

Nuffield Council on Bioethics: Emerging Biotechnologies**Response by the Wellcome Trust**

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Introduction

1. The Wellcome Trust supports the development and use of new technologies that will contribute to the improvement of human and animal health. Focus areas two and three of our strategic plan 2010-20¹ set out the intention to accelerate the application of research and to explore medicine in cultural contexts respectively. In fulfilling these objectives, we support innovative research to develop new technologies and therapies for health benefit, the study of ethical and social issues relating to them and engagement with the public on scientific issues.
2. Many of the aspects of the consultation are relevant to all areas of research, not solely emerging biotechnologies. It is therefore not clear what the remit of the working party is. Given the vast breadth of research and development of new technologies taking place worldwide we are considerably concerned that this consultation lacks focus. With this in mind, our response aims to provide comments on:
 - **Regulation:** A risk based approach to regulation is important for the efficient and ethically sound translation of research into health benefit.
 - **Public engagement:** There is a need to establish early stage public engagement activities around new developments in research that are fit for purpose.

The importance of appropriate regulatory frameworks to facilitate the translation of research

3. The UK must maintain a facilitative regulatory framework for the translation of research into health benefits that enables the safe conduct of research, maintains an appropriate degree of checks and balances, and meets the highest ethical standards without introducing unnecessary barriers. We believe that a risk-based approach to regulation is beneficial to the efficient translation of research and that a 'one size fits all' approach is not appropriate. This is essential for the regulation of emerging biotechnologies where each may have unique issues associated with them and different levels of risk and benefit.

Public engagement and the exploration of ethical and social aspects of research

4. There is a need to develop early-stage public engagement strategies around new technologies, which bring together scientists, the public and policy makers to discuss the science and any associated ethical and social issues. We do not believe that one particular type of public engagement activity is necessarily valuable for all new technologies, but that they should be tailored to the needs of the issues or research in question.
5. Results of public dialogue or other engagement activity should be taken seriously and seen to be considered by researchers and policy makers. However, it should be clear that this only forms part of the input required for effective decision making. Experts – from science and ethics - are integral to the progression of research and science policy by providing considered expert opinion, advice and evidence.

¹ Wellcome Trust Strategic Plan 2010-20: Extraordinary opportunities

http://www.wellcome.ac.uk/stellent/groups/corporatesite/@policy_communications/documents/web_document/WTDV027438.pdf

6. With regard to 'what is public engagement', our experience is that it takes many forms, which can be categorised into three broad groupings:
- Opening up: through dissemination, information sharing, discussion and informed debate;
 - Involving: seeking views from the public through a variety of mechanisms to inform policy, research agendas and decision-making;
 - Collaborating: joint processes between researchers and the public to set agendas, processes and make decisions.
7. Further, in terms of 'why do public engagement', from the perspective of a funder, researcher or policy-maker there are three ways to consider the need to conduct public engagement. The type of public engagement (i.e. the 'what') deployed, as well as the level of engagement, will be dependent on the nature of the research:
- **Must do** - to ensure that research is ethically and morally acceptable and legal (e.g. ensure that the appropriate governance, consultation or advisory processes are in place). As part of our commitment to ensuring ethically sound science, we fund research into biomedical ethics that keep pace with scientific developments, for example:
 - i. The London and Brighton Translational Ethics Centre (LABTEC)². This programme looks at ethical issues surrounding key developments in human embryonic stem cell research and neuroscience as critical instances of the translational interface between research and treatment.
 - **Smart to do** – to enable effective engagement and communication of research: to enhance the likelihood of take-up of research or technology; to enable the public to contribute to shaping research or policy agendas, for example:
 - i. We support our funded researchers to communicate their research in public settings by providing training for a range of activities including media and broadcasting, and talking directly with the public and patient groups³. We also fund wider national debate on scientific issues, for example the "Battle of Ideas" - an annual public debate tackling subjects such as genomics and personalised medicines⁴.
 - **Wise to do** – to ensure that science and technology is part of the cultural landscape and create an environment conducive to research; to enhance the status of research as a contributor to the social and democratic debate and stimulate interest in and excitement about science, for example:
 - Our own Wellcome Collection provides a free public space to engage the public about science through events and exhibitions⁵. We also fund exhibitions such as "Human +"⁶, which explores the future of our species, asking questions such as what enhancements will we choose to become better humans? How can we author our genetic futures?

The Wellcome Trust is a global charitable foundation dedicated to achieving extraordinary improvements in human and animal health. We support the brightest minds in biomedical research and the medical humanities. Our breadth of support includes public engagement, education and the application of research to improve health. We are independent of both political and commercial interests.

² <http://www.wellcome.ac.uk/Funding/Biomedical-ethics/Funded-projects/Research-profiles/WTDV030186.htm>

³ <http://www.wellcome.ac.uk/Education-resources/Communicating-your-research/index.htm>

⁴ <http://www.battleofideas.org.uk/>

⁵ <http://www.wellcomecollection.org/>

⁶ <http://www.sciencegallery.com/humanplus>