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Editorial

HUGO Ethics Committee: ten years on

Next year it will be ten years since the publication of the first Statement of the Ethics Committee of the Human Genome Organisation (HUGO), although the committee was first established in 1992.. It laid out the so-called ten 'Cs' for the principled conduct of genetic research, including competence, communication, confidentiality, choice and consent, and continual review.

Last year (2004) following the resignation of Bartha Knoppers, who had led the committee in a way that set a very difficult standard to follow, I became Chair of the committee, and it is timely to reflect on what the work of the committee has been and where it is going. The field of genomics has of course changed a great deal during that time, and there have been concomitant developments in bioethics and in governance. The move towards the large population biobanks as in Iceland, the UK and Estonia, for example, has led to a large literature reviewing the applicability of existing ethical provisions and guidelines and to both legislative and non-legislative responses.

The HUGO Ethics Committee has as its primary audience the members of the Human Genome Organisation, but its Statements have been read considerably more widely. While some may see these 'edicts from on high' and question the value of guidelines from such committees, it is necessary to have regard to their point and purpose. They are valuable perhaps not primarily in so far as they make recommendations, which

have no sanctions associated with them, but for the reflection that goes into them and for their role in widely promoting awareness and further debate. Some of the HUGO Statements such as the *Statement on Benefit-Sharing*, have been very influential in this respect.

The Committee has an international membership; approximately half have a medical or scientific background, the remainder coming from fields such as Bioethics, Philosophy, Law and Social Science. Members work to achieve consensus rather than by majority vote: to date we have not had cause to attach any dissenting opinions to our Statements. That does not mean that it has been easy to reach agreement, or that agreement has always been reached: sometimes in fact we have decided not to say anything on a certain issue at a particular time, where agreement was not possible. We meet at least once a year at the Human Genome Meeting and are normally joined by a number of observers.

The most recent Statement of the HUGO Ethics Committee dealt with stem cell research. This was disseminated at the annual Human Genome Meeting in Kyoto, 2005. The Committee first dealt with this issue, briefly, in its *Statement on Cloning* in 1999. At that time stem cells were only just beginning to emerge on the agenda. The thrust of the 1999 Statement was supportive of therapeutic cloning, but advised against reproductive cloning in the light of various concerns. We stopped short, however, of declaring reproductive cloning to be wrong in itself. . We also drew attention to the dispute over the meaning of 'embryo' – whether all constructs created by somatic nuclear transfer counted as 'embryos' in the strict sense. Nevertheless, we were prepared to countenance the deliberate creation of embryos as conventionally understood for research in some circumstances, where there was the possibility of indisputable and widespread humanitarian benefit. Nuclear transplantation was supported in order to avoid mitochondrial disease.

The 2005 Statement on Stem Cell research reiterated the conclusions on cloning, and drew attention to the different interest groups that could be affected by stem cell research and therapy, including scientists, potential patients, donors of tissue and 'spare' embryos, and the moral order. It argued against arbitrary timelines and morally artificial distinctions, allowing research on some (e.g., imported) embryos but not on others.

In so far as the work of the Committee has its remit focused on genomics *per se*, however, the statements on cloning and on stem cells are arguably not its principal concern. After the *Statement on the Principled Conduct of Genetic Research* in 1996, the committee issued further statements on DNA Sampling (1998), Benefit-Sharing (2000), Gene Therapy (2001) and Human Genomic Databases (2002). It is possible to see a developing ethical position in these statements. While the Committee has always been concerned with humanitarian benefit (as in the 1999 *Statement on Cloning*, the focus has gradually shifted to issues of equity. There is of course considerable scepticism, among critics and commentators, that attaches to some claims for the benefits to genomics, but in so far as there *are* benefits it is important to give attention to issues of access. The *Statement on Benefit-Sharing* discussed benefits to communities (noting the different kinds of community that might be involved) and interpreted 'benefit' broadly so that it should not be considered to be limited to financial benefit. The Statement is arguably best known, however, for its recommendation that profit-making entities should donate between 1 and 3% of their annual net profit to humanitarian endeavours.

In the 2002 *Statement on Human Genomic Databases* the Committee went further, declaring human genomic databases to be global public goods, where global public goods were said to be goods that are non-rivalrous and non-exclusive – enjoyable by all without detriment to anyone. While some may suggest that to say they *are* global public goods goes too far, and that at best it can be argued that they should be treated *as* global public goods, this position has important implications as a strategy for maximising equitable access to such benefits as do emerge from the results of the Human Genome Project.

In the postgenome era there is discussion in the genomics community as to where the science goes next. The Committee has also given attention to identifying a work programme for the coming period. We will begin by completing work on a Statement on pharmacogenomics, on which we have been working for two years. In the light of the way pharmacogenomics has been presented in terms of personalisation and individualism, and in the light of our priorities, we will be specially concerned with the possibilities for solidarity between different groups in view of concerns about the potential of pharmacogenomics to produce new forms of stratification. At the same time, we will begin work towards a revisiting of the first Statement, concerned with basic principles, to mark the ten year anniversary of the issuing of *Statement on the Principled Conduct of Genetic Research* in 1996. Membership has changed significantly since the production of that first Statement, but the opportunity to undertake consultation on this issue and to review these principles will provide an important focus for evaluating the work of the Committee.

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