

Comments on HGC consultative document, “Choosing the Future”

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We begin with some very general concerns. First, though there is a lot of mention of social context, this is very much assumed rather than described. As a very basic instance, it is taken for granted that human couples “tend to prefer to produce a baby from their own eggs or sperms” (3.12). This may well be true, but it needs to be understood in relation to the technological developments that have shaped the current state of these attitudes. The possibility of pursuing this goal beyond the traditional choices of sexual partner are very recent, and prior to these developments it would have been extremely odd to express the goal in these terms. Moreover the uncritical assumption tends to preclude a comparative discussion of alternatives such as the use of donated gametes, adoption, fostering, and so on, themselves possibilities profoundly shaped by technological advance (for example the lack of candidates for adoption is a consequence of efficient contraceptive technology). More strongly, the need to address failures to satisfy the wish to produce a baby from ones own gametes is assumed to be an imperative medical problem. This leads in turn to a failure seriously to weigh the costs of the medicalised solution against the assumed benefits. So, for example, though risks of miscarriage consequent on amniocentesis or chorionic villus sampling are mentioned in passing, as are adverse consequences of ovarian stimulation, these are not quantified nor their significance discussed.

Perhaps a more disturbing aspect of the failure to consider seriously the social context of these issues (and perhaps the underlying rationale of the failure) is the consistent presentation of reproductive problems as questions of almost existential individual choice. Widely held assumptions and ways of conceiving such issues will in fact inevitably have major effects on individual choices, especially to the extent that these assumptions are articulated by expert authorities. Indeed, we cannot help feeling that this document in its present form is to a considerable degree just such an authoritative articulation of a set of assumptions that are currently shaping ‘individual choices’. One crucial framing assumption for which this strikes us true is the increasing geneticisation of disease. Conditions with complex environmental and physiological causes are increasingly presented as most fundamentally genetic and therefore a problem for the individual. The current document views this situation mainly in terms of safeguarding individuals’ autonomy vis a vis making decisions about the “treatments” offered by these new technologies; we feel the focus should be on public policy on what kinds of treatments people are presented with in the first place, and whether the conditions that the new treatments address we, as a society, want to consider as “diseases” best addressed by individualised treatment using genetic medicine. These last points will be elaborated in our responses to the specific questions at the end of the HGC paper, to which we now turn.

1. We are very concerned about the growth in the number of conditions being screened and thereby conceptualised as disease states. We also believe that while it is correct to see the issue as a kind of 'slippery slope' attention has generally been focused on the wrong slope, and this paper continues that tendency. The slope generally discussed is from screening of serious disease conditions to 'positive eugenics' the selection of babies with enhanced beauty, intelligence, and so on. We are fairly confident that this is not a realistic scenario, certainly not one we should be concerned about at present. What does concern us is the slide from serious or fatal monogenic conditions to genetic conditions that predispose more or less to common diseases. Many such genetic predispositions have been identified, and in the commercial end of the spectrum we now witness the alarming rise of 'nutrigenomics' which advises people to eat greens or stop smoking on the basis of a multifactorial genetic screening. On a more serious note, it is currently technically possible, and in some cases part of normal clinical practice, to test people for a predisposition to complex conditions, such as Alzheimer's disease, breast cancer, diabetes and deep vein thrombosis, and questions about whether this information should be used to guide reproductive decisions are already raised. At Egenis we are investigating well established genetic predispositions to deep vein thrombosis, and there may well be legitimate clinical applications of such tests. But there is almost certainly no legitimate use for screening for such genes in PND or PGD. Recalling a point made in our introductory remarks, the effective social responses to conditions such as heart disease, cancer, stroke, asthma, schizophrenia etc. are environmental and behavioural. The tendency, which this paper unfortunately furthers, of reconceiving these diseases as individualised genetic problems should be resisted.
2. This question is a striking example of the naïve picture of existential individual choice that informs much of the HGC document. Given the situation of the counsellor as an expert on a subject on which most patients will have little knowledge it is almost unimaginable that counselling will be non-directive. It is well established and unsurprising that patients will often or usually defer to medical experts, and counselling will inevitably tend to promote what is conceived as medical best practice. The model of wholly autonomous individuals making entirely personal choices on the basis of value-neutral information with which they are provided by counsellors is naïve. (Indeed the organising role of this picture of individual choice is clear in both the title and the subtitle of the document, which perhaps makes it unsurprising that there is no systematic attention to the crucial aspects of social context.)
3. A great deal of research has substantiated this view and we expect that some of those who have done this work will comment in more detail.
4. The real interest of this question lies in the bullet points preceding it. What is really needed is a sociological explanation of why the behaviour described occurs, and of the process by which certain couples are constructed as patients who are appropriate subjects of this expensive, unreliable, and sometimes hazardous

medical technology. This relates also to the assumptions mentioned at the outset about the demand for a (healthy) baby with the right genetic ancestry. The question takes all this for granted, and it would be inappropriate to try and answer it in its own terms.

5. This is a question not really about genetics in a contemporary sense, but old-fashioned selective breeding. It is unclear why it should be raised in the present discussion.
6. This has already been addressed. Our most serious worry concerns the increasing geneticisation of ever larger parts of medicine and the consequent localisation of the problems in individual patients, and the extent to which this process is being driven by commercial and administrative interests rather than medical and social insights.
7. and 8. Our main concerns under these headings have already been raised.