

Church of England - Mission and Public Affairs Council

Response to the Nuffield Council on Bioethics Consultation on Emerging Biotechnologies

The Mission & Public Affairs Council of the Church of England is the body responsible for overseeing research and comment on social and political issues on behalf of the Church.

The Council comprises a representative group of bishops, clergy and lay people with interest and expertise in the relevant areas, and reports to the General Synod through the Archbishops' Council.

1.1 We welcome the opportunity to make a submission to this consultation. We note the helpful invitation to respond to those questions in the consultation that are most pertinent to us and on which we believe we have something distinctive to say. Also helpful is the freedom to re-order the questions as best suits our contribution to the consultation. Consequently we have chosen to submit a response to questions 9 and 11-17, re-ordered as outlined below:

Q11 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?

2.1 It is important to underline the need to take into account common ethical principles that ought to guide our practice in all areas dealing with health and well-being: principles, rather than reaction to individual cases, form the basis for ethics. Chief among these principles are: affirming life, caring for the vulnerable, building community and respecting individuals. These principles complement one another, *displaying an order of precedence* with the effects of each principle 'cascading' to succeeding principles.

2.2 Affirming Life: The right to life and protection of life form the foundations both for human rights and for much of our criminal code. Affirming life includes both of these concepts, but it goes further. To affirm life is to argue that each individual life has purpose, value and meaning, even if some individuals may doubt that for themselves and their own lives. It also means that we wish to see everyone attain the highest quality of life possible

in whatever circumstances they may find themselves. Affirming life takes precedence over other principles because it is fundamentally the most important and most basic guarantee that society can offer its members. Other principles are undergirded and set in a positive context by the principle of affirming life. While the Church sees human life as a gift from God, we recognise that people of various religious faiths and none share our conviction that affirmation of life is foundational for bioethics.

2.3 Caring for the Vulnerable: A civilised society is one that fundamentally affirms life and that ensures that this and other benefits and protections are fairly experienced by all of its members. In practice, this means that particular attention must be given to vulnerable individuals and groups. History indicates that the powerful will often neglect or abuse the vulnerable unless strong and specific action is taken to protect them. Caring for the vulnerable, however, goes beyond issues of protection: it includes ensuring that vulnerable people are supported, cared for and enabled to live fulfilled lives, being afforded the same respect as all other members of society.

2.4 Building Community: Relationship is at the heart of what it means to be human and this ought to be reflected in the way that society organises itself. While totalitarian regimes are unacceptable in that they demand control over the lives of their citizens, an individualistic ‘free for all’ would mean that the principles of affirming life and caring for the vulnerable are unlikely to be upheld. Individual autonomy and freedom are important, but these can only be pursued within a society that places limits on them. Building a cohesive and humane society provides the best environment for individual freedom, ensuring that every individual’s life is affirmed and that the vulnerable are cared for. Carefully gauged limitations on individual freedom that enable the building of a truly humane society ought to be welcomed by all.

2.5 Respecting Individuals: Within the context of building a cohesive and humane society in which life is affirmed and the vulnerable cared for, maximum individual freedom of choice and opportunity ought to be given. It has been too easy for societies to marginalise, victimise and to persecute individuals and groups on the basis of sex, race, religion, age, disability, sexual orientation and a host of other characteristics, chosen by the powerful as indicators for discrimination. Wherever possible, in keeping with the principles already

advocated, maximum individual freedom of choice ought to be underwritten by society to ensure that individuals are enabled to live their lives in the manner of their choosing.

2.6 These foundation principles are essential in pursuing the common good, placing this quest within a workable framework. With particular reference to biotechnologies, this framework indicates that while life-enhancing and life-prolonging technologies may be welcomed in principle, they ought not to be accepted uncritically. The potential benefits to individuals have to be balanced over against the potential harm that may be done (directly or indirectly) to other vulnerable individuals or to the character or cohesion of society as a whole.

2.7 These foundation principles ought to be supplemented with other principles that may be seen as emerging from them such as guarding against the ‘commodification’ of human beings or of ‘human material’, upholding the principles of free and informed consent, ensuring an ethical distribution of limited resources and promoting health equality (or, at the very least, limiting disparity) between various social groups nationally and internationally.

2.8 In examining the potential applications of complex biotechnologies it is necessary to ensure that the principles above are not compromised or lost sight of in the course of their detailed development and application. It is essential that proposed biotechnology interventions are checked and re-checked against these criteria.

