

# **Guidelines on professional education in genetics**

Guidelines on genetic education which are available at national level in Europe and published by international organizations.

## 1.1 EU NATIONAL GUIDELINES

### 1.1.1 Medical undergraduate students

#### France

Guidance of medical genetic issues for undergraduate students.  
Jeanpierre M et al. Objectifs pedagogiques de l'insegnement de Genetique. La commission pedagogique du College national des geneticiens, 2001.

#### Germany

Catalogue of teaching objectives\_\_DGMBT Gegenstandskatalog Medizintechnik, Biomedizinische Technik und Klinikingenieurswesen, VDE, 2001.

#### UK

Teaching medical genetics to undergraduate medical students.  
British Society for Human Genetics, 2003.  
[http://www.bshg.org.uk/documents/official\\_docs/Undergrad.doc](http://www.bshg.org.uk/documents/official_docs/Undergrad.doc)

### 1.1.2 Post graduate, Geneticists

#### Italy

Conference State-Regions. A guidance for the medical genetics activity's organization. 15.07.2004, G.U. 23.09.2004.  
<http://www.altalex.com/index.php?idstr=5&idnot=7526>

National Report on the Implementation of the Bologna process (2003). This document is a national report on the implementation of the Bologna process about the adoption of a system of easily readable and comparable degrees.  
[www.bologna-berlin2003.de/pdf/Italy.pdf](http://www.bologna-berlin2003.de/pdf/Italy.pdf)

### Belgium

Carrier testing in minors: a systematic review of guidelines and position papers.

P. Borry et al. (2006) Eur J Human Genetics 14, 133-138. A review of all published ethical and clinical guidelines concerning the genetic carrier testing of minors.

### Netherlands

Unclassified variants in disease-causing genes: nonuniformity of genetic and counselling, a proposal for guidelines. Vink GR. t al (2005) Eur J Human Genetics 13:525-527. Dutch guidelines about the communication of genetic tests by the clinical geneticists to the counselee.

### 1.1.3 Post graduate, Health Professionals

### UK

Fit for practice in the genetics era: a competence based education framework for nurses, midwives and health visitors. Kirk M et al. 2003. It is a competence based education framework for nurses, midwives and health visitors across the UK prepared by the NHS Genetics Team. They represent the minimum knowledge, skills, and attitudes necessary for health professionals from all disciplines to provide patient care that incorporates genetic perspectives and reflects sensitivity to related ethical, legal, and social concerns.  
<http://www.glam.ac.uk/socs/research/gpu/FinalReport.pdf>

## 1.2 EUROPEAN GUIDELINES

In this chapter guidelines that are relevant to genetic education published by the European Society of Human Genetics are discussed.

Genetic information and testing in insurance and employment: technical, social and ethical issues.

Recommendations of the European Society of Human Genetics  
European Journal of Human Genetics (2003) 11, Suppl 2, S11–S12.

Provision of Genetic Service in Europe: current practice and issues.

Recommendations of the European Society of Human Genetics  
about Provision of genetic services in Europe.  
European Journal of Human Genetics (2003) 11, 900-902

Population genetic screening programmes: technical, social and ethical issues.

Recommendations of the European Society of Human Genetics  
European Journal of Human Genetics (2003) 11, Suppl 2, S5-S7.

Recommendations for quality improvement in genetic testing for cystic fibrosis.

Recommendations of the European Society of Human Genetics.  
European Journal of Human Genetics (2000) 8, S1-S24. They  
provide general strategies for testing as well as guidelines for  
laboratory procedures, internal and external quality assurance, and  
for reporting the results. This document was prepared within the  
framework of the European Concerted Action on Cystic Fibrosis.

EU, Council directive 93/16/EEC 1993.

This EU directive facilitates the free movements of doctors and the  
mutual recognition of their diplomas and other forms of qualifications.  
[http://www.ilo.org/public/english/employment/skills/recomm/instr/eu\\_5  
.htm](http://www.ilo.org/public/english/employment/skills/recomm/instr/eu_5.htm)

EU, Council of Europe, Recommendation N. R (92) 3 on genetic testing and screening for health-care purposes, 1992.

Recommendations to ensure respect for principles in the field of  
genetic testing and screening including medical research.  
<http://www.coe.fr/cm/ta/rec/1992/92r3.htm>

EU, Council of Europe, Recommendation N. R. (94) 11 on screening as tool of preventive medicine, 1994.

Recommendations to be considered by EU member countries in their national health planning.

<http://www.coe.fr/cm/ta/rec/1994/94r11.htm>

EU, Council of Europe, Recommendation N. R. (97) 5 on the protection of medical data, 1997.

In this recommendation there are specific regulations about genetic data in order to avoid any prejudice or discrimination.

[http://www.coe.fr/dataprotection/rec/r\(97\)5eexp.htm](http://www.coe.fr/dataprotection/rec/r(97)5eexp.htm)

EU, Council of Europe. Convention on Human Rights and Biomedicine

It contains two dispositions that are of particular interest from the domain of genetics: articles 11 (prohibition of any form of discrimination on the ground of genetic heritage) and 12 (predictive genetic testing only for health purpose and subject to appropriate genetic counselling).

