

Professor Montgomery's speech at the International Conference "Role and functions of Bioethics Committees". Rome, 23rd November 2012.

It is a pleasure and a privilege to address this conference on the Role and Functions of Bioethics Committees and I am very grateful for the invitation to discuss the work of the Nuffield Council on Bioethics. Part of what I will explore is the sense in which that Council is not a National Bioethics Committee in the way in which you have a Committee here in Italy and about which my colleagues have been talking in relation to France and Germany. I will also seek to explain the complexity of the way in which the United Kingdom in general, but particularly England, deals with some of the issues that are addressed in other countries by national bioethics committees. This will enable me to consider what can be learned about the work of national bioethics committees from this experience.

The Role of the Nuffield Council on Bioethics

The Nuffield Council on Bioethics, in terms of the "age range" that Patrick Gaudrey considered, is probably an "adolescent". It was founded in 1991. In 2011 it published a stocktake of its work over the first twenty years,¹ and it has undertaken a strategic review of where it should go next.² It is important to remember that the Council is not the only UK organization that has been active in the field of bioethics. The first UK entry into the history of national ethics committees could have been identified at a number of other points in that the history of national ethics committees.³ Although we arrived on the scene as the Nuffield Council in 1991, there had been a special Commission looking at issues around fertilization and embryology in the early 1980's.⁴ That commission, known as the Warnock Committee, made a series of recommendations that led to the creation of a supervisory body for clinical and research practice in the area, the Human Fertilisation and Embryology Authority.⁵ In 1999 a review of governance in bioethics led to the establishment in 2000 of the Human Genetics Commission.⁶ The UK has had a number of other very

¹ *Nuffield Council on Bioethics, Anniversary review 1991-2011: 20 years of investigating and illuminating ethical issues in biology and medicine* (2011) available from <http://www.nuffieldbioethics.org/publications>.

² *Nuffield Council on Bioethics, Strategic Plan 2012-2016: Exploring ethical issues in biology and medicine* (2012) available from <http://www.nuffieldbioethics.org/publications>.

³ Cross-ref to French paper

⁴ *Report of the Committee on Inquiry into Human Fertilisation and Embryology* (1984) Cmnd 9314.

⁵ See www.hfea.gov.uk. The Authority was established under the Human Fertilisation and Embryology Act 1990, later amended in 2008 following a major review; Department of Health, *Review of the Human Fertilisation and Embryology Act*, Cm 6989, (London: TSO 2006).

⁶ Cabinet Office, Office of Science and Technology, *The Advisory and Regulatory Framework for Biotechnology: Report from the Government's Review* (London: OST 1999); Human Genetics Commission, *Final Report* (London, HGC 2012).

specific committees, some of which I will consider briefly later, who have picked up particular topics and issues at various stages in more recent history. Most of these, in contrast to the Nuffield Council, have been established by Governments to advise them or to exercise regulatory powers. More recently, other non-government commissions have also re-emerged in the field as the current Coalition Government seeks to reduce the activity of non-governmental but official bodies in the name of increasing democratic accountability and reducing bureaucratic costs.⁷ While in many ways the Nuffield Council operates as if it were a national ethics committee, it has no official legislative recognition and is not the only body used by our society to deliberate on bioethical issues.

Thus, the UK has been very active in the field of bioethics but it has not adopted the approach of establishing a standing National Bioethics Committee in the way that most states have done.⁸ One of the reasons why the Nuffield Council was founded was to try and deal with some of the gaps opened up by the fragmented approach taken in the UK and in response to a call for the creation of a national commission that was not acted upon by Government.⁹ Ironically, one of the reasons that are now commonly given by Governments for rejecting proposals for a national ethics committee is that the Nuffield Council on Bioethics already exists to cover the field.¹⁰ It was established in 1991, not by the UK Government but by a charitable foundation. We are now funded by three organisations: the Nuffield Foundation, the Wellcome Trust and the Medical Research Council. Although independent of Government, the Medical Research Council does spend taxpayers' money and so the Nuffield Council receives some state funding indirectly. The MRC's principal role is to fund medical research but it has also at various stages funded work on bioethics and is a partner in funding the Nuffield Council on Bioethics.¹¹ The Wellcome Trust is a charitable foundation. Most of its spending is on research in Medicine and the Life Sciences but it also spends quite a lot on a range of ways of supporting scholars