Q9 Do you think that some social and ethical themes are commonly overlooked in discussions about emerging biotechnologies? If so, what are they?

3.1 As stated above (2.8) there is some concern that the overall ethical picture may be lost sight of in the course of detailed discussions regarding the practical applications of emerging biotechnologies. The ethical principles outlined in the answer to Q11 are foundational for our society, but they may be taken for granted, disputed, ignored or dismissed as belonging to a ‘theoretical realm’ while scientists and policy-makers get on with the business of making ‘real-life’ decisions. The net result may be not only a measure of ethical confusion but also a degree of inconsistency or even contradiction in policy-

making and practical application. Restrictive, as it might appear to some, it is essential that all new biotechnologies are considered in the context of the moral and social matrix within which they will operate.

3.2 Societal attitudes are not always clearly informed by rational debate alone, but are also influenced to a greater or lesser extent by historic precedents, prevailing attitudes and perceived moral norms and mores. While all of these ought to be open to challenge and ought not to be determining factors, they ought not simply to be ignored. An in-built communal reticence to embrace 'the new', especially where risk factors and a full range of potential applications are not fully known, can act as a useful brake on hasty development, especially where commercial factors may be uppermost in the minds of some. Similarly, while the 'yuk' factor ought not to be determinative, it may, at times, be seen as a positive counter-balance to ill-considered experimentation, rather than as a prejudiced hindrance to progress. A fine line must be drawn between pandering to societal prejudice on the one hand and ignoring societal sensibilities on the other. What matters, is that such attitudes are taken fully account of in every debate on the development and application of biotechnologies.

3.3 Three particular areas tend to generate noticeable societal concern: blurring the distinction between the human and the non-human, the creation of 'artificial' as distinct from 'natural' biological entities (or the introduction of the 'artificial' into the 'natural') and the impact that biotechnologies may have on biodiversity, ecosystems and food or energy supplies. There are significant ethical and philosophical issues involved in these areas such as whether or not human beings are definitively different in kind from other species and whether or not there is anything intrinsically better in being 'natural' as distinct from being 'artificial'. Many philosophers, theologians and ethicists advocate the view that humans and others species occupy distinctive positions in the spectrum of living beings with 'blurred' edges separating one species from another, rather than a model that views each species as intrinsically distinct with clearly defined borders between them. Similarly, both examples of successful xeno-transplantation and the widespread use of 'mechanical' implants have indicated that the barrier between 'the natural' and the 'artificial' is a more porous one than many had previously assumed. In spite of this, there is still widespread reticence to the ideas that there is nothing definitively different between humans and other species and that 'artificial interference' in nature is merely an indicator of technological

progress. Areas such as these require careful regulation in order to be ethically defensible and to be socially acceptable.

Q12 Who should bear responsibility for decision making at each stage of the development of an emerging biotechnology? Is there a clear chain of accountability if a risk of adverse effects is realised?

4.1 It is important that society as a whole takes responsibility for the development of emerging biotechnologies and that society does not abdicate its responsibilities in favour of research bodies, interest groups or commercial organisations. In practice, this means that Parliament must set the legal context within which biotechnologies are developed and government, through its agents, must regulate such development.

4.2 It is essential that clear lines of responsibility and accountability exist in the approval, regulation and monitoring of emerging biotechnologies. These ought to be clearly mapped and delineated in such a way that members of the public as well as relevant participants may have readily accessible information on the procedures and protocols involved.

4.3 Within the legislative framework established by Parliament in any given area of biotechnology, research programmes and projects ought to be regulated by a named government agency, for example the Biotechnology and Biological Sciences Research Council or the Human Fertilization and Embryology Authority. Once research results in approved procedures, these ought to be effectively regulated and monitored by agencies such as the Medicines and Healthcare Products Regulatory Authority.

Q14 To what extent is it possible or desirable to regulate emerging biotechnologies via a single framework as opposed to individually or in small clusters?

5.1 Biotechnologies are so diverse that it is improbable that they could be effectively regulated via a single framework. Expert knowledge is required at each stage of development, from an initial research proposal to the monitoring of an established procedure. While it would be possible to create a single umbrella body composed of a number of discrete departments each of which deals with a particular area or cluster of biotechnologies, this runs the risk of giving the impression that such a comprehensive body

could effectively cover all aspects of biotechnology. Biotechnologies invariably affect a number of agencies and gain the attention of a range of interested groups and organisations even if these are not involved in their regulation. It is more likely that concerns with regard to any given biotechnology will be better addressed if it is regulated by a specific lead agency to which other relevant agencies and bodies may relate.

