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ABSTRACTS

HGM2008 ethics, culture and genomics symposium abstracts

026: Ethics, culture and genomics—an Indian perspective

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Although certain ethical principles are universal, their application varies in different countries. India has many cultures and religions, and minority groups are allowed to follow special personal laws. Ethical issues begin with the consent form. People with poor science literacy have difficulty in understanding the intricacies of a long consent form. The investigators have less time to explain it. The patient gives consent without full understanding. In community studies among indigenous groups the consent is not by an individual but by the community. Therefore, ethic committees have a special duty to see that genetic and other research studies are conducted with sufficient safe guards for the rights of the patients, including compensation. There is an increasing tendency for some multinational companies to conduct trials in developing countries, to bypass the stringent laws in their own countries. The ICMR guidelines stipulate that phase 1 trials with new drugs should be conducted only in their home country. Genomic studies require large sample size, and there are no immediate benefit to the individual. The physician—patient relationship should not be used to exert moral pressure on the patient to join in the study. The issue of benefit sharing of a new discovery from the samples given is accepted by investigating agencies, but in practice is difficult to enforce. Another important issue is that of discrimination against a person with a genetic defect. This discrimination is less in those societies with good science literacy. Protection against this is required by enacting suitable legislation, which has not yet been done in India. The discrimination is not only in employment, in health insurance but also in finding a mate in societies with arranged marriages. Tests during pregnancy raise special ethical concerns. Sexing for social reasons has been forbidden by law in India. However when the patient and the doctor are both going to benefit from a test, ways are discovered to bypass the law. Abortion was permitted with liberal indications up to 20 weeks of gestation, to stop illegal abortions. However, the newer technologies often lead to the identification of defects after 20 weeks, thus creating serious ethical dilemmas for the patient and the doctor. Laws need constant revisions, but the time lag in their introduction raises significant ethical issues. These are some examples how local factors affect ethical decision making.

027: Challenges of implementing international ethics guidelines for genetics into the realities of Asia and Pacific communities

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There have been debates in almost every corner of the globe over the ethical issues of genomics and gradual increase in the internationalization of the issues being discussed. Ethics is a concept balancing benefits and risks of choices and decisions. The foundations of modern ethics have been built upon concepts of the right for each person to make decisions. The capacity for decision-making is found in underlying heritage of ethics can be seen in all cultures, religions, and in ancient writings from around the world. Associated with autonomy is personal responsibility. Codes of behaviour have existed informally in many societies over history, and there are certain professional codes that have been used to identify the medical profession for several millennia, such as the Hippocratic Oath. As the profession of science has emerged we are also now seeing the emergence of a number of codes of ethics to guide behaviour in science and technology. The appropriate implementation of international standards in ethics of science and technology and bioethics is important, and there are three International Declarations on Bioethics unanimously accepted by governments of the world during the UNESCO General Conferences (Universal Declaration on the Human Genome and Human Rights 1997; International Declaration on Human Genetic Data 2001; Universal Declaration on Bioethics and Human Rights 2005). These Declarations were prepared because of a need for a social, cultural and ethical response to the challenges in these fields in the changing social order, and for scientists they could be seen as providing some elements of a code of ethics. HUGO also has adopted a series of ethical statements produced by the HUGO Ethics Committee. Despite the unanimous acceptance of international declarations relating to ethics of genomics and human rights in UNESCO, and related international instruments by other UN agencies, there are gaps in the implementation of these standards into national laws and guidelines in many countries because there are differences between the ideals and the realities of communities in many countries. This paper will discuss the situation relating to implementation of such standards, and the accompanying debates, in particular in the Asia and Pacific region.

028: Disease-related genome research: novel opportunities for developing countries

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In the late 1980's, the proposal to sequence the entire human genome was largely motivated by the expectation that it would lead to the elucidation, prevention and eventually, cure of all genetic defects. The Human Genome Organization was founded to assist with the coordination of this research, then envisioned as an international effort involving many different genetic laboratories worldwide. Very soon, however, large Genome and Sequencing Centers were founded, and multifactorial disorders became the new target of genome research. This left little room for contributions from small laboratories, and for many years, disease-related genome research was almost entirely dominated by industrialized countries. There are at least two reasons why this is likely to change. First, research into single gene disorders is re-gaining popularity, but it is largely dependent on the active participation of developing countries with large families and a high degree of parental consanguinity. Secondly, next generation sequencing and related techniques are about to revolutionize the elucidation of genetic defects, and these methods should become affordable even for small labs within the next few years. Thus, emerging countries are well positioned for becoming key players in the world-wide effort to study disease-related variation in the human genome.

029: Ethics and international interoperability

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Health research is touted as both a domain worthy of private and public investment and as a contribution to potential socio-economic and individual well-being. Since the inception of the Human Genome project in the 1990's, genomic research in particular has captured the imagination of both funders and research participants alike. While attention has been paid to the nature of modern genomic research in terms of scale, costs and complexity (to say nothing of the need for interdisciplinary and international collaboration), less is known about the ethical roadblocks that are unique to these large-scale endeavours. Three particular areas merit further scrutiny, discussion and reform:

1. new ethical principles and approaches to frame and evaluate this research.
2. international data access and sharing (open source; controlled access; patents; creative commons licensing etc…)
3. appropriate governance mechanisms.

It would be axiomatic if the broad consent and altruistic participation that characterize these large population studies based on public trust in their necessity and worthiness were to be stymied by research ethics and procedures not suited to their evaluation.