⁷ Colloquially known as the 'Bonfire of the Quangos' (Quasi-Autonomous Non-Governmental Organisations). For Parliamentary Inquiry into the issues, see *Public Administration Select Committee Smaller Government: Shrinking the Quango State* (London: TSO, 2011) HC Pap 2010-11 537 (available from <http://www.parliament.uk/business/committees/committees-a-z/commons-select/public-administration-select-committee/inquiries/parliament-2010/quangos/>), and the *Government Response to the Public Administration Select Committee Report, "Smaller Government: Shrinking the Quango State"* (London: TSO, 2011) Cm 8044 (available from <https://www.gov.uk/government/publications/public-bodies-reform-reports>).

⁸ See, www.who.int/ethics/committees/euro/en.

⁹ See e.g. I. Kennedy, *The Unmasking of Medicine* (London: Granada, 1983), 129–30; M Brazier, 'Patient autonomy and consent to treatment: the role of law?' (1987) 7 *Legal Studies* 169-193 at 191; M. Warnock, 'A National Ethics Committee' (1988) 297 *British Medical Journal* 1626.

¹⁰ E.g. the debate in the House of Lords on 28 January 2008 on an amendment to the Human Fertilisation and Embryology Bill that proposed the creation of such a committee <http://www.publications.parliament.uk/pa/ld200708/ldhansrd/text/80128-0009.htm> .

¹¹ www.mrc.ac.uk.

in the humanities who are thinking about bioethics and helping scientists and researchers becoming more literate in bioethics and understanding the ethical issues in their work.¹² It is another of our funders for the Nuffield Council's work. Then our third and founding funder, is the Nuffield Foundation which initially funded the entire programme. The Nuffield Foundation funds a whole range of research but it is not particularly known for wider activity in bioethics.¹³ It is more active in social science research, in making contributions to political and economic understanding and we are probably its main piece of work around bioethics. So we are not a government sponsored organization. That gives us considerable independence and it also gives us some challenges, to which we will return, in terms of influence. This non-Governmental status is the first sense in which we play a slightly different role from the more familiar role of a National Ethics Committee, which we have been exploring in this conference.

The second is that our terms of reference focus only on a subset of the issues that have been dealt with by some of the other Committees we have been talking about. So, the first part of our Terms of Reference requires us 'to identify and define' ethical issues that come out of 'recent advances in biological and medical research' and the purpose for asking us to do that is expressed to be in terms of dealing with ('respond to, and to anticipate') public concern. What lay behind that aspect of the terms of reference is what is sometimes described as the 'problem' of law and ethics 'lagging behind' scientific advance. These terms of reference mean that we are not set up to talk about euthanasia. We are not set up to talk about "termination of pregnancy" as we would call it (rather than abortion). So, we only deal with a subset of the bioethical concerns with which other committees are, and have been, concerned.

Nor do we tend to issue what you would describe as "opinions". Our job is to explore, define and identify, the 'examine' and 'report' on the questions. Our primary task is not to promote government understanding. It is not to tell government what to do. It is not even really to develop our own understanding, although of course we do need to do that. Our task, captured in the second of our terms of reference, is to create a better 'public understanding and discussion' of the implications of advances. So what we publish are not so much opinions, as reports, and they cover a range of things including trying to summarize the available evidence both on ethical issues and science. We do make recommendations, and we do address those recommendations to Government (amongst others), but the recommendations are a small part of our reports. Consequently, the usage of our reports goes beyond the specific proposals we make for change. It is about informing people of the advances and of the contexts in which new scientific possibilities are emerging. It is also about enabling them to explore for themselves the suggestions we make about the way

¹² <http://www.wellcome.ac.uk/index.htm>.

