding has been noted in an earlier IPSOS MORI study on animal experimentation (see http://www.sciencewise-erc.org.uk/cms/assets/Uploads/TrackedDocuments/Health--Wellbeing/Animals-in-Med-and-Science-1999.pdf page 13). In this quantitative study, high proportions reported that animal experimentation is always or sometimes justified for research into life threatening diseases such as cancer (42% always justified, 35% sometimes); and AIDS (33% always, 38% sometimes). However, this fell off considerably for 'learning how cells work' (13% always, 43% sometimes).

quality of life (colour blindness, migraines and burns). For many respondents these conditions were also regarded as an acceptable basis for research, if only a slightly lower priority. However, a minority of participants were prepared to set a boundary at this point; research could only be done to treat the most serious conditions.

The development of enhancements was also discussed, for example improving physical performance, stamina or memory. Participants found it much harder to decide on research aimed at these purposes; some could see advantages whilst others tended towards the view that it was unnatural or unwanted. For example, the more hesitant participants argued that it is normal to lose memory as we age and therefore wrong or unnecessary to try to alter that. These types of research also tended to create discussion about how fairly the outputs could be used across society. It is reasonable to conclude that participants were ambiguous about these types of purposes, with many deciding that they did not constitute a good reason for doing ACHM research, or believing that the priority must always be research that helps an ill person become well (relative to their stage of life) rather than that which helps a well person perform more highly.

Finally, this research indicated that people do not support ACHM research (or indeed animal research in general) for what is described as 'cosmetics research purposes'. This is not at all surprising; earlier research[25] has tested attitudes towards 'cosmetics research' and found people to be significantly less favourable towards it than for different types of medical research. Indeed, the word 'cosmetic' itself denotes superficiality and triviality so this may even be a tautological observation.

However, after further discussion some participants would decide that there might be a need to test new products on animals before they are used by humans, or that they themselves are probably using products or ingredients that were tested on animals in the past. We suspect, therefore, that a slightly different balance of opinion might be achieved by avoiding the word 'cosmetic' in favour of more specific terminology, for example 'soap' or 'shampoo'. However, it remains unlikely that people would support all but the most basic type of ACHM research for these purposes.

> *"If for something like spray or make up that doesn't necessarily need to be tested [then not acceptable]. Body Shop don't test on animals. But if somebody has been disfigured, and they need to trial something using tissue then more reasonable. But if only about making you look good [it's not acceptable]."*
> London, Event 2

The following sections now cover the concerns that participants set against the value of the research objective.

3.3.3 Newness

An important dynamic seems to be the extent to which an experimental process (or more importantly an experimental subject, i.e. animal) is perceived as something new or whether it is seen as a continuation or extension of existing activities. Essentially, if something becomes understood or is framed as 'new' then it can be much more problematic for people. The difficulty is in determining where 'continuation' stops and 'new' starts. For example, during the discussions the moderators often felt that there were moments where the group made this leap, from comfortably discussing things as a fairly uncontroversial extension of existing techniques, to something different and perhaps even frightening. For example, on the morning of the second day in London (about half-way through the dialogue) controversy abruptly emerged around the notion of a human and monkey chimera, as if people had suddenly grasped the newness of the idea.

[25] See for example, Ipsos MORI (1999): Views on Animal Experimentation. http://www.ipsos-mori.com/researchpublications/researcharchive/poll.aspx?oItemId=1883

As a dimension of acceptability, 'newness' vs continuity is cross-cutting. In other words it can be applied to each specific dimension below and might be an important determinant of where the boundaries are placed.

3.3.4 Level of development of animal, and type of mixing (transgenic/-chimeric)

In-vitro techniques
Participants were mostly untroubled by the idea of scientists undertaking ACHM research in-vitro (cells which were described to them as 'not having the potential to grow into a whole animal'). The issue was mainly addressed through the first case study and found almost universal acceptance, to the extent that some participants asked why this case study was even used as it appeared so obviously acceptable.

Any concerns that were raised about in-vitro techniques related to the other dimensions of acceptability. These included a) risk; whether the material used had any potential to contaminate other creatures or the environment; b) how the material would be disposed of after use; and c) where the material was sourced from (essentially seeking assurance that no human or animal had been harmed).

However, it was also observed that the more sceptical participants - whilst finding in-vitro techniques acceptable - were inclined to wonder what the next step might be and so were somewhat tentative in their support.

In-vivo techniques
As the dialogue process progressed, participants were introduced to alternative examples of in-vivo experiments. These also tended to be viewed as acceptable when they were described as being smaller scale changes to internal organs, for example mice being given human liver or even brain cells. Indeed, for many participants these types of in-vivo experiments were no more problematic than in-vitro experiments (although there was usually more concern about the welfare of the animal, discussed in sections 3.3.7 and 4.2 below).

Transgenic vs chimeric
One hypothesis which informed the design of materials for the study was that the public might see a *difference in acceptability between transgenic or chimeric animals*. To this end, facilitators took the public through a range of information sources on genetics and how cells work, in order to ensure they understood the difference between the two types of ACHM research and could make an informed judgement.

However, the overall finding here is that participants **did not mind whether the experiment was done at the gene level or at the cell level** – they were generally more concerned with the **outcome for the animal**. This outcome was considered in terms of the **physical appearance, welfare and capability of the research animal**, not its genetic makeup or, necessarily, the quantitative proportion of human or animal material in the organism.

There appeared to be marginally more concern around examples of whole human organs (or organs with a high percentage of human tissue) being developed inside chimeric animals but it is important not to overstate this. The majority of participants found these experiments acceptable, particularly when the reason for undertaking the research was believable and persuasive. Many participants asked themselves whether they would accept an organ developed this way and the answer was almost always "yes".

Similarly transgenic techniques were also generally regarded as acceptable. Case study 2, which discussed the breeding of sheep capable of producing a human protein in their milk, was welcomed by most participants, even though it was clear that the sheep could breed and pass on the modification to future generations. There were a minority who expressed concerns that the sheep breed or 'species' itself would be compromised in some way, but this concern was about the practical risk of other sheep being contaminated rather than the transgenic approach in principle.

More serious concerns emerged when participants discussed the possibility of living animals which were hybrids of humans and other creatures, or of animals with human physical

features (imaginary examples used to generate discussion). These ideas were generally much more troubling to people as they were increasingly regarded as something different or unique and which might be able to live outside of strict laboratory conditions.

One reason for the generally high level of acceptability of experiments on internal organs may be that people cannot imagine what the experiments might look like or how – if at all – they change the appearance of organs. This is in contrast to ideas such as animals with human eyes, skin, or limb parts (which were presented as more imaginary examples of research) and to which participants often had a visceral reaction because of the image it created in their minds. Participants were often quite aware of the inconsistency of these arguments and struggled to rationalise their thought processes. This was the one way in which the dialogue found some evidence of the 'yuk factor' which has been discussed in previous research[26] to characterise emotional as opposed to rational responses to bio-technology[27].

In summary, key determinants of where the boundaries might be set in relation to the type of ACHM research can be stated as people's understanding of the *outcome for the animal*, and their *capacity to visualise the experiment as something unnatural*.

3.3.5 Tissue/organ type

The type of tissue, organ or cell type influenced views of ACHM research. Whilst adaptations of most internal organs such as the liver, heart, lungs, were regarded as fairly equivalent in terms of acceptability (and not very worrying for people), boundaries did shift in relation to three distinct types of tissue: external features, the brain, and reproductive cells.

External features (tissue/organs/limbs)

The distinct feature of external organs or tissue is that people can visualise them and know how they are supposed to look. Participants' taxonomy of what constituted different animal species and breeds within species (and what constituted the human species and different ethnic groups) was often based on physical appearance (as discussed in Chapter 3, values), so the look of the animal was important when considering where the boundaries might be between humans and animals. Hence, giving animals human hair, skin, or limbs was typically met with distaste, in part because people felt it blurred the distinction between what was proper to the different species. It was also relevant that participants struggled to appreciate why scientists might do these types of experiments.

The brain

The brain was generally a controversial and difficult organ to discuss with participants. Often people had to think quite hard about their views and could struggle to articulate what they felt. It may also have been the case that some participants were unaccustomed to grappling with issues which could become quite philosophical. The main consequence of the difficulty of the subject area was that a consistent or coherent view did not really emerge.

Participants did appreciate that the brain was the source of their consciousness, personality, who they are, etc. and therefore is the most important human organ. Against this however, participants were also quite capable of regarding the brain as simply 'tissue', especially when thinking about smaller quantities or bits of the brain. It was also seen as tissue that can go wrong in quite a mechanical sense, resulting in different illnesses or conditions.

We interpret this as participants having a somewhat dual interpretation of the brain. Firstly, a physiological conception, which is that the brain is part of the machine of the body and

[26] See for example: Uncertain World: Genetically modified organisms, food and public attitudes in Britain (1997) Grove-White, R., Macnaghten, P., Mayer, S. and Wynne, B. Centre for the Study of Environmental Change, Lancaster University

[27] See also section 2.4 of the literature review conducted as part of this dialogue.

performs functions like other organs, but also that it is 'greater than the sum of its parts' because it produces consciousness, thoughts and human qualities that are not physical.

This distinction would appear to have important an important bearing on how ACHM research on the brain is communicated and discussed. For example, the case study experiments discussed during the dialogue stressed the physical nature of the brain, made up of cells. The majority of participants did not seem overly concerned about putting human brain cells into animals' brains, or vice versa. In fact they drew little distinction between these examples and case studies involving other organs. However, it was only when thinking about the *whole* brain, that it was seen as the organ which bestows human qualities. Moreover, it is not just the tissue of the brain that produces humans, but also the environment around the human brain, the *cultural and educational stimuli that interacts with the brain.* As a result of this few people seemed to believe that small changes to animals' brains at the cellular level would have a discernable impact on cognitive function.

In some instances, participants even seemed reluctant to engage in thought experiments about animals with altered or improved intelligence, dismissing them as something that could never happen. The implication here is that some people will tend not to believe that this level of change is really possible, or if it is, it is hard to imagine.

> *"So what's the problem? Toenails or liver or brain - you're changing an aspect of the mouse in order to test it. Rationally, there shouldn't be any difference."*
> Newcastle, day 1

> *"[I'm comfortable], a mouse brain is so much smaller, I don't think a little brain will be able to sit there and "think therefore I am"."*
> London, day 1

The boundary is reached when people move away from the directly physical view of brain cells and begin to imagine that human thought processes might be given to animals. However, in the dialogue this concept did not appear easy for participants to grasp. Participants would jump from a strictly physiological view, involving a few cells or bits of tissue, towards much more far-fetched examples in which animals were thinking and talking as humans, without really engaging with what might occur in between.

In Chapter 4 we show that when defining human and animal differences and similarities, biological features were much less frequently mentioned than personality or societal features. We suggest that this finding is significant, in that participants did not readily believe that what was perceived as small-scale mixing of human and animal material would have any major impact on what makes humans and animals different, which is defined less by biology than by other factors.

However, it is important to stress that this does not mean to say that participants were universally accepting of research involving ACHM that involves the brain. Some individuals retained a clear sense of unease because of the significance attributed to it when viewed as the core of human capabilities rather than from the physiological view.[28] Whilst these participants shared an unwillingness to imagine that the brain experiments described might have anything other than a biological effect, they seemed to have a greater focus on the 'newness' of the research and concerns about where the research might lead.

> *"I don't have a problem with it until it gets to the brain – liver, heart etc all fine. It's the brain which makes people humans."* Facilitator*: "Which parts of the brain are important?"* Participant*: "If it controls movement, then fine, but bits to do with memories, that would be too far – it's a human thing to have a memory."*
> Newcastle, day 2

[28] In section 3.4.3 we describe the different typologies of individuals and identify which types of people expressed this unease.

Reproductive cells

Like brain cells, cells associated with reproduction were believed to be highly significant as they represent:

- how we produce our children and establish bonds with them;
- how we develop and are nurtured as people - our physical and cultural birth experiences are seen as being critical in who we are, and in turn affect how we can influence and support our children;
- how we pass our family qualities to future generations (from a biological perspective);
- how human culture and development is sustained.

All of these considerations led to discussions that were more passionate than those about the brain or other organs. Participants were opposed to the idea of animals being able to produce human reproductive cells, or indeed to be involved in human reproduction in any way, but the concern seemed to go further. For example, when asked to rank the acceptability of different hypothetical examples of research, participants tended to say those that related to reproduction were the least acceptable. In some cases, participants (both male and female) almost seemed offended by some of the hypothetical experiments described in the exercise.

> *"That is so far out there, just awful. Perhaps if there was no sperm left on earth, but otherwise no way."*
> One-to-one follow-up interview

A variety of hypotheses can be used to suggest why participants reacted like this:

Firstly, there is the point that reproductive cells have a particular moral or cultural significance due to their association with sex.

Secondly, whilst reproductive cells might be seen as just as *significant* as brain cells, in other respects they are quite different. For most participants, reproductive cells were seen as easier to 'abuse' than brain cells. The brain was seen as an organ which does something beyond the tasks of its individual cells, (so, changing a few cells might not matter). Reproductive cells are simple, small and basic, but each one is seen to do an important job. So participants were uncomfortable with any change to these cells, even on a small scale, as this might have more immediate and more profound consequences.

Thirdly, additional concerns may have been felt around reproductive cells because negative impacts from the research would be felt by humans themselves, rather than animals. In the brain examples, the subject of concern might be an animal experiencing human mental powers, whereas in reproductive experiments the creature produced from human germ cells is thought to be basically a human child, with the rights of a human and the potential of a human, rather than an animal. However, this creature was seen as something very problematic. For example, participants imagined baby humans with subtle traces of the animals within them, in terms of behaviour or appearance. A more complex thought was that even if a human baby gestated by an animal would be technically and genetically human, it might miss out on part of the experiences that make the foetus human by not gestating inside a human mother. In this case, would the creature be fully human? There were considerable ethical questions raised around this.

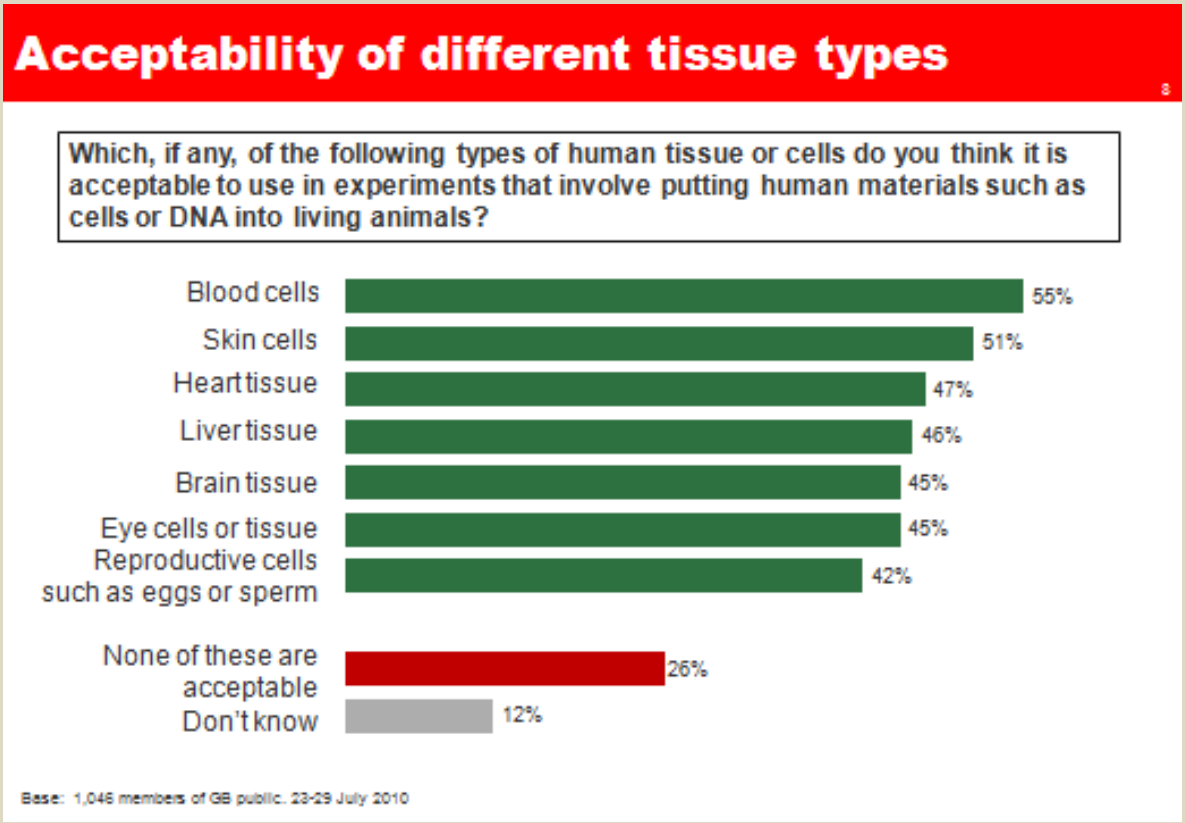
Fourthly, participants found it harder to understand the possible purpose of research involving ACHM that involved reproductive cells. Clear examples were given around the value of current brain research, whereas reproductive research tended to be presented as a hypothetical future option.

