

**The Nuffield Council on Bioethics:  
an Ethical Review of Publications**

**Sarah Chan and John Harris**

## **Executive Summary**

### **Ethical principles**

The following ethical principles emerge from the Council's reports. These principles are generally accepted throughout the reports, although the manner of their application may be seen to vary, sometimes considerably.

- Avoidance of causing harm
- Prevention of harm
- Duty of beneficence
- Respect for persons and autonomy
- Justice and just resource allocation
- Informed consent
- Confidentiality and privacy
- Moral status: to whom do these principles apply (scope)?

Some further principles are raised and discussed within the Council's publications, but are not necessarily accepted or affirmed throughout, nor defined in a consistent manner:

- Respect for dignity
- Naturalness

### **Ethical frameworks and their utilisation in the reports**

The principles listed above have in some of the Council's reports been stated and applied in the context of various ethical frameworks. Some reports devote very little or no attention to the establishment of a framework within which to consider the problems posed by their subject, while others clearly set out such a framework. The uses (or otherwise) of ethical frameworks in the reports is summarised in the report below.

It can be observed that in cases where an ethical framework has been stated clearly, it has generally been used systematically in determining the policy recommendations of the report, whether or not the process of defining and deciding on the framework has been made explicit. By contrast, some (though not all) of the reports which do not clearly adopt an ethical framework also display a more piecemeal approach to the application of the principles cited, sometimes resulting in less coherent policy guidance or inconsistencies within a single report's treatment of its principles and their application.

### **What do the Reports tell us about the Nuffield Council on Bioethics?**

When considered in rough chronological order as we do in the report below the publications of the Council demonstrate the evolution and refinement of an overall approach to bioethics that stretches across the entire publication output. Of particular note is the manner in which the reports have moved from making primarily policy-based recommendations to considering the underlying ethical principles. Another feature of note is the development, particularly in recent reports, of considerations of theoretical moral philosophy: being self-reflective in terms of the chosen ethical framework and how it applies. The reports thus demonstrate an overall trend towards incorporating more theoretical components into the Council's manner of dealing with the problems of bioethics – a trend of which this review may itself be an element.

### **The role of the Nuffield Council in bioethics**

The picture of The Nuffield Council On Bioethics that emerges from an external perspective is of a liberal democratic, secular body that attempts to span both theoretical ethics and practical policy. This is betimes a difficult position, and an

analysis of the Council's work must therefore acknowledge the role of Council in producing practical policy advice, not just generating tracts of theoretical academic philosophy.

### **Ethical frameworks and their uses**

Ethical principles, whether in theory or in application, do not exist in a vacuum: to be meaningful, they must relate to each other in some way and be applied consistently. Most problems of practical bioethics will invoke multiple principles, which if applied in isolation may produce incoherent results. The function of an ethical framework, then, is to provide a context within which the component principles may be applied consistently and coherently to achieve practical outcomes.

*Is there a "Nuffield Council" Ethical Framework, and is one wanted or needed?*

As we indicate in the Introduction to this report, we consider that an ethical framework comprises a set of principles susceptible of coherent and consistent application that can be applied in a particular context of ethical decision-making. Given this account is perhaps neither surprising nor inappropriate that no single, universally applicable framework can be distinguished across the Council's entire *oeuvre* to date, dealing as it does with such a range of issues and contexts.

This pluralism of frameworks has led to some inconsistencies at times between the findings of the reports as to different ethical principles and how they should be applied. One obvious advantage of defining a harmonious and universal "Nuffield Council Ethical Framework for Bioethics" would be to reduce such inconsistencies and to confer greater predictability for future work, in the same way that the doctrine of precedent does for judicial decisions.

Equally, however, there are strong reasons against establishing such a framework. Policy-making and law-making are not the same thing, and there is a need for policy advisory bodies to retain greater flexibility to incorporate new or different elements in response to the changing social and technological environment.

Bearing these considerations in mind, we therefore offer the following comments on best practice and the use of ethical frameworks, which we hope may assist the Council in its future work.

*Procedure and best practice in ethical decision-making*

As with individuals, so with institutions and indeed with advisory bodies, best practice in ethical decision making involves making decisions on the basis of the best available evidence, in the light of consistently applied and relevant moral principles which are either generally agreed and accepted or which can be established to be relevant by moral argument. Finally the evidence and argument which justify and support the conclusions reached must be part of the report and articulated in detail sufficient to enable them to be either challenged or seen clearly to be cogent on the face of it.

For example, the incorporation of public sentiment and unjustified (although not necessarily unjustifiable) intuitions into policy decisions when they clash with the chosen ethical framework or indeed when they cannot be supported by persuasive evidence or argument may be a poor example of this standard unless it is explained why a particular sentiment ought to be taken into account.

As previously noted, the authors of this report have been struck by an apparent shift towards the explicit use of ethical frameworks in the Council's more recent reports. This seems to us to lend both added authority and greater clarity to the reports, and the Council might like to consider whether or not future Working Parties should be invited to consider the appropriateness of determining an ethical framework to help in the formulation of appropriate questions for consideration, as part of their Terms of Reference.

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# **The Nuffield Council on Bioethics: an Ethical Review of Publications**

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## **I. Introduction**

### *1.1.1. Aims of the review*

Since 1991, the Nuffield Council on Bioethics has been one of the United Kingdom's premier independent bioethics advisory organisations. It has produced a dozen reports and a number of discussion papers on the ethical dimensions of various medical and biological technologies, which have been highly influential in the shaping of public policy and bioethical debate both within the UK and internationally.

In this review we were asked to address the following aims:

To identify and critically review:

- the range of ethical frameworks, principles, norms and guiding concepts used in the Council's published Reports
- strengths and weaknesses in particular publications relating to the way in which ethical frameworks, principles, norms and guiding concepts have been justified and/or used.

To discuss:

- whether criteria could be identified to help determine minimal standards, and/or best practice in the use of ethical frameworks, principles, norms or guiding concepts to assist members of new Working Parties
- whether there are overarching implicit or explicit ethical frameworks, principles, norms or guiding concepts which are used in all, or specific clusters of publications
- the reasons for and against possible future attempts at harmonisation of different approaches taken in different publications.

### *I.1.2. What is an ethical framework?*

In attempting to address these aims, it was necessary to begin with a clear account of the concept of an ethical framework. An ethical framework is a set of ethical principles capable of being applied consistently and designed to guide our response to a particular problem or set of problems. This is to be contrasted with an ethical *approach* such as consequentialism or deontology, or a set of ethical *imperatives* like the Ten Commandments. Unlike the latter, an ethical framework dictates not what is to be done, but what factors should be considered in deciding what is to be done. In contrast also to the former, although an ethical framework may articulate or be consistent with a particular underlying ethical approach, identification of and agreement on the underlying approach is not necessary to delineate and apply the framework. We will consider these various levels of consistency in our analysis of the Council's work and address the aptness of determining ethical guidance in these terms.

### *I.1.3. Authors' statement*

Although the review has been commissioned and funded by the Council, it is intended to provide an independent evaluation of the Council's work from a philosophical ethics perspective. Neither the authors nor their institution have any affiliation with the Nuffield Council on Bioethics outside the context of this review.

## **II. Principles used in the Council's reports**

We begin our investigation by examining each of the Council's publications in an attempt to identify the ethical principles, implicit and explicit, that have been considered relevant in the Council's treatment of each particular topic. In this analysis, we shall list principles that are stated or implied within the ethical discussion, observe how these principles are framed, determine whether they find support from the Council and observe how the accepted principles are applied in each case. We shall also comment on the ethical frameworks and approaches that may be discerned, and how these apply.

## **II.1. Human Tissue: Ethical and Legal Issues (1995)**

### *II.1.1. Prevention of harm*

The principle of prevention of harm in this context is phrased as the necessity for “avoidance and limitation of injury”<sup>1</sup>. Harm and injury are further defined within the medical context such that acts carried out in the “therapeutic context” or with “therapeutic intent”, although they may cause injury in themselves, are considered to be medical treatment undertaken in the patient’s interests and therefore not a harm. The taking and use of tissue for non-therapeutic purposes, however, may be seen to cause harm<sup>2</sup>

### *II.1.2. Respect and human dignity*

The report describes certain actions as being ethically unacceptable because “these sorts of actions fail to respect others or to accord them dignity, that they injure human beings by treating them as things, as less than human, as objects for use”<sup>3</sup>. There is “considerable agreement about a central range of injurious activity that would constitute disrespect for human beings and for human dignity. Conversely, lack of respect for human beings and their bodies is often expressed in action that injures”<sup>4</sup>. The range of “injurious activity” is taken to cover uses of human tissue “without any therapeutic intent, direct or indirect”<sup>5</sup>.

Respect for human dignity is therefore an important principle applied in this context. It is notable, however, that the report does not attempt to further define the concept of human dignity beyond identifying what sort of actions might fail to respect it. Although it is true that there is “considerable agreement” as to what might disrespect dignity, there is little basis for justification of this agreement and the notion of what

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<sup>1</sup> *Human Tissue: Ethical and Legal Issues* (1995), 6.4, p 40.

<sup>2</sup> *Ibid.* 6.16, p 43.

<sup>3</sup> *Ibid.*, 6.7, p 40.

<sup>4</sup> *Ibid.*.

<sup>5</sup> *Ibid.*, 6.16, p 43.

dignity itself constitutes remains vague, both in this report and in many bioethical writings.

### *II.1.3. Consent*

The report emphasises the importance of consent in any medical procedure including obtaining biological material. An implied principle that gives rise to this imperative is that of *respect for autonomy*, although this is not explicitly stated: to perform medical procedures or take tissue samples without consent is to infringe the patient's bodily integrity, to interfere with the patient's control of his or herself, and by so doing to compromise autonomy. Valid consent, in order to recognise autonomy, must therefore also include an element of understanding as to what is being consented to and its likely effects, a test long established in law as the principle of informed consent.

The Council's stated view regarding consent is that "[t]he ethically significant requirement is not that consent be complete but that it be genuine"<sup>6</sup>. This statement is referred to and quoted in a number of the Council's subsequent reports, underlining its importance as a central doctrine of consent according to the ethical framework that emerges.

It is notable that according to the report, consent cannot justify injury, even if the consent is a valid expression of a person's autonomy. This distinction is not further discussed, but does hint at the establishment of a principle of consent as more than just derivative of respect for autonomy.

### *II.1.4. Ethical frameworks and approaches in this report*

The principles expressed and applied in this report fall within an established framework of medical ethics. This centres on patients as individuals and the way in which they are treated: the significant ethical considerations concern harm to, consent of and respect for the patient. There is little discussion in terms of an explicitly

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<sup>6</sup> Ibid., 6.20, p 45.

adopted ethical approach of why these considerations should be deemed important; but the principles themselves can be seen to follow a consistent framework.