¹³ <http://www.nuffieldfoundation.org/>.

society should grapple with things. Thus, we work to assist people making their own minds up about the issues even if they do not accept the Council's position.

The Nuffield Council in Context

From what has already been set out, it will be clear that it is necessary to consider briefly how else the UK does the work that is done in other countries by a National Bioethics Committee. In particular, to set out how matters beyond the scope of the Nuffield Council are addressed, and also to explain how the Nuffield Council's work relates to that of the other bodies.

We have a very large number of such bodies, only some of which can be described here. The Human Fertilisation Embryology Authority is both a regulator of assisted conception and embryo research and also an advisory body to grapple with ethical issues. So, there is some considerable overlap in the work we do at the Nuffield and at that the HEFA undertakes. This can be illustrated in relation to the work that we recently undertook looking at the implications of mitochondrial donation, which reported in 2012.¹⁴ This is an area in which the HFEA is also interested and it has already undertaken one piece of work dealing with safety issues,¹⁵ and is currently undertaking another piece of work looking at regulatory questions.¹⁶ The reports are independent of each other, and explore different aspects of the issues, but to understand fully how thinking is developing in the UK you would want to consider all three.

So, if you were trying to understand how the UK is grappling with bioethical issues, you can't just look at what the Nuffield Council does. We have heard about various issues around human research and some national bioethics committees have oversight of the Research Ethics Committees that provide independent ethical review of research protocols.¹⁷ This is not a role that the Nuffield Council undertakes. In England, this now falls within the remit of the Health Research Authority, created in December 2011 to protect and promote the interests of patients, participants and the general public in relation to health research.¹⁸ The HRA is responsible for the regulation of research approvals but it is not really a bioethics regulator as it does not set ethical standards. Rather, it ensures robust and proportionate review against the

¹⁴ Nuffield Council on Bioethics, *Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review* (London: NCoB 2012).

¹⁵ N. Haites, R. Lovell-Badge, *Scientific review of the safety and efficacy of methods to avoid mitochondrial disease through assisted conception: Report to the HFEA* (London: HFEA 2011), available from <http://www.hfea.gov.uk/6372.html>.

¹⁶ See the consultation 'Medical Frontiers: debating mitochondria replacement' at <http://mitochondria.hfea.gov.uk/mitochondria/>.

¹⁷ *National Bioethics Committees in Action* (Paris: UNESCO 2010).

¹⁸ www.hra.nhs.uk. The author was appointed as chair of the Health Research Authority in June 2012.

ethical standards developed by other bodies. It is looking at the mechanics of research approvals and the support of research and development in the United Kingdom rather than bioethics itself.

We also have strong history in the UK of issues in bioethics being explored and taken forward by non-government organizations, especially within the health professions. Important contributions have been made by the British Medical Association, especially its Medical Ethics Committee (of which I was privileged to be a member for a number of years) which comprises both doctors and experts in relevant disciplines (including law, theology, philosophy).¹⁹ This is one of the many bodies coming out of the medical professions which have done important work. These include the various medical Royal Colleges, which have provided leadership and reports on matters that often fall within the remit of national ethics committees. Examples include the work of Research Ethics Committees,²⁰ defining death,²¹ and the care of patients in permanent vegetative state.²²

Although there is some overlap with topics on which the Nuffield Council has made contributions,²³ it is not usual for the Council to look at matters that are essentially limited to defining good health care practice. The contribution of Nuffield is not just about what doctors think and should think, but to engage with the public and stakeholders to try and grapple with the sort of wider topics that would be your business as a National Bioethics Committee.

Finally, we have a long tradition of responding in the UK to scandals by setting up dedicated Groups to explore what went wrong and how to put it right. So, our legislation on human tissue donation came about as a result of by dedicated Commissions set up to explore mishaps and misconduct that came to light in a scandal around the Alder Hey hospital in Liverpool.²⁴ Quite separately, we have had a task force looking at questions around presumed consent for organ donation. This was part of a wider programme of work which was set up by our Government in

¹⁹ See <http://bma.org.uk/about-the-bma/how-we-work/professional-activities-and-special-interest/medical-ethics-committee>.