Q13 What roles have ‘risk’ and ‘precaution’ played in policy decisions concerning emerging biotechnologies?

6.1 In the past forty years or so, policy decisions in the area of the biological sciences have moved from being harm-based to being either risk or precautionary based. Until the 1970s the onus was on scientists to demonstrate the likelihood of harm (to the environment or to persons) before policy-makers would ‘intervene’ to control or to regulate practice. It became increasingly obvious that this often led to shutting the gate after the horse had bolted, resulting in damage-limitation measures that failed to address fully the human, environmental and economic cost of permitting hazardous practices in the first place.

6.2 Consequently, a risk-based approach developed that took the form of assessing the potential risks and benefits of a given action or procedure, based on the best relevant scientific evidence available. This acted as a defensible ‘check and balance’ on unproven scientific techniques: if risks were believed to be outweighed by benefits, then, by and large, a procedure was approved.

6.3 The precautionary approach suggests, however, that scientific knowledge may be inadequate properly to make such risk-assessments in some cases. It also suggests that before new procedures are adopted criteria other than scientific criteria (such as societal approval or economic impact) also have to be met. All new procedures under the precautionary principle have to negotiate an established set of criteria and only when these have been met, will approval for action be given.

6.4 Under a risk-based approach, approval comes at the end of a relatively short and precise assessment and once the ‘green light’ is given, action follows and continues unless a new or unforeseen risk presents itself. Under a precautionary approach approval comes through a

series of green lights; passing one criterion does not imply that action follows or that if it does it may not be halted if further criteria are not met.

6.5 Risk-based decision-making often works satisfactorily when applied to innovations or changes in practice in established procedures. New practices, especially those that lack clear societal acceptance benefit from a precautionary approach.

Q15 What role should public opinion play in the development of policy around emerging biotechnologies?

7.1 The nature of the relationship between public opinion and policy is one that continues to engage the minds of political scientists. There is general agreement that the capacity of a political system to respond to the preferences of its citizens is central to democratic theory and practice. Theorists disagree, however, with regard to the actual impact that public opinion has on policy. Some find a strong and persistent link, others reject the idea that public opinion is ever consistent enough to influence policy effectively while still others suggest that even where public opinion is strong and consistent it seldom plays more than a minor role in formulating public policy.

7.2 Concerns exist with regard to the ways in which public opinion is garnered and perceived. The efficacy of opinion polls depends on the wording used and the methods of polling. Public opinion may be ‘fashioned’ by interest groups or by political parties. Conversely, politicians may feel under pressure to ‘pander’ to public opinion. This, in itself, may make them less sensitive to the issues involved than to the ways in which they are perceived to react to public opinion.

7.3 The coherence and consistency of public opinion is also linked to how specific the issue is that is under consideration. Very specific and very general issues are more likely to lead to ascertaining coherent public opinion than are complex issues with multiple implications. Public opinion may still be divided on such issues, but it is easier to discover what public opinion is.

7.4 The degree to which an issue is seen as being of high relevance to individual or group wellbeing is also a factor in ascertaining public opinion. Where the public feels that it has a

high stake in an issue, public opinion is likely to be more readily and more cogently expressed.

7.5 Public opinion has, undoubtedly, a role to play in the formulation of public policy, but there are difficulties in gathering it and assessing it. Public opinion does not remove the onus on policy-makers to formulate policies that are consistent, defensible and that have a cogent ethical base.

Q16 What public engagement activities are, or are not, particularly valuable with respect to emerging biotechnologies? How should we evaluate public engagement activities?

8.1 Given that the nature of emerging biotechnologies is complex, gauging public opinion by polling or by generalised questionnaires is likely to be of very limited value. Asking for written evidence will, undoubtedly, lead to more nuanced and considered responses, but such responses may be heavily influenced by interest groups that wish to promote particular agendas. Workshops and seminars, open generally or targeted at ‘interested’ groups that may include but that also extend beyond interest groups is also a useful way of gauging public opinion. For the above to be useful, it is essential that individuals and groups are furnished with accurate, unbiased and accessible scientific and other relevant information.

Q17 Is there something unique about emerging biotechnologies, relative to other complex areas of government policy making, that requires special kinds of public engagement outside the normal democratic channels?

9.1 Assuming that ‘normal democratic channels’ include the types of public engagement noted above (supported by relevant information), there is nothing in emerging biotechnologies that requires special kinds of public engagement.