## **II.2. Animal-to-Human Transplants: the ethics of xenotransplantation (1996)**

### *II.2.1. Beneficence and prevention of harm*

According to the report, the moral significance of improving human health and preventing suffering means that it is important to attempt to address the shortage of transplant organs. This provides a possible justification for the use of animals as xenotransplant donors<sup>7</sup>, if to do so would relieve suffering and benefit humans.

Another relevant consideration in the context of xenotransplantation might be the prevention of harm to animals caused by suffering either through xenotransplantation research or the use of the therapy itself<sup>8</sup>. A further possible harm might be the harm to xenotransplant recipients, which might take psychological or emotional form<sup>9</sup>. The moral imperative to prevent these harms, however, must be balanced against the imperative to prevent the harms that might occur if xenotransplantation were not performed.

### *II.2.2. Risk (of harm)*

Xenotransplantation research and treatment would involve several potential risks: the risks inherent in creating transgenic animals, the danger of zoonotic diseases transmitted from animal donors to human recipients, the risk to experimental subjects and patients undergoing the procedure<sup>10</sup>.

Having established that it is important to prevent harm occurring but also that there may be benefits that result from xenotransplantation, the ethically relevant question is therefore what level of risk is acceptable. The principle of risk balancing would thus seem to derive from the first principle of beneficence and harm prevention.

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<sup>7</sup> *Animal to Human Transplants: the Ethics of Xenotransplantation* (1996), 4.5-4.6.

<sup>8</sup> *Ibid.*, 4.7-4.8.

<sup>9</sup> *Ibid.*, pp 103-105.

<sup>10</sup> *Ibid.*

### *II.2.3. Personhood and moral status*

The question of the moral status of animals is of great relevance to the issue of xenotransplantation, since in determining how to balance the harms and benefits involved to both animals and people it is necessary to decide what weight to give to each.

On this issue, the Council focuses on the idea of self-awareness as an indicator of moral status: “the crucial point is the extent to which animals share the features supposed to be important to human interests and rights. The feature to which most importance has generally been attached is that of self-awareness...”<sup>11</sup> The argument here is that if animals possess “self-awareness, complex social relationships and many of the other characteristics that have often been supposed to make human beings unique... then these animals should be accorded the same moral status as human beings.”<sup>12</sup>

### *II.2.4. Speciesism*

Despite acknowledging that animals may be deserving of the same moral status as humans, the report finds reasons that humans and animals should be differently treated: “Our natural emotional response to, and concern for, members of our own species is clearly built deeply into our nature and it is not clear that the option of responding to members of other species, with the same concern in every case, is open to us. We should consider therefore what our treatment of non-human animals should be in its own terms, rather than in terms of consistency with our treatment of human beings.”<sup>13</sup> Personhood is not, apparently, the sole or even most important moral criterion; the sentiment that we should accord our own species particular moral privilege is to be heeded, whether rationally justified or not, and the reasoning for

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<sup>11</sup> Ibid., 4.9, p 39.

<sup>12</sup> Ibid., 4.11, p 40.

<sup>13</sup> Ibid., 4.15, pp 41-42.

accepting the principle of speciesism appears to be that “[t]hese sentiments are too strong to be easily cast aside”<sup>14</sup>.

In this sense, the use of this principle is axiomatic rather than reasoned. The fact that some popularly held sentiments are not easily cast aside is not in itself a justification for promoting such intuitions to the status of moral principle; the test should not be whether they can be easily cast aside but whether, according to rational and philosophical dictates, they *ought* to be cast aside.

#### *II.2.5. Nature and naturalness*

A number of arguments about “the relationship of human beings to nature”<sup>15</sup> and the relevance of this to xenotransplantation are raised in the report: that “human beings should not seek to dominate nature”; and that the use of animals for xenotransplantation is wrong either because it is unnatural<sup>16</sup> or because it requires “adopting a wholly instrumental attitude towards nature”<sup>17</sup>. If accepted, these principles might oppose the use of xenotransplantation, however the soundness of the moral arguments is not evaluated. Instead there seems to be tacit recognition that they may stem from root intuitions about what we like, or do not like to see about ourselves “when we look honestly in the mirror”<sup>18</sup>; the moral argument or principle here (if indeed there is one) is difficult to discern.

#### *II.2.6. Consent*

The report reiterates the importance of consent thus: “It is a paramount principle of contemporary medicine that patients should give properly informed consent to any treatment or therapeutic research...”<sup>19</sup> As it is a well-established and accepted principle, the moral arguments underlying the requirement for consent are not considered, although some additional concerns are raised about the anticipated level

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<sup>14</sup> Ibid., 4.14, p 41.

<sup>15</sup> Ibid., 4.19, p 43.

<sup>16</sup> Ibid., 4.21, p 43.

<sup>17</sup> Ibid.4.20, p 43.

<sup>18</sup> Ibid.4.22, p 44.

<sup>19</sup> Ibid., 7.15, p 87.

of information that might be available to participants in xenotransplantation procedures<sup>20</sup>.

### *II.2.7. Respect for conscientious objection<sup>21</sup>*

The report specifically outlines a “principle of respect for conscientious objection”<sup>22</sup>, by which it first refers to objections on the part of potential xenograft recipients. Obviously if the principle of consent is adhered to then no person should be forced to undergo xenotransplantation, but respect for conscientious objection goes beyond this to protect the interests of those who do refuse and ensure that they are not disadvantaged further as a result of refusal.

Conscientious objection in the context of other medical procedures has also been relevant to health care professionals who might be asked to perform the procedure, a notable example in this respect being abortion. On this, the report recommends that “the right of conscientious objection should also be extended to health care personnel” but “the right cannot be understood to be absolute”<sup>23</sup>.

There is little discussion of the ethical reasoning behind this principle, other than the cited reason, that “public policy must reflect the ethical pluralism that characterises this and many other societies”<sup>24</sup>. While this is true, it is not necessarily (as we shall discuss later) grounds to formulate an ethical principle.

### *II.2.8. Justice and resource allocation*

The final ethical issue considered is the possible effect on the NHS of allowing xenotransplantation<sup>25</sup>. This is principally a concern about allocation of health care resources and justice, and the report focuses on the practical difficulties of answering this concern rather than scrutinising what a principle of justice might mean in the

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<sup>20</sup> Ibid., 7.14-7.21, pp 87-89.

<sup>21</sup> Ibid., pp 91-92.

<sup>22</sup> Ibid., 7.29, p 92.

<sup>23</sup> Ibid., 7.32, p 93.

<sup>24</sup> Ibid., 7.27, p 91.

<sup>25</sup> Ibid., pp 95-100.

health care context – a question, indeed, that has occupied many theoretical ethicists at some length!

### *II.2.9. Ethical frameworks and approaches*

This report does not overtly adopt a particular ethical framework or approach. Some of the principles cited, such as consent, fall within the patient-centred medical ethics framework of the previous report (see II.1.4); others such as the analysis of personhood and moral status take a broader approach; while some principles such as naturalness, “speciesism” and conscientious objection seem to be based on policy considerations rather than ethical principles.

## **II.3. Mental disorders and genetics: the ethical context (1998)**

“[T]he limitation of harm and suffering to all humans... and the maintenance of respect for human beings and human dignity”<sup>26</sup> are two fundamental ethical principles identified clearly in this report.

### *II.3.1. Preventing and avoiding harm and suffering*

The limitation of harm and suffering in this context is characterised as “seeking to cure, to care and not to injure”<sup>27</sup>. This entails the usual requirements of medical treatment and research to avoid harm to patients and research subjects.

Another area in which preventing harm might be relevant in the context of dealing with mental illness is the “stigma of mental disorder”<sup>28</sup>, which itself both constitutes and can cause harm or injury to sufferers and others<sup>29</sup> through its possible consequences: discrimination in areas of insurance, employment, education and so forth<sup>30</sup>.

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<sup>26</sup> *Mental Disorders and Genetics: The Ethical Context* (1998) 1.8, p 3.

<sup>27</sup> *Ibid.*, 1.9, p 3.

<sup>28</sup> *Ibid.*, 6.2-6.10, pp 55-56.

<sup>29</sup> *Ibid.*, 6.6, p 55.

<sup>30</sup> *Ibid.*, 6.11-35, pp 56-61.

### *II.3.2. Respect for persons*

This report attempts to set out a clearer definition than the last of what respect for persons might entail: It is “shown by treating others as persons who can make their own decisions and lead their own lives; it is expressed in action and procedures that give due weight to personal autonomy and integrity, to human (including patients’) rights, and to the obligation of doctors and researchers to seek informed consent, to preserve confidentiality, to respect privacy and to communicate effectively with patients.”<sup>31</sup>

The underlying reason given for the existence of a moral imperative to respect persons invokes the concept of moral agency: “Failure to respect persons is wrong because it threatens or undermines the very sources and possibility of any moral action”<sup>32</sup>.

### *II.3.3. Respect for autonomy*

This principle is related but not identical to the principle of respect for persons. The idea of autonomy weighs here on both sides of the debate: the autonomy of persons may be infringed by coerced or unwanted genetic testing, but knowledge gained through genetic tests and the choice it provides can also promote autonomy<sup>33</sup>. The report recognises this in its discussion of eugenic concerns associated with genetic testing: that providing reproductive choices is not eugenic, at least in the negative, coercive sense, and that the principle of free and informed consent should ensure that choice is maintained<sup>34</sup>.

### *II.3.4. Respect for human dignity*

The importance of “respect for human beings, their autonomy and dignity”<sup>35</sup> is reiterated a number of times in the report<sup>36</sup>. However there is no exploration of what

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<sup>31</sup> Ibid.

<sup>32</sup> Ibid., 1.10, p 4.

<sup>33</sup> Ibid., 5.38-39, pp 44-45.

<sup>34</sup> Ibid., 5.45-54, p 48-50.

<sup>35</sup> Ibid., 5.22, p 40.

<sup>36</sup> See also Ibid., 1.8, p 3 and 1.13, p 4.

dignity means in this context, other than that respecting it is important, and some examples of how dignity is to be respected<sup>37</sup>.

### *II.3.5. Consent*

According to the report, respect for persons, autonomy and dignity requires that informed consent be sought for genetic testing, as with any medical treatment<sup>38</sup>.

Similarly, “[a] request for consent to participation in research is an expression of respect for persons and for human dignity”<sup>39</sup>. There is no further elaboration of the reasons why seeking consent expresses respect for these things, although as the principle is well established in medical ethics and law, it might be thought unnecessary to do so.

### *II.3.6. Best interests*

Acting in their best interests is considered to be the best way of demonstrating respect for persons whose autonomy is compromised, which will presumably also entail a consideration of respect for the person’s dignity<sup>40</sup>. Therapeutic interests are often involved when considering medical treatment, but less so for participation in research. The report interprets this to mean that “individuals who are intermittently competent should only be approached about participation in research when competent”<sup>41</sup>. In other words, consent to participation in non-therapeutic research should come from the competent individual if possible. (We note that this imposes a slightly different standard of consent for the intermittently competent than the permanently incompetent.)

