

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Give and take? Human bodies in medicine and research between April 2010 and July 2010. The views expressed are solely those of the respondent(s) and not those of the Council.

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## **Comments on "Give and Take? Human Bodies in Medicine and Research." Consultation Paper, Nuffield Council on Bioethics, April 2010.**

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### *Introduction*

Ethical analysis requires thinking through the meaning of a proposed activity in terms of individual, social and cultural norms and concerns. The Consultation Paper explores the current, separate regulations for first-in-human clinical trials and transfers of body parts, for any purpose, from any donor, and considers “whether or not such regulatory differences can be justified” (p.10). The Consultation Paper fails to fully think through the meanings of these activities before developing how they can be regulated.

This comment is in three parts. The first part thinks through the values the Consultation Paper suggests are appropriate to ethical analysis of the relevant activities and proposes a more inclusive and social understanding of those values (p.16). The second part discusses property and bodies. The third part addresses some of the specific questions posed by the Consultation Paper in light of the approach in the first part.

#### *1. Thinking Through Ethical Values:*

The Consultation Paper leaves out a very important value – that of “equality”, and in particular “gender equality”. There are two traditional approaches to equality: formal equality and substantive equality. Formal equality tends to centralize sameness and strives to treat everyone the same. Substantive equality centralizes outcomes – people have differences and may be treated differently in order to produce equal outcomes. Formal equality can be beneficial – for example, every Canadian citizen, no matter what their social characteristics are, has a right to vote. But always treating people the same may lead to other inequalities through failing to recognize their differences. For example, a person with diabetes may require different treatment – more frequent meal breaks at a place of employment – in order to have access to the same employment opportunities as a person without diabetes. The equality is in the outcome, the access to employment.

“Gender equality” matters in ethical considerations of human bodies in medicine and research. All donations of body parts come from bodies that exist in a social world where people are treated differently, often valued differently, based on gender. Specifically, the achievement of gender equality may require recognition of gender differences in order to ensure equality of outcome.

But the Consultation Paper treats every potential donor and clinical trial participant with formal equality, that is, as the same. This is, in part, how biomedicine creates the bioethical subject as explained by my colleague, Dr. Lorna Weir, in her comments to the Working Party. Applying “gender equality” as a value means that there must be a consideration of the role of gender in social norms, experiences and interactions around the practices involved in human bodies in research and medicine, as well as within the values referred to in the document. It must be remembered that gender interacts with many other social categories through which we are categorized and often, devalued – such as race, class, sexuality, religion, age and ability.<sup>1</sup> The failure to apply gender equality as an ethical value hides the indisputable fact that certain tissues only come from the bodies of those socially and biologically categorized as women. Overall, the failure to include “gender equality” as a value means that gender *inequality* can easily become the norm in frameworks of informed consent, public campaigns promoting body part donation as well as researcher, transplant coordinator and family requests for donation or participation in clinical trials.

Of the values listed by the Consultation Paper, “altruism”, “solidarity” and “justice” are in most urgent need of gender equality analysis.

“Altruism” is understood simply by the Consultation Paper as a selfless gift without expectation of return. There is acknowledgement of the possibility of coercion by family members, i.e. where a relative is on a waiting list and ‘expects’ a suitable relative to donate to them (p. 29). But gender is ignored. The document notes that live donors are beginning to increase over deceased donors. Of live donors, several studies show evidence that women make up the preponderance of live kidney donors (Scheper-Hughes, 2007). Why? Only a gender-based analysis that sees men and women in terms of social relations, not simply as individuals, can begin to answer this question. Some body parts, such as eggs, fetal tissue, cord blood and placentas only come from women. Only women have such tissue to give, and only women can consent to such a donation. This last factor cries out for a gender-based analysis for these donation and requests for them. Without applying the value of gender equality to requests to donate and informed consent in donating such tissues, there is little chance of developing any system of valid consent.

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<sup>1</sup> I cannot address these intersections in this brief comment. For research addressing these intersections in terms of ARTs see Dorothy A. Roberts, Maura Ryan and Heléna Ragoné and Frances Winddance Twine under references.