As with all the discussions of boundaries, these views were not universally held and different individuals even switched views at different times. There were people in the discussions who made less of a distinction between reproductive cells and others, indeed the group recruited

because of their faith were quite happy to accept ACHM research involving reproductive tissue if it could help produce a new human life.

Quantitative Findings

The findings from the dialogue outlined above were broadly supported when tested through the nationally representative survey. In the chart below different organs or tissue types are ranked in terms of their level of acceptability to people. A total of 37% regarded all the different types of cell/tissue as acceptable, to which we have added those who selected each individual type to create a combined score. Blood and skin are the most acceptable for ACHM research but only marginally more so than internal organs, such as heart, liver and brain (which are all treated about the same). Consistent with the above, reproductive cells are regarded as acceptable by the fewest number of people.



To summarise, the brain and reproductive cells were ultimately found to be the most significant organs for people (perhaps apart from external features, but for different reasons). Their significance meant that people regarded them in somewhat similar ways and were generally opposed to the more extreme implications of ACHM research. However, by separating the function of the brain from its physiology people were able to accept experiments that involve putting human brain tissues into animals, and were generally unwilling to engage with the idea that this would have much impact on the animal. In contrast, the potential harm of ACHM research involving reproductive cells was felt to be greater.

> *"I just think there are no boundaries when you go messing in that direction, opens up everything, to everybody, to do what they like"*
> *London, Day 2*

3.3.6 Risk

Notions of risk were a critical aspect of concerns about the process of ACHM research[29]. For example, in the post-event questionnaires, risk issues were those most often selected as 'extremely important'. There were two main types of risk identified:

i) Contemporary risk

These are the immediate risks posed by ACHM research which often drew upon real life examples. For example the specific risks cited during the course of the dialogue were:

- New germs or other contaminants that could escape from laboratories, with the 2007 foot and mouth outbreak cited as a memorable example of this.
- Germs or contaminants which once escaped could have unknown and dramatic impact, even to epidemic proportions. Two major reference points for this fear were CJD/'mad cow disease' (which has its origins in supposedly safe practices) and HIV/AIDS about which there is a hypothesis that the infection originated in a compromise to the boundary between humans and primates.
- Meat or other products from modified animals that could somehow "enter the food chain" which was a fear most associated with the case study that described transgenic sheep and participants also cited CJD as a reference point.
- Modified animals that might breed and spread their change to their offspring, thereby altering their species permanently. The concern here was both about the deterioration of species and also about the environment - that new species might have an unpredictable effect on natural flora and fauna (an example is the introduction of minks into the UK habitat).

These types of risks were mentioned throughout, although it is also true to say that none of the case-studies provoked dramatic levels of concern. As is described more fully in section 4.4 participants exhibited a degree of underlying trust in the UK's regulatory practices and the intentions and professionalism of most scientists. As such, it seems appropriate to conclude that whilst participants were conscious of these risks, they did not regard them as an immediate threat given the case studies they were presented with.

ii) Future risk

For some participants there were major issues around what might happen in the future if we permit certain types of ACHM research now; the 'thin end of the wedge' or 'slippery slope' argument.

> *"Once you start down this road, it doesn't really matter to what extent you do it."*
> London, day 1

Therefore, in addition to the risks above the following were also seen as future risks:

- the creation of abnormal hybrid between a human and an animal that might be hideous, suffer indignity/pain and/or significantly compromise the natural order;
- producing a human child with traces of animal who will suffer through their life;
- moving evolution "too quickly", precipitating changes rather than allowing things to happen naturally, with unintended consequences on species or even the whole ecosystem;
- creating new species or creatures that challenge or threaten human dominance;
- creating new species or creatures that could be used for malign purposes, such as terrorism or warfare;

[29] See section 2.6 of the associated literature review for a more detailed discussion of the concept of 'risk' and how it relates to these issues.

- creating new species or creatures that pose ethical dilemmas about how they are treated;
- creating new species or creatures that anger God;
- conducting experiments that result in a Pandora's box of harm and destruction.

Whilst participants were not immediately concerned about these risks, some did see them as a plausible logical consequence of the experiments they saw as especially new.

> *"It shouldn't be done because once you start you can't stop or control it… The consequences would leak out somewhere."*
> London, day 2

The significance of these issues varied a lot by individual. Some participants did not take future risks particularly seriously or feel that ACHM research had this potential, whilst others were genuinely concerned. Sometimes discussions would crystallise around this topic. For instance, a discussion in London around the controversial topic of transferring human sperm cells into monkeys became split trenchantly between one individual who felt that the advantages of such an experiment were important and the risks negligible, and others who felt that it would set a precedent for the scientific community that might lead to increasingly unnatural or unpleasant consequences.

When it came to judging the acceptability of ACHM research, those participants who were genuinely concerned about future risks were faced with a dilemma. Although the purpose of some research was seen to be important, the precedent that it seemed to set was also troubling. Most often, the judgement made was that research could go ahead but with strict conditions, in particular the condition that the research was absolutely necessary and that permission was only granted on a case-by-case basis, rather than allowing the research to proceed in general. In the typology presented in section 3.4.3 this attitude is clearly shown in group 3, *"I have real doubts, I don't like it. It should only be done in extreme cases, as a last resort, only after everything else has been tried"*.

A small number of participants were rather pessimistic or fatalistic about the more negative consequences of science. Some commented that the scientific community will always find a way to do what it wants, regardless of public will or control. Another related argument was that the progress of science is inexorable, such that if permission is granted for one seemingly innocuous experiment, that contains within it the seeds of more radical experiments. This may explain why 'newness' is an important dynamic, in that outside of immediate concerns (e.g. animal welfare) the construction of boundaries is primarily an exercise in containing what is new, because scientific progress will almost inevitably deliver on its threatening potential.

> *"Extremely difficult to see where it takes us. Is the next step to do this with children? As a stand-alone idea this is acceptable."*
> Newcastle, day 2

3.3.7 Animal welfare

This section looks at how participants traded off animal welfare issues against the purpose or objective of the research to judge its acceptability. In doing so, it should be made clear that exploring attitudes towards animal research was not an objective for this study. This has been covered comprehensively elsewhere by Ipsos MORI and others[30]. Rather, the coverage of wider animal testing issues was felt to be relevant in two possible ways: the extent to which judgements about animal research in general influenced participants' judgements on ACHM research, and whether ACHM research was felt to introduce new dimensions to concerns about animal welfare.

[30] See section 2.3 of associated literature review and also, for example http://ipsos-uk.com/DownloadPublication/1343_sri-views-on-animal-experimentation-2010.pdf

Judgements about animal research in general and ACHM research

The overall finding of the dialogue is that for many participants, underlying concerns about animal welfare in general were transferred directly on to the issue of ACHM research. Despite facilitators encouraging participants to focus on the *new or unique* aspects of ACHM research, many participants were unable or unwilling to overlook the overarching issue of animal welfare in scientific experiments. Concern about animal welfare was pervasive and consistent throughout the dialogue process, although, as section 4.2 shows, it did vary from individual to individual.

> *"You don't want to take it into a discussion about animal rights, but it has to be considered, you cannot see it separately."*
> Newcastle day 1

This meant that often the first and main reaction when hearing about different ACHM research techniques was to query the associated animal welfare issues, and therefore the case studies which typically generated the most severe reaction were those in which 'higher' forms of animals (mammals, primates) were seen to suffer.

Ultimately, however, animal welfare was rarely seen as a sufficient reason to stop research that was believed to have a compelling purpose. In making these choices, people were often quite aware of the contradiction involved, even unapologetic about it. However, it appeared that the importance of the stated research objective was so high that it could overrule even the most powerful opposite convictions.

Moreover, when participants were compelled to make difficult choices some interesting reactions emerged:

- participants in the patient group were relieved that they did not have to decide on whether animals should have to suffer, and some were even unhappy about being told the experiments were happening;
- more widely, participants were quick to say that there ought to be limits and controls (e.g. a certain number of monkeys used, a certain amount of time to prove the work's effectiveness and so on).

Only one participant (outside the animal welfare group) took the position that ACHM research was wholly ethically unacceptable. Furthermore, whilst ethical objections were found in the animal welfare group, it was not their sole objection; rather they set out a broader environmental and political critique (described in the following section). Indeed, even within the animal welfare group there was some willingness to view animal experimentation as acceptable under certain conditions.

Does ACHM research cause new types of suffering?

When asked explicitly, most participants did not believe that ACHM research experiments would cause more suffering than the (albeit sometimes high level) of suffering felt by normal laboratory animals.

> *"It's a great deal of suffering. The fact that it has human material makes no difference really."*
> Newcastle, day 2.

However, there were a few examples of research discussed which were felt to be outside the boundaries because they might cause a different or specific type of animal suffering. For example, the hypothetical idea of a monkey being given the DNA to grow a human hand led to discussions of whether the hand growing would hurt the monkey. Most objected that it would not, just as a human's hand does not hurt to grow. But some pointed out that the monkey might suffer mental distress through having an asymmetric body, or through having a mental model of its shape which contradicted the physical reality. Some, in one of the

London discussions, discussed whether a dog with a human eye would become disturbed, because they imagined the dog would get visual stimulus that it could not interpret.[31]

Some participants also reflected on the fact that some brain experiments might have unknown consequences on how animals interpret their own welfare and suffering. Whilst it was challenging to follow the implications of these thoughts, ideas did emerge (for example, a monkey with an element of human cognition might have more scope to *realise* it was trapped in a cage or to experience greater suffering in other ways).

A final issue to consider here is that some participants felt ACHM research might have implications for how experimental remains were treated. The main issue here was the need to prevent contamination by disposing of remains thoroughly. There was also a small group who queried the fact that if remains were partly human, would they need to be treated differently, i.e. as human remains?

A very small minority (one or two people) took this thought further. They argued that some potential experimental animals with elements of human cognition might also gain human rights, such as the right to life, in which case it might become impossible to ethically justify running experiments on them or killing them when experiments ended.

3.3.8 Type of animal

A related dimension which made an occasional difference to participants when weighing up the acceptability of ACHM research was the type of animal involved. Discussions tended to focus on the welfare issues for the animal rather than the unique features of ACHM research. As shown in section 4.2, concerns were most frequently expressed about the use of primates and pets, then for farmyard animals, then for rodents and other animals (which seem to be known to be typical laboratory animals).

The special circumstances surrounding ACHM research appeared to make little or no difference. However, for two particular animals, some tentative issues can be identified.

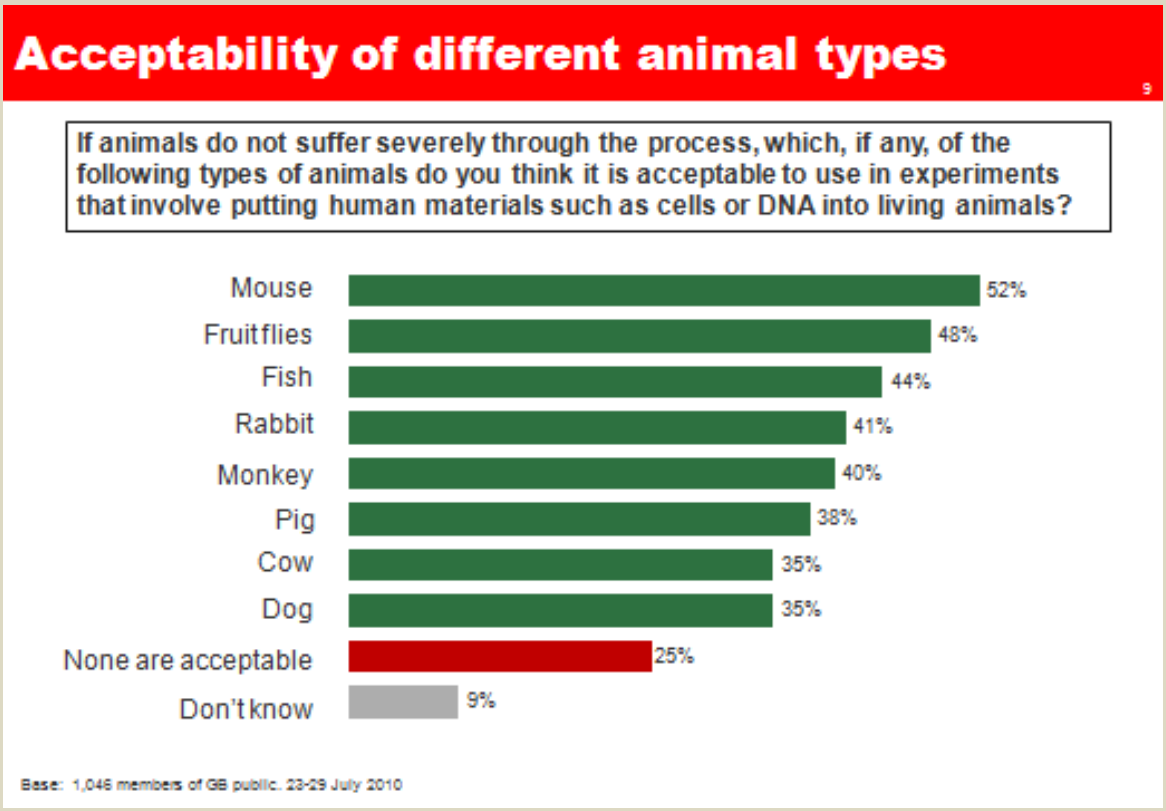
Pigs: participants from certain communities were more resistant to the use of pigs in research involving ACHM because of cultural associations. This applied most obviously to participants from the West Indian and Moslem communities, but it might be equally true of other communities who were less well represented in the dialogue.

Monkeys, especially chimpanzees: participants were perhaps slightly more challenged about examples involving monkeys. In an early part of the dialogue, participants were informed (through the quiz) about the genetic similarity between humans and chimpanzees. This information, combined with existing knowledge of the capabilities of these animals, may have made people more ready to imagine that research involving ACHM could have an effect on the boundaries between them and humans. Recalling the earlier observation in section 3.3.5 that participants were generally unwilling to accept that experiments might change other animal's cognition, it seemed that only examples involving chimpanzees really gave purchase to this idea. The conclusion from this would be that brain research involving chimpanzees might cause people to shift from the biological view of the brain and encourage people to be stricter about where the boundaries should be placed.

[31] It should be noted that these example experiments were described clearly to participants as far-fetched and were used only to encourage thought experiments.

Quantitative Findings

The ranking of animal species was broadly echoed in the nationally representative survey, the results from which are shown below. In this question, 'mouse' and 'fruit flies' were the most acceptable animals to use in ACHM research whilst 'dog' was the least acceptable. However, there is some difference between these results and the attitudes expressed during the qualitative dialogue, namely that a monkey was seen as acceptable by as many people as a rabbit and even more acceptable than a cow. One hypothesis to explain this is that people are more accustomed to the use of monkeys in medical research or more likely to feel that monkeys are an effective surrogate for humans. Conversely, using cows in research is uncommon and people might also feel that cows are for food rather than experimentation (as illustrated by current concern about cloned beef entering "the food chain").



3.3.9 Who benefits?

The last of the main dimensions around which participants established the boundaries and considered their acceptance of ACHM research is described here as 'who benefits?'. It is somewhat different to others described in this chapter, in that rather than being a concern about the process of conducting the experiment it is:

- a precondition for acceptance; and
- related to the context of the research rather than the experiment itself.

However, it is a crucial component of peoples' judgements about ACHM research. It includes the following aspects/questions:

Who will ultimately benefit from the research? To be acceptable, it needs to be demonstrated that the beneficiaries will be ordinary people - not only the rich or better-off. This was often extended as far as the developing world.

Who is doing the research? Participants were happier with the thought that universities or other 'not for profit' institutions were doing the research, rather than private companies (by which were meant large multi-national companies rather than smaller businesses).

Will the cost of the treatments be reasonable? There seemed to be considerable awareness and focus on the costs of drugs to the NHS, and participants were keen for assurance that these costs would not be excessive.

What is the motive behind the research? Participants were attracted to pure altruism and the desire to help people; they rejected other motivations such as money, fame, curiosity.

Will it be done for the right reasons? I.e. to address serious illnesses rather than more trivial concerns or providing physical enhancements for people.

The degree of concern about these issues reflected a certain level of scepticism about large institutions, government and big business in general. However, as is described in section 3.5 this was partially offset by participants' faith in medical science and appreciation of the benefits (which was actually observed during the dialogue itself as participants generally accepted the contextual explanations provided by the scientists who were present).