The question with respect to incompetent individuals, then, is how their best interests are construed. The answer given here is that if the research relates to patient’s condition and research on those able to consent is not possible, and if the patient’s best interests are taken into consideration and there is “negligible risk of harm”, then

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<sup>37</sup> See II.3.5, II.3.6.

<sup>38</sup> *Mental Disorders and Genetics: The Ethical Context*, 5.22-27, pp 40-41.

<sup>39</sup> *Ibid.*, 7.2, p 64.

<sup>40</sup> *Ibid.*, 5.26, p 41.

<sup>41</sup> *Ibid.*, 7.7, p 65.

it may be ethically acceptable<sup>42</sup>. Thus we see that, according to this interpretation, serving an individual's best interests is primarily about the prevention of harm.

### *II.3.7. Confidentiality and genetic information*

The principle of confidentiality derives from respect for persons and autonomy: to disclose sensitive information about a person would be to fail to respect them. It also relates to the principle of preventing harm, in that confidentiality is seen as protecting the patient's interests and without it, patients might be deterred from seeking treatment; but preventing or avoiding harm may sometimes require breaching confidentiality. The report does not explicitly apply these arguments in stating the principle of confidentiality, although it does recognise the individual interest of persons in their own genetic information and discuss the balance of risk and harms<sup>43</sup>.

### *II.3.8. Ethical frameworks and approaches in this report*

As the Executive Summary to this report states: "A broad and humanistic perspective may be considered to have two basic ethical requirements: respect for human beings and human dignity, and the limitation of harm to, and suffering of, all human beings." This, if anything, may be said to be the framework of this report, and there is some discussion of these two principles as the core of such a framework<sup>44</sup>. As noted, "[i]t is often difficult... to establish exactly what the principles of limiting suffering and respect for persons require in practice"<sup>45</sup>, but they have been aptly emplaced as the core of an ethical framework to guide an attempt to do so.

## **II.4. Genetically modified crops: the ethical and social issues (1999)**

The ethical principles perceived by the council as relevant to this topic are clearly expressed in the introduction and reiterated throughout the report: the principles of "welfare, rights and justice"<sup>46</sup>.

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<sup>42</sup> Ibid., 7.15-7.16, pp 67-68.

<sup>43</sup> Ibid., 5.55-5.61, pp 50-52.

<sup>44</sup> Ibid., 1.8-1.13, pp 3-4.

<sup>45</sup> Ibid., 1.12, p 4.

<sup>46</sup> *Genetically modified crops: the ethical and social issues* (1999)

#### *II.4.1. Welfare*

The “principle of *general welfare*” is expressed as the obligation to “protect and promote the interests of citizens”<sup>47</sup> When examined carefully, the principle as phrased might here draw a distinction between the protection and promotion of welfare interests specifically and of persons’ interests generally. From the subsequent exposition of the principle, however, it seems that general interests and well-being may be included in the concept of welfare:

“[O]ne major consideration, perhaps the overriding one, is to increase human well-being, or promote general welfare”: it is “a question of discovering how many people are affected for the better or for the worse, and by how much”<sup>48</sup>.

#### *II.4.2. Prevention of harm*

A principal interest of citizens must be in not being harmed, and since to cause harm is to affect people for the worse, the Council thus construes the principle of general welfare to extend to preventing or avoiding harm. The possible harms that might be caused by genetically modified crop research include “harm to human health” and “damage to the environment”<sup>49</sup>

In relation to the risk of harm<sup>50</sup> that GM crops might pose, the report invokes what it terms the “precautionary principle”<sup>51</sup> intended to prevent harm. According to this interpretation, this requires an assessment of “the conditions under which the avoidance of harm should take priority over the attempt to do good”; “it is right to balance the good achieved against the harm imposed”<sup>52</sup>. This might more properly be referred to as the principle of risk balancing, as the precautionary principle is often used to mean something stronger: While it is true that attempts to do good may risk causing harm and that therefore the possible risks should be weighed carefully, the

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<sup>47</sup> Ibid., 1.4, p 6.

<sup>48</sup> Ibid. 4.1, p 58.

<sup>49</sup> Ibid., p 2.

<sup>50</sup> Ibid., 1.11, p 8.

<sup>51</sup> Ibid., 1.12-1.13, pp 8-9.

<sup>52</sup> Ibid., 1.13, p 9.

precautionary principle in its strong form dictates that if a particular course of action involves *any* risk of harm, no matter the magnitude of the potential benefit to be gained, it should be avoided. This is, of course, an irrational principle (and often applied to produce irrational results); the risk balancing advocated here is a more logical approach and it is proper that the two not be confused.

#### *II.4.3. Justice*

The principle of justice, as stated in this report, “requires the burdens and benefits of policies and practices to be fairly shared among those who are affected by them”<sup>53</sup>. This in turn requires a determination of “where the balance of burden and benefit is to be struck”<sup>54</sup>. Recognition of the significance of this principle does not, however, tell us how to make such a determination; only that it is important that it be made.

As well as justice at the individual level, concerns of global justice are also raised, particularly with respect to developing versus developed nations. The Council’s recommendation is that the impact of widespread introduction of GM technology on developing nations should be taken into account, for example if it is likely to have an adverse effect on the country’s current economic system<sup>55</sup>.

GM technology might also be used, however, to actively promote global justice. In particular, the resource shortage in the developing world that exists in terms of food supply might be a problem that GM technology could address<sup>56</sup>.

Prevention of harm, in combination with the principle of justice, requires consideration of the effects that GM technology might have on people in different socio-economic and environmental circumstances, in terms of possible harms as well as benefits. This includes taking into account the risk to the environment<sup>57</sup>, which in this context may be not inconsiderable. The Council’s conclusion, however, is that

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<sup>53</sup> Ibid. 1.4, p 6.

<sup>54</sup> Ibid. 1.20, p 10.

<sup>55</sup> Ibid. 3.64-3.65.

<sup>56</sup> Ibid. 4.5-4.19.

<sup>57</sup> Ibid., 6.19-45, pp 99-105.

the possible risk of harm posed by GM technology to people in developing countries need not prevent the use of the technology to address global injustice<sup>58</sup>.

#### *II.4.4. The “maintenance of people’s rights” (1.4, p 6)*

The importance of “rights” with respect to GM food is phrased in terms of consumer choice: the right to choose whether to buy GM food or not<sup>59</sup>. In this sense, the principle of maintaining (protecting and respecting) rights derives from respect for persons and autonomy. But the right to choice is not absolute; it must take account of the costs and burdens to others<sup>60</sup>. “The point of claiming rights is to limit other people’s freedom.”<sup>61</sup>. Is it justifiable to limit the freedom of producers by forcing them to make non-GM food available? The issue of consumer choice is discussed at length in Chapter 5.

#### *II.4.5. Naturalness*

Another principle discussed in this report is that of the primacy of the natural environment.

Objections to genetic modification of crops include that it is “unnatural”, produces “disgust and revulsion”<sup>62</sup> or constitutes “improper tampering with nature”<sup>63</sup>, particularly for example in the case of cross-species transgenic modification. In support of these objections, principles such as “the ethical status of the natural world itself”<sup>64</sup> are sometimes cited: “it is unethical to treat nature in an ‘industrial’ fashion, not simply because of the unfortunate consequences of so doing, but because... it is intrinsically wrong”<sup>65</sup>. This relates to the principle of moral conservatism<sup>66</sup>, which

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<sup>58</sup> Ibid. 4.2, p 58.

<sup>59</sup> Ibid., 1.15-1.19, pp 9-10.

<sup>60</sup> Ibid., 1.17, p 10.

<sup>61</sup> Ibid., 1.19, p 10.

<sup>62</sup> Ibid. 1.32, p 13.

<sup>63</sup> Ibid. 1.34, p 14.

<sup>64</sup> Ibid. 1.7, p 7.

<sup>65</sup> Ibid. 1.8, p 7.

<sup>66</sup> Ibid. 1.41, p 15.

alludes to Heidegger's view of the world: that it exists to be received, not controlled or manipulated<sup>67</sup>.

The Council, however, is not strongly inclined to accept the idea of "naturalness" as an ethical principle. "[H]ow does nature set boundaries and why is their transgression wrong?"<sup>68</sup>. They express the view that "many of the yearnings for natural purity have little or no justification"<sup>69</sup> and conclude that "[w]e can see no reason in ethics to draw a distinction."<sup>70</sup>. Therefore it would seem that the principle of adherence to what is natural has found little support in the Council's treatment of this particular instance. While they refrain from denying the principle outright, their view gives clear precedence to concerns of welfare, justice and autonomy. "[I]t is the deleterious consequences of our farming techniques to our environment and human health, not their 'unnatural' character that should preoccupy us."<sup>71</sup>

#### *II.4.6. Ethical frameworks and approaches in this report*

The elements of a defined ethical framework are clearly present here in the focus on "welfare, rights and justice". It is not always clear what these three principles entail, particularly the principle of rights (what subjects, after all, are the rights intended to protect? Perhaps, given the way this principle is applied, it might have been better phrased as a principle of free choice, liberty or autonomy) but the report does set itself this framework as a course and steer by it. The odd principle out here is the idea of naturalness, which in any case is not strongly accepted; it falls into a category of "principles" (if we can call them that) which seems to be emerging, namely those that attempt to justify widely-held intuitions or beliefs.

### **II.5. Stem cell therapy: the ethical issues (2000)**

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<sup>67</sup> Ibid. 1.43, p 16.

<sup>68</sup> Ibid. 1.39, p 15.

<sup>69</sup> Ibid.

<sup>70</sup> Ibid. 1.40, p 15.

<sup>71</sup> Ibid. 8.8, p 123.

This discussion paper builds first on some substantial prior discussions of the ethics of embryo research including those contained in the Warnock Report (1984) and the Polkinghorne Review (1989) as well as the operations of the Human Fertilisation and Embryology Authority. It considers the issues raised specifically in the context of deriving stem cell lines for research, from embryos donated or created for research, cadaveric foetal tissue and nuclear transfer.

#### *II.5.1. Personhood and moral value*

The Council's report summarises the issue thus: "The debate about the moral status of the human embryo has focused on the question of whether the embryo should be treated as a person, or, at least, a potential person. If the embryo is so considered, then it will be morally impermissible to use it merely as a means to an end, rather than as an end in itself. This would preclude both embryo research and any other procedure not directed to the benefit of that actual embryo."<sup>72</sup>

This paragraph implies the application of a number of further principles: that it is wrong to cause harm to persons (the principle of *harm avoidance* that we have seen applied in earlier reports); and that to use a person "merely as a means to an end, rather than an end in itself" is also wrong, a principle that owes its heritage at least partly to Kantian notions of *respect*.

