This response was submitted to the consultation held by the Nuffield Council on Bioethics on Emerging biotechnologies between April 2011 and June 2011. The views expressed are solely those of the respondent(s) and not those of the Council.

What role should public opinion play in the development of policy around emerging biotechnologies?

Emerging biotechnologies have the potential to have major consequences for the future generations of patients receiving healthcare in the UK. For instance, human enhancement technologies that aim to overcome physical or mental limitations could have major implications for patients with debilitating conditions that are currently managed conservatively. To make these technologies successful in treating patients they need to be perceived favourably by the public. Is it feasible and desirable to consider public opinion when developing new biotechnology policies? We aim to discuss these issues in the context of an argument for and against involving the public in developing policy regarding emerging biotechnologies. Finally we will contextualise these opinions within our own views as medical students.

FOR

Alongside growing biotechnologies there is a growing public voice and they have the right to contribute and express their opinion on emerging biotechnologies. If policies are developed without public knowledge there is likely to be mistrust from the public of these technologies and the possibility that they will not be used.

Since public funding contributes to the development of some technology surely the public should be able to decide whether it is appropriate to continue or whether alternatives could be sought. Seeking public opinion may be the best way of allocating scarce resources in line with the public's needs.

Public opinion looks at whether it is acceptable morally, ethically, socially and religiously. They should be able to give an informed opinion on the topic. This may require an improvement in scientific literacy to allow greater acceptance of scientific literature. Educating the public and allowing them the opportunity to help shape policies on technological advances could improve future acceptance of treatment that may result as a consequence of the research. Does this mean that the public should be presented with all the available information regarding the technological advances or should the information be streamlined to the non-scientific community?

Future generations may be involved in future biotechnologies and we should educate current generations in order to pass on information and awareness. It may be considered arrogant of scientists to think they know best and make decisions for the public that if given the resources could make those decisions for themselves.

AGAINST

Is incorporating public opinion into policy development essential in making a democratic decision or is it just an exercise to appease the conscience of the people developing the policies?

As with screening and clinical trials, participant bias should be taken into account, as the people who are likely to respond and take part are unlikely to be representative of the population.

The people that develop technologies have a huge knowledge of potential harms and benefits and maybe they should be left as the people with the knowledge and decide the policies, instead of a possible lack of understanding and scepticism by the public leading to a rejection of a technology with the potential to have a profound benefit for the greater good.

With the greatest of intentions is there ever going to be a consensus between public and scientific opinion? On the subject of resource allocation it has been shown that the public have a different opinion on where resources should be allocated compared to doctors. The public does not have an invested interest in what research occurs compared to scientists who are possibly blinded by their knowledge and ambition and cannot see the bigger picture. However the public tends to have a more emotionally driven interest and tends to favour vulnerable members of the population rather than objectively making rational decisions. Taking these points into consideration it would be very difficult to gain a consensus between the two parties involved.

MEDICAL OPINION

As future doctors we are aware of growing public involvement in their own healthcare and the public will not partake in something they have not been consulted on or do not find acceptable. The public needs to be informed why it is important for them to give an opinion and this could make it more likely that a true representation of the population will participate. We believe in order to generate public opinion you first have to inform them on the topic. To this end we think there should be more integration between the scientific and non-scientific world and informed choice is required.

What ethical principles should be taken into account when considering emerging biotechnologies? Are any of these specific to emerging biotechnologies? Which are the most important?

There are a number of ethical principles that need to be addressed when considering emerging biotechnologies. Biotechnology is not a new concept, however, and there have been recent advances, particularly in the field of genetics, which have raised novel ethical dilemmas.

It is vital to consider the benefit of a new and emerging biotechnology versus any harm that it may cause. Ethical issues surrounding such advances focus on the necessity for beneficence and non-maleficience. Questions regarding the safety of emerging technologies arise due to the novel nature of many of the interventions, the overall effects of which are yet to be reliably determined. Many biotechnologies, for example those involved in human enhancement, bring about further issues with regards to patient autonomy. Individuals may choose to have unnecessary treatment through a possible misinformed decision, potentially leading to patient-doctor conflicts.

Further concerns occur with particular biotechnologies which appear to being ‘playing God’ - interventions which go beyond treating a medical condition to alter and enhance human performance in a *preferential* rather than *beneficial* manner. Finally, the principle of justice with regards to expenditure on development, allocation and availability of emerging technologies is also a key concern. As well as money spent on research and development, there will also be a cost assigned to each biotechnology which will fall onto the healthcare provider. There is a risk of unfair rationing and an imbalance in availability between particular geographical locations and socioeconomic backgrounds. Furthermore, money used to focus on producing new biotechnologies may hinder the development and improvement of already successful interventions and healthcare.

Emerging biotechnologies such as germ cell therapy and genetic engineering play close to the boundaries of what is considered beneficial therapy and what could be seen as indulging in the sheer scope of their capabilities. The potential of ‘playing God’ in this way questions ones’ basic morals before even entering ethical considerations. While our advancement in biotechnology is commendable and exciting, there is an ominous temptation to perfect what is imperfect. There are, of course, many religious and moral arguments against such technologies, a consequence of which are the strict regulatory restrictions placed on genetic engineering and other similar technologies. Of particular concern are the looser restrictions in place in countries which fall beyond the regulatory eye of western governments. It is still unknown just how far unregulated laboratories have progressed in this field.

One crucial but often overlooked ethical aspect of emerging biotechnologies concerns the way in which such technologies are distributed. It has wide ranging aspects affecting not only local and national governments but also biotechnology manufacturers, developers and distributers. It could be argued that, although biotechnology companies have an obligation to their shareholders, they also have a moral and ethical obligation towards humanity. This begs the question as to whether or not biotechnology companies should be obligated to develop technologies which are affordable to as many people as possible, including those in developing countries.

There are also a number of ethical issues surrounding the patenting of new technologies. Biotechnology companies will, obviously, protect their technology by taking out patents, but by this there is always the danger that development of, and further research into, the new biotechnology is hampered in some way due to restrictions put in place by the patenting process. If this is the case then there needs to be encouragement for biotechnology manufacturers/developers to communicate with each other concerning their research, whilst protecting intellectual property.

Regarding the development of new biotechnologies, it is pertinent to discuss the ethical issues surrounding who the emerging biotechnology is aimed at. For example, is it ethical to divert funds away from potentially life-saving biotechnologies in order to develop cosmetic biotechnology, regardless of how profitable that may be? If we let the market dictate the development of new biotechnologies, then it could put those who can least afford it in an increasingly disadvantageous position, widening the rich/poor divide?

As medical students, we are constantly aware of the ever changing environment into which we are progressing through. We are aware that, as future doctors, we will be at the front line of patients' access to biotechnology, and that we have a duty to keep up to date with not only therapeutic innovations but also the emerging ethical issues that come with them.

Whist we continually push the boundaries of science, we must ensure we do not push the boundaries of ethics; ethical guidelines will ensure that we will always act in the patients' best interest.

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