Science and Technology Select Committee (Commons) Science Communication Inquiry

Written evidence submitted by the Nuffield Council on Bioethics

April 2016

Introduction

1   The Nuffield Council on Bioethics is an independent body that examines and reports on ethical issues in biology and medicine. This response draws on the conclusions and recommendations made in the following Nuffield Council on Bioethics publications:

- Novel neurotechnologies: intervening in the brain (published June 2013)
  http://nuffieldbioethics.org/project/neurotechnology/

- Ideas about naturalness in public and political debates about science, technology and medicine – Analysis Paper (published November 2015)
  http://nuffieldbioethics.org/project/naturalness/

- Emerging biotechnologies: technology, choice and the public good (published December 2012)
  http://nuffieldbioethics.org/project/emerging-biotechnologies/

- The collection, linking and use of biodata in biomedical research and health care: ethical issues (published February 2015)
  http://nuffieldbioethics.org/project/biological-health-data/

2   This response touches on two of the issues set out by the Committee to which the approach and recommendations in the Council's reports are most relevant, as follows:

- Further steps needed by the media and broadcasters to improve the quality, accessibility and balance of their science coverage; and science coverage in broadcasters' programme-making.

- The extent to which public dialogue and consultation is being effectively used by Government in science and technology areas of policy-making.

Science coverage in the media

3   The ways in which science and technology are presented in the media helps to shape public understanding and expectations. This in turn can affect attitudes, opinions, policy and perhaps investment decisions. In our report on novel

neurotechnologies[1] we identified a number of concerns about media coverage of new technologies in general, which may result in misapprehensions amongst the public:

- headlines that misrepresent research findings;
- inaccuracy, mistakes or lack of detail in reporting studies;
- misuse of 'balance' – i.e. presenting a minority view in a way that creates a false impression of balance of opinion amongst scientists or the public;
- focussing only on, or overstating, the possible benefits of a technology (and not reporting negative results, risks, long term uncertainties);
- over-reliance on a narrow range of sources; and
- uncritical reproduction of press releases.

4   The resulting misapprehensions can be problematic for a number of reasons, for example in the case of new health technologies or treatments they can affect patients' ability to make informed treatment choices and they may instil false hope amongst patients if the limits or risks of its applications are not reported.

5   Our report set out recommendations aimed at ensuring responsible communication that is accurate, avoids undue speculation and takes account of the possible impacts on those most affected by the issues that the technology or treatment aims to address. These recommendations were made in relation to reporting of novel neurotechnologies specifically, but we believe the principles should apply to communication of science and technology in general [*see paragraphs 9.71 to 9.74*]:

- **Researchers, press officers and journalists involved in the communication of the use of novel neurotechnologies should reflect on how their representations might contribute to hype, and exercise caution when describing the possible applications of a technology.**

- **Companies and universities developing and promoting these products should consider their corresponding responsibilities carefully when seeking investment or promoting their products.**

6   The Council's later work on naturalness[2] explored the significance of people's ideas about the concept of naturalness and how this may be influencing debates relating to developments in science, technology and medicine. We found that the terms *natural*, *unnatural* and *nature* are often used by journalists, parliamentarians and others as placeholders for a range of different values or beliefs that are meaningful and important to people. The report sets out five

---

[1] Nuffield Council on Bioethics (2013) Novel neurotechnologies: intervening in the brain. See Chapter 9 – Communication and the Media
http://nuffieldbioethics.org/report/neurotechnologies/communication-media/

[2] Nuffield Council on Bioethics (2015) Ideas about naturalness in public and political debates about science, technology and medicine – Analysis Paper
http://nuffieldbioethics.org/wp-   content/uploads/Naturalness-analysis-paper.pdf

understandings of *naturalness* that show the different ways in which the terms are used:

- **Neutral:** a neutral/sceptical view that does not equate naturalness with goodness

- **Wisdom of nature**: the idea that nature has found the correct or best ways of doing things and should not be 'tampered' with

- **Natural purpose**: the idea that living things have natural purpose, essence or functions which is linked to what is good for them and which science shouldn't seek to change

- **Disgust and monstrosity**: a response of disgust, revulsion or fear prompted by novel technologies

- **God and religion**: the idea that certain technologies distort God's creation or go against the will of God.

7   The report concludes that confusion over what people mean when they describe science, technology and medicine as 'unnatural' could be causing people to talk at cross-purposes and therefore hampering public debates. With this in mind, it is important that policy makers understand these different values and beliefs and engage with them, if they are genuinely to take account of the views of the public when developing policies for science, technology and medicine.

8   Recommendations are made to journalists, policy makers, science communicators, manufacturers and advertisers, aimed at reducing the risks of people talking at cross-purposes. The suggestions aimed specifically at journalists and policy makers are:

- **Journalists and policy makers should avoid using the terms *natural*, *unnatural* and *nature* when talking about science, medicine and technology without conveying the values or beliefs that underlie them**

- **Policy makers should explore fully what people mean when they use the terms *natural, unnatural* and *nature* when engaging with the general public to inform the development of science or health policy**

A public ethics approach to policy making

9   Regarding public dialogue and consultation and whether this is being effectively used by Government in science and technology areas of policy-making, the Council's report on emerging biotechnologies[3] addresses these issues in relation to the development of biotechnologies. The report sets out the case for a 'public

---

[3] Nuffield Council on Bioethics (2012) Emerging biotechnologies: technology, choice and the public good
http://nuffieldbioethics.org/project/emerging-biotechnologies/

ethics' approach to help guide improved practice in policy making, research and regulation, given that there is a significant public interest in the development of biotechnologies. A public ethics approach is centred on the public good, taking into account broad social contexts, circumstances, implications and alternatives rather than focussing narrowly on the impacts on individuals or on specific drivers or objectives such as economic development.