It is interesting to note the Council's apparent belief that potential persons might also be entitled to the same protections as actual persons. This is an idea that has been the source of much argument amongst bioethical philosophers, and it remains highly debated; so its inclusion without further discussion here might seem surprising. The Council goes on to conclude, however, that "the removal and cultivation of cells from such an embryo does not indicate lack of respect for the embryo,"<sup>73</sup> (21, p 8) and so this subtlety, at least in the particular context, remains moot.

Concerns about personhood and moral status are surely also behind discussion of the ethical acceptability of abortion in relation to the use of cadaveric foetal tissue for

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<sup>72</sup> *Stem Cell Therapy: The Ethical Issues* (2000) 19, p8.

<sup>73</sup> *Ibid.*, 21, p 8.

stem cell research (28-33, pp 11-13), for if the foetus *in utero* is not considered to possess moral standing, abortion – for whatever reason – would not be such a charged issue. In an environment where public policy and opinion overwhelmingly recognise the controversy over the issue, however, the Council (perhaps wisely) avoids any detailed consideration of whether such concerns are justified, referring instead to previous policy recommendations of the Polkinghorne Review and the NBAC. Interestingly, while accepting the potential for “morally dubious uses” of abortion against which the previous recommendations were intended to guard, the Council’s report ventures to differ on the issue of consent to use of foetal tissue for stem cell research (see II.5.4, below).

### *II.5.2. Prevention of harm and beneficence*

The discussion of the moral status of the embryo is of relevance presumably because if embryos are recognised as persons, it would be a moral imperative to avoid causing them harm.

The principle of preventing or avoiding harm to persons and its corollary principle of benefiting persons apply to the possible outcomes of stem cell research as well as its origins in the initial derivation of the cells. “Research into potential therapies is not qualitatively different from research into diagnostic methods or reproduction... both may be of benefit to people in the future.”<sup>74</sup> This benefit is clearly seen as a reason in favour of carrying out the research, even though the principle is not made explicit: it is a moral good to benefit others.

### *II.5.3. Respect*

The principle of respect for persons (or potential persons?) is alluded to in the language of the report as discussed in II.5.1, above. Later the report notes, in relation to the creation of embryos for the sole purpose of research, that “[so]me would argue that such an instrumental use, where the embryo is essentially a means to an end, does

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<sup>74</sup> Ibid., 22, p 9.

not accord with the respect owed to a potential human life”<sup>75</sup>. The applicability of this principle is at least partly rejected in the Council’s statement quoted above: “the removal and cultivation of cells from such an embryo does not indicate lack of respect for the embryo,”<sup>76</sup>. However the report seems to shy away from considering in detail whether this *does* amount to instrumental use and, if it does, whether the principle of respect ought to apply to prevent such use. Instead, a comparative policy-based approach is preferred:

“Each form of research involves using the embryo as a means to an end but, since we accept the morality of doing so in relation to currently authorised embryo research, there seems to be no good reason to disallow research on the embryo where the aim of the research is to develop therapies for others.”<sup>77</sup>.

It may be noted that this statement does not draw any conclusions about the morality of using embryos as a means to an end, although it is certainly a pragmatic observation and of much use in a debate that has often tended towards becoming mired in theoretical, rather than practical, considerations.

#### *II.5.4. Consent*

The principle of obtaining informed consent applies firstly in this context to donors of embryos that may be used for stem cell research: “where specific research regarding the establishment of an ES cell line is contemplated, embryo donors should be asked explicitly whether or not they consent to such research and subsequent use of the cell line”<sup>78</sup>. The reason for this requirement is primarily that the embryo carries the DNA, genetic information, of its donors

This represents an interesting development in the application of the doctrine of consent. This principle, as we have seen, has been well established by the Council’s

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<sup>75</sup> Ibid., 27, p 11.

<sup>76</sup> Ibid., 21, p 8.

<sup>77</sup> Ibid., 22, p 9.

<sup>78</sup> Ibid., 25, p 10.

previous reports in relation to medical and research procedures that involve the patient's own body and tissues, which may include genetic testing on samples taken from the patient. However, the requirement for consent has previously focused on the physical intervention first, with other elements such as the nature of genetic information encompassed under this umbrella requirement (see for example II.3.5.) The stipulated requirement for consent in this context indicates a growing recognition of need for consent to protect the uses of genetic material alone, absent any physical procedure to which consent might be required – a theme that is further developed in subsequent reports of the Council, for example the report on pharmacogenetics (see II.9.1).

A similar requirement for specific consent is seen as necessary for the use of foetal tissue to create stem cell lines: “if specific consent is required for the donation of an embryo where an immortal cell line is to be produced from it, it would be only consistent to require special consent for the production of such a cell line from fetal tissue also”<sup>79</sup>. This recommendation runs counter to the findings of other reports, which view the risk of “inappropriate incentives” inducing “morally dubious uses” of abortion as so overwhelming that specific consent to particular uses (such as stem cell derivation) ought to be disallowed<sup>80</sup>. While, as noted above, the Council does not take a position on whether the previous recommendations are justified in themselves and by extension whether abortion for research purposes is the absolute moral wrong that the previous reports appear to assume, they do state: “We do not consider that concerns about inappropriate incentives resulting from a potential benefit deriving from the establishment of an EG cell line are so great that the donation of fetal tissue for such purposes should be prohibited.”<sup>81</sup>. Further, in requiring specific consent for these uses, the report upholds the Council's tenet that individuals' control over their bodies and biological material should be protected, even in the face of vaguely articulated concerns about abortion and its uses.

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<sup>79</sup> Ibid., 32, p 13.

<sup>80</sup> Ibid., 29-32, pp 12-13.

<sup>81</sup> Ibid., 32, p 13.

### *II.5.5. Ethical principles and approaches*

It is notable that this report adopts no sort of theoretical framework in its analysis of the issues, relying heavily on ethical principles and policy decisions elucidated in the work of previous bodies in this area (which themselves may or may not have worked within a consistent framework). Many of the recommendations contained in the report seem to rely on existing policy justifications as a practical solution, even if the underlying ethical issues remain entangled – though in the research and policy environment of the time, this may perhaps have been a wise course nonetheless.<sup>82</sup>

## **II.6. The ethics of patenting DNA (2002)**

The ethical principles invoked in this report are somewhat more difficult to discern, as it is primarily concerned with the application of a legal framework, that of intellectual property and patent law, to the specific case of genetic information and gene patenting. Many of the issues discussed therefore relate to the suitability of genes as patentable material under this legal framework, rather than the broader ethical issues associated with the patenting of genes and policy reasons why gene patenting might or might not be morally acceptable.

However the case studies allude to some more basic principles of ethics, although these are not necessarily made explicit.

### *II.6.1. The “principle of common heritage”<sup>83</sup>*

This principle, quoted in the report, holds that “the human genome is a shared natural resource and therefore private property claims over it (such as patents) should not be

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<sup>82</sup> An interesting comparison may be made here between this report of the Nuffield Council on Bioethics and the Eurostem Ethical Framework for Stem Cell Research, the aim of which was to lay out the very type of framework which this report so persistently avoids setting for itself. Unlike the report, the Eurostem Framework was intended to contain not policy recommendations themselves, but the principles by which policy recommendations might be arrived at in a range of different environments. It may be wondered, however, whether if the Nuffield report had considered and adopted a similar framework-based approach, its policy conclusions might have been further strengthened by the ethical clarity thus achieved.

<sup>83</sup> *The Ethics of Patenting DNA* (2002) 3.5, p 21.

recognised. human DNA has a special nature... the human genome is unique and distinctive”<sup>84</sup>. The Council declines to take a specific stance on the application (or failure thereof) of this principle, although evidently it cannot be accepted *per se* or there would be no possibility of patenting DNA and no further discussion required.

#### *II.6.2. Public interest*

This heading incorporates two principles: promotion of public benefit and prevention of harm.

Case Study 1<sup>85</sup> considers the public interest involved in allowing gene patenting and its possible effects on the development of further (presumably beneficial) research.

Case Study 5: “Do complex and contradictory patents on research tools serve the public interest if they hinder the development of products related to healthcare?”<sup>86</sup>.

Here the Council’s conclusion is that although potentially deleterious effects on research (and hence damage to the public interest) caused by gene patenting are not conclusively shown, naturally occurring gene sequences which can be discovered with little novelty of application are not an appropriate subject for the patent system<sup>87</sup>. If patents have already been granted, wide licensing for research is recommended<sup>88</sup>, again presumably to promote the public good that research constitutes. “patents have promoted the public interest by encouraging the development of new medicines and vaccines”<sup>89</sup>.

This analysis is notable for its assumption that research equals public benefit. This may seem self-evident: for example it is “clearly in the public interest to provide the best conditions for innovation as regards the development of new medicines”<sup>90</sup>, but nevertheless this recognition of the benefits of research contrasts somewhat with more conservative principles about the prevention of possible harms caused by research.

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<sup>84</sup> Ibid., 3.3, p 21.

<sup>85</sup> Ibid., pp 39-40.

<sup>86</sup> Ibid., p 44.

<sup>87</sup> Ibid., 5.40-5.41, p 59.

<sup>88</sup> Ibid., 5.42, p 60.

<sup>89</sup> Ibid., 6.2, p 69.

<sup>90</sup> Ibid., 5.50, p 62.

Risk and prevention of harm are also relevant in the context of gene therapy<sup>91</sup>.

### *II.6.3. Ethical frameworks and approaches*

As we noted at the beginning of this section, this report has a definite legal, rather than ethical, flavour. If anything it may be said to be operating within the legal framework of intellectual property and patent law; but no distinct ethical framework appears to be either stated or applied.

## **II.7. The ethics of research related to healthcare in developing countries (2002)**

The principles relevant to this issue are stated explicitly in the report:

- “(i) the duty to alleviate suffering
- (ii) the duty to show respect for persons
- (iii) the duty to be sensitive to cultural differences and
- (iv) the duty not to exploit the vulnerable”<sup>92</sup>.

The first two of these principles accord with well-established principles that have been stated in previous publications; the others can be seen as deriving from these.

### *II.7.1. Prevention of harm*

“[T]he duty to alleviate suffering... enjoins us to do what we can to reduce the amount of suffering in the world”<sup>93</sup>.

It also pertains to the standard of care provided to research participants: the duty of beneficence imposes a requirement on researchers to provide adequate standards of care to their subjects as far as is possible within the constraints of the research procedure and the research environment.

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<sup>91</sup> Ibid., 6.15, p 73.

<sup>92</sup> *The ethics of research related to healthcare in developing countries* (2002) 4.6.

<sup>93</sup> Ibid., 4.9, p 50.

