EXECUTIVE BOARD 113th Session Provisional agenda item 3.16 EB113/13 27 November 2003

Genomics and world health: report of the Advisory Committee on Health Research

Report by the Secretariat

- 1. The complete sequencing of the human genome, announced in 2001, marked the culmination of unprecedented advances in the science of genomics, the study of the genome and its functions. The availability of genome sequences for many living organisms clearly has important implications for health improvement, and it has been widely predicted that elucidation of the sequences will lead to a revolution in medical research and patient care.
- 2. Recognizing the potential of genomics for health improvement, the Director-General requested the Advisory Committee on Health Research in January 2001 to prepare a report on genomics and world health. Accordingly, a wide-ranging consultative process was undertaken, engaging scientists, clinicians, ethicists, public and private funders of genomics research, health policy-makers, nongovernmental organizations and civil society groups concerned with the ethical, legal and social implications of genomics.
- 3. The report¹ details the latest advances in genome research and explains how this research could result in clinical applications in many diseases, including those that are endemic in poor countries. At the same time, it warns of the potential risks of such research, in particular the possibility that recombinant DNA technology will exacerbate global health inequalities, and of the need to consider the complex ethical issues that might arise in the context of the different religious and cultural values of the individual Member States. Finally, it makes recommendations on how the fruits of this research can be used to improve the health of populations, especially in the developing world.
- 4. The main points raised in the report are as follows.
 - Any benefits that result from genomics research will be irrelevant to countries that do not have a functioning health-care system.
 - Advances in genomics for global health care must be assessed for their relative value in the practice and delivery of health care compared with the costs and efficacy of current

¹ Genomics and world health: report of the Advisory Committee on Health Research. Geneva, World Health Organization, 2002. Full report accessible at www.who.int/genomics. The executive summary will be available in the Executive Board room.

approaches to public health, disease control and the provision of basic preventive medicine and medical care.

- Conventional, tried and effective approaches to medical research and medical practice must not be neglected while the medical potential of genomics is being explored.
- An overoptimistic picture of the applications and benefits of genetic research has been drawn. The potential medical applications of genomics are considerable and will lead to major advances in clinical practice but the time-scale is difficult to predict.
- Although development costs associated with genomics are likely to be high, some applications (e.g. control of inherited anaemias and diagnosis of infectious diseases) have already been shown to be cost-effective compared to current practices. Approaches such as collaboration between developed and developing countries, public-private partnerships and establishment of regional and local networks may take the field forward.
- Some results of the genome projects are already being applied medically. The diagnosis, prevention and, to some extent, management of common inherited diseases caused by a single defective gene are well advanced. It is likely that within the next few years new diagnostic agents, vaccines and therapeutic agents for communicable diseases will be available. In the same time frame, however, breakthroughs in the diagnosis and management of cancer and new treatments for chronic diseases are far less certain.
- The time has come to plan how recombinant DNA technology and its potential clinical benefits can be distributed fairly. Otherwise, this new field will simply widen the gap in health care between the rich and poor countries of the world.
- The current situation regarding the patenting of genes has gone too far in terms of promulgating a culture of ownership and, if allowed to continue, it will inevitably lead to further inequalities in global health care. A coherent policy framework is urgently required to ensure that DNA patenting stimulates scientific and economic progress by strengthening the contribution of the global research community to the creation and application of medical technology for the health problems of developing countries.
- All forms of recombinant DNA technology, including modification of the genes of plants and animals, raise extremely important safety issues and need careful monitoring and control. The potential risks and hazards must never be underestimated. It is vital that effective regulatory systems are established in countries in which this work is either in the early stages of development or has not yet started.
- All societies must prepare themselves for the ethical complexities of this emerging field of medicine.
- All sectors of society including politicians, health-care professionals, educators and the public need to be educated about the fundamental principles of genetic research, its inherent risks and the ethical issues that it raises.
- 5. The report concludes with recommendations which are set against a background of current and expected future requirements that Member States will need to consider in planning for the genomics

era in order to ensure that the advances of the genomics revolution are effectively and efficiently applied to improving the health of their populations.

6. The report acknowledges that some activities in the genomics field already form part of the Organization's work, but it also urges the formulation and articulation of a WHO policy and strategy to help to ensure that benefits and advances are applied to health improvement in developing countries.

ACTION BY THE EXECUTIVE BOARD

7. The Executive Board is invited to consider the following draft resolution:

The Executive Board.

Having considered the report on genomics and world health,¹

RECOMMENDS to the Fifty-seventh World Health Assembly the adoption of the following resolution:

The Fifty-seventh World Health Assembly,

Having considered the report on genomics and world health;

Acknowledging the remarkable progress in genomics research and the fact that many Member States are not well prepared for this new approach to medical research and practice;

Wishing to promote the potential benefits of the genomics revolution for the health of populations in developed and developing countries alike;

Aware that genomics raises concerns about safety and has complicated and new ethical, legal, social and economic implications;

Reaffirming that advances in genomics must be considered in the context of their value added in the practice and delivery of health care;

Recognizing the urgent need for research into, and applications of, genomics in order to promote benefits that accrue to countries;

Convinced that it is time for governments, the scientific community, civil society, the private sector and the international community to pledge their commitment to ensuring that the advances of genomics are equitably shared by all,

¹ Document EB113/13.

- 1. TAKES NOTE OF the recommendations contained in the report of the Advisory Committee on Health Research on genomics and world health;¹
- 2. ADOPTS, for the purposes of the present resolution and all subsequent activities of WHO, the following definition of genomics: genomics is the study of genes, their functions and related techniques;
- 3. URGES Member States to consider adopting the said recommendations and to mobilize all concerned scientific, social, political and economic parties in order:
 - (1) to frame national genomic policies and strategies, and to set up mechanisms for assessing relevant technologies, cost-effectiveness, ethical review structures, legal, social and economic implications, regulatory systems particularly with regard to safety, and the need for public awareness;
 - (2) to strengthen existing, or establish new, centres and institutions engaged in genomics research with a view to strengthening national capacity and accelerating the ethical application of the advances in genomics relevant to countries' health problems;
- 4. CALLS UPON Member States to facilitate greater collaboration among the private sector, the scientific community, civil society, and other relevant stakeholders in particular within the United Nations system, and engagement in dialogue in order to find creative and equitable ways of mobilizing more resources for genomics research targeted at the health needs of developing countries and building capacity in such areas as bioethics and bioinformatics;
- 5. REQUESTS the Director-General:
 - (1) to provide support to Member States for framing national policies and strategies and strengthening capacity so that they can benefit from the advances in genomics relevant to their health problems;
 - (2) to promote WHO's role in collaboration with relevant United Nations bodies in convening regional and international forums and fostering partnerships among the main stakeholders in order to mobilize resources, contribute to building capacity, and find innovative solutions to issues associated with advances in genomics research.

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¹ Genomics and world health: report of the Advisory Committee on Health Research. Geneva, World Health Organization, 2002.