However, there were also people - most particularly in the animal welfare group - who had a different perspective, and who were inclined to assume that the questions above would be answered negatively. In discussing the issues with more sceptical groups and individuals it appeared that a starting point was established early on – that ACHM research is problematic. Then, new information given was incorporated into that critique. This indicates that these people have a quite different paradigm, based on unwillingness to value the stated purpose of the research. The following briefly lists all the elements of this critique, as it emerged through the animal welfare group:

- Big business will usually benefit more than the 'masses'. As such ACHM research is just another aspect of global capitalism.
- The benefits will not be passed on to the 'masses', particularly in the developing world
- We should focus on preventing disease rather than curing it.
- It is wrong ethically to experiment on animals.
- Humans should stop meddling with things, enough damage has already been done to the planet.
- Humans see themselves as superior but this is questionable, in some respects we may be inferior.
- There should be fewer humans on the planet so we should not be seek to preserve life.
- ACHM research is not a priority on a global scale; rather we should be addressing poverty, global warming etc.
- We are focusing on perfection rather than letting nature take its course.
- The dialogue process itself is an exercise in legitimizing ACHM research

"Half the world is starving – all this should be addressed before we take this further."
London day 1

3.3.10 Which dimensions are most important?

The issues described above were each important in relation to specific issues. During the course of the dialogue two attempts were made to determine which issues were the *most* important through questionnaires; firstly during the qualitative discussions and then again in the nationally representative survey.

Firstly, the table below shows the findings from the questionnaires given to participants at the end of the first day of general public dialogue. It was designed before the meetings and so was based upon consultation work with stakeholders rather than the public and so does not cover all the relevant issues to have emerged. However, it does show the importance given to issues of **risk** and the consideration of the **purpose** of the research.

Response to question asked of general public dialogue participants at the end of the first day: *Thinking about the different research and experiments we have discussed today, how important have each of the following been to you? (table shows raw numbers in rows rather than percentages)*					
	Extremely important	**Very important**	**Fairly important**	**Less important**	**No answer**
Whether the scientists involved can be trusted to conduct experiments according to the rules	**26**	**13**	**3**	**2**	**1**
Concern about whether the research might lead to unforeseen problems such as new viruses	**20**	**12**	**7**	**4**	**2**
What the research is for? (eg. to test new drugs or just to find out more about the issue)	**17**	**17**	**8**	**1**	**2**
The type of animal or human tissue being used in the experiment (eg skin, liver, brain)	**13**	**12**	**5**	**13**	**2**
The amount of suffering that is felt by animal	**11**	**10**	**13**	**10**	**1**
Whether the animal involved develops new characteristics or looks different	**11**	**13**	**11**	**9**	**1**
The extent to which the animal is a new creature that could live outside the laboratory	**10**	**11**	**13**	**10**	**1**
Which type of animal is being used (eg monkey or mouse)	**9**	**11**	**11**	**11**	**3**
How 'natural' the research seems to you	**7**	**18**	**9**	**6**	**5**
Whether or not the experiments seem to be against your religious or personal views	**7**	**11**	**10**	**14**	**3**

Quantitative Findings

Secondly, two questions were asked about the dimensions of acceptability during the nationally representative survey. The wording for these questions was developed after the qualitative work had taken place and hence was more attuned to how people talk about ACHM research and more comprehensive in covering the issues. The first question asked why people felt that ACHM research was acceptable or unacceptable *unprompted,* i.e. they had to explain their response in their own words (which was then coded by the interviewer). As the chart below shows, two clear pro and anti reasons were given by a large number of respondents; "to help cure human health problems" (35% of all respondents) vs "concern about animal welfare/suffering" (19%). Meanwhile, some of the other issues which emerged through the qualitative research were less widely mentioned (for example, contemporary and future risks, profit motivation). This does not necessarily mean that these issues are less important, rather that they are less likely to be among the first things mentioned when people are asked to give an opinion (without any background information).

Q: Why do you feel that experiments which involve putting human materials into living animals are (un)acceptable?	
Base: All except those who did not know whether ACHM research was acceptable (1,011)	
	%
"Acceptable" responses	**53**
Can help to cure human health problems	35
I support medical science/progress	24
Do not see any problem with it	8
Trust scientists	6
Personal experience of illness	5
Curiosity/interest in what might happen	2
Don't care that much about animals	1
Is beneficial for the animals	1
"Unacceptable" responses	**46**
Concern about animal welfare/suffering	19
Against my personal views	11
It's unnatural/shouldn't meddle/'playing god'	10
Concern about where it will lead/slippery slope	6
Do not understand the reason for doing it	6
Concern about risk of contamination/disease/don't know the consequences	4
Don't believe that there are real benefits/they're just doing it for curiosity	4
There are alternatives to doing it this way	4
It's unpleasant/disgusting/"yuk	3
Against my religious views	2
Is being done for profit/business interests	2
Distrust scientists	2
May set a precedent for less reputable scientists	2
Don't know	6
Refused	1

The other approach used in the nationally representative survey was to provide respondents with a series of pre-coded conditions on a showcard and to ask them to say which they felt

were likely to make them more likely to feel that ACHM research is acceptable. The four main answers given were 'studying serious health problems' (relating to the objective), 'done in controlled laboratory conditions' (which related to contemporary risk), 'reduced animal suffering as much as possible' (animal welfare) and 'for a clear medical goal' (objective).

When asked to select just a single condition, this ranking is broadly repeated with the condition of tackling 'serious human health problems' emerging as the most frequently selected condition. Using the qualitative findings to interpret this, it is possible to see again the persuasiveness of the 'human health problem' argument being set against animal welfare and contemporary risk. This provides confidence that the findings of the qualitative dialogue are indicative of the views of the wider population.

In the UK, experiments that involve putting human materials such as cells or DNA into living animals are done to learn more about how the body works and to study human health problems. Here is a list of other conditions which might be applied to these experiments, some of which currently apply in the UK and some of which do not.

	Which, if any, of these would make you more likely to feel that these experiments are acceptable?	**Which of these would make you *most* likely to feel that these experiments are acceptable?**
	%	%
Were only done to study *serious* health problems	40	19
Were only done in controlled laboratory conditions	38	12
Ensured any suffering experienced by animals was reduced as much as possible	40	11
Were done for a clear medical goal, rather than just to learn more	35	10
Were only done with human and animal cells outside the animal's body, for example in a test tube	21	9
Were the only way to study the human health problems concerned	31	9
Minimise the risk of 'contamination', eg. experimental animals breeding with other animals or affecting the environment	16	2
Did not change how the animal looked	11	1
Only used simpler animals or those less likely to have conscious feelings, such as mice or fish	14	1
Other	*	1
None of these would make me more likely to accept these experiments	16	16
Don't know	6	7
Refused	1	1

A further point to note is that 16% of respondents said that none of these conditions would make them more likely to find ACHM research more acceptable. Most of this group were people who also found ACHM research overall to be unacceptable (as opposed to the very small number who found ACHM research so acceptable that none of the conditions made a

difference to them), which provides an estimate of 15% the population who (without background information) find ACHM research unacceptable under any conditions. This group will be discussed further in section 3.4.3 which seeks to segment the population by their views.

3.4 Attitudinal differences between different audiences

3.4.1 Different locations for qualitative research

Across each of the qualitative elements of the dialogue settings, level of support for, or acceptability of, research involving ACHM is described as follows:

General public dialogue

- **Newcastle:** This group were on the whole very accepting and supportive of ACHM research. The presentations developed and delivered by participants at the end of the second day were all supportive of the research and focused on the reasons why it is necessary and the potential benefits it might deliver.
- **London:** This group were also accepting of the research but with more reservations than the Newcastle group. Participants in London tended to draw on more abstract or philosophical arguments to debate how far they accepted ACHM research and in their final presentations tended to illustrate some of the questions posed rather than stating support. However, they reached broadly the same conclusions as Newcastle (for example, in the questionnaire responses, an identical pattern of response is seen between the two locations).

Special interest groups

- **Newcastle, patient group:** This group welcomed any research with clear medical objectives and strongly supported the continuation of ACHM research. However, many also felt uncomfortable about the animal welfare implications.
- **London, faith group:** This group were highly supportive of the research and accepted all the examples of ACHM research that were presented to them. Their outlook was strongly influenced by an underlying view that human life has a pre-eminent value, and that ACHM research was seen to extend or enhance human life. They voiced no objections to ACHM research in theological terms.
- **London, animal welfare group:** In contrast to each of the other groups, participants in this group were broadly opposed to research involving ACHM. Concern about animal welfare was a factor in this but there were also others (as described in section 3.3.9). A minority in the general public dialogue in London also shared some of these views.

3.4.2 Demographic differences

It is possible to make some observations about how levels of support or acceptance differed (or was the same) across sub-groups.

In terms of **gender**, during the qualitative dialogue more extreme positions on both sides of the argument appeared to be taken by men. However, we suspected that this might only have been an example of a quite common finding in qualitative research, which is that men tend to be more vocal.

Looking at the results of the nationally representative survey shows that men were much more likely to agree that animal experiments as a whole should be allowed (61% vs 46% of women) and more likely also to find ACHM research more acceptable (51% vs 37%). Indeed, amongst women in this survey, acceptability of ACHM research was split evenly, with 37% of women on each side of the debate. However, looking at the questionnaires used at the end of the first day of the general public dialogue shows that men and women had similar views. Whilst caution is needed in interpreting this because of the small number

of questionnaires completed (43), it does suggest that women, whilst being more anti animal research and ACHM research in the first instance, adjusted their views when provided with information about the research and in doing so become more accepting. Indeed, this process was remarked upon by one recipient herself during a follow-up interview.

> *"Going into the discussion I think I was very against any kind of animal research but having heard about what it is and what it is for I have completely reversed my position."* One-to-one Interview with Newcastle respondent (female)

By **age**, older people seemed to be slightly more supportive of the research and less likely to voice opposition than younger people (although there were exceptions to this). This difference was apparent in both the qualitative dialogue and the nationally representative survey. In the survey, 50% of the over 50s said they found ACHM research acceptable, compared to just 34% of 15-24 year olds. Three hypotheses might explain this: firstly, older people are at greater risk of suffering from the diseases being investigated by research involving ACHM (or to know someone who suffers from them); secondly, they are more likely to have benefited from treatments developed by medical science; and thirdly, they are more likely to have had children. The latter seemed particularly important during the course of the dialogue; there were a number of occasions when people asked themselves whether or not they would support research that could help their own child, which was treated as the ultimate moral test or dilemma. It appeared that to help children, people are willing to go further in their acceptance of any type of research. Those who had their own children seemed more mindful of this when making judgements about ACHM research.

The **educational level** of participants appeared to have some effect on attitudes but not necessarily levels of support or opposition. It seemed that those with higher level qualifications found it easier to engage with the issues and had greater familiarity with the kind of debates and discussions that were encouraged. The result of this was that those with the highest levels of education tended to take both more considered and more radical positions (both for and against the research), perhaps reflecting their greater confidence to speak out and articulate their views. By contrast, we observed that those with less education opted more often to occupy the middle ground. Educational level was also noticed to be a significant variable in the nationally representative survey, with those with the highest level of qualifications (Degree or higher) being most likely to find ACHM research acceptable (52%) and those without qualifications the least (40%). This pattern of response was observed in other variables that tend to overlap with educational attainment. Hence, 52% of those in social class AB found ACHM research acceptable, compared to 36% in social class DE, and 21% of broadsheet readers found ACHM research *very* acceptable compared to 10% of tabloid readers.

Faith was covered explicitly in the faith special interest group but also sometimes emerged as a factor in the general group discussions. As has been mentioned, those in the faith group took a very permissive stance towards ACHM research, and that view was echoed in the general public dialogue. However, there was also an alternative stance informed by faith, which is to oppose the research because it is interfering with something that God would not want us to interfere with. This view was taken by at least one person in the general public dialogue, but overall only a very small minority of those who participated.

Area: The qualitative elements of the dialogue were too small-scale to make definitive judgments about how attitudes might differ across the country. Moreover, comparisons in the nationally representative survey between the North, Midlands and South do not show any significant differences between them in terms of the acceptability of ACHM research.[32]

Ethnicity was the final issue for which it might have been possible to observe some patterns around support for, or opposition to, animal mixing. However, no such patterns were evident

[32] North = 48% acceptable, Midlands = 40% and South = 44%. These differences are not statistically significant.

and people of different ethnicities were represented across all viewpoints. Similarly, in the nationally representative survey there were no significant differences by ethnicity.

3.4.3 Typologies of approval/acceptance

The preceding section explored acceptance levels across different locations and demographic characteristics. In this section, a typology of attitudes is suggested based upon observations and analysis of the qualitative data. It should be made clear that in doing this we are providing examples of attitudes, not individuals. Individuals may have tendencies towards particular views, but they might equally betray different values or attitudes at different times. The four proposed attitudinal typologies are as follows:

1) "Stop asking and get on with it!" This group was the most positive about ACHM research. These people tended to be instinctively supportive of its aims, even excited about the possibilities. They tended to dismiss concerns about the research as trivial when compared to the benefits, and had faith in scientists to conduct the research ethically and professionally. This group might also be said to include those with a religious standpoint who concluded that anything that might enhance human life is acceptable and, therefore, that humans have the right to do these experiments.

2) "I don't necessarily like it, but if it delivers benefits then it is worthwhile": This was probably the most common tendency. People who voiced these ideas were strongly supportive of the aims of medical science and trust that it is done properly. However, they were also uneasy about the use of animals and also some of the more imaginative examples of ACHM research that were given. This led to interest in how the research was regulated and how animal welfare was provided for, but it would not make them unaccepting.

> *"I have friends with MS and epilepsy. They are still alive thanks to the drugs they are taking. I am glad to still have them around me. I love animals to bits, but we have to move forward in medicine, saving the lives of our families."*
> Newcastle, day 2

3) "I have real doubts; I don't like it. It should only be done in extreme cases, as a last resort, only after everything else has been tried": This group was more troubled about what the research process involved, not just in terms of animal welfare but also about the potential long term consequences of human and animal mixing. This group usually concluded that the research could be acceptable, but did so with considerable reluctance and by placing strict conditions.

4) "I don't accept that this should be done": A minority of participants, mostly in the animal welfare group, rejected the idea of ACHM research altogether. The strongest arguments were that it is wrong to use animals at all; and also to doubt whether the supposed benefits would be delivered to people, or were even were achievable or worthwhile.

Quantitative Findings

Findings from the nationally representative survey also support the hypothesis of there being a sub-group of the population who are particularly opposed to ACHM research. In section 3.4.2, it was estimated that this group represented about 15% of the population. In this section, we briefly describe some of the characteristics of this group, based upon analysis of the survey data:

- 18% of woman were in the particularly anti-ACHM group, compared to 12% of men;
- 21% of those with no formal qualifications were also in the anti-ACHM group, compared to 12% with degrees and just 4% with higher degrees; and
- 28% of those in households that earn less than £6,500 p.a. were in the anti-ACHM group, compared to 9% of those in households that earn more than £25,000 p.a.

There was also considerable overlap between the particularly opposed group and those who stated other measures of scepticism about animal research and ACHM research:

- 60% of people who say that any animal experimentation for medical science reasons should be disallowed were also in the anti-ACHM research group, compared to just 8% who felt that any animal experimentation should be allowed; and
- 61% of people who said they would distrust the UK to have the appropriate rules to regulate ACHM research were also in the anti-ACHM sub-group, compared to 14% who would be trustful.

The three main *reasons* the particularly anti-ACHM research group would find ACHM research unacceptable were;

- 32% were 'concerned about animal welfare' (compared to 17% of those not in this group).
- 28% who said it was 'against their personal views' (compared to 8%).
- 25% who said 'it's unnatural' (compared to 7%).

3.5 Regulation and communication about ACHM research

3.5.1 Regulation

The regulatory aspects of ACHM research were of great interest to participants. Broadly speaking, most participants were aware that medical research is regulated in the UK but did not have detailed knowledge of how it is done or who does it. Notwithstanding this, we also found a degree of trust, and confidence that regulation would be done well, and would reflect peoples' principles and concerns.