### *II.7.2. Respect*

In the context of research on human subjects, whether in the developing world or in developed nations, “the value and respect given to participants in research” and the need for such is part of a more general principle of “respect for persons”<sup>94</sup>. Again, it may be asked from whence the duty of respect for persons arises; according to the interpretation of respect in this instance, it is the “capacity for creating a life of our own” which is “both an essential feature of common humanity and yet also something that marks out each of us as a unique source of value... worthy of respect.”<sup>95</sup> Respect for persons according to this definition entails a consideration of their interests and refraining from causing them harm, as well as avoiding using them as a mere means, this latter requirement drawing on Kantian conceptions of respect and autonomy.

### *II.7.3. Sensitivity to cultural differences*

The ethical imperative to demonstrate “sensitivity to cultural differences”<sup>96</sup> is a principle consequential upon that of respect for persons, in that such respect implies a consideration of the different circumstances, background and cultural assumptions that each person may have<sup>97</sup>. The report is careful to distinguish between such sensitivity and unchecked moral relativism<sup>98</sup>, noting that the requirement of sensitivity to cultural differences “does not require [researchers] to compromise fundamental values”<sup>99</sup>.

### *II.7.4. Refraining from exploitation*

The “duty not to exploit the vulnerable”<sup>100</sup> recognises the inherent inequalities between developed and developing nations; and the responsibility of those with power to “refrain from exploiting to their own advantage the vulnerability of the weaker”<sup>101</sup>. The viewpoint of the Council as expressed in this report is that this is implied by the

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<sup>94</sup> Ibid., 1.7, p 6.

<sup>95</sup> Ibid., 4.10, p 51.

<sup>96</sup> Ibid., 1.7, p 6.

<sup>97</sup> Ibid., 4.15, p 51.

<sup>98</sup> Ibid.4.16, pp 51-52.

<sup>99</sup> Ibid., 4.17, p 53.

<sup>100</sup> Ibid., 1.7, p 6.

<sup>101</sup> Ibid., 4.19, p 52.

principle of respect for persons and their interests, “for in exploiting others we fail to give proper weight to their interests”<sup>102</sup>. It can also be deduced to derive in part from the first principle, in that the vulnerable are (presumptively) harmed by being exploited and that therefore there is a duty not to do so. In the context of health care research in developing countries, this does not necessarily entail a blanket prohibition on carrying out such research, but the agenda for selecting a research environment should not seek to exploit economic or political weakness on the part of developing nations in order to benefit the developed world<sup>103</sup>.

The duty to refrain from exploiting the vulnerable also relates to a fundamental principle not strongly alluded to in this report, that of justice.

#### *II.7.5. Free and informed consent*

The principle of consent is related to respect for persons, which “requires that we do not act against a person’s wishes”<sup>104</sup>. Two pillars of valid consent are identified: provision of information and the voluntary, non-coerced nature of consent given. The report notes a “tension between the requirement that genuine consent to research be obtained from participants and cultural contexts in which giving certain information is not customary”<sup>105</sup>. However, “[s]ensitivity to other cultures cannot override the central requirement of respect for persons, which requires that we refrain from conducting research without consent.”<sup>106</sup>.

The means of obtaining genuine, informed consent can and should be culturally sensitive. Voluntariness of consent may also be an issue in situations where access to healthcare may be perceived to be linked to research participation<sup>107</sup>: care must be taken to avoid inadvertent exploitation or coercion under such circumstances.

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<sup>102</sup> Ibid., 4.20, p 52.

<sup>103</sup> Ibid., 4.21, p 52.

<sup>104</sup> Ibid., 1.9, p 7.

<sup>105</sup> Ibid., 6.11, p 73.

<sup>106</sup> Ibid., Box 6.4, p 77.

<sup>107</sup> Ibid., 6.23-6.32, pp 77-80.

### *II.7.6. Ethical frameworks and approaches*

As some of the previous reports have done, this report explicitly sets its own ethical framework and states the principles of which this is composed. Of these, prevention of harm and respect for persons are the fundamental pillars, but the incorporation of the two secondary principles may be seen as necessary given the particular subject of this report.

## **II.8. Genetics and human behaviour: the ethical context (2002)**

### *II.8.1. Human dignity*

This principle assumes that a concept of human dignity exists, that it has moral significance and that acts which diminish or fail to respect human dignity are morally wrong. “the conception of human dignity... the presumption that one is a person whose actions, thoughts and concerns are worthy of intrinsic respect, because they have been chosen, organised and guided in a way which makes sense from a distinctively individual point of view.”<sup>108</sup>

In this definition, the idea of respect for human dignity veers towards notions of respect for autonomy and autonomous persons. This is reiterated in the conclusion to this section: “the conception of oneself as a free responsible agent, capable of acting for reasons and directing the course of one’s life in accordance with one’s own values and understanding of the world”<sup>109</sup>. The report goes on to say that “[t]his does not exhaust the ethical content of the conception of human dignity, but it is a central component of it...”<sup>110</sup>.

How might behavioural genetics relate to this conception of human dignity? “[I]f it can be shown that behavioural genetics... does not threaten the conception of a person as a rational being capable of taking responsibility for himself or herself in free action, then it ought to be possible to welcome the deeper understanding of the

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<sup>108</sup> *Genetics and human behaviour: the ethical context* (2002), 12.2, p 121.

<sup>109</sup> *Ibid.* 12.37, p 30.

<sup>110</sup> *Ibid.*

springs of human motivation which behavioural genetics promises, without feeling that there is thereby a threat to the inherent dignity of humanity.”<sup>111</sup>

In exploring the idea of “human dignity” as a facet of self-determination, the report explores conceptions of the material self<sup>112</sup> : “the only tenable understanding of human freedom is one which does not postulate an immaterial self as the only real free agent”<sup>113</sup>; fatalism and (genetic) determinism<sup>114</sup>; and free will and rationality<sup>115</sup>: “freedom of action requires that one’s reasons play a causal role in what one does.”<sup>116</sup> This account of human dignity aligns (though is not identical) with ideas of personal autonomy.

### *II.8.2. Prevention/avoidance of harm*

There are various harms that might be caused by behavioural genetic research: psychological harm, changes to clinical treatment procedures, genetic stigmatisation, the risk posed by consequent gene therapies<sup>117</sup>. It is strongly implied that to cause or allow these harms would be wrong, but the principle itself is not stated as it has been in some previous reports.

### *II.8.3. Life is valuable; killing is wrong*

This might perhaps be a sub-principle of the above principle against causing harm – but harm to whom? This question is particularly relevant in the context of pre-natal or pre-implantation genetic selection, if we are to consider pre-birth lives as somehow important<sup>118</sup>.

In discussing the distinction between PNS and PGD, the report seems to assume that PND is somehow morally worse because it involves “the termination of a potential

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<sup>111</sup> Ibid., 12.5, p 121.

<sup>112</sup> Ibid., 12.6-12.9, pp 122-123.

<sup>113</sup> Ibid., 12.7, p 122.

<sup>114</sup> Ibid., 12.10-12.15, pp 123-124.

<sup>115</sup> Ibid., 12.16-12.20, pp 124-125.

<sup>116</sup> Ibid.12.20, p 125.

<sup>117</sup> Ibid., 13.29-13.32, pp 140-141.

<sup>118</sup> Ibid., 13.57-13.66.

human life”<sup>119</sup>. We might ask whether this is consistent with positions expressed in other reports<sup>120</sup>, or with a general framework of rational ethics: why should a *potential* human life be morally significant, and why is a foetus *in utero* a potential human life where an embryo *in vitro* is not?

#### *II.8.4. Liberty, autonomy and freedom of choice*

“There is, quite generally, a strong presumption in favour of the exercise of individual liberty wherever its exercise does not conflict, directly or indirectly, with the legitimate interests of others.”<sup>121</sup> The adoption of this rather Millian philosophy leads to the conclusion that “individuals should be able to exert their autonomy with regard to the use of an intervention,”<sup>122</sup> which extends to the principle of procreative autonomy and the right to use PGD.

There is some discussion of genetic determinism (by parents or children themselves) as a threat to choice<sup>123</sup> and the concept of a child’s right to an open future<sup>124</sup> – does PGD infringe child’s autonomy? “It is not true in a straightforward sense that prenatal selection ‘narrows the options’ for a child.” Counter-arguments of parental control (13.73) and the moral duty of parents to display “natural humility” in accepting their children are noted; but the report avoids an ethical decision on which position should prevail. Instead it takes a fence-sitting approach and holds that “[w]hile not entirely persuaded by this conservative line of argument, we do accept that, at present, the case for permitting prenatal selection based on the identification of genetic predispositions for enhanced abilities remains to be made.”<sup>125</sup> This may be a sensible policy decision in light of the ethical disagreement, but is not necessarily consistent with the view of liberty espoused above, by which surely a case ought to have to be made to prohibit something, rather than to permit it.

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<sup>119</sup> Ibid., 13.66, p 152.

<sup>120</sup> Particularly the discussion of the value of life in the report *Critical care decisions in fetal and neonatal medicine: ethical issues* (2006).

<sup>121</sup> *Genetics and human behaviour: the ethical context*, 13.67, p 152.

<sup>122</sup> Ibid., 13.34, p 142.

<sup>123</sup> Ibid., 13.36, p 142.

<sup>124</sup> Ibid., 13.72, p 154.

<sup>125</sup> Ibid., 13.78, p 156.

### *II.8.5. Equality of opportunity*

Amid concerns about increasing inequality, the report asks in relation to genetic testing: “[W]ho should be able to make use of tests and interventions? And who should bear the cost...?”<sup>126</sup> “We believe that equality of opportunity is a fundamental social value which is especially damaged where a society is divided into groups that are likely to perpetuate inequalities across generations.”<sup>127</sup> The Council recommends, therefore, that genetic interventions should be considered in light of their potential consequences for creating or increasing inequality within society. They note, however, that “if one assumes a background social and political system in which anti-elitist egalitarian values are already well entrenched, it should be possible to accommodate prenatal selection without any great resulting unfairness.”<sup>128</sup>

It is unclear how this might relate to the principle of justice. Although equality of opportunity may often serve justice, the two are not necessarily the same thing. For example, the United Kingdom is hardly an example of a country which possesses “a background social and political system in which anti-elitist egalitarian values are already well entrenched”, yet it might well be one in which “it should be possible to accommodate prenatal selection without any great resulting unfairness.”

### *II.8.6. Ethical frameworks and approaches*

The ethical principles expressed in this report address broad concepts of liberty, justice and the value of life; but these are not specifically adopted as a framework. The nearest thing to an explicit statement of the ethical framework guiding the deliberations of the Council Working Party in this matter is the extolling of the importance of human dignity, including a reference to the UNESCO *Universal Declaration on the Human Genome and Human Rights* in which dignity takes a key role. It is of interest to note, however, that despite the extensive consideration given to how dignity is to be interpreted and respected in the context of this report, the

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<sup>126</sup> Ibid., 13.44, p 145.

