

Researchers urge ethics guidelines for human-genome research

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A global team of legal, scientific and ethics experts have put forward eight key recommendations to establish much needed guidelines for conducting human-genome sequencing research.

Timothy Caulfield, professor and research director of the Health Law Institute at the University of Alberta in Canada, led a consensus workshop to develop rigorous guideline recommendations for research ethics boards. The results appear in the current issue of *PLOS Biology* (March 2008).

Researchers met to develop these recommendations because national and international funding initiatives have substantially increased whole-gene research activities, and media coverage of both the science and the emerging commercial offerings related to human-genome research has heightened public awareness and interest in personal genomics, says Caulfield.

“Yes, these are early days in the field of human-genome research, but research ethics guidance is needed immediately,” said Caulfield. “With how fast this research is growing, it is necessary that we develop carefully considered consensus guidelines to ensure ethical research practices are defined for all.”

Some key recommendations of the paper include the right for participants to withdraw consent (which includes the destruction of tissue samples and written information); the issues associated with

participants' family members and relevant groups; and the means of obtaining clear consent from participants for possible future use of their genes.

“As technology continues to advance, whole-genome research activities seem likely to increase and expand,” says Caulfield. “As the pace of this research intensifies, we need to continue to explore the ethical, legal and social implications of this rapidly evolving field.”

The researchers note that the policy recommendations covered in the report are not the only issues that need to be considered. Commercialization, patenting, benefit sharing and the possibility of genetic discrimination are among other topics that warrant discussion in the future.

Source: University of Alberta

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