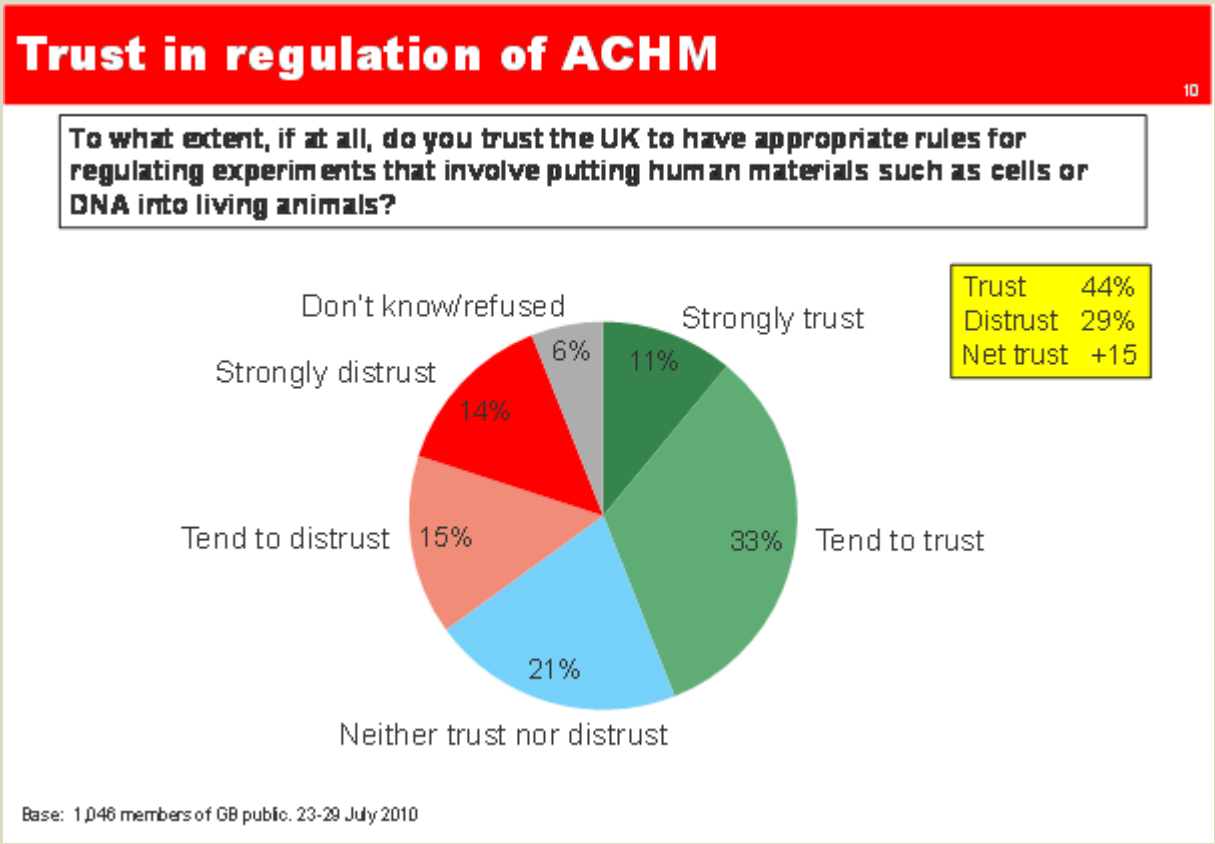
However, there were some ways in which this confidence might be undermined:

- Knowledge of previous errors - for example 'mad cow' disease and the most recent outbreak of Foot and Mouth (which was believed to have been caused by a laboratory in Surrey) - which has exposed people to the possible fallibility of the system.
- People's confidence also seemed to be undermined when they heard that 'Government' was doing the regulation. For some, the word 'Government' tends to be mostly associated with MPs and Parliament, which people can be cynical about.
- There was also much less confidence in regulations internationally.

Despite these concerns, participants were trusting of regulation. The majority believed that, in the UK at least, ACHM would be acceptably regulated.

Quantitative Findings

Levels of trust found in the qualitative dialogue were echoed in the nationally representative survey, where 44% said they would trust the regulation of ACHM research compared to 29% who said they would distrust it. Of course, this profile of opinion was found without any information being provided about how regulation is done, and - based upon findings from the qualitative dialogue - it seems likely that further information about regulation would encourage people to be more trusting.



The following outlines the main considerations that participants wanted to see applied to ACHM research:

Transparency: The general principle that everything should be completely 'up-front' or 'above-board', and also that the science community should proactively communicate what it is doing by placing information/data in the public domain and enabling access to research sites by members of the public. It was also argued that any results or findings from ACHM research must be published in full, to offset people's concerns about 'who benefits?'

Independent supervision: The majority of participants strongly endorsed the view that regulation should be done by clearly independent or impartial people. This might ideally include members of the public themselves but also independent scientists or people employed specifically to supervise. An important point here is that it was felt there should be a *mixture* of different interests represented. Attitudes to 'Government' regulation in this respect are more complex, as hostility towards politics can taint views. However, once

political and administrative functions were separated, 'Government' regulation was more supported.

Focus on animal welfare: Many participants felt that an important goal of regulation should be to ensure animal suffering is minimised. Those who were especially concerned about animal welfare issues tended to be reassured by hearing about the regulation of animal use in science. A further aspect that arose was the *number* of animals used. Whilst for many participants successful medical research would justify any number of animals, others felt there should be a threshold at the point where the number of animals used would be greater than success would warrant.

Focus on contemporary risk: Another key aim for regulation is to eliminate 'contemporary risks'. To achieve this aim, it was felt that regulation ought to be all-encompassing (so that it could not be avoided by 'rogue' or recreational scientists).

Addresses the key questions: Reflecting the concerns raised in previous sections, participants felt that the answers to a number of key questions could constitute the parameters around which the decision to allow the research might be made. These would include;

- What is the objective of the research? How will it benefit human health?
- Has everything else been tried/exhausted?
- Why does the research need to be done in this way?
- What are the chances of success?
- What are the limits? How long will it take? How many animals are involved?
- What are the potential risks? How will these be controlled?
- What are the ethical issues (including animal welfare)
- Who will use the results, and for what?

The acceptability of ACHM research seemed to depend on the answers to these questions, and on the belief that regulations following on from this will be enforced[33].

3.5.2 Communication about ACHM research

The dialogue also provides insights for communicators as to how the debate on ACHM research might evolve if the issue is discussed with a wider public.

The key finding is that communicators will need to discuss ACHM research in the light of the concerns discussed in section 3.3. However, on the basis of this dialogue, the following factors may also influence responses to information and communications about ACHM:

People have pragmatic attitudes: This dialogue suggests that people's views will emerge flexibly and are most likely to be influenced by associations that are made (or suggested in the communications) than by any underlying schema. Underlying values are discussed in more detail in the next chapter, but, as noted earlier, the majority response was pragmatic and strongly influenced by the view that whatever will improve human health is worthwhile.

An 'anti-ACHM research discourse' may develop: In this dialogue, clear, coherent or persuasive arguments against ACHM research were generally absent. However, there was a small vocal group (the animal welfare group) who were more negative towards the whole project of ACHM research and these arguments were significant, even though they were not the majority. It will be important for communicators and decision-makers to engage with these views.

[33] Section 3 of the associated literature review discusses earlier opinion research on the regulation of medical science.

Imagery will be important: There was evidence during the qualitative elements of the dialogue that participants disliked mixtures of human and animal material which they could clearly visualise; hence the relatively high level of acceptability for research on internal organs, where changes were harder to picture. It seems likely, therefore, that any images used in communications about ACHM research will play an important part in how it is ultimately perceived.

People are most worried about 'the new': Stressing the continuity of ACHM research techniques encourages people to regard ACHM research as more acceptable, whilst emphasising the more radical or novel aspects will encourage people to be less accepting. For example, this was seen during discussions about chimeric animals - many participants seemed to be more concerned about the possibility of new or unnatural creatures being created, than they were about in-vitro experiments in laboratories.

People will try and set new information in the context of what they already know: Managing associations, including disabusing those that are wrong or inappropriate, will be an important component of communication.

General lack of knowledge about science: As discussed further in section 4.4, knowledge about science in general is quite patchy, whilst willingness to learn more from scientists was demonstrated throughout the dialogue process. This needs to be considered when communicating about ACHM research, for example, information might be best conveyed alongside broader information about scientific processes.

Media discourses are distrusted: Participants expressed their distrust and scepticism about how issues are presented in media such as TV and newspapers. An appetite for unbiased information was continually stated.

Do people want to know more? Finally, it is worth noting that some participants in the qualitative dialogue said that they would sooner not know much about ACHM research, particularly if it involved animal suffering. These participants wanted important research to continue but also preferred to avoid thinking about the consequences. However, this was a minority view, and most people stated that they would welcome being more informed.

4. Underlying values and knowledge

4. Underlying values and knowledge

This chapter describes the underlying values and ethical positions that were revealed during the discussions, and suggests how these underlying views may have influenced judgements about ACHM research.

4.1 How did the public define 'human'?

At the beginning of the discussions, participants were encouraged to reflect upon their attitudes towards humans and animals; what makes them the same and what makes them different. This was partly to introduce the topic of the dialogue gradually but also to explore underlying values which might affect judgments.

4.1.1 How are we different from animals?

Nearly all participants agreed that human lives were precious and had a special status or value above that of animals or inanimate things. Overall, this appeared to be because they believed **humans to have capacities and potential which go beyond the capacities and potentials of other species.**

Humanness was widely interpreted as ***potential***. Humans, whatever their status (and 'special cases' were discussed, such as babies, those with mental illnesses and those without access to services such as education) will always have an inherent potential to live richer lives than animals. Humans have the potentiality to achieve on many levels, while animals are perceived to accomplish little beyond survival and reproduction. This perception of the value of human life may be the foundation for the support given by participants for research which seeks to prevent death or suffering, and maximise the potential of human life.

Humans were seen as different from animals in the following ways:

Mental capacity: Humans were generally seen to have a greater mental capacity and a higher order of capabilities. These include:

- the ability to reason, rationalise and solve problems;
- ethics and morals (knowing right and wrong);
- self-awareness; our place in the world and our mortality;
- education and the ability to gain wisdom throughout life, as well as learning from others;
- creativity and self-expression;
- compassion and charity (humans care for other species, animals do not).

Language: This was a frequently cited difference between humans and animals, as distinct from communication, which was regarded as a similarity.

Complexity: This was the idea that human lives, institutions and societies, even within more primitive societies, are more complex than those of any animals.

Highly sophisticated tool-makers and environment-shapers: Modern humans use more sophisticated tools and systems to feed and warm ourselves. Overall, humans shape the environment on a scale greater than any animal.

Humans are developing/improving: Human lives today were seen as different from those of our ancestors. Animals on the other hand were seen as static or trapped and governed by their individual instinct to survive. This is linked to the idea that humans have shared **culture**: attitudes, values, goals, practices and histories.

Humans have evolved *further*: Some participants portrayed it in terms of humans having come further on a continuum, with animals further behind.

Humans are dominant: This is the idea that humans are in charge, that they are custodians of animals and the world as a whole. A slight variation on this is the idea that humans are on top of the food chain and have no predators.

Religion: Humans are the only species to know or create gods or to have a spiritual life. (Although this was not mentioned by many, it was brought up in some sessions.)

4.1.2 How are we similar to animals?

The following list describes ways in which participants felt there were similarities between animals and humans:

Relationships and societies: Animals have relationships with one another like humans. Some animals, like monkeys, even appear to have families. Some animals, such as ants and pack animals, collaborate together in what might be described as societies.

Communication: Animals communicate (e.g. whale noises, bird song), although it was not believed to be as sophisticated as human communication.

Use of tools, technologies: Some animals use tools, for example monkeys using rocks as hammers and birds building nests.

Emotions: Pet owners in particular felt that animals had emotions, but there was debate about how sophisticated these emotions were. Examples cited were "gorillas who mourn for their deceased young", and "cows knowing fear".

Work: All animals and humans in their natural habitats have to work to survive.

Intelligence: Animals were seen to have intelligence, albeit of a type that is different. It was seen as an intelligence which is specially developed for what they need and also impossible for us to understand or experience fully, and therefore not necessarily inferior to human intelligence. It was also felt that some animals had the potential to learn like humans.

Behaviour: In some respects human behaviour had parallels in the animal kingdom, e.g. human children behaving like monkeys and humans showing-off and preening like birds.

Share the same environment: The group recruited because of their concern for animal welfare were particularly keen to stress human interrelatedness with animals and the idea that humans and animals are products or parts of the same eco-system.

4.1.3 Implications for ACHM research

The list of differences and similarities shown above is an exhaustive account of what was mentioned across the group discussions, with one exception: in only a single case did an individual mention the point that both humans and animals have eyes, and five senses. Apart from this specific mention, biological similarities and differences were a strikingly absent theme from these opening discussions. Participants did not discuss or mention similarities in terms of tissue types (e.g. vertebrae, hearts) or the makeup of tissue (DNA, cells), nor did they say that both humans and animals need to sleep, breathe, eat, etc. There was also no discussion or awareness of humans' shared evolutionary origins with animals, people did not say that "we had the same ancestors".

Rather, participants were nearly always more focused on what could be described as the 'essences' or distinct characteristics of different animals and humans. Or, in other words, a cat and a dog are different not because of different DNA, but because of their distinct 'catness' and 'dogness'. Discussions in the London sessions in particular, focussed upon the definition of a species. Some participants found it hard to accept a definition that a species of animal means 'those who can breed with each other, but not with animals from different species'. Rather, they preferred to see inherent distinctions between species (perhaps drawing unconsciously on pre-Darwinian taxonomies, or on religious and cultural traditions).

A link can be suggested between this finding and participants' responses to the question of Animals Containing Human Material. Participants were sanguine about the idea of different ACHM research experiments because *they did not really believe that what was being*

discussed was sufficient to threaten the boundaries between human and animal; nor even could they imagine what kind of research could pose this threat.

4.2 Ethical concerns about animals

Of significant importance were the thoughts and feelings about animals and the use of animals in research. This research found nothing to contradict previous studies which have shown that many people in the UK are personally concerned about animals and animal welfare[34].

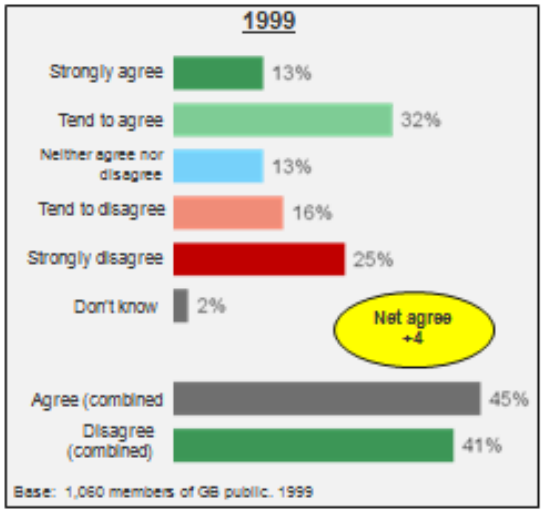
However, this varied considerably between individuals and whilst there were some who were very concerned, it was less of an issue for others. Amongst those who took a particularly strong view, there appear to be two main currents of concern: firstly, an emotional attachment to animals and/or distaste for pain; and secondly ethical, political or environmental reasons for not using or consuming animals (although these were raised by a minority).

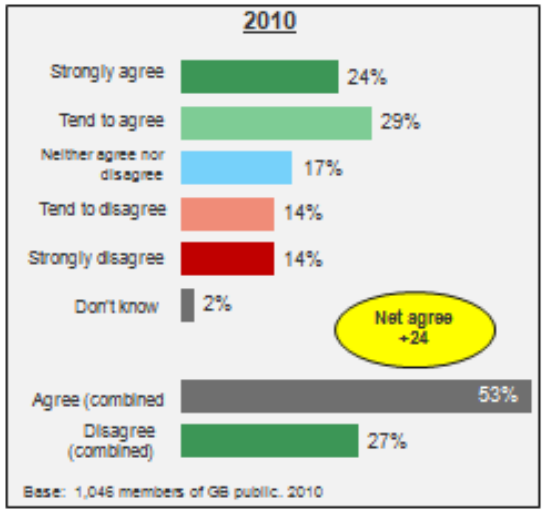
Quantitative Findings

A question about animal research in general terms was asked through the nationally representative survey and the results are shown in the table below. It indicates that broadly one in four people disagree that general animal research should be allowed, which is a large minority of the population, however it should also be noted that this number has decreased significantly over the last 10-11 years.

Support/opposition for animal experimentation

Some scientists are developing and testing new drugs to reduce pain, or developing new treatments for life-threatening diseases such as leukaemia and AIDS. By conducting experiments on live animals, scientists believe they can make more rapid progress than would otherwise have been possible. On balance, do you agree or disagree that scientists should be allowed to conduct experiments on live animals?





[34] See section 2.3 of associated literature review, and also http://ipsos-uk.com/DownloadPublication/1343_sri-views-on-animal-experimentation-2010.pdf

This analysis is consistent with earlier studies[35] which describe how belief in animal cognitive functions ('belief in animal mind') and the 'similarity effect' (the extent to which people recognise human properties in animals) work to produce a 'hierarchy of privilege'; a mechanism to help people balance dissonant feelings about both liking animals but also using them - for food and other purposes. Developing these themes in the discussions about ACHM research, there appeared to be two key dimensions to participants' underlying beliefs about animal research: a) the type of animal; and b) the level of suffering.

Firstly, regarding the type of animal, it is possible to categorise animals into four groups, depending on how people tend to think about them:

Cats, dogs and monkeys: Participants were explicitly more troubled about research on cats, dogs and monkeys, to the extent that many would not countenance any research on these animals or would do so only if it was really necessary. A key aspect of this view is the capacity of these animals to demonstrate emotions and personalities, often as evidenced in their own pets. With monkeys, it also reflects the levels of understanding and communication that monkeys are known to exhibit. There may also be other animals in this group, for example bears, cetaceans, birds of prey, elephants, etc. but this research did not explore this in detail[36].

Farmyard animals such as sheep, cows, pigs and goats: Whilst not having the same level of attachment, participants displayed positive feelings and affection towards these animals. However, they were also seen as having a high use-value (as distinct from the *inherent* value of the lives of humans, and even some pets), so people expect them to be used in research. The greatest concern was perhaps that the uses become accidentally mixed-up, e.g. contaminated meat.

