

Facts:

- The final version of the entire Human Genome sequence was unveiled in April, 2003.
- Prevention and management of genetic disorders are published health priorities in some developing countries, for which the WHO Human Genetics Programme (HGN) is developing significant capacity building initiatives and normative and regulatory guidance.
- Multiple DNA sequences are involved in the complex biochemical processes of human development and diseases and are significant to developing and targeting drugs.
- The Top Ten Biotechnologies for Improving Health in Developing Countries have been identified by a WHO Human Genetics Collaborating Centre.

Genetics in developing countries

Low to middle income countries vary in their capacities in medical genetics. Some may not have the resources to set up appropriate genetic services. Others provide genetic services but need assistance to improve equity of access to

these services. WHO is supporting country capacity building by constructing educational modules and pilot studies to develop national community genetics, including the ELSI.

Ethical, legal and societal implications of genomics

The rapid growth of genetics and its application to medicine provide an unparalleled opportunity to advance the health of all. At the same time, the **ethical, legal and societal implications** (ELSI) of genetics have come into sharper focus.

The Human Genetics Programme (HGN) is particularly concerned with the implications of genomics for global health prevention, promotion, services and equity. Specifically, we aim to:

- Promote the just and equitable access of affordable genetic tests, screening, diagnostics, and other potential technologies.
- Reduce health and ethical risks by providing guidance for safety standards, monitoring and evaluation of genetic databanks, genetic tests, and screening.
- Empower and advocate for women, children, and disadvantaged groups for genomic health research prioritization and affordable access to their benefits.

- Develop tools for genomic capacity building, including educational modules and mechanisms for access to genomic bioinformatics, especially in developing countries.
- Promote health through sound and ethical genomic regulation and genetic service delivery in low to middle income countries.

**Key areas of work**

HGN encourages and supports the establishment of community genetics services in developing countries that are based on:

- Integrating genetic approaches into primary health care.
- Developing regional and country WHO networks on medical genetics.
- Reviewing and analyzing genetic determinants of major noncommunicable diseases and common hereditary disorders.

WHO/HGN's ELSI programme is particularly concerned with global genomic health and equity, especially from low to middle income country perspectives. Currently, we are engaged in the following projects:

- Developing a WHO Action Plan and strengthening inter-Departmental and cross-Cluster collaboration in ELSI.
- Building strategic co-operation with other UN agencies and leading health concerned international organizations.

- Providing normative guidance and regulatory models, especially for developing countries, for ELSI in human genomics.
- Developing recommendations for the ethics of genetic databanks, testing, screening, and patenting, particularly with respect to issues in health equity.
- Developing, through comparative analysis, educational modules and tools for capacity building and advocacy in developing countries.
- Observing that developing countries vary in their capacity and access to genetic services and bioinformatics, HGN also promotes research in genetics and ELSI.

The Genomic Resource Centre (GRC)

The GRC is a comprehensive, Internet-based resource on genomics and health catering to a variety of stakeholders especially in developing countries.

www.who.int/genomics

Key Contacts

Dr R. Beaglehole
World Health Organization
Tel: +41-22-791 2508
Fax: +41-22-791 4769
Email: beagleholer@who.int



Dr V. Boulyjenkov
World Health Organization
Tel: +41-22-791 3442
Fax: +41-22-791 4769
Email: boulyjenkov@who.int



Ms A. Smith
World Health Organization
Tel: +41-22-791 1498
Fax: +41-22-791 4769
Email: smithaly@who.int

