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 described in our full 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. 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:

- 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).

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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.
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. 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.
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.
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.

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