Lower level animals: This group primarily consisted of rodents, amphibians and fish. They are seen as lower, both in terms of cognition and their capacity to show human like qualities. Participants were usually much more accepting of research involving these animals.

Invertebrates: As an extension of the above, people seemed more willing to accept the use of this group.

The other key dimension to understand is the thought of animals *suffering.* The analysis suggests that this should be distinct from the thought of animals dying, which is arguably less problematic for many (especially if they are meat eaters). The thought of animals in distress or prolonged discomfort was the really disturbing factor for many participants. As such, where suffering was seen to be occurring, people were generally against the use of farmyard and lower-level animals (in addition to those in group one).

> *"I know they are dirty and there are thousands of them. But it is pain. A mouse feels the same pain. I'm not saying protect the millions of them. But I feel pain is pain to be honest."*
> London, day 1

> *"A human would express pain in an experiment. Why should an animal go through what a human isn't prepared to go through?"*
> London, day 1

It also important to note that although pain was regarded as the most severe form of suffering, the notion was also applied to animals' ability to live a normal or natural life.

---

[35] Sarah Knight, Karl Nunkoosing, Aldert Vrij, and Julie Cherryman (2003): Using Grounded Theory to Examine People's Attitudes Toward How Animals are Used. http://www.port.ac.uk/departments/academic/psychology/staff/downloads/filetodownload,71760,en.pdf

[36] Earlier Ipsos MORI research describes these difference in perceptions in relation to mice and monkeys. See http://www.ipsos-mori.com/Assets/Docs/Archive/Polls/ns990308.pdf

Hence, just living in a laboratory was regarded by some as a form of suffering, as was changing an animal to the extent that it could no longer relate normally to other animals.

There were two further dimensions to participants' concerns about using animals in research which were less frequently discussed:

- A small number of individuals expressed the view that the scarcity of the animal was important. Whilst it was never suggested in the stimulus materials that experiments might be conducted with rare animals, individuals did want to point out that they would find this very unacceptable.
- Cultural dimensions were also sometimes important. This was particularly around the use of pigs, which have a distinct status in some religions/faiths. One or two individuals cited this as a reason for their unwillingness to accept organs grown in pigs.

4.3 Religious and other personal world-views

Participants in the general public dialogue were recruited to be typical of the UK population so that people with religious views or a faith were represented at the events, both in Newcastle and London. This was in addition to the separate group discussion held with people who had strong faith (defined through a question which asked whether religion played an important role in their daily life). The different religions represented in the discussions were Christianity (Catholic, Protestant and other denominations), Islam and, to a lesser extent, Hinduism.

Participants with religious values or a religious perspective did sometimes bring these values to bear during the discussions, but most people considered the topics without reference to God or religious teaching. Across all of the discussions there appeared to be only one individual who objected to research involving ACHM for religious reasons. The more common view of those with faith was to support any work which had the potential to save or improve human life.

Those who did not express religious views did not seem influenced by other meta-frameworks, whether ethical or political. Rather, tacit views about what is right and wrong appeared to be combined with other sensibilities and prejudices, and then applied to specific situations. Perhaps a more important influence was knowledge of history and the capacity to draw comparisons between what was being discussed and events in the past, which provided a framework in which the benefits and concerns could be considered.

Finally, it is worth noting that the generally secular nature of the discussions was even noticed on occasions by the participants themselves. In Newcastle, one group speculated on how the discussions might differ if they took place in more religious communities, such as parts of the United States. It seems that participants were aware of the relative pragmatism of their approach and were comfortable with taking this position.

4.3.2 A broad typology of values

Although there was little overt affiliation to religious or other systems of belief, participants value systems can still be broadly categorised, and three ways of looking at the world seemed to emerge through the discussions. These expressed how participants viewed the environment, the ethical status of humans, and the relationship between humans and animals. As with the earlier typology in section 3.4.3, these are more appropriately seen as tendencies which people exhibited to a greater or lesser extent.

Type 1: Humans have dominion over the animals; they are the highest form of life and are therefore morally sanctioned to improve and sustain lives by using animals.

"God made all the animals and then he made man to be in charge of animals and take charge of the world. We have ability to do that. Animals look after their own, you wouldn't see an elephant look after a lion."
London, day 1

Type 2: Humans and animals have similarities, which means that humans should respect and not abuse animals. However, at the same time there is an order of beings (in terms of intelligence and emotional capacity), such that when it comes to trading off the needs of different species, the higher level species should prevail.

"Suffering of an animal? I don't believe in it. But My life or animal life? I have to come first. I can contribute more to the world than the animal."
London, day 1

Type 3: Humans and animals should be seen as morally equal inhabitants of the same biosphere. Because humans are so numerous and because of their inherent selfishness and hubris they are exploiting the environment for their own ends. The idea that humans have moral superiority over animals is at least debatable, and perhaps even a harmful misconception.

In the above schema, most of the participants would usually occupy the middle ground (type 2). Attitudes verging on type 1 and 3 were also heard, though less regularly. Communicators may need to be aware of these different ways of looking at the world, as these may influence discussions and dialogue around ACHM research within society as a whole.

4.4 Understanding of and attitudes towards science and medicine

4.4.1 Knowledge of science

Many earlier studies have investigated what people understand about science, and their perceived knowledge of recent developments. Most recently an Ipsos MORI survey of the UK population[37] found that only 4% feel 'very well informed' about recent scientific developments, whereas nearly one in four (23%) felt 'not at all well informed'.

Consistent with this, the dialogue found that existing knowledge of science varied considerably and was limited in places (although it should be noted that anyone who said that they felt 'very well informed' about 'scientific and medical research' were excluded from the dialogue process).

Whilst it was not an aim of the dialogue to segment people by their general levels of knowledge, an important observation is that only a minority appeared to know a lot about either science or medical research, whilst a greater number held a mixture of some basic science and miscellaneous references to news/media stories. This mixture or lack of knowledge was recognised by participants themselves. For example, when asked what they had most valued during the process many responded that it had been the opportunity to meet and talk to 'real' scientists, and to improve their understanding of what they do.

"It was quite interesting to have taken part in something like this, especially if you've got a background where you don't know much about science, so it's made me more aware of what's going on and the world that's behind the scenes working on curing diseases."
Newcastle, plenary day 1

[37] Ipsos MORI/BIS (2010): Views on animal experimentation

Importantly, despite a lack of detailed knowledge most participants could find ways to engage with the topics and talk about them. This was even the case in the special interest groups in which participants were given little basic scientific information. Among the more commonly understood concepts and information were:

- Cells - the idea that everything living is made of smaller things which are quite similar.
- DNA - that who and what we are biologically is determined by the properties of a chemical that we inherent from our parents.
- The value of animal research – the idea that animals are sufficiently similar to humans to do research on them.

Aside from these there were many areas where knowledge was more limited. This prompted questions to the scientists throughout the dialogue process. The areas of greater uncertainty or lack of knowledge are described below:

What goes on inside a laboratory? The actual business of running or working in a laboratory was something that people did not know much about.
How is science funded/planned/conducted? This included lack of knowledge about the institutions involved, how it is decided what to research, how methodologies are decided upon, how information is shared between scientists, or how research is funded.
What is the role of industry in science? Participants were broadly aware that businesses were involved in science, and were rather suspicious about their motives and practices. However, it was not known how much influence business has, how they exert that influence and how they tend to use the results. It should also be noted that when participants talked about business they were generally referring to large multi-national corporations; there was little knowledge about smaller science companies.
How is scientific and medical research regulated? Participants were aware that there are *rules* but not what these rules were, who enforces them and how.
What is the scientific method itself (including hypothesis testing, peer review)? There were varying degrees of knowledge about the process of scientific discovery - for example the need for exploratory research, trial and error, hypothesis testing, peer-review and so on. There were certainly many participants who seemed not to appreciate the extent of work that is needed before treatments can be developed (although there was recognition that treatments seemed to take a long time to become available). This limitation in participants' knowledge ultimately had a bearing on their interpretation of the purposes of research as described in ACHM research case-studies (and ultimately on how they judged acceptability). Without appreciating that exploratory research is essential, participants would be more likely to say that the examples presented were too remote from actual treatments and therefore less important, unjustified, even frivolous. It may also have led to unrealistically high expectations about when the treatments from research might be available.
How are animal subjects sourced? How are they used? Some participants did not know where the animal subjects used in medical research came from (that they are bred especially rather than being captured in the wild). This confusion was also extended to the supply of material such as cells or DNA for in-vitro experiments, some participants did not appreciate that cells and DNA can be extracted without harm. In contrast, facilitators often found that they had to be quite explicit about the fact that animals could experience suffering or death, as participants did not necessarily draw that conclusion for themselves.

4.4.2 Attitudes to science

Many earlier studies have shown varying levels of trust and favourability towards science. In the 2002 ESRC study[38], the authors coined the phrase "critical trust" which was used to describe "a practical form of reliance on a person or institution combined with some healthy scepticism", a concept that seems to have been reflected by this public dialogue on ACHM research. Essentially, participants were generally very aware and very grateful for the benefits that medical science had provided them and their families; for example it was widely felt that increases in life-expectancy were attributable to the work of medical scientists over the last century.

> *"All the scientists in the world today are doing marvels. My uncles died in their 50s and now people live till they are in their 80s and 90s."*
> Newcastle, day 1

However there were also some more negative views, and in describing these it is probably worth drawing the distinction between 'medicine' and 'science'. The former was viewed with almost universal acclaim because of associations with health and the National Health Service, whilst the latter can sometimes be associated with more negative aspects. The two prominent negative discourses about science are described below.

Firstly, it was felt that some science is undertaken by big business or multi-nationals without ethical or societal considerations. Scientists employed by these companies are believed to do experiments or develop treatments with profits in mind, which favour the rich, overcharge the NHS and fail to pass on the benefits of their research to the poorest people in the world. Whilst there were many people in the discussions who were aware of the argument that research innovations might be driven by profit, this was rather begrudgingly acknowledged and the prevailing mood remained either sceptical or exasperated by the dilemma it posed.

> *"You have to have safeguards in place as the bottom line is profit and not ethics."*
> *Newcastle, day 1*

The second negative view was that there are individuals within the scientific community who cannot be trusted or who possess an inherent curiosity that will inevitably find an outlet. These scientists are typically imagined to be working in secluded or secretive places without supervision ("behind closed doors"). They were also perceived to be more motivated by curiosity or fame than altruism and will take risks to further their research without due regard to the risks. From the analysis, it seemed that this discourse is recognised as somewhat fictitious or far-fetched. However, participants did seem to keep it at the back of their mind and used it to test the parameters and the robustness of regulation. There were also echoes of the discourse in the way people talk about the enforcement of regulation; that no matter how good the regulatory system is there will always be rogue scientists who evade the authorities and the rules.

An important corollary of the 'rogue scientist' discourse was the notion of the unregulated foreign scientists who might take things too far, for example scientists in other countries who lack the correct principles or are unaware of safety procedures. There was also the notion of the miscreant domestic scientist who opts to emigrate to other countries with less regulation and concern for malpractice. For some participants this was a key concern and strongly influenced the boundaries and controls they would set around ACHM research.

> *"You trust your doctor and your scientists. Not in other countries but the UK is fine."*
> *Newcastle, day 2*

[38] ESRC (2002): Public Perception of Risk, Science and Governance

5. Reflections on the dialogue process

5. Reflections on the dialogue process

This section addresses the following aim of the dialogue:

To enable the Academy and the wider science community to build on previous experience in public dialogue, to pioneer innovative approaches in public engagement where appropriate, and to develop knowledge and understanding of public dialogue and its potential for future applications.

5.1 Overall dialogue design

Overall, we believe that the structure of the dialogue process has been effective in understanding public attitudes towards ACHM research and then testing the extent of these attitudes through a nationally representative survey.

- The initial general public dialogue sessions were effective at exploring participants' initial reactions and how these changed as different information was introduced. Participants responded to the discussions in a largely engaged and interested manner.
- Presence of observational researchers helped us identify what people were thinking as well as saying, through body language and other signs, thus adding to the robustness of the findings.
- The special interest groups were effective in focusing on people who we suspected might have different views. The animal welfare group in particular highlighted a different perspective, which has greatly added to the results.
- The one-to-one follow up interviews were effective in helping to target issues and further questions that emerged through analysis, providing an additional opportunity to go back to people and explore variations on the original issues.
- The nationally representative survey used a standard approach.[39] The advantages of conducting the survey after the qualitative components were demonstrated, as the wording and content of the questionnaire reflected peoples' concerns and the analysis of the survey results was consistent with that of the qualitative data.

Whilst we suggest that this dialogue structure has proved to be effective, the one improvement which might be considered for future dialogue was that it would have been useful to convene **greater numbers of the special interest groups** to assess how typical the views expressed were.

The remainder of this chapter will focus in more detail on the qualitative elements of the dialogue.

[39] See, for example http://www.lse.ac.uk/collections/manpower/datasets/wrps/ukWprs/bWRPSintroduction_v3.pdf and http://ukpollingreport.co.uk/blog/faq-sampling

5.2 Reflections on the qualitative elements of the public dialogue

Background to the public dialogue approach

Public dialogue is a qualitative research method which aims to improve understanding of how people conceptualise issues and trade-off different ideas and priorities. It is most appropriately used when (as is the case for ACHM research):

- the question to be discussed is complex;
- there are a range of disputed points of view on an issue, or a range of different ways of framing a question - these may all be valid, but different stakeholders may express the core questions or issues differently;
- the public know little about the area for discussion before the dialogue, or, specific technical knowledge is needed before a truly informed view can be expressed.

They key to good dialogue is capturing how public perceptions of an issue develop as more, and different, information is provided. This enables researchers to capture both spontaneous, and mostly uninformed, views towards an issue, as well as more considered responses and trade-offs. In this dialogue, information was delivered in a variety of ways, including fact-sheets, a film, case studies and face-to-face contact with scientists.

Dialogue is felt to differ from more traditional deliberative research approaches by bringing scientists, and other experts, into direct conversation with public participants. In practical terms, this means scientists joining small groups of participants rather than presenting a one-way flow of information to the room. Experts become an ongoing resource for participants. The aim is for participants, as far as possible, to lead the dialogue and seek answers to the questions they want, and need, to pose so that they can come to their own understanding of the issue.

Many different approaches were used to capture views during the ACHM research dialogue. This included small group sessions and presentations, larger discussions, plenary presentations, exercises to complete, homework tasks and questionnaires to gather individual thoughts.

By providing the views of a general public group, the dialogue process is intended to highlight the principles and priorities that are likely to be present in public discourse on a given topic. The qualitative elements of this report therefore reflect the views of a group who have focused on an issue and been through a range of complex arguments. Their views changed during the process – some shifted and maintained these altered views at the end, while others moved between different points of view and returned to their original views later. It can be reasonably assumed that the concerns, priorities and principles they expressed as they went through this process reflected those of other general public groups, (had they the time and space to interrogate the issues). In some cases numerical indications of views from pre- and post-dialogue questionnaires have been included. These are illustrative of the views of a very small sample, rather than statistically valid quantitative findings.

Knowledge of ACHM research developed through the dialogue process

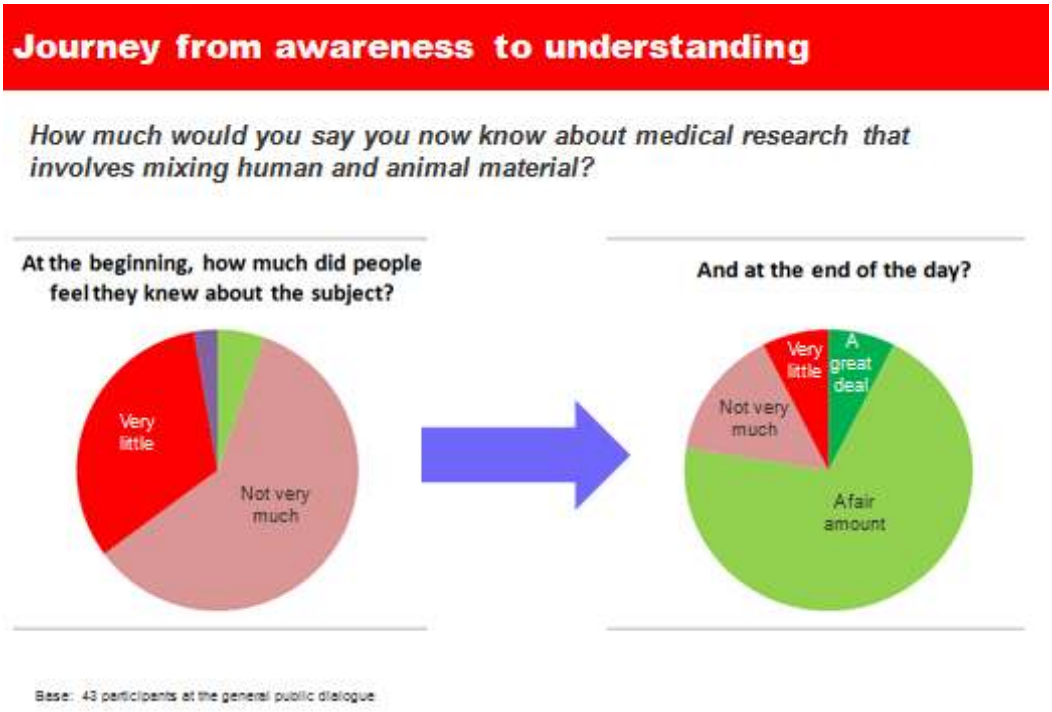
As was noted in section 3.1, most participants had at least some knowledge of research or experiments they felt were similar to ACHM research and, as such, when ideas were introduced participants did not seem particularly surprised. This lack of surprise did not, however, mean that participants were not curious or interested. Indeed, the case studies generated a large number of questions, especially as the more unique aspects of them were pointed out. The most frequent questions were:

- How exactly is the animal treated? Where does the animal come from? How do you extract the parts you need? What happens to the animal at the end?
- How is material taken from humans?
- How have you reached the point where this research is needed?
- Why couldn't another approach provide the answer you need?
- What safeguards are put in place? How do you stop contamination?
- How likely is it that this research will lead to a cure? When will that cure be available?
- Who is doing the research and who will benefit from it?