²⁰ Royal College of Physicians, *Guidelines on the practice of ethics committees in medical research with human participants* (4th ed London: RCP 2007), available from <http://bookshop.rcplondon.ac.uk/index.aspx>.

²¹ Academy of Medical Royal Colleges, *A Code of Practice for the Diagnosis and Confirmation of Death* (London: AcMRC 2008), available from http://www.aomrc.org.uk/publications/reports-a-guidance/doc_details/42-a-code-of-practice-for-the-diagnosis-and-confirmation-of-death.html.

²² Royal College of Physicians, *The Vegetative State: Guidance on diagnosis and management* (London: RCP 2003), available from <http://bookshop.rcplondon.ac.uk/index.aspx>.

²³ For example, the report on *Critical care decisions in fetal and neonatal medicine: ethical issues* (London: NCoB 2006).

²⁴ *The Royal Liverpool Children's Inquiry Report* (London: Stationery Office, 2001), HC12, which led to the Human Tissue Act 2004, setting up the Human Tissue Authority.

response to concerns around low organ donation rates.²⁵ The Committee of the Ethical Aspects of Pandemic Influenza, of which I have been a member since it was established in 2006, was set up to develop an ethical framework for government planning.²⁶ In each of these cases, the discussion was not routed through a standing Bioethics Commission as might have been possible in other countries. One consequence is that in the UK we risk losing the continuity and consistency that you could develop if you had a single way of dealing with things. However, you might suspect from the fact that I have mentioned my own involvement in a number of those bodies, that the group of people who are engaged in such work overlaps considerably.

Independence: A Key Characteristic

So, you shouldn't therefore think that the Nuffield Council has to define itself in quite the same way as you would need to do if you were grappling with the legislative framework of a National Bioethics Commission. Indeed, the Council has identified as its core value, given that context, its independence from external control.

So, we have to work out how we can contribute to the bioethics debate precisely by not being a government sponsored organization but rather to promote a healthy and intelligent exploration of bioethical issues across the Country. We are funded with relatively few strings. We have a five year funding program and therefore we have to justify ourselves periodically but we don't have to justify it every year or by every project, as we would, if we were receiving a research grant from these funders. We are not held to account by government in the way a National Bioethics Committee would expect to be. We are entirely free to select our own topics for investigation and I will describe how we do that shortly.

Of course, most Bioethics Committees insist on being very independent, and it is a question of degree rather than a binary question – independent or not. But it is absolutely core to our justification to speak in our society with any authority. Similarly, we are free to appoint the people we think we need to have around the table, as members of the Council. The only person appointed by the funders is the Chair of the Council. The Council appoints its own members and it is very clear that it seeks to appoint people for their individual expertise. Not to represent any group, but to ensure that the range of expertise, the range of experience, the range of sections of society that are needed to participate in debates, are there around the table; but

²⁵ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_090312 I was part of the Task Force's work on presumed consent, although not the earlier report which recommended changes to system reform around donation, retrieval, transportation and transplantation.

²⁶ See Cabinet Office & Department of Health, *Responding to pandemic influenza The ethical framework for policy and planning* (London: COI 2007), available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080751 and the background material at http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/PublicHealth/Flu/PandemicFlu/DH_065163.

without any need to satisfy any form of *quota* and without any need to report back to sponsoring bodies. So, our independence is our key “selling point”.