<http://www.vib.be/NR/rdonlyres/6EE92136-7F13-403F-83ED-05CD3506283B/0/conventionhumanrightsandbiomedicine.pdf>

Organization for Economic Cooperation and Development (OECD), Genetic testing :policy issues for the new millennium, 2000.

In the workshop of 2000 the OECD considered the areas requiring a coordination of international policies.

[http://www1.oecd.org/dsti/sti/s\\_t/biotech/act/gentest.pdf](http://www1.oecd.org/dsti/sti/s_t/biotech/act/gentest.pdf)

EU, Charter of Fundamental Rights of the EU, 2000.

Art.35 is about the right for everyone of access to preventive health care and the right to benefit from medical treatment.

[www.europarl.eu.int/charter/pdf/text\\_en.pdf](http://www.europarl.eu.int/charter/pdf/text_en.pdf)

EU Parliament, Temporary Committee on Human Genetics and Other Technologies in Modern Medicine, Report on the ethical, legal, economic and social implications of human genetics, 2001.

The Committee reported about the orientation of EU Institutions regarding research in human genetics and other new technologies.

[http://www.europarl.eu.int/comparl/tempcom/genetics/rapfin\\_en.doc](http://www.europarl.eu.int/comparl/tempcom/genetics/rapfin_en.doc)

EU, Council of Europe, Recommendation 1512: Protection of the Human Genome, 2001.

The recommendation is about the human genome international research project and its possible consequences.

<http://star.coe.fr/ta/TA01/EREC1512.htm>

#### EU Commission, 2002

Genetic Testing. Patients' rights, insurance and employment. A survey of regulations in the European Union.

[http://europa.eu.int/comm/research/biosociety/pdf/genetic\\_testing\\_eur20446.pdf](http://europa.eu.int/comm/research/biosociety/pdf/genetic_testing_eur20446.pdf)

#### EU Commission, 2004

25 Recommendations on the ethical, legal and social implications of genetic testing.

[http://europa.eu.int/comm/research/conferences/2004/genetic/pdf/recommendations\\_en.pdf](http://europa.eu.int/comm/research/conferences/2004/genetic/pdf/recommendations_en.pdf)

### 1.3 INTERNATIONAL ORGANIZATIONS

#### WMA, Declaration of Helsinki

The World Medical Association has developed the Declaration of Helsinki as a statement of ethical principles to provide guidance to physicians and other participants in medical research involving human subjects. This can be found on the website in the continuing medical education section.

<http://www.wma.net/e/policy/b3.htm>

#### Standards and Guidelines for Clinical Genetics Laboratories.

Technical standard and guideline: Prenatal screening for open neural tube defects. American College of Medical Genetic Vol.7(5), May/June 2005 pp 355-369. These standards and guidelines are designed primarily as an educational resource for clinical laboratory geneticists.

[www.geneticsinmedicine.org](http://www.geneticsinmedicine.org)

#### Principles of Genetics for Health Professionals.

USA National Coalition for Health Professional Education in Genetics (NCHPEG).

A guidance document that should constitute basic instruction in genetics for those in health care.

<http://www.nchpeg.org/eduresources/core/coreprinciples.pdf>

The NCHPEG core competencies

USA National Coalition for Health Professional Education in Genetics (NCHPEG).

It provides the guiding framework on teaching programs throughout the United States about genetics and about strategies to incorporate genetics as a recurring theme in graduate curricula.

<http://www.nchpeg.org/eduresources/core/Corecomps2005.pdf>

Recommendations for educating nurses in genetics.

Jenkins et al. Professional Nursing, 17(6), 283-290, 2001. USA recommendation for genetic education for nurses.

Ethical issues in identifying and recruiting participants for familial genetic research.

Beskow L et al. Am J Med Genetics 130A:424-431, 2004

The Cancer Genetics Network Bioethics Committee (USA) developed recommendations about appropriate approaches in cancer genetic research.

WHO, Medical Genetics Services in Latin America

This is the report of WHO Collaborating Center for Community Genetics and Education in Latin America following the 9<sup>th</sup> international congress of Genetics published by a group of experts in medical genetics from Latin America about genetic services and to give recommendations for the continuing development of the field in the areas of services, training and research.

[http://whqlibdoc.who.int/hq/1998/WHO\\_HGN\\_CONS\\_MGS\\_98.4.pdf](http://whqlibdoc.who.int/hq/1998/WHO_HGN_CONS_MGS_98.4.pdf)

US Preventive Services Task Force, USPSTF Recommendations

Genetic risk assessment and BRCA mutation testing for breast and ovarian cancer susceptibility: recommendation statement. Ann Intern Med 143:355-61, 2005.

Ethical guidelines in genetics and genomics. An Islamic perspective.

Al-Aqeel Al. Saudi Med J. 2005 Dec;26(12):1862-70