The case study phase of the dialogue was completed on the first day of the general public dialogue. Through discussions and the evaluation forms, we were able to confirm that the information participants had received had increased their levels of knowledge about ACHM research considerably, as well as wider knowledge.

> *"The amount of information we were given and the effect it had on our discussions. By the time it was 3 in the afternoon everything was being discussed very sensibly. This has changed our views considerably. This wouldn't have been the case if we were asked this without the information."*
> Newcastle, day 2, plenary first thing

Another indication of increased levels of knowledge is shown in the chart below, which displays how participants perceived their own levels of knowledge at the beginning and end of the day.



Following the case study approach taken on day 1 of the public dialogue, day 2 focused on future possibilities for the research. Some suggestions were deliberately far-fetched or provocative in order to encourage exploration of the limits of participants' acceptance of ACHM research. Whilst this approach was effective in encouraging people to talk about their concerns (and in exploring the ways in which ACHM research was something more or different to existing research) it remained a challenge to get participants to imagine the more dramatic implications of the ACHM research. As noted in section 3.3, participants were generally unwilling to engage with or accept these implications, or to take them seriously, although several participants did express fears.

Other observations about how knowledge and interaction developed

Observations about how groups reacted to information about ACHM research and reflected upon them in a group context are shown below. The importance of these observations is two-fold: firstly, they provide further background to participants' judgements about ACHM research; secondly, they offer reflections on the validity of the deliberative process.

Sensitivity: The format for the general public dialogues was to bring together around 20 people who had not met before and were broadly representative of the cities in which they lived. This meant that all discussions involved participants considering formidable and sometimes quite personal subjects with strangers. This fact appeared to apply subtle constraints over participants, and we noticed occasions when people were maybe not saying things they would have liked to have said (which were then explored through later conversations). For example, a participant in the London meetings was seen to be suppressing her views because she did not feel sufficiently confident, or that it would be inappropriate, to set out her deeply-held and quite complex religious views about the relationship between human beings and animals. Such meetings are not always conducive for the implications of personal values to be properly explored. Facilitators responded to this through engagement in one-to-one discussions, both on the day and afterwards through follow-up interviews.

Polarisation: It was sometimes observed that views became polarised, especially if 'pro' and more 'sceptical' views were strongly held and promoted by persuasive participants. For example, the Newcastle meetings provided some evidence of how moderate views could be hidden under the surface. A breakout group was dominated on day 1 by the view that everything should be allowed. A different group on day 2 contained a contrasting balance of views and this, together with the facilitator pushing for other views and the reading of homework, allowed alternative views to emerge and the areas of doubt to become more apparent. Interestingly, these areas of ambiguity were lost again when it came to the group presenting their final conclusions in a plenary session. One group, which contained the most 'anti' viewpoint', became dominated again by a person with a strident 'pro' view, who actually wrote the script of the presentation.

Framing: Participants were offered a fair amount of technical information early on and, as described in this section, given examples of ACHM research that were generally more likely to be acceptable first. This does raise the question of whether starting off with less extreme examples subconsciously shifted participants' boundaries of what is acceptable, so that by the time they came to the more provocative examples they were more likely to find them admissible. Similarly, there is the question of whether framing the examples in scientific terms led participants to judge them according to criteria that are more utilitarian than moral or political. Moreover, there were a number of examples of participants saying that their views had changed as they learned more, which raises the possibility that their views would have changed in different ways if the issues and examples had been framed differently.

Because of concern about framing, after the first event in Newcastle the discussion guide was altered for London, so that preliminary views were collected before any examples were

given or other information imparted. The conclusion, based on subsequent observations of the London meetings, was that fairly consistent views did emerge when approached from different standpoints, and that participants' ethical views and boundaries remained essentially consistent, even as they became better informed.

5.3 Contribution of scientists

Professional scientists assisted in the general public dialogue. Two scientists were available on each day so that small discussion groups (of about ten people) each had access to the scientists present. [40] The information provided to scientists on their role is shown at Appendix A3.2.

The scientists in the general public dialogue were active throughout the two days, answering questions mainly about the science behind ACHM research and the scientific reasons for doing it, but also about how science works (for example funding, regulation and the amount of time needed to do research). This proved to be very interesting for many respondents and the conversations flowed into informed and productive discussions. It was also noted that the participants regarded the input from scientists as serious and authoritative. These observations were then borne out through the follow-up interviews, which showed that many participants regarded the opportunity to talk to scientists to be the most interesting and informative aspect of the experience. However, two tensions emerged, which we would recommend considering when conducting future dialogue with scientists.

The attending scientists had the inclination to quickly disabuse groups of misconceptions or misinterpretations, whereas in some instances the facilitators would have preferred to investigate and record these further. The outcome of this is that whilst the groups became increasingly correctly informed, discourses that could prevail in more uninformed discussions might have been less widely heard. To address this, the day was designed to look at the same ideas in a number of different ways, plus participants worked in small groups during the day and not everyone heard every comment by every scientist. Furthermore, as more than one scientist was present, participants were able to hear views expressed in different ways. Our analysis for this report has brought together the main concerns from many conversations between different groups and over the course of the days, hence individual comments are unlikely to carry more weight than they deserve.

Occasionally, discussions could digress to off-topic issues, either because participants had particular interests that they wanted to talk to scientists about, or because the scientists veered towards their particular specialism. On one level, this is an important part of the dialogue process in that people should be free to explore in their own terms, but from a social research perspective it is important to remain focused on the study objectives.

In contrast, scientists were not recruited for the special interest group discussions and much less scientific information was given to participants. This provides an opportunity to reflect upon the relative merits of the two approaches. Firstly, it was certainly the case that participants in the special interest groups were able to have good discussions about the issues without any basic scientific information provided (just the case studies). However, secondly, in part because of the time available but also because scientists were not present, these discussions did not develop or evolve to the same extent; rather viewpoints were established and recorded, but there was little opportunity to reflect upon these.

[40] Details of the scientists who joined the sessions can be found in appendix A3.1

5.4 Observational research

Observational researchers were used to observe and interpret the dialogue, without being involved themselves in facilitation. The value of observational researchers proved to be in providing an additional strand of data on which to build hypotheses about how participants thought and felt about the issues under discussion. It was also an effective tool for validation, in that ideas generated through the main analysis process could be compared to those of the independent observational team and modified or reconsidered if necessary. During the days themselves observers were also a very helpful resource for highlighting individuals who were not participating or forthcoming with their views, and for taking remedial action to address this (for example talking to individuals one-to-one or highlighting issues to moderators).

A lesson from this dialogue is that viewed as a stand-alone piece of work, the outputs from observational research need to be treated in the right way. This is because:

- the number of individuals observed intensely was relatively small, and it is impossible to know to what extent their thoughts and feelings were typical;
- the conduct and behaviour of every group affects its members - it may be that these same participants would have thought and felt differently in a different group or in a non-group context;
- the researchers' observations were by definition subjective; with this in mind, the observational research field notes were written up into a separate document, which has been drawn upon in the writing of this report.

Notwithstanding these reservations, combining the work of observational researchers with those of the wider dialogue team has been shown here to be valuable, and has contributed significantly to the findings presented in this report.

Appendices

Appendices

A1 Materials used in qualitative dialogue

Hybrid cells, developed in the lab, that never grow into animals

What is this?
Cells are taken from human or animal tissue and grown in a controlled environment such as a test tube ("*in vitro*").

They can be stored and can continue to reproduce. There are many cell banks where different types of human and animal cell are kept so that further research can be done on these cells.

Since the 1960s scientists have been able to fuse two cells together, for example cells from a human, and a mouse or hamster cell line. These *hybrid cells* contain genes from each species.

Why is it done?
Thousands of cells like these have been generated since the 1960s, involving many different species combinations. These have contributed extensively to knowledge of human genetics and cell biology.

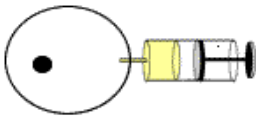
For example, these hybrid cells helped scientists in the 1970s map human genes, leading to the Human Genome Project – mapping the sequence of all the 20,000 – 25,000 genes of the human genome.

Nowadays introducing human genetic material into a mouse cell in the lab is a standard procedure in laboratories across the world. Those cells are used for further research, both exploratory and to test new treatments.

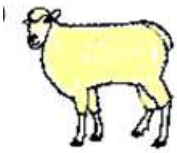
For example, scientists can learn about genes that turn normal cells into cancer cells (oncogenes), by transferring DNA from human cancer cells into mouse cells; the difference between the species helps to identify the relevant gene.

Human proteins from sheep, cow, or goat milk

Human gene is added to sheep embryo…



which grows to become a…



Transgenic sheep with human protein in milk…

Which is extracted and used in medicine.

What is this?

Scientists can make animals which produce human substances by adding a human gene to a cell within an animal embryo.
In 2000, researchers inserted the human gene for *alpha1-antitrypsin*, a human protein, into a sheep genome. Sheep were born which produced milk containing a very high proportion of this protein.

These sheep are called "transgenic" animals, because they contain genetic material from another species.

Very recently biotech companies have been able to market the proteins that the "transgenic" sheep, goats, and cows produce. Hens are also in development that can produce proteins in egg white.

The proteins must be harvested and purified before they can be used.

Why is it done?

The proteins which are produced can be used to treat people who lack these because of disease.

For example, some people are deficient in 'antithrombin' which can mean they have a tendency to blood clots – they can be treated with a protein from a transgenic animal.

Why do we need to use animals? It is more difficult and expensive to make these kinds of proteins in a lab, because they are made of complex molecules. Molecules taken from a human would have to be extracted from tissue or blood, which makes them very expensive and there is a risk of infection.

Mouse liver with human liver cells

What is this?
Recently, scientists have taken human liver cells and implanted them into the liver of a mouse. The human cells grow and populate the liver, so that it responds more like a human liver.

Why is it done?
The mouse can be given human diseases that attack the liver, such as Hepatitis B and C, or malaria, and the researchers can test the effects of different therapies.
You can study liver cells taken out of the body, and this will help to provide some information – but studying the biology of cells in real working liver gives more accurate results.

Also, when new medicines are being developed, there is a legal requirement to test them on animals before testing on humans. This includes testing for toxic reactions in the liver, the body part responsible for the breakdown of chemicals, medicines and toxins.

Animal cells and organs sometimes behave differently from human ones; so by making the mouse liver as near as possible to a human liver, medicines might be tested more effectively before moving to human trials, making the process quicker and safer.

?

Future possibilities…

It may be possible in future to grow a human liver inside a pig, and then use the liver for a liver transplant into a human.

Normally, if you transplant material from one (human) person into another, the body will reject it. This type of reaction is even more severe between species.

In this future, it might be possible to genetically modify pigs so that human bodies would not reject transplants from them.

How close is this to happening?
Humanised pig livers have already been used in 'extra corporeal transfusion' – using the livers outside the body (like artificial kidney dialysis machines), as a way of keeping patients alive until they can have a full transplant.

Huntington's Disease in monkeys

Huntington's is incurable and hereditary – it is caused by a single abnormal gene which causes certain nerve cells in the brain to waste away.

In 2008 researchers developed monkeys which contain the human gene responsible for Huntington's disease in humans.

These monkeys will be used to investigate how Huntingdon's disease develops and progresses, and may in the long term help to support the development of new treatments.

The gene which is given to the monkeys makes their brains degenerate in a similar way to Huntington's patients. In early studies, several monkeys born carrying the gene died at an early stage, but at around 10 months of age one developed involuntary movements of the hands and face (which might be comparable to Huntington's symptoms).

Down's syndrome in mice

Some people are born with Down's syndrome, a genetic disability caused when a baby inherits an extra chromosome. It affects not only physical appearance, but cognition and intellect - your ability to learn and develop mentally. It is a lifelong condition and there's currently no cure.

To help study Down's Syndrome, a team of researchers in London have created a mouse strain that carries an almost complete extra copy of human chromosome 21 – just like people with Down's syndrome. This means that the mouse has thousands of human genes transferred into it.
The mouse could prove to be a valuable way of studying of human Down Syndrome, and in many ways is the best option currently.

In part, the mouse has been developed to help to understand aspects of Down's syndrome that research may be able to help with - for example, one of the biggest worries for parents is that many individuals with DS succumb to early onset Alzheimer's disease.

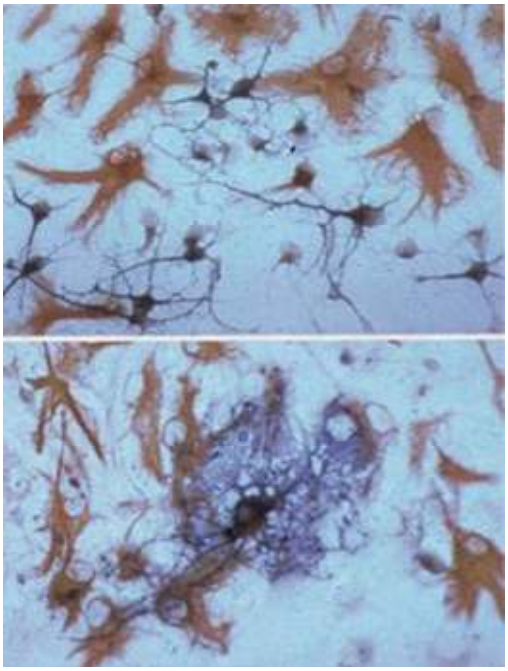
Stroke in rats and monkeys

Stem cells are cells which have the potential to develop into a range of different types of cells and tissues. As part of working towards developing a therapy for stroke, a drugs company put human stem cells (a type that would develop into brain cells) into the brains of rats.

The stem cells were able to grow into human brain cells within the brain of the rat.

To develop a possible treatment further, before trials could be attempted in humans, the company were obliged (by regulatory authorities) to study what happens when the same cells are put into the brains of non-human primates.

Stroke is a brain disorder which causes damage to the nerve cells in the brain and a loss of bodily functions. Researchers are now testing a new form of stem cell treatment by injecting specially prepared human stem cells, which should grow in the brain of the patient and repair damaged tissue. Without a stage of developing this on animals first, this would not have been possible.



Brain stem cells

Quiz : Work together on your tables , see how many you can get…

EXPLORING THE BOUNDARIES
public dialogue on animals containing human material

1) Three of these creatures have actually existed, and three are made-up. Tick the ones you think are real?

A "Minotaur" – a cross between a human and a bull

A "Liger" – a cross between a lion and tiger hybrid

A "Zeedonk" – a cross between a donkey and zebra

A mermaid – a cross between a human and a fish

A Russian talking meercat

Homo Habilis –a close relative of both chimpanzee and humans

2) By roughly what percentage do human DNA sequences differ to the DNA sequences of?

1) Other humans_____ 2) Chimpanzees_____

3) Mice_____ 4) Cabbage_____

3) How many genes does a human have? (Tick which you think is correct)

1) About 20,000 _____ 2) About 100,000_____

3) About 4,000_____ 4) About 10,000,000_____

Quiz : Work together on your tables , see how many you can get…

EXPLORING THE BOUNDARIES
public dialogue on animals containing human material

4) Down a microscope, how can you tell the difference between a human cell and a mouse cell? (Tick which you think is correct)

1) Mouse cell is smaller_____ 2) Mouse cell has a tail_____

3) Mouse cells are less regular_____ 4) Mouse cells grow more quickly_____

5) None of the above_____

5) When did researchers first fuse human and animal cells together?

1) in the 1990s _____ 2) They haven't succeeded in doing it yet ____

3) in the 1960s_____ 4) In the 1930s_____

6) Which of these examples involve introducing human materials to animals? (Tick which you think is correct)

1) Mouse with a human-like ear on its back 2) Chimps able to use sign-language___

3) Dolly the sheep_____ 4) Mouse used to study Alzheimer's disease

5) A talking parrot_____ 6) None of these_____

7) By law which of the following must take place before and during any licensed scientific animal experimentation?