Relevance and Timeliness

If we were set up to anticipate public concerns, we need to make sure that the work we do is relevant, not just in terms of the timeliness of the topics that we select, but also the speed with which we are able to contribute to the debate. This is one of the challenges the Nuffield Council has had to grapple with recently. Our reports have become longer and longer, because they aim to both capture and inform the debate, and the debates are so wide-ranging that this takes both time and space. It has probably become less and less likely that many people actually read the entire reports from the beginning to the end. One of our responses is to try and create two streams of working. One stream which is designed to be comprehensive; gathering all the available evidence and opinions, trying to provide a synthesis so far it is possible, explaining the differences where that is not possible, and providing a foundation for detailed further consideration.

Another stream, is more of a snap shot. We’ve only had one go so far, around the mitochondrial work,²⁷ where we defined much more narrowly the issue that we wanted to capture and explore. We are in effect seeking to do only that bit of our terms of reference which is to identify and define (as opposed to resolve) the issues that are there. Because we think these things are complex, and the public debate moves so fast that we will not be able to assist it if we cannot move more quickly.

Inclusiveness, Quality, Rationality and Rigour

A second value is around making sure that all the opinions in society and across the frame of bioethical learning, are incorporated into our work. So we never start from any particular position or view. We worry a bit less, therefore, about consistency between opinions than we might. What we do want to try to do is to pull in the various ways in which the debates are being explored and test them against our ideas of quality. So, you will see from the values set out in our strategic plan that we are saying to ourselves and to our stakeholders “all voices should be heard” but they shouldn’t expect to avoid the tests of rationality of argument.²⁸ We should make sure we have strong quality processes to make sure that we explore all those areas. So while we aim to be open in terms of our learning and listening we aim to be quite rigorous in terms of standards of coherence, consistency around arguments and that’s

²⁷ Nuffield Council on Bioethics, *Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review* (London: NCoB 2012).

²⁸ Nuffield Council on Bioethics, *Strategic Plan 2012-2016: Exploring ethical issues in biology and medicine* (2012), p 4.

where we see our ability to go beyond merely recording what's said to us and offer back something valuable.

Topic Selection

I identified earlier the importance of independence in topic selection. We initiate that process through a small group of our Council grappling with the questions. But we do it in a way that draws on an awful lot of feedback and suggestions from others. So, as we meet to discuss possible topics, we pull in ideas from government, from industries of various sorts, from non-government organizations, from people who have been involved in our works previously. We have opened up for the first time in this current cycle of topic selection an open call on our website for people to make suggestions about topics that might be there. From this, the sub-group will usually identify about four topics, out of which we will probably end up selecting two, to go to a 'Forward-Look' meeting.

This will be supported by background papers, which we either produce internally or we commission, to explain the issues that might emerge, and that seem to require much more detailed consideration. These provide the foundation for a workshop. This is not a public workshop, but nor it is a workshop of just Council members. It includes invited people who brought things forward to us or who we think would have something to say about the issues. The papers that go to that workshop and the summary of a workshop discussion, are publically available, so they are contributions to improving ethical debate in their own right.²⁹ When we have selected the couple we might choose as projects, we will then proceed by setting up a working party.

We have set out selection criteria we use to make that step from something that is considered in the "forward look" meeting into selection for a topic, and they are very much linked to our terms of reference. So, first, it needs to be a novel problem and this is our justification, or excuse depending on how you are looking at it, for not being drawn into the debates that surround euthanasia or termination of pregnancy. This is because it is rare for those debates to be driven by new developments in biology or medicine. They are mostly driven by long standing concerns and clashes of value.

The second criteria is that the issues to be explored need to include complex ethical questions. It is not our remit just to comment on things that are straightforward. It is, however, our remit to facilitate the exploration of complexity. Thirdly, it needs to be good in terms of timeliness, it needs to be an appropriate time for us to look into this process: neither too early nor too late. From our terms of reference we need to anticipate that if we did this piece of work, we would be providing thinking that that would be useful in terms of developing policy, although not necessarily government policy. We produce recommendations that are aimed at

²⁹ Available at <http://www.nuffieldbioethics.org/future-work/future-work-forward-look-meetings>.

whole range of people or aim to help resolve practical challenges. Finally we have to check that the topics fall within our terms of reference although broadly, if we get through those other hurdles, we will usually find that they are.

