Genetic Benefit Sharing

Human Genome Organization Ethics Committee

Commercialization of genetic information is a phenomenon concomitant with the near completion of the Human Genome Project. Furthermore, there is considerable likelihood that future for-profit research in genetics will increase inequalities between rich and poor nations and between rich and poor people within each nation. Until recently, there has been little comment from national or international ethics committees.

Huge profits are expected to accrue from genetic research. Although corporate members of the Biotechnology Industry Organization (BIO), which represents over 800 companies that do much of the commercial genetic research, reported a collective loss of $5 billion last year, a turnaround is expected as pharmaceutical companies allied to BIO members begin to market drugs and vaccines based on genetic research. The pharmaceutical industry as a whole has the highest percentage of net profits—19%—of all Fortune 500 industries. Applied research in both the industrial and academic sectors has focused on diseases commonly found in North America, Europe, Japan, Israel, Australia, and New Zealand, where significant numbers of people can afford the new genetic technologies.

Yet, there is now increasing international recognition that benefits should be more equally distributed. To date, the concept of benefits seems to be limited to the payment of research participants or the therapeutic benefits of clinical trials. Unless action is taken, it is likely that benefits from the Human Genome Project may accrue only to rich people within rich nations. This, we believe, is unfair and inequitable. Thus, the Human Genome Organization (HUGO), an international organization of genetic researchers, has developed a statement* addressing this critical issue and suggesting benefit sharing as an attempt to address inequities.

The issues surrounding benefit sharing are complex. Should it be specific to families or communities that contributed to research? Should it be limited to those with particular disorders, or should it be more general? The most practical solution is that benefits be distributed broadly, perhaps to the health care infrastructures of entire nations.

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There are three fundamental arguments in favor of benefit sharing. First, we share 99.9% of our genetic makeup with all other humans. In the interests of human solidarity, we owe each other a share in common goods, such as health. Second, starting with Hugo Grotius's law of the sea in the 17th century and proceeding to international law governing air and space in the 20th century, such global resources have been viewed as common, equitably and peacefully available to all humanity, and protected in the interests of future generations. International law may therefore set a precedent for regarding the human genome as a common heritage. Third, when there is a vast difference in power between an organization carrying out research and the people providing material for that research, and when the organization stands to make a substantial profit (albeit taking the risk of investment), concerns about exploitation arise that benefit sharing can address. Considerations of justice require action to meet basic health care needs.

Creating specific mechanisms for benefit sharing may well prove difficult, especially in the cases of large groups and multifactorial diseases. Further, profits may accrue many years after the initial research and to a different entity. Patent rights may expire before or soon after a product becomes profitable. It is therefore preferable that companies act directly, voluntarily, and in harmony with community values and preferences.

The payment of corporate taxes does not fulfill the moral obligation of benefit sharing, as this is clearly a civic duty that falls on everyone. Companies involved in human health have special moral obligations above and beyond payment of taxes. Canada's Newfound Genomics devotes 1% of net profits to a charitable trust for the general population. A figure of 1 to 3% of net profits for benefit sharing (which is over and above R&D on diseases found in developing nations) seems most reasonable. In setting this figure, we intend to provide a minimal moral guideline to encourage companies to become good global citizens. Our views are not meant to antagonize but to promote discussion and set a realistic benchmark for sharing our common heritage.

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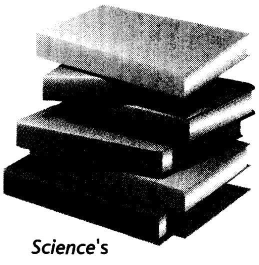

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*HUGO Ethics Committee, Statement on Benefit-Sharing (http://www.gene.ucl.ac.uk/hugo/benefit.html).