1) Monthly unplanned visits by inspectors

2) Provide proof that the research cannot be done using non-animal methods

3) An ethical review that examines the ethics of proposed projects

4) Provide proof that the potential results are important enough to justify use of animals

5) All of the above _____

6) None of the above_____

The meaning of some of the words you might hear today….

Cell: A cell is the basic unit of all living organisms. Many organisms are unicellular, i.e. live as single cells (bacteria for example). Mice and humans are multicellular, comprised of many hundreds of different types of cell, which cooperate to make a living being.

Chimera: In scientific research, a chimera is an animal made up of cells of two different animals. These can be of the same species (e.g. mouse + mouse) or different species (e.g. mouse + human).

Chromosome: A structure made up of thousands of genes. Although humans and mice have a similar number of genes, they have different numbers of chromosomes (46 & 40, respectively) - the genetic material has been mixed up during evolution.

DNA: An acid that contains the genetic instructions used in the development and functioning of all known living animals and plants.

Gene/Genetic material:. A single unit of biological information. Genetic material can be more than one gene or less than one.

Genome: This refers to the total "blueprint", i.e. the sequence of all the DNA of all the chromosomes; e.g. human genome or mouse genome.

Germ cells: These are specialised cells normally destined to form eggs in a female and sperm in a male. They are set aside early in the developing embryo and are distinct from normal body cells, which will never contribute genetic material to offspring. They have nothing to do with germs, which make us ill.

Hybrid: An animal or plant or even a single cell that is a mix of two distinct genomes that had been kept separate. For example, a mule is a hybrid between a horse and a donkey. Many plant varieties in our gardens are hybrids. An animal egg fertilised with a human sperm is also a hybrid (to assess male fertility), as is a human cell fused with an animal cell.

In vitro: This literally means "in glass" (such as a test tube, but it can be in a plastic dish, or any other type of container. It is used to describe experiments conducted outside an animal or human body (which would be "in vivo" experiments).

Stem cells: These are special cells that have the distinct property of being able to renew and divide themselves and become different specialised cell types. There are many different types of stem cell. Those in the adult body tend to give only those cell types that are relevant to the tissue in which they reside – skin stem cells give skin cells, gut stem cells give cells of the intestines etc. Stem cells in the embryo, however, tend to have a much greater repertoire. So-called "embryonic stem cells", are obtained from embryos just a few days old. Because these come from such early embryos, they can give rise to any cell type in the body.

Tissue: The stage between individual cells and a whole animal. Your hair for example .

Transgenic: A transgenic animal is one that carries genetic material that has been introduced in the lab. The introduced DNA can be from the same species (e.g. mouse into mouse), or from a different species (e.g. human into mouse).

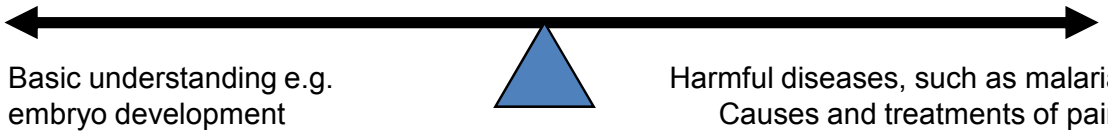
Regulation of animals in medical research

The Home Office regulates animal research.

What to permit?

The Home Office balances the degree of suffering (which may depend on the type of animal) against the potential benefit.

Less suffering acceptable? — **More suffering acceptable?**



Basic understanding e.g. embryo development

Harmful diseases, such as malaria
Causes and treatments of pain

The Home Office tries to continually improve research on animals, by …

Replacement — **Use non-animal replacements where possible**

Refinement — **Use the best techniques**

Reduction — **Use the fewest number of animals you can, to get the data**

BUT – the Home Office don't fully take into account the issues we're talking about today – incorporating human DNA or cells into animals.

To think about at home...

My name:
City:

Think about all you have learned today about scientific research which involves putting human materials into animals. At home, please think about these questions, complete the exercise, and bring it with you to the next event.

If you were the person who was writing the rules to regulate this area of science, what would you include?

Things I think should be allowed

Things I think should not be allowed

Things I think should be allowed under certain conditions (tell us what conditions?)

A2.1 Nationally representative survey questionnaire/findings

- Based on 1,046 interviews conducted face-to-face with UK public aged 15+ between 23 and 29 July 2010
- Data weighted to known population profiles
- Sample sizes for individual questions shown in brackets
- All figures presented are percentages
- Results do not always total 100% because of rounding
- A '*' represents a figure between 0 and 0.49

Introductory text

TEXT 1: **Medical scientists working in laboratories in the UK have been running experiments for a number of years which involve putting human materials such as cells or DNA taken from consenting adults into living animals.** ***They do this to learn more about how the body works and to study human health problems.***

TEXT 2: **Medical scientists working in laboratories in the UK have been running experiments for a number of years, which involve putting human materials such as cells or DNA taken from consenting adults into living animals**.

Q1 SHOWCARD **From this card how acceptable or unacceptable are these experiments to you?**

	Text 1	Text 2
	(565)	(481)
	%	%
Very acceptable	13	12
Fairly acceptable	35	27
Neither acceptable not unacceptable	19	19
Fairly unacceptable	15	14
Very unacceptable	16	23
Don't know	2	4
Refused	1	*
Acceptable	48	40
Unacceptable	31	37
Net acceptable	+17	+3

Q2 **Why do you feel that experiments which involve putting human materials into living animals are** (TEXTFILL) **(un)acceptable?** PRECODED LIST, INTERVIEWER CODES

Base: All except 'don't know' at Q1	(1,011)
	%
"Acceptable" responses	**53**
Can help to cure human health problems	35
I support medical science/progress	24
Do not see any problem with it	8
Trust scientists	6
Personal experience of illness	5
Curiosity/interest in what might happen	2
Don't care that much about animals	1
Is beneficial for the animals	1
"Unacceptable" responses	**46**
Concern about animal welfare/suffering	19
Against my personal views	11
It's unnatural/shouldn't meddle/'playing god'	10
Concern about where it will lead/slippery slope	6
Do not understand the reason for doing it	6
Concern about risk of contamination/disease/don't know the consequences	4
Don't believe that there are real benefits/they're just doing it for curiosity	4
There are alternatives to doing it this way	4
It's unpleasant/disgusting/"yuk	3
Against my religious views	2
Is being done for profit/business interests	2
Distrust scientists	2
May set a precedent for less reputable scientists	2
Other	*
Don't know	6
Refused	1

In the UK, experiments that involve putting human materials such as cells or DNA into living animals are done to learn more about how the body works and to study human health problems. Here is a list of other conditions which might be applied to these experiments, some of which currently apply in the UK and some of which do not.

Q3 SHOWCARD **Which, if any, of these would make you more likely to feel that these experiments are acceptable?**

I F MORE THAN ONE MENTIONED

Q4 **Which of these would make you *most* likely to feel that these experiments are acceptable?**

	Q3	***Q4***[41]
	(1,046)	(1,046)
Were only done to study *serious* health problems	40	19
Were only done in controlled laboratory conditions	38	12
Ensured any suffering experienced by animals was reduced as much as possible	40	11
Were done for a clear medical goal, rather than just to learn more	35	10
Were only done with human and animal cells outside the animal's body, for example in a test tube	21	9
Were the only way to study the human health problems concerned	31	9
Minimise the risk of 'contamination', eg. experimental animals breeding with other animals or affecting the environment	16	2
Did not change how the animal looked	11	1
Only used simpler animals or those less likely to have conscious feelings, such as mice or fish	14	1
Other	*	1
None of these would make me more likely to accept these experiments	16	16
Don't know	6	7
Refused	1	1

[41] Figures include those who said single codes, 'none of these' and 'don't know' from Q3.

Q5 SHOWCARD **Which, if any, of the following types of human tissue or cells do you think it is acceptable to use in experiments that involve putting human materials such as cells or DNA into living animals?**

Base: All	(1,046)
	%[42]
Blood cells	55
Skin cells	51
Heart tissue	47
Liver tissue	46
Brain tissue	45
Eye cells or tissue	45
Reproductive cells (such as egg or sperm)	42
None of these are acceptable	26
Don't know	12
Refused	1

Q6 SHOWCARD **If animals do not suffer severely through the process, which, if any, of the following types of animals do you think it is acceptable to use in experiments that involve putting human materials such as cells or DNA into living animals?**

Base: All	(1,046)
	%[43]
Mouse	52
Fruit fly	48
Fish	44
Rabbit	41
Monkey	40
Pig	38
Cow	35
Dog	35
None of these are acceptable	25
Don't know	9
Refused	1

[42] All acceptable figures include those who said that "all of these were acceptable" (37%)
[43] All acceptable figures include those who said that "all of these were acceptable" (32%)

Q7 **To what extent, if at all, do you trust the UK to have appropriate rules for regulating experiments that involve putting human materials such as cells or DNA into living animals?**

Base: All	(1,046)
	%
Strongly trust	11
Tend to trust	33
Neither trust nor distrust	21
Tend to distrust	15
Strongly distrust	14
Don't know	5
Refused	1
Trust	45
Distrust	29
Net trust	+16

Segmenting question, asked earlier in the questionnaire

Q8) **Some scientists are developing and testing new drugs to reduce pain, or developing new treatments for life-threatening diseases such as leukaemia and AIDS. By conducting experiments on live animals, scientists believe they can make more rapid progress than would otherwise have been possible. On balance, do you agree or disagree that scientists should be allowed to conduct experiments on live animals?**

	1999	2010
Base: All	(1,060)	(1,046)
	%	%
Strongly agree	13	24
Tend to agree	32	29
Neither agree nor disagree	13	17
Tend to disagree	16	14
Strongly disagree	25	14
Don't know	2	2
Agree	45	53
Disagree	41	27
Net agree	+4	+26

A2.2 Statistical Reliability

We express our certainty with regard to observed percentages as levels of confidence. In the following table, we have set out two of the more common tests for statistical accuracy.

(i) Confidence Intervals for a Single Percentage

Table A sets out the 'confidence intervals' which can be given to percentages, according to the size of sample used. The larger the sample, the narrower the band, and the more the observed percentage is likely to lie close to the true population figure.

Example: For a sample size of 300, and an observed percentage of around 20%, the table shows that there are 95 chances in 100 of the true percentage lying between 15% and 25%, in other words, our sample percentage of 20% is accurate to ±5%.

Table A: Confidence Intervals applicable to percentages at or near the following levels:						
Sample	5 or 95%	10 or 90%	20 or 80%	30 or 70%	40 or 60%	50%
Size	±%	±%	±%	±%	±%	±%
30						
50						
75						
100						
200						
300						
500						
750						
1000						
1500						
2000						

(ii) Testing Differences Between Two Non-Overlapping Percentages from the same sample

Type of use: Brand used most often, preference between brands

Example: For a sample size of 200, where the average of the non-overlapping is 20% we require a difference between two percentages of 9% for significance at the 95% level (of 196 standard errors).

Table B: Difference required between two percentages whose average is:						
Sample	5 or 95%	10 or 90%	20 or 80%	30 or 70%	40 or 60%	50%
Size	±%	±%	±%	±%	±%	±%
100	⊥	⊥	⊥	⊥	⊥	⊥
200	⊥	⊥	⊥	⊥	⊥	⊥
300	⊥	⊥	⊥	⊥	⊥	⊥
500	⊥	⊥	⊥	⊥	⊥	⊥
1000	⊥	⊥	⊥	⊥	⊥	⊥
1500	⊥	⊥	⊥	⊥	⊥	⊥

A3 Recruitment of scientists

Scientists were recruited through the British Science Association and paid for their input. The following scientists were involved at each of the events:

Event experts	
London Event 1	Dr Alex Dedman, Mental Health Sciences, University College London Dr Bettina Berndl, University College London, Cancer Institute
London Event 2	Dr Alex Dedman, Mental Health Sciences, University College London Dr Gregor Campbell, Cell and Development Biology, University College London
Newcastle Event 1	Dr Debbie Hicks, Institute of Human Genetics, Newcastle University Dr Sarah Robinson, Centre for Life
Newcastle Event 2	Dr Debbie Hicks, Institute of Human Genetics, Newcastle University Prof John Burn, Institute of Human Genetics, Newcastle University

A3.1 Stakeholders who contributed to the development of materials

The following people all contributed to the development of the case study materials used during the dialogue process

Barbara Davies (Understanding Animal Research)
Brendan McCaarthy (Church of England)
Frances Rawle (Medical Research Council)
Geoff Watts (Freelance)
Maggy Jennings (RSPCA)
Isobel Pastor (Department for Business Innovation and Skills)
John Sindon (Reneuron)

The following stakeholders attended a preliminary meeting to discuss materials for the dialogue on 22 April.

Dr Sara Ellis (AMRC)
Dr Brendan McCarthy (Church of England)
Lee Perry (GlaxoSmithKline)
Isobel Pastor (Department for Business Innovation and Skills)
Sophie BrosterJames (Medical Research Council)
Maggy Jennings (RSPCA)
Barbara Davies (Understanding Animal Research)
Jacob Leveridge (Wellcome Trust)

In addition the following stakeholders were Interviewed by phone ass part of the process of developing materials for the dialogue

Professor Gill Bates (King's College London)
Dr Alison Harvey (King's College London)
Dr Claire Bale (Parkinson's UK)
John Sinden (ReNeuron)

A4 Standard instructions to scientists/experts

Hello, and thank you for agreeing to come along to our public dialogue event. This document tells you about the objectives for the dialogue, a little about the methodological approach, and the principles which underlie this. We explain your role and give you some guidance as to what we ask of you, and also tell you about timing and locations, and other logistics.

1. Background and aims of the dialogue

The dialogue is supported by Sciencewise-ERC, a programme which helps policy makers to commission and use public dialogue to inform policy decisions in emerging areas of science and technology. The dialogue sits in the context of a wider study – lead by the Academy of Medical Sciences, with support from the Department of Health, Medical Research Council and Wellcome Trust.

The wider study is in two parts; consultation within the expert community, including research scientist and ethicists; and dialogue with the general public. The Academy has commissioned **Ipsos MORI, Dialogue by Design** and the **British Science Association** to carry out the public dialogue.

The subject of this dialogue is medical research involving Animals Containing Human Material. Overall, the dialogue aims to establishing a clearer platform for developing policies on these issues, through a thorough examination of the scientific, social, ethical, safety and regulatory aspects of the research.

You are attending one of the public dialogue events. The objective of these events is :-

To explore with members of the public the societal and ethical aspects of medical research involving animals containing of human material. In particular the dialogue will seek to understand public aspirations and concerns and identify areas of consensus, disagreement or uncertainty.

We will be teasing out some of the biggest questions around research involving animals incorporating human material. The following areas have been identified by the steering group and external stakeholders as some of the key areas we'll be discussing.