Working Parties

So, having decided that a topic meets that set of criteria, like many other groups, we realize that our Council members can't do all the work that needs to be done. We will typically have around twenty Council members although it is up to us how many we need. We could have a few more, we sometimes have a few less. We usually take a couple of those Council members to go onto our working parties and then we select our working parties to try and identify the range of expertise and experience needed to inform that discussion. We will recruit a Chair for the working party, whom we will then co-opt on to the Council. So, for the duration of the working parties, which is usually a couple of years, they will also play a full part in the broader council debates.

Previously, we have approached people whom we think would be likely to assist us. Those who wish to contribute but whom we had not identified could contribute to our evidence gathering but not as working party members. We have recently begun inviting people to express an interest in being members of working parties. The more open recruitment process is a new step for us and we are just trying it for the first time round with our working party currently established, around data linkages.³⁰ It will be interesting to see what challenges emerge; saying yes to people who wish to become members will be easy, explaining why they were not selected will be more difficult.

Once the working party is set up, it pulls in through public consultation an enormous amount of information that we did not previously know about. We will typically produce a consultation document raising some questions and then invite people to send in evidence and opinions that relate to that. All of the submissions that we receive are published unless we are asked by those who send them to keep them confidential. So, part of the contribution we make to public debate is actually through making available what people say to us, and not just what we say to them. We analyse the material that we receive and identify issues (either from the evidence that has come in or from a lack of it) where the working party needs to explore specific questions in 'fact-finding' sessions. They are not held in public although a record of them will find its way through into our processes. We also sometimes commission particular bits of work to inform the deliberations.

The Council as whole will be kept aware of the working party's progress, including tentative conclusions and can push back questions to help them avoid going down dead ends. However, the positions taken in the reports are developed

³⁰ <http://www.nuffieldbioethics.org/future-work/future-work-call-expressions-interest-new-biodata-project>

autonomously by the working parties. Quality is assured by an external peer review, which is an international process, and that informs the final version of the Report which needs to be signed off by the Chair of the Council. Our reports thus have the authority of the Council, but within that authority has to come a degree of expectation of independence of working parties. We do not, at the Council, necessarily like every word of what the working party says, Rather, we satisfy ourselves that the work meets those criteria which we set out in terms of quality and value. That does mean that not all working parties reports are consistent with each other. It means that there isn't a single ethical framework that the Nuffield Council has produced. We would regard that as a valuable characteristic of our work, but others might find it frustrating.

Reports and other activities

This process results in the robust and thorough reports on which the reputation of the Nuffield Council on Bioethics is based. However, there is much more to our work than the production of reports. Once we have them, we identify a whole range of activities that we need to undertake because of the variety of public audiences. There's just a couple I would pick up for reflection because they may be of interest to observers. One is the way in which we encourage young people to engage with the things we are exploring. We produce short versions of our reports and associated materials for schools. We started for the first time last year a student film competition, Box Office Bioethics,³¹ which invited students in separate categories from school, early in their university careers and near to graduating, to produce short videos about bioethical issues. There is even a YouTube clip from the winners of one of the categories about their trip to London to get their award, which is every bit as interesting as the entry they produced about the bioethical issues. We found the response to that competition very encouraging. It enables us to encourage not just medical schools, some of whom participated, but all sorts of educational organisations in thinking about bioethical issues.

We have also tried to raise awareness at the level of the interested public intellectual community. We hold an annual public lecture where we invite a speaker, usually alternating between a UK speaker and a speaker from abroad, to explore a topic in bioethics of their choosing.³² We identify the speaker, with a broad idea of a topic in mind, but they have the chance to tell us what they think we should ask them to talk about.

We also have some pieces of work where we have identified that some thematic exploration would be helpful. We had a big piece of work on the concept of solidarity a couple of years ago where we commissioned a fellow to conduct a

³¹ <http://www.nuffieldbioethics.org/education/education-box-office-bioethics>.

