HUGO approves ethics code for genomics

Heidelberg. Genetics researchers should not offer "undue inducement" to individuals, families and population groups taking part in gene mapping and other related experiments, according to a code of ethics for genomics research approved last week by the Human Genome Organization (HUGO).

But the code does endorse various types of agreement that might be reached in exchange for such participation, ranging from the provision of health care or "information infrastructures" to "the possible use of a percentage of any royalties for humanitarian purposes".

At the same time, it underlines the importance of obtaining informed consent for such participation "free from coercion by scientific, medical or other authorities". Such consent, it adds, can be "individual, familial or at the level of communities and populations" — a potentially controversial statement, as it does not require that consent be expressed by an individual participant.

The code was endorsed last week by the executive council of HUGO, the umbrella organization which loosely oversees both the Human Genome Project (HGP) and the Human Genome Diversity Project (HGDP). It was immediately distributed to members of the organization attending its first full international meeting held in Heidelberg in Germany.

Grant Sutherland, director of the department of molecular genetics at the Women's Hospital in Adelaide, in Australia, and president of HUGO, says that the organization felt it was important to make a statement about ethics that tried to be culturally sensitive, but without giving in to the dictates of any one particular culture. "The code is not law, and it cannot be imposed on anyone," says Sutherland. "But we believe it is a useful starting point for anyone in this area."

The working group which drew up the statement says that its recommendations are based on four principles: recognition that the human genome is part of the common heritage of mankind; adherence to international norms of human rights; respect for the "values, traditions, culture and integrity" of participants; and "acceptance and upholding of human dignity and freedom".

The sections of the statement likely to attract the most attention, following recent controversy over the implementation of the HGDP, are those dealing with the need to ensure that the informed consent has been obtained from participants, and for the provision of appropriate compensation (see *Nature* 377, 373; 1995).

But the first principle listed in the statement concerns the way that research should be carried out, specifying that "scientific competence is the essential prerequisite for ethical research".

"It can no longer be assumed in this field

that there is sufficient quality control for public safety always to be taken into account in genetic testing programmes," says Bartha Knoppers, professor of law at the University of Montreal in Canada, and chair of the working group which drew up the statement.

Knoppers also defends the decision not to specify that consent must always be at the level of the individual — standard practice in Western countries — on the grounds that in some societies, such decision are normally taken "at the level of the whole community."

Furthermore, although acknowledging that the working group which drew up the ethics statement has refrained from criticizing any specific practice, Knoppers argues that more specific judgement needs to be based on a clear agreement on underlying

principles. "Rather than working backwards, we have a chance to prospectively guide countries so there is no 'shopping' and 'tourism' by geneticists between different locations," she says, a reference to fears that a patchwork of different guidelines would lay populations open to exploitation.

Eric Lander, director of the Whitehead Institute at the Massachusetts Institute of Technology, suggested that, as well as being agreed to by publicly-funded researchers, the principles should be publicly endorsed by biotechnology companies engaged in searching for potentially useful genes among human population groups. "I would urge companies to say whether they sign on [to these principles] or not," says Lander.

David Dickson

NIH seeks rapid sequence release

Heidelberg. Intense negotiations are taking place between the US National Institutes of Health (NIH) and six anticipated recipients of grants for large-scale genome sequencing over the speed with which these centres should place the data obtained from their efforts in the public domain.

The National Center for Human Genome Research (NCHGR) is due to announce the allocation of \$15 million earmarked by NIH for advanced sequencing projects within the next ten days. Francis Collins, the director of the centre, is seeking a commitment from grant recipients that their results will be rapidly disseminated.

In particular, Collins wants the centres to agree to adopt release procedures as close as possible to the terms of an informal agreement reached by representatives of sequencing centres from the United States and Europe in Bermuda in February.

These suggest that a desirable goal would be for assembled sequences greater than 1 kilobases to be released daily — a practice already adopted by the UK Sanger Centre, funded jointly by the Wellcome Trust and the Medical Research Council, as well as Washington University in St Louis.

John Sulston, director of the Sanger Centre, defends this policy on the grounds of the need "to avoid unnecessary competition and duplication in the human genome community", suggesting that the most important result of rapid release of data is that it promotes openness between researchers.

Others sequencers, however, are less convinced by such arguments. While

accepting the principle endorsed at the Bermuda meeting — that sequences developed with public funds should be placed in the domain with the minimum delay — there remains strong disagreement over how short this delay must be.

Some argue that the published sequences should be carefully checked for accuracy before release; others that they should be scrutinized for potentially patentable information. In both cases, say some critics, the type of immediate release favoured by Sulston could have unforeseen, and potentially damaging, implications.

Those who have reservations about Sulston's approach include Craig Venter, the director of the Institute for Genomic Research (TIGR) in Rockville, Maryland, which has high expectations of being among the recipients of NCHGR funds for large-scale sequencing.

Venter says that he is prepared to abide by NIH policy on the question of the speed with which the sequences are released to the public. He also agrees that it is important to get sequencing data out to scientists as soon as possible. "But I feel that it should be accurate and clean," says Venter.

Collins, meanwhile, says that the NIH is keen that the agreements reached with sequencing centres reflect the philosophy of the informal agreement reached in Bermuda without violating the terms of the Bayh-Dole Act.

Sulston remains committed to the principle that, in the absence of further information about biological function, human genomic sequence information should be regarded as "pre-competitive information".

D.D.