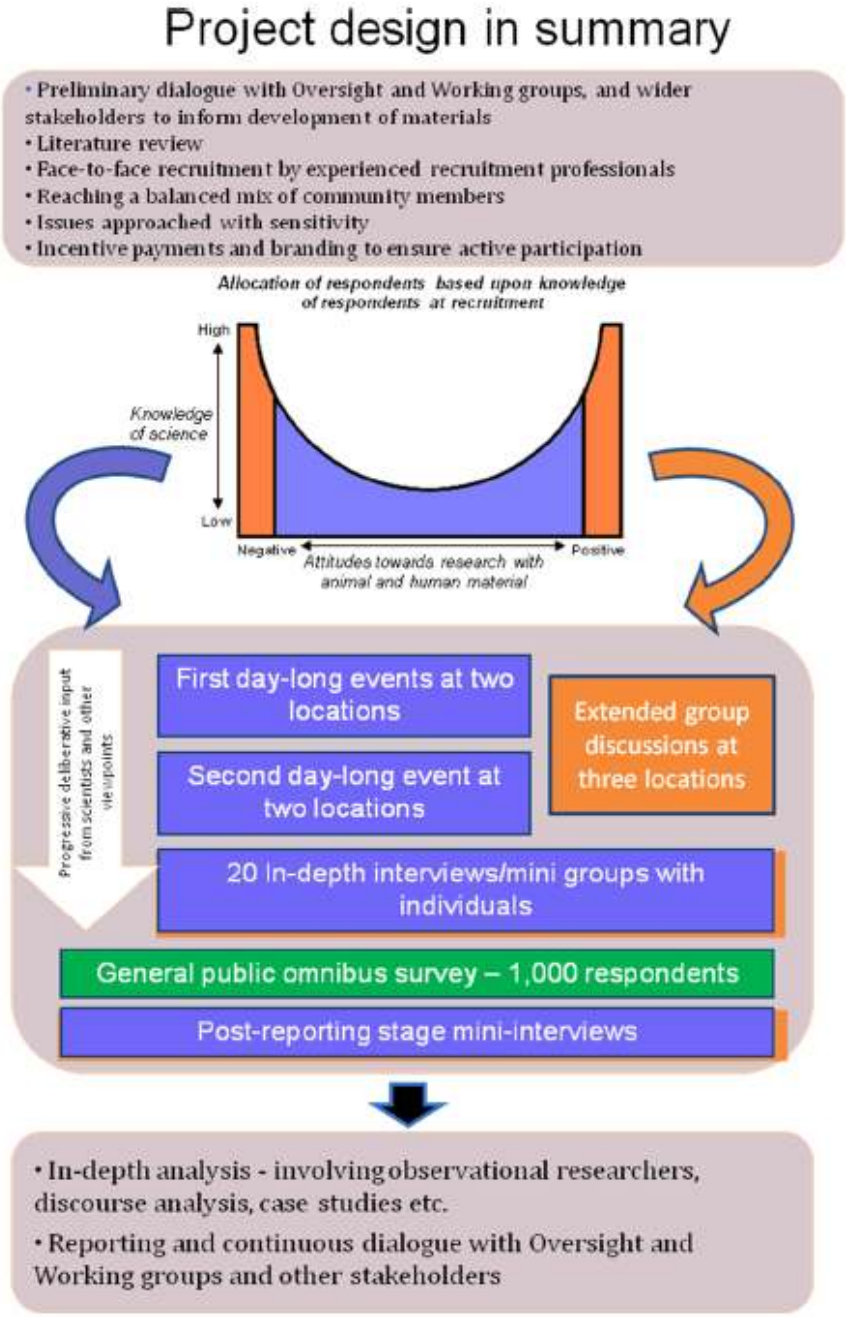
Dimension	Discussion
1) Type of animal involved	Ranging from fruit-fly (and other invertebrates) through small mammals to primates. May not be whole animals, but animal cells. Not just size/intelligence but domestic/companion animals (cat, dog, horse) versus others .
2) Risk of contamination	Potential to spread conditions, qualities into outside world, eg. causes new human diseases.
3) Scope for intergenerational impact	That the new animal is capable of breeding, leading to long-term impact and environmental changes.
4) The type of experiment	Specifically transgenic vs chimeric
5) Types of tissue:	a) Liver, brain, tissues which produce sperm and eggs b) quantity/proportion of human tissues c) issues of appearance – when something appears like a human tissue (e.g. hand-like appendage)
6) Reason for conducting research	a) Ranging from entirely exploratory to testing new treatments; b) Who benefits? Patient versus commercial interests; c) different types of conditions being studied (fatal/non-fatal illnesses, animal illnesses)
7) Level of change in animal:	a) whether behaviour or appearance of animal is altered b) unique forms of suffering introduced;
8) Development of human characteristics:	In particular sentience, cognition, consciousness
9) 'Naturalness'	a) maintaining the integrity of human and animal species; b) peoples' emotional responses to different types of experiment

2. The Dialogue Process

The diagram right sets out the key events which are taking place.

The major events of the dialogue are the **two day-long events** with **20** participants at each, in **London** and **Newcastle**.

The dialogue is being independently evaluated, so evaluators present on the day may ask you questions about your experience of the project and the process.



3. Logistics

Forum	Location	Event 1	Event 2
1	Newcastle	**22nd May** Rooms A007/A008 University of Northumbria, Ellison Place, Newcastle Upon Tyne, Tyne And Wear NE1	**5th June** Rooms A113/A114 University of Northumbria, Ellison Place, Newcastle Upon Tyne, Tyne And Wear NE1
2	London	**5th June** The Dana Centre, 165 Queen's Gate South Kensington, London SW7 5HD	**12th June** The Dana Centre, 165 Queen's Gate South Kensington, London SW7 5HD

The public will arrive at around 9.30 for a 10am start. **Please can you arrive at around 9am** so that you can meet the team, get to know the place and the materials we're using, and the team can answer any outstanding questions you may have.

Tea/coffee will be served on arrival and lunch will also be served. The day finishes at **4.15pm** when the participants go home. If you can spare another half hour after this to catch up with the team and give your first impressions this would be very useful as it will really help our analysis – but don't worry if you have to dash off.

4. What will the participants experience?

We've given you our **facilitation plan** for the day, and the **case studies** that participants will be using as a start point for considering the issues. Do take a look at these for your own interest. You won't need to refer to these on the day as we will guide you through the day, as we guide the participants. By the way, the discussion guide is not a 'confidential' document as such, but we would prefer it if you didn't give it to the participants.

The participants will experience the research process as follows:

A week or two ahead of Event 1 they will have been recruited face-to-face by an Ipsos MORI recruiter who will capture some initial opinions and views as well as basic demographic data. The people coming are not a 'representative sample' –that's not possible with 20 people – but they reflect, broadly, a range of ages and a demographic makeup that reflects the area in which the dialogue is taking place.
They must be able to attend both events, and will be given a cash incentive at each event. Please don't get into a discussion with any participants about money – just refer them to an Ipsos MORI team member!
When they arrive we'll give them name badges and sort them into groups – these groups will be based on some of their initial answers to questions at recruitment, but the participants won't necessarily know.
During event 1 they will hear some basic science background and explore the case studies. They will be provided with crib sheets, glossaries, a short film and have experts on hand (you!) to answer any questions about the science around genetics.

5. Further useful background documents for you to read

The Sciencewise-ERC Expert Resource Centre for Public Dialogue in Science and Innovation (Sciencewise-ERC), funded by the Department for Innovation, Universities & Skills, provides assistance to policy makers to carry out public dialogue to inform their decision-making on science and technology issues. **Sciencewise-ERC has developed a set of principles** which are very useful to those engaged in public dialogue. We've provided these to you and we urge you to take a look, and adhere to these guidelines on the day.

6. So what is your role?

The aim of the day is to give the public access to relevant information relating to the subject under discussion. We give participants a basic 'pack' of information during the day and drip feed more information as we go along. Our facilitators play a neutral role, not 'taking sides' or appearing to hold the 'right answer'. This helps participants feel at ease and engage with the discussion. Furthermore, the facilitators do not necessarily have scientific backgrounds or a depth of knowledge in any of the fields we are discussing.

So as well as facilitators, we also need other experts who can give more detailed information to participants. This will be your role. You won't need to be an expert on the specific projects that the case studies refer to.

We ask you to do the following things specifically

During the Event	▪ Be present for the duration of the day, (including breaks in case participants want to talk individually). ▪ Be introduced as an expert who can answer questions during all sessions on medical research involving Animals Containing Human Material. ▪ Give help to individuals and groups as required to ensure that they understand the concepts and ideas we are explaining to them. ▪ Use simple, clear language and honestly explain when you cannot give a simple answer.

Though we are using case studies to bring up discussion of some of the broad techniques and ethical questions around animal/human research, we hope that when participants see these, they will have a whole host of other questions and thoughts, and your role is to help shed some light on these as they emerge. You will be an expert resource on which participants can draw. For example, participants might questions about the scientific method, the way experiments are carried out, and questions of clarification about words and concepts used in the materials.

You are not there to hold a specific brief for any particular kind of research practice, 'argue the case' for any particular approach to the subject, nor do you have to represent any company or academic community doing research involving Animals Containing Human Material. And where you know there is debate in the academic or commercial research community you can feel free to acknowledge this. Of course, if you have a well developed professional opinion which emerges from your own experience, feel free to share it with participants.

If participants are asking questions about something that is an ethical dilemma for scientists (issues around animal suffering, for example) it's fine to acknowledge areas of uncertainty or debate within the scientific community.

It is worth remembering that one of the aims of our dialogue is to understand participants' *uninformed* opinion as well as their informed views. We are interested in participants 'wrong answers' and will always want to collect their spontaneous reactions to materials, even if these comments are based on misconceptions - because that shows us where people start from.

From your perspective, this might be frustrating! It can be difficult to listen to people airing false assumptions - you might want to correct them, instantly! But we'll ask you to let members of the public speak before you do; and just to come into the discussion when the facilitator asks you, or when you're asked a direct question by a member of the public.

We have found in other projects of this nature that the public really appreciate the chance to talk to you and hear about your work, and we find that our 'experts' get a lot out of it too. We anticipate that things will flow quite naturally, you'll hear a lot of interesting stuff, and all will have a good time.

Thank you again for agreeing to join in with the dialogue, and we'll see you at the events!

A5 Recruitment of questionnaire for participants

Good morning/afternoon/evening. My name is . . . . . from Ipsos MORI, the opinion poll company. We are currently doing a project for the Academy of Medical Sciences who have asked us to recruit a group of people who are willing to share their views on different types of scientific[44] research. Taking part would involve meeting with Ipsos MORI researchers and a group of other people, to learn more about different types of scientific research and to discuss their views on the subject.

IF QUESTIONED FURTHER ABOUT THE TOPIC OF THE RESEARCH...
"The discussion will be about the kinds research that scientists do to learn about animal and human disease, and how animal and human tissues can be combined as researchers try to develop new treatments."

I wonder if you could help me? This will take place at ….. The workshop will last around between 10am and 4.30pm on both days. To say thank you for your time and cover any expenses incurred we would like to offer £55/£65 for the first event and £75 for the second so £140 in total because you MUST come to both.

THE INCENTIVE OFFERED REPRESENTS COMPENSATION FOR THEIR TIME, TRAVEL EXPENSES AND ANY CHILDCARE. EXCEPT IN EXCEPTIONAL CIRCUMSTANCES

We are looking for particular groups of people, therefore I would like to ask you some questions about yourself. All information collected will be anonymised.

Q1. **Would you be interested in taking part?**

Yes	1	CONTINUE
No	2	CLOSE

Q2 SHOWCARD A **Do you or any members of your immediate family work in any of the following areas, either in a paid or unpaid capacity?**

Journalism/the media	1	CLOSE
Bio-medical research	2	
Public relations (PR)	3	
Market Research	4	
For the Department of Health, Home Office, Department of Business Industry and Skills	5	
For the Medical Research Council or the Wellcome Trust	6	
No, none of these	7	CONTINUE
Don't know	8	

Q3	**Have you participated in any kind of public dialogue or social or market research discussions in the last 2 YEARS?**		
	Yes	1	THANK AND CLOSE
	No	2	CONTINUE

NOTE TO INTERVIEWER:

NB: please note that the shaded area indicates that the interviewer must check quotas and recruit to quota.

Q4. CODE SEX (DO NOT ASK)			
	Male	1	RECRUIT TO QUOTA
	Female	2	

Q5. WRITE IN & CODE EXACT AGE **Exact Age** ☐☐			
	18-34	1	RECRUIT TO QUOTAS
	35-54	2	
	55+	3	

Q6.	**Which of the following best describes your household?**		
	Children under the age of 18 living at home with you	1	RECRUIT TO QUOTA
	No children under the age of 18 living at home with you	2	
	Other (WRITE IN & CODE '8')	3	
	Not stated	4	

Q7.	**Are you a UK citizen?**		
	Yes	1	CONTINUE
	No	2	THANK AND CLOSE

Q8.	**How interested would you say you are in issues to do with science and medical research?**		
	Very interested	1	ELIGIBLE FOR BOTH GENERAL PUBLIC DIALOGUE AND SPECIAL INTEREST GROUPS
	Fairly interested	2	
	Not very interested	3	
	Not at all interested	4	CLOSE

Q9.	**How well informed do you feel about issues to do with scientific and medical research?**		
	Very well informed	1	EXCLUDE FROM GENERAL PUBLIC DIALOGUE. RECRUIT TO RELEVANT SPECIAL INTEREST GROUP IF ELIGIBLE AT C2, C4 OR C6
	Fairly well informed	2	ALL ELIGIBLE
	Not very well informed	3	
	Not at all well informed	4	

Q10	**It is possible that there may be some people from the media attending the events. Please note, they will only be given your first name and will not attribute comments to you personally unless you give your permission.** **Secondly, some events may be filmed, and some of this footage may be used for broadcast purposes (e.g. on the television news). This will be general footage and not close ups of individuals.** **Can you confirm you will be happy to attend and be filmed for these purposes**		
	Yes	1	
	No	2	THANK AND CLOSE
	Don't know	3	

Q11. **Occupation of Chief Income Earner**
Position/rank/grade
Industry/type of company
Quals/degree/apprenticeship
Number of staff responsible for

PROBE FULLY CODE FROM ABOVE

Social grade		
AB	1	
C1	2	
C2	3	RECRUIT TO QUOTA
D	4	
E	5	

Q12. SHOWCARD B **To which one of the groups on this card do you consider you belong?** SINGLE CODE ONLY.

A	WHITE	British	1
B		Irish	2
C		Any other white background	3
D	MIXED	White and Black Caribbean	4
E		White and Asian	5
F		Any other mixed background	6
G	ASIAN OR	Indian	7
H	ASIAN	Pakistani	8
I	BRITAIN	Bangladeshi	9
J		Any other Asian background	0
K	BLACK OR	Caribbean	X
L	BLACK BRITISH	African	Y
M		Any other black background	1
N	CHINESE	Chinese	2
O	OR OTHER ETHNIC GROUP	Any other background	3
		Refused	5

QUOTAS WILL VARY DEPENDING ON THE COMMUNITY IN WHICH WE ARE RECRUITING

ASK ALL

Q13. **I am going to describe three types of experiment that scientists might do to study life threatening human diseases such as cancer. Could you tell me in each case whether you think such experiments are 'always justified', 'sometimes justified', 'rarely justified' or 'never justified'?**

	Always	Sometimes	Rarely	Never	
i) Experiments using animals such as mice for medical research	1	2	3	4	IF 4, GO TO QUESTION 14; IF 1, 2 OR 3, GO TO QUESTION 15
ii) Experiments using cells drawn from human embryos	1	2	3	4	

IF ANSWERED 'NEVER JUSTIFIED' TO i) or ii) AT QUESTION 12

Q14. **How strongly do you feel about the answer you have just given?**		
Very strongly	1	CHECK ELIGIBILITY
Fairly strongly	2	
Not particularly strongly	3	GO TO Q15
Not at all strongly	4	

IF VERY OR FAIRLY STRONGLY AND '4' AT Q13 I) RECRUIT TO GROUP 3 AND GO TO Q16
IF VERY OR FAIRLY STRONGLY AND '4' AT Q13 II) CLOSE

Q15.	SHOWCARD C **Which, if any, of the following things would you say you have done over the last two years or so? Just read out the letter or letters that best apply?**		
A	Been a vegetarian or vegan	1	IF SELECTED FOUR OR MORE RECRUIT TO ANIMAL WELFARE GROUP OTHERWISE ELIGIBLE FOR GENERAL AND FAITH GROUPS
B	Been a member of an organisation involved in animal welfare	2	
C	Bought 'cruelty free' cosmetics or other products, not tested on animals	3	
D	Taken protest in a protest or demonstration against animal cruelty	4	
E	Signed a petition on an animal welfare issue	5	
F	Written a letter or email to an MP or editor of a newspaper/magazine about an animal welfare issue	6	
G	Commented on the Internet about an animal welfare issue	7	
H	Discussed animal welfare issues with friends	8	
I	Donated money to an animal charity	9	
J	Been an active member of an organisation committed to animal rights	10	DO NOT RECRUIT
K	None of these	11	RECRUIT TO GENERAL PUBLIC DIALOGUE

ASK ALL

Q16.	**SHOWCARD D Do you personally or any of your immediate family[45] suffer from any of the following medical conditions?**		
A	Motor Neurone disease	1	RECRUIT TO SPECIAL INTEREST GROUP (NEWCASTLE)
B	Alzheimer's disease	2	
C	Parkinson's disease	3	
D	Multiple sclerosis	4	
E	Stroke	5	
F	Huntingdon's disease	6	
G	None of these	7	RECRUIT TO ANY

Q17[46].	SHOWCARD E **Which of these best applies to you?**		
	Christian	1	GO TO QUESTION 18
	Muslim	2	
	Jewish	3	
	Hindu	4	
	Sikh	5	
	Buddhist	6	
	Other religion	7	
	No religion	8	GO TO NEXT SECTION

ASK IF IDENTIFY A RELIGION AT QUESTION 10

Q18.	SHOWCARD F **From this card to what extent do you agree or disagree that your religion influences the way you live your day to day life?**		
	Completely disagree	1	RECRUIT TO GENERAL PUBLIC DIALOGUE
	Strongly disagree	2	
	Tend to disagree	3	
	Neither agree nor disagree	4	
	Tend to agree	5	
	Strongly agree	6	RECRUIT TO FAITH GROUP
	Completely agree	7	
	Don't know	8	GO TO NEXT SECTION

WILLINGNESS TO TAKE PART

If the respondent is suitable for the main dialogues or special interest groups provide further details on how the research will be conducted, the dates /time/place, the incentive payments and then finally confirm their commitment to take part and record contact details and any special needs (access, dietary etc.)

If the respondent is not suitable for any strand of discussion they will be told;

"Thank you very much for answering these questions. From you what you have told us it seems that we have already recruited enough people who have your viewpoints and we want to make sure that we have a wide spectrum of all relevant views. Therefore I'm afraid we can't invite you to participate on this occasion. Thanks once again for taking part and sorry for any inconvenience"

[45] Defined as partner, mother/father, child or sibling

[46] Religion questions were not asked in Newcastle. Hence people with any religious views could have attended the general public workshop.