

Issues concerning ethical conduct and genetic mapping raised at Montreal meeting

John Lyttle

In Brief

ETHICAL CONCERNS ABOUT THE HUMAN GENOME DIVERSITY PROJECT were discussed in Montreal last year during the 1st International Conference on DNA Sampling and Banking. This article, the second in a 2-part series, looks at the potential for misuse and commercialization of DNA samples and discusses some of the ethical concerns surrounding genetic mapping.

En bref

LES PRÉOCCUPATIONS ÉTHIQUES SOULEVÉES PAR LE PROJET SUR LA DIVERSITÉ DU GÉNOME humain ont été abordées à Montréal l'année dernière au cours de la première Conférence internationale sur l'échantillonnage et les banques d'ADN. Dans cet article, le deuxième d'une série de deux, on examine la possibilité de mauvaise utilisation et de commercialisation d'échantillons d'ADN et on discute de certaines préoccupations éthiques relatives à la cartographie génétique.

The Human Genome Diversity Project (HGDP) was conceived in 1991 in an attempt to find answers to the ultimate mysteries: Who are we as a species, and how did we come to be this way? But even though completion of this massive genetic-mapping project is still only a proposal, calling a halt to the research would not be in mankind's best interests, delegates attending the 1st International Conference on DNA Sampling and Banking were told during the Montreal meeting.

Henry Greely, a professor of law at Stanford University, said calling a halt to the project — a move that has been recommended by many activists — would be bad for both science and humanity. He argued that killing the project would simply maintain and entrench an unhappy status quo in which invisible research takes place without discussion or group consent. "The HGDP is an opportunity to work together in a way that benefits everyone and hurts no one," he argued.

Greely said debate surrounding intellectual-property issues is taking a disproportionate amount of time and effort when compared with discussions about the misuse of human genetic information, including persecution on the basis of ethnicity and culture. "Science needs to proceed in partnership as much as possible with the cultures it wishes to study," he told the conference.

The abuse and misuse of genetic data concerned protesters from 16 different groups, who gathered outside the building where the conference was being held. Groups represented at the protest included Rural Advancement Foundation International and Cultural Survival Canada.

A letter circulated to participants denounced HGDP as a "vampire project" because it "violates fundamental sanctity of human life, threatens to fuel the flames of racist science and raises the spectre of coercive medical research and biological warfare on indigenous peoples."

Issues concerning genetic information are already turning up in some courts. In the United States, some jurisdictions permit the legal system to issue subpoenas concerning the genetic information of people accused of a crime. Is there a risk of abuse or injustice because of this? "You do have the spectre of people get-



Features Chroniques

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ting hauled in because they have DNA samples similar to the actual perpetrator," commented Jean McEwan, a visiting professor at the New England School of Law.

And the risks aren't necessarily the same for everybody. Catherine Twinn, a lawyer from Slave Lake, Alta., noted that native Canadians account for only 1.5% of the general population but a much larger share of Canada's prison population. This means that expanded use of DNA sampling could affect some populations much more than others, she warned.

There is also concern that commercial interests could corrupt policies that guide genetic research. "Market forces should not be driving genetic research, not driving the kind of consent forms we build [and] not be driving the kind of policies we make," said Bartha Knoppers, chair of the conference organizing committee and professor in the University of Montreal's Faculty of Law.

Even among pharmaceutical firms there is no consensus about whether the patenting of genetic information is a good idea, University of Michigan law professor Rebecca Eisenberg said. One major drug company has concluded that unless a genetic invention is patented, it is unlikely that a related therapeutic product will ever be available to the public. However, Christopher Austin, senior research fellow for Merck Research Laboratories, cautioned that indiscriminant patenting is equally stultifying; unless an invention is both useful and novel, a patent can slow down therapeutic research.

Progress

Applying the science of DNA sampling in the real world is a very complex operation. Practical judgements need to be "worked out," not just "thought out," said David Roy, director of bioethics at the Clinical Research Institute of Montreal and a professor at the University of Montreal and founder, director and coordinator of the Quebec Research Network in Clinical Ethics.

The Human Genome Organization (HUGO) has been considering ethical problems related to genetics. It published a statement on the principled conduct of genetic research, known as the "10 Cs," in the May 1996 edition of *Genome Digest*. It says the principal issues are:

- scientific competence;
- communication with populations, families and individuals;
- consultation prior to recruitment of test subjects;
- consent to participate;
- respect of choices made by participants regarding how the sample will be used;
- confidentiality of genetic information;
- collaboration among individuals, populations, researchers, programs and nations;

- prohibition of conflict of interest;
- prohibition of undue inducement through compensation;
- continual review.

In August the National Centre for Human Genome Research in Bethesda, Maryland, released a guide on ethical issues that are to be considered when recruiting donors for large-scale DNA sequencing. The major issues include the benefits and risks of genomic DNA sequencing; privacy and confidentiality; informed consent; consent from an institutional review board, and use of existing DNA libraries for large-scale sequencing.

Thomas Murray, director and professor at the Center for Biomedical Ethics at Case Western Reserve University in Cleveland, said researchers should approach a DNA sample as if it is a gift, and not an item for sale, since no money is or should be exchanged. Viewing samples as gifts not only captures the idea that they involve a voluntary transfer but also serves as a reminder that the recipient should be "much obliged" for the gift.

Keynote speaker Victor McKusick, a physician and professor of Medical Genetics at Johns Hopkins University and the founding president of HUGO, wondered how Canada's William Osler would have responded to genetics-related research and its impact on medicine. Osler represented the ideal physician of his time, McKusick said, but what wisdom would he have for us today?

Of medication, Osler said: "If most of the drugs in pharmacopoeia were dumped into the sea, it would be all the better for humanity and worse for the fishes." Would he say the same of DNA samples?

McKusick concluded that Osler would optimistically say that research is not far removed from primary care of patients. "I think the true physician is asking questions all the time he is practising medicine," he said, and a doctor needs to consider not only diagnosis, prognosis and treatment but also ask why certain symptoms and phenomena have arisen in the first place. ?

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