10 Applying public ethics to the governance of emerging biotechnologies does not mean that all the conditions that affect emergence should be set by the public, or in public, or that research and development should only take place in the public sector. We propose a 'public discourse ethics' as a way of establishing the context for policy decisions (and for evaluating them) in accordance with the public good. The report sets out a number of virtues that are intended to foster a public discourse ethics in practice, addressing the problems of privacy and partiality [*see paragraphs 4.41 – 4.59*]:

- **Openness and inclusion** – members of society should have the information required and, where appropriate, access to participate in biotechnological governance.

- **Accountability** – there should be explicit acceptance and acknowledgement of where responsibility for governance lies and how it might legitimately and democratically be influenced.

- **Public reasoning** – reasoning should be clear, explicit and aimed at finding common ground rather than promoting sectional interests, including in the presentation of evidence.

- **Candour** – uncertainties associated with emerging biotechnologies should be represented truthfully and in good faith**.**

- **Enablement** – appraisal of emerging biotechnologies should highlight alternative social and technological choices and the implications of each, and encourage wider political debate.

- **Caution** – the degree of uncertainty and ambiguity associated with emerging biotechnologies should mean there is a responsibility to gather more extensive knowledge prior to making policy commitments.

11 The report considers the various ways in which public engagement may help to shape emerging biotechnologies and responses to the benefits and hazards they hold. We note that since no single individual or community can have relevant expertise in all the areas that are relevant to decision making, engagement with non-specialist groups has an important role to play in developing policy for emerging biotechnologies and can contribute to a more ethically robust public decision making process [*see paragraphs 5.28 – 5.31*].

12 There are many approaches to public engagement, each with their own advantages and disadvantages. We do not recommend one method above another, but in this report have identified a number of dilemmas associated with

public engagement, including, for example: upstream and downstream engagement; representativeness and interestedness; and informing and eliciting *[see paragraphs 5.38 – 5.60]*.

13 We conclude that public engagement activities in principle provide an operational methodology for framing biotechnology policy and governance in terms of the public ethics, helping ensure that social, as well as commercial, values are brought to bear. However, the terms on which engagement exercises are undertaken and the way in which they are incorporated as part of the processes of policy development and governance may result in their effectiveness being limited or their outcomes narrowly evaluated.

14 The Council recommends that:

- **Careful and critical attention must be given to the alignment of the method with the underlying rationale for engagement, and the aims and expectations of engagement should be understood in advance.**

- **The outcomes of public engagement, just like expert technical advice, should be reported in a properly contextualised and conditional way rather than as simple prescriptive advice.**

Public participation in data initiatives

15 The Council's report on biological and health data[4] suggests that public participation should be at the heart of big data projects in health care and biomedical research. It concludes that good governance involving public participation and accountability is essential to maintaining public trust.

16 The principle of participation is one of four ethical principles put forward in this report for the design of and continuing governance of data initiatives. The four ethical principles are summarised as follows:

- **Respect for persons**: the terms of any data initiative must take into account both private and public interests. Enabling those with relevant interests to have a say in how their data are used and telling them how they are, in fact, used is a way in which data initiatives can demonstrate respect for persons.

- **Respect for human rights**: the terms of any data initiative should respect people's basic rights, such as the right to protection of private or family life. This includes limitations on the power of states and others to interfere with the privacy of individual citizens in the public interest.

- **Participation:** decision makers should not merely imagine how people ought to expect their data to be used, but should take steps to discover

---

[4] Nuffield Council on Bioethics (2015) The collection, linking and use of biodata in biomedical research and health care: ethical issues
http://nuffieldbioethics.org/project/biological-health-data/

how people do, in fact, expect their data to be used, and engage with those expectations.

- **Accounting for decisions:** data initiatives should include formal accountability, through regulatory, judicial and political procedures, as well as social accountability through periodic engagement with a broader public, as a way of re-calibrating expectations. Data initiatives must tell affected people what will be done with their data, and must report what actually has been done, including clear reports of any security breaches or other departures from the established policy.

17 Regarding the principle of participation, the Council argues that the set of expectations about how data will be used (or re-used) in a data initiative, and the appropriate measures and procedures for ensuring that those expectations are met, should be determined with the participation of people with morally relevant interests. This participation should involve giving and receiving public account of the reasons for establishing, conducting and participating in the initiative in a form that is accepted as reasonable by all. Where it is not feasible to engage all those with relevant interests – which will often be the case in practice – the full range of values and interests should be fairly represented *[see paragraphs 5.17 – 5.25]*.

18 Furthermore, a data initiative should be subject to effective systems of governance and accountability that are themselves morally justified. This should include both structures of accountability that invoke legitimate judicial and political authority, and social accountability arising from engagement of people in a society. Maintaining effective accountability must include effective measures for communicating expectations and failures of governance, execution and control to people affected and to the society more widely.