<sup>127</sup> Ibid., 13.48, p 146.

<sup>128</sup> Ibid., 13.70, p 154.

major recommendations of this report stem almost entirely from the other principles quoted.

## **II.9. Pharmacogenetics: ethical issues (2003)**

### *II.9.1. Consent*

Consent is identified as an ethical requirement for genetic testing: “genetic information should only be obtained from persons when they have given genuine consent.”<sup>129</sup> “[T]he ethically significant requirement of consent is not that it be complete, but rather that it be genuine”<sup>130</sup>.

The voluntary nature of consent is emphasised<sup>131</sup> and the report notes the difficulty that “patients might not feel able to refuse... taking part in a clinical trial may be the only way for a patient to have a chance of obtaining a particular medicine.”<sup>132</sup>

With respect to consent and genetic information, they conclude that the level of consent required should depend on the nature of the information obtained by the test<sup>133</sup>. In this context two possible types of consent are suggested, broad consent vs narrow consent<sup>134</sup>: broad consent is permissible where samples are anonymised; otherwise consent should be sought separately for further testing.

Unlike some of the previous reports which have also held consent as a central principle, this report explicitly identifies consent as a means of “respecting [patients’] autonomy”<sup>135</sup>.

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<sup>129</sup> *Pharmacogenetics: ethical issues* (2003) 1.6, p 5.

<sup>130</sup> *Ibid.*, 3.29, p 31.

<sup>131</sup> *Ibid.*, 3.30, p 31.

<sup>132</sup> *Ibid.*, 9, p xv.

<sup>133</sup> *Ibid.*, 5.16-5.17, p 63.

<sup>134</sup> *Ibid.*, 3.38-3.39, p 35.

<sup>135</sup> *Ibid.*, 5.9, p 61.

### *II.9.2. Privacy*

“[E]very person is entitled to privacy. Privacy in the context of genetic testing can be understood as a person’s right not to be obliged to disclose information about his or her genetic characteristics.”<sup>136</sup>

In the context of pharmacogenetic testing, the report identifies two issues: “(i) what level of anonymisation of samples is appropriate, and (ii) should individual patients be given feedback regarding tests carried out on their samples?”<sup>137</sup> The recommendation given is that “... to protect the privacy of participants in research, the greatest degree of anonymity should be imposed on the samples, compatible with fulfilling the objectives of the research.”<sup>138</sup>

### *II.9.3. Confidentiality*

The principle of confidentiality is expressed in this context thus: “genetic information should not be communicated to others or used for new purposes without the consent of the person disclosing the information”<sup>139</sup>.

In the context of pharmacogenetics, this raises additional concerns about how information might be communicated<sup>140</sup>, possibly inadvertently<sup>141</sup>; and how this information might be used and possibly abused, such as by insurers<sup>142</sup> – or be useful, for example to other family members.

### *II.9.4. Resource allocation and justice*

The problem of resource allocation is briefly discussed and the tension between a purely utilitarian approach versus considerations of justice and equity is noted<sup>143</sup>; but no further deliberation on the merits of the different ethical approaches is undertaken,

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<sup>136</sup> Ibid., 1.6, p 5.

<sup>137</sup> Ibid., 3.31, p 31.

<sup>138</sup> Ibid., 3.36, p 34.

<sup>139</sup> Ibid., 1.6, p 5.

<sup>140</sup> Ibid., 5.31-5.33, p 67-68.

<sup>141</sup> Ibid., 5.32, p 68.

<sup>142</sup> Ibid., 5.36-5.41, pp 69-70.

<sup>143</sup> Ibid., 19-20, pp xvii-xviii.

the report merely endorsing the current policy approach in the UK embodied by the National Institute of Clinical Excellence<sup>144</sup>.

#### *II.9.5. Beneficence*

The report does not articulate this as a principle, but it is clearly a consideration supporting the imperative towards pharmacogenetic research: “the application of pharmacogenetics has the potential to bring substantial benefits... of great value, not only to individual patients, but also to society”.

#### *II.9.6. Ethical frameworks and approaches*

The first few principles elucidated from this report reflect a traditional medical ethics framework, as it has appeared in some previous reports<sup>145</sup>, while other, broader principles are mentioned or alluded to. The report does not overtly consider which ethical framework should be, or has been, used in the Working Party’s deliberations on this issue.

### **II.10. The ethics of research involving animals (2005)**

This debate revolves around two main principles. The use of animals in research is ethically contentious because it involves causing possible harm (suffering and death), but also has potential benefits including the advancement of knowledge and alleviation of future suffering. Therefore the principles of primary relevance are those that relate to the avoidance of causing harm and the duty to prevent harm and to do good. When the simple application of these principles would directly conflict, as in this case, further refinement (in part through the application of additional, implicit principles) is necessary.

#### *II.10.1. Beneficence and harm prevention*

The relevance of this principle to the issue is here expressed in the words of submissions made to the Council in the preparation of this report, “Man has the duty

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<sup>144</sup> Ibid., 4.21, p 46.

<sup>145</sup> See II.1.4, II.2.9.

to treat sick people”; “prevention of human suffering is a moral obligation”<sup>146</sup>. This implies that there is a duty to act to alleviate suffering as well as to refrain from acting to cause it, a proposition which is considered and accepted: “there exists a *prima facie* ethical duty to help alleviate suffering through acts, provided research efforts are in proportion to the extent of suffering to be alleviated.”<sup>147</sup> This second clause, relating to proportionality, acknowledges the balancing point between this principle and others, including that of refraining from causing harm.

### *II.10.2. Harm avoidance – not causing harm*

The simple principle here is this: it is wrong to cause harm.

The more complex question implied is: what is harm? Is an animal that is not self-aware harmed by being killed in a painless fashion? This principle may seem to be somewhat at odds in this report with the concept of absolute moral value and the value of life: for example the discussion of the “sliding-scale view”<sup>148</sup> of moral status does not seem to admit of the notion that harm may be caused by inflicting suffering on beings of lesser moral status and that causation of harm is the moral wrong in this case, rather than the mere use of beings of a particular moral status. This is further explored, however, in the evaluation of “possession of a life” as a morally significant feature<sup>149</sup>. Substantial further consideration is given to the ways in which animals may be harmed by being made to suffer<sup>150</sup>.

### *II.10.3. Moral value*

The above principles of doing good and of preventing and avoiding harm imply a moral object: good or harm to whom? The implicit assumption is that certain entities have moral value and it is in respect of these that the duties of beneficence and harm avoidance apply.

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<sup>146</sup> *The Ethics of Research Involving Animals* (2005) 3.9, p 35.

<sup>147</sup> *Ibid.*, 3.12, p 36.

<sup>148</sup> *Ibid.*, 3.22, p 39.

<sup>149</sup> *Ibid.*, 3.47-3.49, p 47.

<sup>150</sup> *Ibid.* Chapter 4, pp 59-81.

The moral status of different beings<sup>151</sup> is discussed at length in the report, which sets out various positions but does not explicitly favour any. It considers the question of what the features relevant to moral status might be<sup>152</sup> and discusses five characteristics: sentience<sup>153</sup>; higher cognitive capacities<sup>154</sup>; the capacity to flourish<sup>155</sup>; sociability<sup>156</sup>; and the possession of a life<sup>157</sup>.

The report concludes that “[w]ith the possible exception of the last feature, each provides reasons for moral concern”<sup>158</sup>. The principle is articulated thus: “the proper moral treatment of a being depends on the characteristics it possesses, rather than simply on the species to which it belongs.”<sup>159</sup>

They note, however, that in application, each of these positions may still fail to provide a solution: “consideration of the relative moral status does not settle the question of the permissibility of animal research, or of any other use of animals, in a helpful manner.” While simply allocating different status to different creatures does nothing to settle the legitimacy of particular ways of treating those creatures, the reasons for allocating such status are almost certain to have this effect. This claim is therefore somewhat disingenuous.

#### *II.10.4. Duty of stewardship*

This principle is expressed thus: “it may be that although humans are morally more important than animals, they have a moral duty of *stewardship* to ‘lesser’ beings”<sup>160</sup>.

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<sup>151</sup> Ibid., 3.20, p 38.

<sup>152</sup> Ibid., 3.27, p 41.

<sup>153</sup> Ibid., 3.29-3.39, p 41.

<sup>154</sup> Ibid., 3.30-3.36, pp 42-44.

<sup>155</sup> Ibid., 3.37-3.43, pp 44-46.

<sup>156</sup> Ibid., 3.44-3.46, pp 46-47.

<sup>157</sup> Ibid., 3.47-3.49, p 47.

<sup>158</sup> Ibid., 3.50, p 48.

<sup>159</sup> Ibid., 3.50, p 48.

<sup>160</sup> Ibid., 3.21, p 39.

When carefully considered, this might be thought to combine the duties of harm prevention and avoidance with a judgment that animals are of *some* moral value, even if less so than humans. However it is a principle that seems to sit a little awkwardly with the framework of the main discussion; one might wonder from whence it arose during the Working Party’s deliberations on this issue.

#### *II.10.5. The primacy of the natural*

“Some people assert that it is an essential trait of humans to strive for knowledge through methodological enquiry. Hence, independent of the value of the results of research, it could be argued that research activity itself holds significant intrinsic value.”<sup>161</sup> Additionally, “different species must always compete for survival... it is natural for any species to put itself first.”<sup>162</sup>

In this case, the Council evaluates this principle that what is natural is also a moral imperative with more scepticism, advancing a number of arguments against it<sup>163</sup>. Additionally, they note reasons why it should not necessarily apply to support research *on animals* as a morally valuable activity in itself<sup>164</sup>.

#### *II.10.6. Ethical frameworks and approaches*

It is of some note that this report contains an explicit and not insubstantial consideration of theoretical ethics frameworks or approaches themselves and the application of such to the topic at hand<sup>165</sup>.

The report characterises its own approach as a hybrid of consequentialism and deontology: “some prohibitions and some weighing”<sup>166</sup>, an unsurprising compromise. They are further able to distil some factual questions that can be used in the application of this approach<sup>167</sup> that may be said to form a policy framework for

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<sup>161</sup> Ibid., 31.5, p 37.

<sup>162</sup> Ibid., 3.24, p 40.

<sup>163</sup> Ibid., 3.24-3.26, p 40.

<sup>164</sup> Ibid., 3.16, p 37.

<sup>165</sup> Ibid., 3.52-3.61, pp 49-53; Chapter 14, pp 241-258.

<sup>166</sup> Ibid., 14.2, p 241.

<sup>167</sup> Ibid., 14.3, p 241.

addressing the deep ethical disagreements that the report reveals surrounding this issue.