³² <http://www.nuffieldbioethics.org/events/events-annual-lecture-archive>.

review.³³ We are just engaging in some discussions as part of this year's "forward look" process as to whether something on what is 'natural' or 'normal' might be needed. This would probably not be carried out in quite the same way as the solidarity work, but perhaps some form of facilitated public debate about how people use the concepts in debates would be a valuable contribution. So that is all about trying to encourage debate.

We also need to try to make sure that some notice is taken of our work. So we engage with our Parliamentarians. We produce materials around our Reports specifically to inform them. We target them when we have made recommendations, offering meetings and we often go to speak to them, but we have no right "to get in the door". Were we an established National Bioethics Committee, I think it would be rather more difficult to "close the door" to us. However, this does not in practice mean we lack impact. We are able to point quite specifically to things that happen as a result of our Reports. Sometimes this is within our health profession communities. Our work on decision making into fetal and neonatal medicine has prompted work from the relevant medical association on developing more specific guidelines. We've seen some of the recommendations that we made on the forensic use of bioinformation finding its way into European Court's decision making and to also legislative change through the UK Crime and Security Act.

I think, rather more subtly but in some ways much more interesting, we have seen how the *way* in which we have looked into things has been influential in addition to specific recommendations. So, in the working party that reported in 2007 on a range of ethical issues in public health,³⁴ two concepts were developed in our framework of thinking which were proved to be quite influential, not just in public health areas but also elsewhere. One was what we described as an "intervention ladder". This means, broadly, that we need to think about the degrees of intrusion that government intervention, or non-government organization intervention, might take, and consider the different levels of justification required. The greater the intrusion, the stronger the justification required. This may be a peculiarly Anglo-American anxiety, but it has become important whether you are 'nudging' people or requiring people to do things. Our report suggested that you can make it more likely that people make the type of judgments we believe are ethical without taking away their ethical responsibility to be agents and the intervention ladder captures the idea that you should use less coercive techniques in preference to those that restrict choice further.

Secondly, we developed a concept of 'stewardship' to try and explain the roles of government beyond the classic liberal position of allowing people to do what they like unless they harmed each other. This may be one of the important features which may distinguish the way in which we operate in the UK from our mainland continental colleagues. The reason we needed that model was driven by the political background which was a very non-interventionist libertarian background where all

³³ B. Prainsack & A. Buyx, *Solidarity: reflections on an emerging concept in bioethics* (London: NCoB 2011).

³⁴ *Public health: ethical issues* (London: NCoB 2007).

interventions by government needed to be justified. So, we needed a model that tried to explain that it was entirely consistent with that broad political framework to expect government to take responsibility for public health issues. If you come from a different political and social tradition you might not have needed that model. It does not necessarily translate in quite those terms. In contrast to that, I think that our work on dementia which has been influential in the UK, in various elements of the current political program,³⁵ is remarkably similar to the work on dementia that the German Ethics Committee produced.³⁶ We may have possibly started with some different concepts and some different points but actually the vision of what a dementia friendly society would look like, we've learned in our exchanges, is remarkably similar.

Conclusion

I can then just conclude by saying that the Nuffield Council on Bioethics has been around a reasonable amount of time and is an established part of the landscape. We very much value our international collaborations and one of the things that it has told us is that people are probably as likely to read our reports abroad as they do in the UK, which is really helpful in terms of feeding back. We believe we've achieved quite a lot and we believe that the key to that lies in the combination of our independence from government, the value-based stance that we have adopted, the processes we have created to make sure that the work we produce is of high quality and the fact that we have managed to pick topics, through those processes, that people believe are important topics and need to be grappled with. None of that quite makes us a National Bioethics Commission in the sense that you have in Italy. We have some opportunities that you do not have and we also have some difficulties that you probably find it rather easier to overcome.

³⁵ *Dementia: ethical issues* (London: NCoB 2009).

³⁶ Demenz und Selbstbestimmung (2012) <http://www.ethikrat.org/publications/opinions> .