

The response reproduced below was submitted to the consultation held by the Nuffield Council on Bioethics on the ethics of research involving animals during October-December 2003. The views expressed are solely those of the respondent(s) and not those of the Council.

Genetic Interest Group, UK

Introduction

The Genetic Interest Group welcomes the opportunity to submit a response to this consultative exercise. As the alliance of support groups for individuals and families affected by or at risk of all types of genetic disorder we speak from the perspective of those who live with the consequences of currently incurable and/ or intractable disorders, and who are potentially the greatest beneficiaries of medical research – and who, without this, will continue to suffer the consequences of diseases which might otherwise have become treatable, if not curable.

This response has been discussed with and agreed by the Trustee Board of GIG.

In framing our responses to the questions asked in this consultation we have considered the issues as they present themselves to our members and the families they represent. We have not attempted to give scientific justifications – other respondents are better able to provide this scientific and technical perspective. Nor have we considered research uses outside the context of (eventual) medical applications or the advancement of scientific understanding that may lead to these through insights into the basic biology of disease processes.

Q1/ What is your view of the use of animals in research?

Research using animals has led to substantial advances in our understanding of the biological mechanisms which result in sickness, disability and premature death. Without this we feel certain that much of which we know today would remain closed off to us with the result that we would now be further away from the prospect of early and accurate diagnosis, appropriate advice and support and in an increasing number of cases the effective therapies that have been produced through (in part) the knowledge acquired by animal based research. Clearly research involving animals must be properly regulated, and where alternatives exist these should be used. However, we do not believe that it is yet possible to exclude the use of animals completely without either compromising safety, slowing research or both, with the result that the harm inflicted on animals used in research would be transferred to humans in the form of prolongation of disease or an increased element of risk in therapies taken through the toxicity testing and into clinical trials. We do not feel it is ethical to subject humans (even if they are potentially willing volunteers) to these risks when there is a means to reduce them.

Q2/ What are your views about the use of genetically modified animals in research?

The use of genetically modified animal models has allowed researchers to generate more accurate and appropriate models of human diseases. This has facilitated progress and makes it more likely that research will transfer to human subjects more quickly. This is a welcome development. The increase in the number of genetically modified animals used in research is an encouraging sign of progress towards treatment in a widening range of diseases. As such it is to be welcomed, not seen as a retrograde step

as it holds out the hope for future patients that it will be possible sooner rather than later that human based trials will be possible. It should not be forgotten that animal based research is a step on the way, not an end in itself, and those who engage in the work are generally anxious to be able to move on, because it means they are nearer the goal of effective therapy. The image of the medical scientist or doctor undertaking animal based research out of pure curiosity is not a reflection of reality and should be resisted.

Q3/ What is your view of the use of alternatives?

Alternatives to animals have an essential role to play in the generation of new knowledge about serious diseases. The use of cell lines, computer simulations etc have all played a significant role in developing our understanding, but they are an adjunct to, not a replacement for, animal based work at the present time.

Although this situation may change in future, and efforts should certainly be directed at increasing both the range and sophistication of non-animal based disease models, at present even the most complex of these does not offer a replacement for the study of the multiple interactions that occur in a living organism. While results obtained from animals are not a perfect guide to what will happen in humans, they help to bridge what would otherwise be an unacceptably wide knowledge gap between even the most elaborate alternative systems currently available and the potential impact of first human use. Whilst patients might be willing to volunteer as experimental subjects, it is unethical to put them into a situation where the possible risks that they may be willing to face in order to move closer to effective therapies or cures can be reduced or eliminated because the means exist to reduce that risk. The proper use of animal based experimentation provides such a means.

Q4/ What is your view of the ethical issues relating to the use of animals in research?

People living with severe, currently untreatable or intractable disorders are not usually there because of some choice on their part. Rather, they find themselves in the situation they are in as a result of genetic, environmental and other factors over which they probably had no control. Given a choice they would generally express a wish not to be affected by whatever the condition they have to live with. However, biology does not stop because we are ignorant, and the way in which the entirely legitimate expectations of those with serious diseases for effective treatments can be met is through biomedical research and its application. At the present time animal based research is an essential part of this process. This is not to argue for carte blanche, but for appropriate use, properly justified and controlled. In our view, if the possibility of reducing the impact of serious disease is missed, and as a result people continue to be adversely affected who might otherwise have been relieved, then this is a potentially unethical course of action.

Q5/ What is your view about the UK regulations on research involving animals in the UK?

Current regulations provide a robust, transparent and appropriate framework for controlling animal experimentation. Instances of abuse are rare, and transgressors subjected to significant sanctions. Whilst there may be a case for boosting the number of inspectors appointed to police the system, we do not believe that the system itself needs substantial revision. The balance between the proper protection of animals and progress towards understanding and treating disease seems about right. Significant tightening of regulation would make either research more difficult, increase costs and delay patient benefits or move research off shore to less stringent regulatory climates, at a significant cost to the UK's science base as well as to the welfare of the animals involved.

Q6/ What do you think about the information that is available to the public about research involving animals?

Much of the information presented to the public is inaccurate, alarmist, out of date and fuelled by a desire to win the propaganda "war" by those opposed to all forms of animal research. Such groups have an entirely legitimate right to present their case to the public, and in some instances they have performed a valuable public service in exposing cases of abuse or cruelty, but this right does not extend to wilful misrepresentation of the facts, as this creates an intimidatory climate that is detrimental to rational discourse. Public information from government industry and academia is generally rather dry – although some efforts have attempted to secure a higher profile, and the research charities sometimes seem reluctant to acknowledge the part that animal based research plays in the projects they fund – perhaps for a fear that this would attract attention of so-called animal "rights" activists and this reduce the support they receive. In this context the voice of groups such as Seriously Ill for Medical Research is an important one.

In an ideal world the debate about animal use would be evidence based. However, the issue generates strong emotions, making such a rational approach impossible to envisage. Opinion surveys seem to indicate that the overwhelming majority of the public accept the legitimacy of animal research but they would rather not know too much about the detail. In order to sustain this tacit endorsement, those who regulate the research must be fair, transparent and robust in the enforcement of the regulations and in the reporting of the outcomes of their policing activity – whether positive or negative.