## **II.11. Critical care decisions in fetal and neonatal medicine: ethical issues (2006)**

### *II.11.1. The value of human life*

The principle that life is valuable is argued seldom in outline but endlessly in detail: which lives are valuable and why? The report considers two interpretations of this principle that it terms the “sanctity of life” view, whereby all human lives are of equal (and possibly absolute) value, and the “quality of life” view “that does not recognise an absolute right to life nor a duty to preserve it, but rather judges whether a life is worth preserving (or having in the first place) in terms of its quality.”<sup>168</sup>

The report openly recognises a lack of consensus within the Council Working Party as to which interpretation of this principle ought to prevail. They do however agree that there may be circumstances “when the degree of suffering outweighs the baby’s interest in continuing to live,”<sup>169</sup> a concept they term “intolerability”. These circumstances encompass cases of unbearable pain and suffering as well as those in which the baby’s life is of no meaning or benefit to itself because it “may be incapable of sustaining any meaningful relations with other people and lack any potential for an independent existence”<sup>170</sup> or be “a life bereft of any of those features that give meaning and purpose to human life (for example, being aware of his or her surroundings or other people)”<sup>171</sup>.

The identification of these factors which make human life more meaningful and its preservation therefore a more worthwhile endeavour would seem to reflect a view that allows that some lives may be of more value than others. Thus the Council’s expressed position, despite the acknowledged lack of consensus, appears to support

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<sup>168</sup> *Critical care decisions in fetal and neonatal medicine: ethical issues* 2.09, p 11.

<sup>169</sup> *Ibid.*, 2.11, p 12.

<sup>170</sup> *Ibid.*, 2.15, p 13.

<sup>171</sup> *Ibid.*, 2.13, p 12.

the principle that human life is not of absolute value but that other factors such as “meaningful relations with other people”, “independent existence” and (self)-awareness are what confer value upon it.

### *II.11.2. Best interests and the prevention of harm*

If (some) life is valuable, then one moral reason against taking life and in favour of preserving it is the principle of *avoiding or preventing harm*, a recurring theme, since to deprive someone of life could be to harm that person. But there are other things that can also cause harm, such as the infliction of (or failure to relieve) suffering. In some cases the harm caused by allowing continued suffering must be balanced against the harm of taking (or failing to preserve) life; and it is in this cause that the report devotes several paragraphs to a consideration of “best interests”<sup>172</sup>. “A person benefits from having their interests promoted and suffers from having their interests neglected,”<sup>173</sup> and therefore to avoid causing harm and to benefit persons, it is necessary to act in their best interests. What these interests may entail is a subject for further consideration, but the underlying principle remains the same.

### *II.11.3. Moral status is acquired at birth*

“It would be naïve to suppose that divergent positions on the status of prenatal and postnatal life can be easily reconciled.”<sup>174</sup>. This is true, and it is certainly true that a gradual scale or single moment of post-natal acquisition of moral status may be well-nigh impossible to apply as well as being politically dangerous ground. The Council uses this as a rationale to regard “the moment of birth, which is straightforward to identify, and usually represents a significant threshold in potential viability, as the significant point of transition not just for legal judgements about preserving life but also for moral ones.”<sup>175</sup>

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<sup>172</sup> Ibid., 2.21-2.32, pp 15-17.

<sup>173</sup> Ibid., 2.22, p 15.

<sup>174</sup> Ibid., 2.19, p 14.

<sup>175</sup> Ibid.

While the philosophical mores of this statement may be debatable, it represents a clear statement of ethical principle by the Council. It does not resolve all the difficulties of application by any means, but it is clear that according to this report, moral status begins at birth.

#### *II.11.4. Killing is wrong (but why?)*

In the context of neonatal critical care, withholding or withdrawing life-preserving treatment may both result in death. Although it is sometimes suggested that there is a moral distinction here between failing to give treatment and deliberately withdrawing it, the report's conclusion is that "there are no good reasons to draw a moral distinction between them, provided these actions are motivated in each case by an assessment of the best interests of the baby."<sup>176</sup> By contrast, the active administration of treatment designed to hasten death is regarded as morally unacceptable: "the Working Party unreservedly rejects the active ending of neonatal life even when that life is 'intolerable'."<sup>177</sup>

While this may seem like another statement of principle, that killing is always wrong (even where death may be in the person's best interests), the justifications given by the report refer in fact to current social standards and practices as well as the potential negative impact on doctors, the medical profession and society. The former may not be a rationale for setting principles of moral philosophy, but if the potential negative impact is perceived as a harm that might be caused, this conclusion is understandable in light of the harm-prevention principle.

#### *II.11.5. Respect for autonomy*

This principle, mentioned only in passing, here is interpreted to mean that restricting pregnant women's autonomy in the best interests of the unborn child is seen as morally unacceptable<sup>178</sup>.

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<sup>176</sup> Ibid., 2.33, p 18.

<sup>177</sup> Ibid., 2.37, p 19.

<sup>178</sup> Ibid., 2.20, p 14.

### *II.11.6. Justice*

“At the macroeconomic or social level, decisions must be taken about the proper distribution of what will necessarily be finite resources for the purposes of the provision of healthcare.”<sup>179</sup> The issue of resource allocation in this context applies not only to the resources of the moment involved in providing neonatal care, but also to the resources that may be needed to sustain a disabled child into and through adulthood. With respect to the latter, the report wisely advises that these projected costs must also be provided for by any State-based allocation of health care resources<sup>180</sup>.

It is always difficult to reconcile principles of global justice with decisions at the level of individual interests. Despite the difficulties of distributing health care resources fairly, the report recommends that “decisions at the microeconomic or individual level should still be determined, not by economic considerations, but by clinical judgements of priority, which take into account the best interests of the babies concerned.”<sup>181</sup>

### *II.11.7. Ethical frameworks and approaches*

Like the previous report, this report delves deeply into considerations of moral philosophy in addressing its subject. It also makes clear at the outset the goal of outlining “a framework within which we can consider the principal ethical issues that are raised”<sup>182</sup> and applying this to the practical problems that arise in this area. The framework draws elements from principles of medical ethics relating to patient care (best interests, ending of life and treatment considerations) and broader moral principles about the value of life and justice. Clear policy recommendations are achieved through the exploration each of these principles balanced with practical

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<sup>179</sup> Ibid., 2.41, p 21.

<sup>180</sup> Ibid., 2.42, p 21.

<sup>181</sup> Ibid., 2.43, p 21.

<sup>182</sup> Ibid., 2.1, p 9.

concerns, a good example of the definition and application of an ethical framework to a practical problem.

### **III. Discussion**

#### **III.1. Common ethical principles**

Considering the publications of the Council as analysed above, there are some clear common ethical principles that emerge<sup>183</sup>.

*III.1.1. Avoidance of causing harm*

*III.1.2. Prevention of harm*

*III.1.3. Duty of beneficence*

*III.1.4. Respect for persons and autonomy*

*III.1.5. Justice and just resource allocation*

*III.1.6. Informed consent*

*III.1.7. Confidentiality and privacy*

*III.1.8. Moral status: to whom do these principles apply (scope)?*

These principles are generally accepted throughout the reports, although the manner of their application may be seen to vary, sometimes considerably.

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<sup>183</sup> The present order of these principles reflects our reading of the importance accorded to them by virtue of their frequency, emphasis and status in the development of the Council's conclusions in the various reports.

## **III.2. Other principles**

Some further principles are raised and discussed within the Council's publications, but are not necessarily accepted or affirmed throughout, nor defined in a consistent manner:

### *III.2.1. Respect for dignity*

### *III.2.2. Naturalness*

## **III.3. Application of principles**

We have noted that consistency in the application of, or indeed in appeal to, ethical principles is important, and that clear inconsistencies between reports might tend to undermine public confidence in the Nuffield Council. If this is right, then some importance should be attached to the avoidance of such conflicts.

For example, a contrast might be drawn between the application of the principle of moral status in the reports *The ethics of research involving animals* and *Critical care decisions in fetal and neonatal medicine*. In the former, the applicability of moral status as a principle to determine the ethical acceptability of conducting research on animals is largely rejected, perhaps for practical reasons since (as the report notes) the divergent views on this issue are likely to prove impossible to reconcile on a theoretical level. The latter report, conversely, regards moral status as a key feature for determining ethical conduct in medical treatment of neonates, but employs a different strategy of dictating an absolute form of the principle (born children have full moral status) in the face of theoretical disagreement to find a practical solution.

Both these reports were confronted with a similar conundrum in the irresolvable tension between conflicting views of moral status, but chose to state and apply the relevant principle differently to resolve this problem. While neither is clearly wrong, perhaps some unified approach to resolving ethical disagreements through the application of ethical principles and policy compromises might be desirable.

#### **III.4. Ethical frameworks and their utilisation in the reports**

The principles described above have in some of the Council's reports been stated and applied in the context of various ethical frameworks. Some reports devote very little or no attention to the establishment of a framework within which to consider the problems posed by their subject, while others clearly set out such a framework. The uses (or otherwise) of ethical frameworks in the reports is summarised in the table following<sup>184</sup>.

It can be observed that in cases where an ethical framework has been stated clearly, it has generally been used systematically in determining the policy recommendations of the report, whether or not the process of defining and deciding on the framework has been made explicit. By contrast, some (though not all) of the reports which do not clearly adopt an ethical framework also display a more piecemeal approach to the application of the principles cited, sometimes resulting in less coherent policy guidance or inconsistencies within a single report's treatment of its principles and their application.

The comparison also demonstrates that there is no single framework which has been consistently adopted or used in the reports of the Council thus far. There are certainly various principles which have been used and adhered to more or less consistently, and from the commonality of these might be discerned some sort of framework that has underpinned a number of reports: elements of beneficence, harm prevention, respect for persons and autonomy and justice are among the principles most consistently applied. There are distinct echoes of the Georgetown "four principles" framework in this, understandably: this approach to bioethics has proven widely applicable and useful, and not for nothing is it often dubbed a "mantra". However, Nuffield's approach to practical ethics also draws in other principles (notably consent, which seems to have become enshrined in its own right); and the frameworks used (where they *are* used) often incorporate additional elements drawn from the specific context of the report.

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<sup>184</sup> See Table 1 below.

We shall return to a discussion of ethical frameworks and approaches and their role in the work of the Council in Section IV.

