

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.

## Nowgen response to Nuffield Council on Bioethics consultation on 'Emerging biotechnologies: ethical issues'

Nowgen is a centre of excellence in public engagement, education and professional training in biomedicine. Nowgen was established in 2003 as one of six Genetics Knowledge Parks – funded by the Departments of Health and Trade & Industry – to address the challenges of genetic medicine in the 21st century. The Northwest Regional Development Agency and the European Regional Development Fund awarded additional funding for a landmark building. The Nowgen Centre is located in the midst of Manchester's biohealth cluster between Central Manchester University Hospitals NHS Foundation Trust (CMFT) and The University of Manchester (UoM).

Nowgen is now proud to be part of the NIHR Manchester Biomedical Research Centre within the Research and Innovation Division of CMFT and The School of Biomedicine in The Faculty of Medical and Human Sciences at UoM.

Nowgen's Public Programmes facilitate dialogue with diverse audiences about biomedicine. Ultimately, we want to foster an environment in which citizens are empowered to make informed decisions about their healthcare and where biomedical research can flourish. Our Public Programmes includes an extensive schools programme, organising informal public dialogue events, exhibitions, collaborations with artists and social research on public perceptions and awareness. We run public engagement projects on many different areas of biotechnology, including enhancement and regenerative medicine. Further details on our activities are described on: [www.nowgen.org.uk](http://www.nowgen.org.uk)

We wish to comment on the last three questions in the consultation.

### **15. What role should public engagement play in the development of policy around emerging biotechnologies?**

We believe strongly that public views should be used to help shape policy around emerging biotechnologies. Public engagement can help address research priorities, research questions and governance issues. We are aware that these processes are not always easy and can sometimes raise more questions than answers, but their role is still vital. Public engagement activities can help to inform, stimulate and explore public perceptions. The diversity of opinions and levels of awareness held by different publics can be captured using various approaches (some of which are described below in question 17) and fed into the policy development process.

As part of Manchester's Biomedical Research Centre, we are especially aware of the needs of patients. When a new technology has healthcare applications, it will be of particular significance to some members of public (patients and healthcare professionals).

There are many examples where public opinion has made a significant difference to the way that biotechnologies are incorporated by society, so it is vital to incorporate public views into the process of policy development. To successfully incorporate public views into the development of new policy requires detailed and recognition of the importance of genuinely listening to public. We support dialogue-focused models of public engagement, as described in the first paragraph on page 14 of your consultation paper. We also want to reinforce the importance of making public engagement an early priority, as mentioned in the final paragraph on page 15.

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

There are a range of public engagement approaches that might be valuable, depending on the circumstances. The activities should be tailored to the purposes of public engagement. It might be suitable to hold discussions in small groups to explore key policy questions in detail (such as focus groups or Citizen's Juries). It might also be suitable to find out about broader public attitudes and perceptions (eg. using opinion polls and surveys). It is also likely to be important to provide balanced and accessible information to introduce the technologies and the associated implications to the public (eg. through a multimedia website, exhibition, leaflet). It is also likely to be valuable to provide opportunities for the public to discuss emerging biotechnologies (eg. dialogue events to explore different perspectives). These activities could be run successfully through different networks, such as working with Science Museums, schools or patient support groups).

Emerging technologies often involve researchers from different disciplines. Public engagement activities can help to elucidate these perspectives and break down disciplinary barriers.

Nowgen believes strongly in evaluating its public engagement activities, to the extent that one member of the Public Programmes team works exclusively on research and evaluation. It is only possible to evaluate the activities after clearly setting objectives, but even then it is sometimes very challenging to measure the success of public engagement activities, as the outcomes are not clearcut. For example, if we run a dialogue event we are not aiming to change someone's mind or teach them new knowledge, but we want to stimulate their thinking. Consequently we might ask attendees at the end of the event whether they believe they are likely to discuss it further with someone. This indicates whether they have found it interesting and thought-provoking. At Nowgen, we use a mix of qualitative and quantitative methods, depending on the project and we would always aim to use both formative and summative evaluation.

The impact of public engagement activities are notoriously hard to capture, but there are many excellent resources to help evaluate public engagement activities, such as the

RCUK's Evaluation: Practical Guidelines toolkit and Manchester Beacon for Public Engagement has also produced a valuable Evaluation Guide.

**17. 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?**

Some areas of biotechnology have implications for human health, so are particularly important and relevant to the public, especially patients affected by conditions that might be treated using new technologies and the NHS professionals who would be overseeing their care.

There might also be significant risks associated with biotechnologies that make it particularly important for the public to be involved in the development of new policy.

There are also a number of controversies associated with some biotechnologies that have the potential to create extensive public concern and these need to be treated sensitively (such as fundamental questions on moral status of the embryo or DNA screening/new therapies that could alter the future gene pool).

We believe that there are circumstances when emerging biotechnologies might require special public engagement activities due to the pertinence and potential risky implications on human health and also the controversies involved.