Given the preponderance of women donating kidneys, as well as the demand for donations of tissues specific to women's bodies, there is an important question to be asked: what is the connection between altruism and women's bodies? I suggest that the answer is found somewhere in the cultural understandings that connect motherhood and self-sacrifice, enabling society to take women's bodily gifts of birth-giving for granted, thus rendering them the 'natural' choice when looking for a family member who can be expected to give bodily, to sacrifice bodily for the benefit of another family member. Bringing awareness of gender inequality to the value of altruism, however, will bring a clearer understanding of the social connection between gender and altruism, and the social factors that drive donations from women, of both specifically female body parts and other body parts. Awareness of such factors may assist in preventing coercion based on gender, whether in the family or in other social contexts before it occurs.

"Solidarity" is understood as "we're all in this together". Who gives and who benefits from bodily gifts given in solidarity? For whom is such a gift a 'natural' or 'normal' way to express solidarity or caring? An example of how "solidarity" can manifest in a gendered way is found within infertility treatment programs where requests for donations are often about treating an anonymous 'other' for the same issue, infertility, as the donor is experiencing. Donations of eggs and embryos closely echo the social norms of motherhood in western society – bodily giving for the sake of a child. Women participating in (and potentially donating within) such programs often desire motherhood deeply, and it is possible that such a donation is a way of expressing this identity, especially in the face of infertility. Feminist ethicist Rosalyn Diprose argues that women's bodily reproductive gifts are gifts of ambiguous, undefinable sexual difference. That is, the gifts of women's specifically sexed bodies cannot be truly recognized or acknowledged through a gender neutral law. In a world where many inequalities and oppressions are based on gender, ignoring the 'sexual difference' in the regulation of such a gift is unethical (Diprose 1996: 132 – 135).

"Justice" is defined in the document as a 'fair' distribution of burdens and benefits within and/or between societies. This is a thin definition of justice – feminist, equality and social justice perspectives offer a more robust concept of justice which is required when dealing with the important issues of dignity, bodily integrity, life-creation and life-extension, and the relief of suffering, which are at the heart of bioethical issues. Centralizing distributions of resources, material goods and expenses, however, may restrict the concept of justice because it ignores the social norms and practices that shape people's differing abilities to seek out possible futures and develop their own capacities (Shanley and Asch, 2009: 853). Justice may also be seen as the "fulfillment of society's obligation to provide people with those resources needed to develop essential human capacities" (Shanley and Asch 2009: 859). Maura Ryan advocates use of a human rights paradigm to understand and navigate the complex interrelations between access to ARTs in rich and poor countries, in particular, as well as between rich and poor women:

“Bringing a human rights paradigm to bear casts both analysis and response not just in biological and individual terms, but in social, economic and political terms...it resists the tendency to isolate reproductive health and agency from all other conditions of women’s agency, such as access to education, stability in employment, safe water and adequate nutrition, and freedom from gendered discrimination and gendered violence” (2009: 819)

The concept of justice in the Consultation Paper and the more robust concept of justice briefly outlined here provide two very different answers to question of whether receipt of payment for undergoing the risks of egg donation, and providing an egg through which a research program may develop a profitable cell line, is “just”. The two concepts of justice would also support two different approaches to obtaining informed consent, or informed choice, from a young person living in poverty to undergo a first-in-human trial. A recognition of the role gender plays in structuring women’s opportunities and abilities to develop their own capacities around the globe is necessary for meaningful conceptions and applications of justice. Ethical analysis that focuses on the status of the embryo, and ignores the source of eggs, women, has been critiqued as lacking ‘gender justice’ (Dickenson 2002: 60-62). In regulatory proposals across jurisdictions feminist and social justice values and principles are currently invisible (Jesudason 2009:901). These values need to be brought forward if there is to be a full thinking through of ethical implications, followed by regulation that reflects a deeper justice, as well as the interrelated social worlds donors, recipients and transplant doctors and researchers find themselves in.

I thus recommend that the Working Party bring recognition of social norms of gender and their potentially oppressive aspects, that is, a gender analysis to all of its deliberations, develop a more robust and inclusive concept of justice and apply substantive equality within its structure and substance of bioethical thought and deliberation.

## 2. *Property and Bodies*

For the most part, Euro-American legal systems see sharp distinctions between ideas of property and ideas of personhood. Slavery is seen as a violation of personhood; selling one’s body parts is, for many, a violation of personhood. This is because one’s personhood exists in one’s body; one’s personhood is expressed in the use of one’s body. It is as a body existing in the world that we, as persons, have both social and moral meaning (Diprose, 2005: 237). Thus, it is not surprising that personhood is strongly connected to control over one’s body, what can be done with one’s body and body parts, before and after death.