Report	Elements of stated framework	Principles	Comments
Human Tissue (1995)	None stated	<ul style="list-style-type: none"> <li>• Prevention of harm</li> <li>• Respect and human dignity</li> <li>• Consent</li> </ul>	Fits within medical ethics framework for patient care.
Animal-to-Human Transplants (1996)	None stated	<ul style="list-style-type: none"> <li>• Beneficence, prevention of harm</li> <li>• Risk balancing</li> <li>• Moral status and personhood</li> <li>• Speciesism</li> <li>• Nature and naturalness</li> <li>• Consent</li> <li>• Respect for conscientious objection</li> <li>• Justice and resource allocation</li> </ul>	No cohesive framework
Mental Disorders and Genetics (1998)	“[R]espect for human beings and human dignity, and the limitation of harm to, and suffering of, all human beings.”	<ul style="list-style-type: none"> <li>• Prevention/avoidance of harm and suffering</li> <li>• Respect for persons</li> <li>• Respect for autonomy</li> <li>• Respect for dignity</li> <li>• Consent</li> <li>• Best interests</li> <li>• Confidentiality</li> </ul>	Elements of framework specifically outlined and followed in application

Genetically Modified Crops (1999)	“[W]elfare, rights and justice”.	<ul style="list-style-type: none"> <li>• General welfare</li> <li>• Prevention of harm</li> <li>• Justice</li> <li>• The “maintenance of people’s rights”</li> <li>• Naturalness</li> </ul>	Elements of framework specified; some lack of clarity in definition but consistent framework followed.
Stem Cell Therapy (2000)	None stated	<ul style="list-style-type: none"> <li>• Personhood and moral value</li> <li>• Prevention of harm; beneficence</li> <li>• Respect for persons</li> <li>• Consent</li> </ul>	No framework defined; comparative policy recommendations rather than ethical principles in application
The Ethics of Patenting DNA (2002)	None stated	<ul style="list-style-type: none"> <li>• “Common heritage” of genetics</li> <li>• (Public) benefit</li> <li>• Prevention of harm</li> </ul>	No distinct ethical framework; analysis of practical problems within legal framework
The Ethics of Research Related to Healthcare in Developing Countries (2002)	<p>“(i) the duty to alleviate suffering</p> <p>(ii) the duty to show respect for persons</p> <p>(iii) the duty to be sensitive to cultural differences and</p> <p>(iv) the duty not to exploit the</p>	<ul style="list-style-type: none"> <li>• Prevention of harm</li> <li>• Respect</li> <li>• Sensitivity to cultural differences</li> <li>• Refraining from exploitation</li> <li>• Free and informed consent</li> </ul>	Framework explicitly stated and followed

	vulnerable”.		
Genetics and Human Behaviour (2002)	Refers to human dignity as a central principle; no explicit framework.	<ul style="list-style-type: none"> <li>• Human dignity</li> <li>• Prevention and avoidance of harm</li> <li>• The value of life – killing is wrong</li> <li>• Liberty, autonomy and choice</li> <li>• Equality of opportunity</li> </ul>	Importance of dignity emphasised but other principles more significant in application
Pharmacogenetics (2003)	None stated	<ul style="list-style-type: none"> <li>• Consent</li> <li>• Privacy</li> <li>• Confidentiality</li> <li>• Justice</li> <li>• Beneficence</li> </ul>	No explicit framework, although not inconsistent
The Ethics of Research Involving Animals (2005)	Hybrid approach: consequentialism and deontology.	<ul style="list-style-type: none"> <li>• Beneficence, prevention of harm</li> <li>• Avoidance of causing harm</li> <li>• Moral status</li> <li>• Duty of stewardship</li> <li>• Naturalness</li> </ul>	Ethical approach considered and adopted; policy principles derived.
Critical Care Decisions (2006)	Value of human life; best interests; ending of life and treatment decisions; resource allocation	<ul style="list-style-type: none"> <li>• The value of life and moral status</li> <li>• Best interests and prevention of harm</li> <li>• Respect for autonomy</li> </ul>	Elements of ethical framework defined and considered, then applied to produce recommendations

		• Justice	
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**Table 1: Ethical frameworks and principles in the reports of the Nuffield Council on Bioethics**

## **IV. What do the Reports tell us about the Nuffield Council on Bioethics?**

When considered in rough chronological order as we have done above, the publications of the Council demonstrate the evolution and refinement of an overall approach to bioethics that stretches across the entire publication output. Of particular note is the manner in which the reports have moved from making primarily policy-based recommendations to considering the underlying ethical principles. Another feature of note is the development, particularly in recent reports, of considerations of theoretical moral philosophy: being self-reflective in terms of the chosen ethical framework and how it applies. The reports thus demonstrate an overall trend towards incorporating more theoretical components into the Council's manner of dealing with the problems of bioethics – a trend of which this review may itself be an element.

### **IV.1. The role of the Nuffield Council in bioethics**

In this critique, to evaluate the use of ethical frameworks in the Council's work with a view to making recommendations for future work, the first question we must address is how the Council sees itself, and how what is revealed in these documents positions the Council.

The picture that emerges from an external perspective is of a liberal democratic, secular<sup>185</sup> body that attempts to span both theoretical ethics and practical policy. This is betimes a difficult position, and an analysis of the Council's work must therefore acknowledge the role of Council in producing practical policy advice, not just generating tracts of theoretical academic philosophy.

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<sup>185</sup> Secular – not as in non-religious, but that has issued itself a self-denying ordinance which requires it to use arguments of universal appeal (which by definition religious arguments cannot be)

## IV.2. Policy versus philosophy

“How far should public policy be based on concerns about the underlying attitudes that the development of a particular technology is thought to reveal? ... [T]here is undoubted force in the moral argument that rests upon the question: what sort of people do our social and technical practices reveal us to be? If we do not like what we see when we look honestly in the mirror, then there is cause for thought at least.”<sup>186</sup>

This paragraph, from the Council’s report on xenotransplantation, both poses the dilemma that practical ethics advisory bodies so often face, and illustrates the trap into which they are liable to fall in attempting to resolve it. A body that makes recommendations intended to apply to public policy but that pays no heed to the attitudes or concerns of the public themselves (no matter how ill-founded these attitudes may be) will likely prove to be irrelevant at best; at worst it will be disruptive and hinder the establishment of appropriate policies to deal with issues of concern. As the same report notes later, “public policy must reflect the ethical pluralism that characterises this and many other societies”<sup>187</sup>. The way in which public opinions are addressed and incorporated, however, will be crucial to the success of such a body not only in grappling with the philosophical issues and the public’s concerns, but in leading the way to a solution that can satisfy both.

Intuition and gut reactions are not moral arguments as such. We might wonder, examining the above paragraph, what exactly the moral argument is “that rests upon the question: what sort of people do our social and technical practices reveal us to be?” It appears that they have here conflated reasons for looking for a moral argument with an actual example of a moral argument. If we do not like what we see in the mirror, that

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<sup>186</sup> *Animal to Human Transplants: the Ethics of Xenotransplantation*, 4.22, p 44.

<sup>187</sup> *Ibid.*, 7.27, p 91.

gives us reason to look for a moral argument (or indeed, a beautician); it is not a moral argument in itself.<sup>188</sup>

#### *IV.2.1. Resolving the dilemma*

This, then, is the question that the Council must face: is demonstrating sensitivity to public opinion inconsistent with ethical consistency itself? The answer, as variously illustrated through the reports reviewed above, is: not necessarily. It is important, however, to be open about the procedural elements of policy-making and the different factors that inform the Council's approach to bioethics policy.

It is surely appropriate for an organisation in the Council's position to take account of public attitudes or of people's sensibilities, even when these do not sit well with the ethical framework within which the Council may be operating in a particular context. Instead of attempting to incorporate such intuitions into the framework, which has been the source of inconsistencies in a number of reports studied here, any conflict that thus arises should be openly acknowledged and the decision-making process, including the weight given to these conflicting elements, should be made clear<sup>189</sup>.

### **IV.3. Ethical frameworks and their uses**

Ethical principles, whether in theory or in application, do not exist in a vacuum: to be meaningful, they must relate to each other in some way and be applied consistently. Most problems of practical bioethics will invoke multiple principles, which if applied in isolation may produce incoherent results. The function of an ethical framework, then, is

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<sup>188</sup> And what if we do like what we see, or if we are sufficiently content that it does not occur to us to look? What evidence does that provide about the ethical acceptability of our current practices? Surely no more than distaste provides concrete evidence of ethical unacceptability. Perhaps we ought to devote some attention to defining moral arguments for the things we accept easily as well as the ones we do not.

<sup>189</sup> This was perhaps done most adeptly thus far in the reports on *The Ethics of Research Involving Animals* and *Critical care decisions in fetal and neonatal medicine: ethical issues*.

to provide a context within which the component principles may be applied consistently and coherently to achieve practical outcomes.

*IV.3.1. Is there a “Nuffield Council” Ethical Framework, and is one wanted or needed?*

As we indicated in the Introduction to this report, we consider that an ethical framework comprises a set of principles susceptible of coherent and consistent application that can be applied in a particular context of ethical decision-making. Given this account is perhaps neither surprising nor inappropriate that no single, universally applicable framework can be distinguished across the Council’s entire *oeuvre* to date, dealing as it does with such a range of issues and contexts.

This pluralism of frameworks has led to some inconsistencies at times between the findings of the reports as to different ethical principles and how they should be applied. One obvious advantage of defining a harmonious and universal “Nuffield Council Ethical Framework for Bioethics” would be to reduce such inconsistencies and to confer greater predictability for future work, in the same way that the doctrine of precedent does for judicial decisions.

Equally, however, there are strong reasons against establishing such a framework. Policy-making and law-making are not the same thing, and there is a need for policy advisory bodies to retain greater flexibility to incorporate new or different elements in response to the changing social and technological environment.

Bearing these considerations in mind, we therefore offer the following comments on best practice and the use of ethical frameworks, which we hope may assist the Council in its future work.

*IV.3.2. Procedure and best practice in ethical decision-making*

As with individuals, so with institutions and indeed with advisory bodies, best practice in ethical decision making involves making decisions on the basis of the best available evidence, in the light of consistently applied and relevant moral principles which are either generally agreed and accepted or which can be established to be relevant by moral argument. Finally the evidence and argument which justify and support the conclusions reached must be part of the report and articulated in detail sufficient to enable them to be either challenged or seen clearly to be cogent on the face of it.

For example, the incorporation of public sentiment and unjustified (although not necessarily unjustifiable) intuitions into policy decisions when they clash with the chosen ethical framework or indeed when they cannot be supported by persuasive evidence or argument may be a poor example of this standard unless it is explained why a particular sentiment ought to be taken into account.

As previously noted, the authors of this report have been struck by an apparent shift towards the explicit use of ethical frameworks in the Council's more recent reports. This seems to us to lend both added authority and greater clarity to the reports, and the Council might like to consider whether or not future Working Parties should be invited to consider the appropriateness of determining an ethical framework to help in the formulation of appropriate questions for consideration, as part of their Terms of Reference. Of course it is true that additional ethical principles are likely to recommend themselves as deliberations proceed. Attempts should then be made to fit these into the chosen ethical framework "on the hoof" and the consequent necessity to reflect on the congruence of the component principles, one with another, will help to ensure the consistency of the overall conclusions.

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