Concepts of property, however, are creeping into social and legal understandings of body parts, for example through the UK decisions in *Yearworth* (frozen sperm seen as property given the purposes for which it had been generated) and *R. v. Lindsay and Kelly* (where human skill

has been applied, thus giving the body parts different attributes, they may be seen as property). And, when bioethical questions about corporeal substances ranging from kidneys to eggs to cell-lines are asked, the legislative responses “share with the questions the assumption that the corporeal substances at issue are someone’s property” (Diprose, 1996: 120).

Informed consent has become the standard vehicle through which bodies and body parts can be put to certain uses for certain purposes by another. Ikemoto argues that informed consent has developed as the vehicle which transfers both responsibility for risk and ownership in human tissues in the U.S (2009). In that informed consent is seen as a process which allows decision-making and self-protection, it is understood as sufficient to manage the donation of body parts ethically. In three American states, legal decisions have commented that to allow donors to control samples or benefit from commercialization of the research toward which they donated body tissues, would chill biomedical research, and that informed consent was sufficient to more-or-less “transfer exclusive ownership of human cells and tissues to another entity” (Ikemoto 2009: 778). It is now law in California that potential egg donors must be informed that there may be potential patent and profit from research, and that the donor will receive no financial benefit should the research be commercialized (Ikemoto 2009: 776).

The focus on informed consent shifts attention away from the purposes of research and treatment, and the uses to which bodily parts and tissues may be put, towards how such consent might be obtained. The ethical question – what is the meaning of these practices – is lost in the assumption that some kind of ‘property’ in bodies can be transferred through informed consent.

A true process of informed consent cannot ignore or devalue personhood. The question to be asked is not ‘how do we get informed consent?’, nor even ‘how can we ensure consent is fully informed?’ but ‘how can personhood be respected in use of bodies and bodily tissues in research and therapy?’ This last question keeps personhood and the body connected in that it does not assume a hidden property right in bodily tissues. I believe that answering this key question requires ethical analysis of specific uses of body parts and social practices of request and donation prior to developing norms of informed consent. Further, a process of request and donation that arises from answering this question would look different from current standards of informed consent.

I thus recommend that the Working Party develop a full and prior recognition and understanding of the connections between personhood and bodily materials, including recognition of the effects of gendered social norms on women’s embodied personhood.

### *3. Responses to Specific Questions in the Consultation Paper*

Q 2 Should any particular types of human bodily material be singled out as ‘special’ in some way?

Life-creating materials should be singled out as ‘special’ for two reasons. The first reason is that another person can result from their use, and another family can be created. The norm around such donations is anonymity, and this is meant to hide the ‘blood’ connection that exists with donors. In much of Western society, ‘blood’ connections are key to defining kin and belonging. Donating life-creating tissues opens a donor up to potential connections. Pretending that anonymity removes these potential connections contradicts everyday beliefs about kin and belonging. The second reason relates to my argument that bioethical analysis requires consideration of gender. Life-creating gifts are highly gendered – and those that come from women such as eggs, embryos and fetal ovarian tissue – involve markedly different physical risks and social meanings than those that come from men such as sperm (and arguably, the male contribution to an embryo). The physical risks of donating eggs or fetal tissue are much different than those of donating sperm. The social meanings of ‘mother’ and ‘father’ are different. These bodily materials are different. To not recognize their difference is to deny the personhood that attaches to the different bodily and sexual contributions of men and women to reproducing and creating a family.

Q 9 Are there any other values you think should be taken into consideration?

See previous comments on gender in/equality.

Q 21 In your opinion are there any forms of encouragement or incentive to provide bodily material or participate in first-in-human research that could invalidate a person’s consent?

I am very concerned about financial incentives to provide bodily material. Scheper-Hughes has documented kidney-selling in the Philippines as a direct method of dealing with poverty (2007). Several American researchers have found that young women donate eggs primarily for the money (Ikemoto 2009: 770; Jesudason 2009: 907-908). Dr. Weir mentions in her comment to the Working Party that people in need of income are more likely to participate in first-in-human trials. There are arguments that everyone – researchers, hospitals, biobanks – benefits commercially except the donors, so why should donors not be paid? I believe, however, it is the for-profit aspects of research that need to be questioned, rather than extending profitability as a reason to ‘donate’ body parts.

Q 22 How can coercion within the family be distinguished from the voluntary acceptance of some for of duty to help another family member?

Many family members donate kidneys willingly to family members who are in need of them. Coercion within the family to provide such as donation, however, is not unknown. Women who have been requested to donate eggs by their sisters sometimes feel as if they are not 'being a good sister' if they refuse (Mykitiuk and Nisker, 2008: 114). There is also evidence that in Canada, where payment for eggs is prohibited, social pressures from recipient parents who would like another child, and thus another egg from a donor, result in women taking extraordinary physical risks to donate eggs (Motluck, 2010). Family pressure is also found in kidney donation (Scheper-Hughes, 2007). It will be difficult to distinguish voluntary acceptance from family coercion in all cases. For some families and individuals, the line between fulfilling family duty and coercion will be blurred. The preponderance of women acting as live kidney donors and as the only egg donors means that bringing a gender analysis to requests and donations is very important in order to conceptualize and reduce, at least, the aspect of coercion that is based on gender. Thinking direct donation through a prism of equal value of all members of a family, and regulating direct donation on that basis, may also assist in the reduction of the possibility of coercion.

Q 23 Are there circumstances in which it is ethically acceptable to use human bodily material for additional purposes for which explicit consent was not given?

I am concerned that the use of bodily materials for purposes for which consent was not given violates personhood in the body; and heavily impacts women's personhood in the body. If there is to be some control of body parts after death or after donation, materials cannot be used for purposes which the donor knew nothing of. To abstract body parts from their source in a person is unethical, in that it violates that connection between personhood and the body.

The Consultation Paper refers to "material removed from the body in the course of another procedure such as...cord blood or amniotic membrane which may be retrieved at childbirth" and mentions that these "have often been treated as 'waste' but may have value both for the person from whose body they have come and to others" (p. 13). The document also refers to 'residual' blood or tissue (p. 23) or that 'left-over' after diagnostic or other treatment (p. 20). These include placentas, and the products of conception following spontaneous or induced abortion. Only women can provide these tissues. Although the Consultation Paper recognizes that such tissues may have value to the women from whom they came, I do not believe that this is the norm in hospitals and research laboratories. Rather, they are seen as waste or resource, approaches that again, separate personhood from the body, in particular women's personhood from women's bodies.

For women, the decision to have an induced abortion is a decision not to continue a particular pregnancy and bear a child at that particular time. Use of fetal ovarian tissue, or any tissue from an induced abortion, to create new life, fundamentally contradicts that decision. While the use of

fetal ovarian tissue is currently not permitted in the UK, the emphasis on supply and demand and the focus on regulatory streamlining in the Consultation Paper raise my concerns about a potential reversal. I recommend that, at the very least, the Working Party recognize the uniqueness of fetal ovarian tissue, and maintain the ban on its use.

Further, induced abortion is publicly and privately stigmatized in many segments of society. Spontaneous abortion may raise a fear of being unable to have children – another stigmatized condition in our society (Pfeffer 1987). Requests made of women to ‘donate’ material during the course of these procedures, which may be emergency procedures, may confuse receipt of treatment as a patient and donor-participant in research. The receipt of medical attention during spontaneous or induced abortion, or during childbirth, may become an additional site of the growing stress on the demarcation between patient and research subject (Mykhalovskiy and Weir 2004). Women may agree to donations of the products of conception at such times under a host of pressures that cannot be recognized or accounted for without some recognition of social norms regarding gender in our society, nor without gender analysis being brought to bioethical analysis of these practices.

### *Conclusion*

I appreciate very much the opportunity to participate in this consultation, as well as the Working Party’s recognition that biomedical regulation in the UK may affect individuals, families and regulatory policies beyond its borders.

A full recognition of personhood, of individuals as social actors, of the nuances of social practices of ‘give and take’ around research on human beings, deceased donation, living body part donation and the gifts of reproductive materials can only make bioethical analysis more ethical. The concerns raised by these practices are not narrow, rather they reflect social and moral meanings about what it means to be a person. I urge the Working Party to consider the responses it receives, and determine its course of action, within the broadest understanding of ethics and humanity.

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