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The GenInfo team of the "Genetics and Society Project" has reviewed its' knowledge translation strategy. The result is a fresh "GenInfo" newsletter designed to provide a wealth of information to readers in a more accessible format. GenInfo readers will continue to access new policies at the national, regional and international levels. In addition, we have added a section on the publications and activities of the "Genetics and Society Project". Readers can be informed about the ethical, legal and social implications of specific areas of human genetics through a "FAQ" section. Finally, an abstract of our editorial "GenEdit" will be available. I invite you all to discover and comment on this exciting new addition to GenInfo!

Bartha M. Knoppers
Director
Genetics and Society Project

**NEWS**

The News section of GenInfo provides a brief listing of events that will be held in the coming year which are organized by our team or linked organizations. We are also pleased to include a publications section with a summary of all books, articles and editorials written by members of our team which have been recently published.

EVENTS**MARCH 2004****Discriminations sociales et discriminations génétiques: enjeux présents et à venir**

Date : March 30 & 31 2004

Location : Université Laval, Québec

Hosts : *Genome Quebec and Canada Research Chair in Bioethics and Environmental Ethics*

Description : This conference will present various analysis concerning social discrimination and the issues in genetics that are present internationally and within Quebec. This conference is open to the public.

For additional information visit: http://www.fp.ulaval.ca/fp/bio_pre.asp

MAY 2004

Journées Génétiques : Who does What?

Date : May 17 & 18, 2004

Location : Omni Hotel, Montreal

Host : Network of Applied Genetic Medicine (RMGA)

Description : In order to assist genetic basic research, the RMGA organizes bi-annual scientific meetings. These "Journées" are an occasion for Quebec researchers to present the latest developments and their recent discoveries in human genetics.

For additional information visit : <http://www.rmga.qc.ca/en/>

OCTOBER 2004

Dix-Septièmes Entretiens du Centre Jacques Cartier "Symposium on Oncogenetics : Achievements and Challenges"

Date : 7th - 8th October 2004-02

Location : Crowne Plaza, Montreal

Hosts :

- Centre Jacques Cartier, Dix-septièmes entretiens
- Centre National de Recherche Scientifique, The National Centre for Scientific Research
- CIHR INHERIT BRCA (Canadian Institutes of Health Research, Interdisciplinary Health Research International Team on Breast Cancer Susceptibility)
- Université de Montréal, Centre for Research in Public Law, Canada Research Chair in Law and Medicine
- Université Laval, Canada Research Chair in Oncogenetics

Description : World experts will discuss the latest developments as well as achievements and challenges in cancer genetics.

The topics will include genetic susceptibility to breast, ovarian, paediatric, gastro-intestinal cancers, as well as multiple endocrine neoplasia.

For additional information visit: <http://www.humgen.umontreal.ca/CJC/>

PUBLICATIONS

BOOKS

Hervé C, Knoppers BM, Molinari PA, Moutel M, *Éthique médicale, bioéthique et normativités*, Éditions Dalloz, Paris, 2003.

Abstract: This book reproduces a series of texts that were prepared during the second expert seminar, organized by the *Institut international de recherche en éthique biomédicale (IIREB)*, that was held on December 3 & 4, 2002, in Paris.

Knoppers BM, Scriver C., *Genomics, Health and Society: Emerging Issues for Public Policy*, Policy Research Initiative (Canada government), Ottawa, 2003.

Abstract: Edited by Bartha Maria Knoppers and Charles Scriver, this new volume tackles critical issues that will need to be addressed for us to reap the potentially tremendous health and economic benefits that genomics promises, while managing the associated risks. Fourteen papers deal with a range of topics, including genetic medicine and privacy, issues of intellectual property, and implications for the developing world.

Knoppers BM, *Populations and Genetics : Legal and Socio-Ethical Perspectives*, Martinus Nijhoff Publishers, Leiden, 2003.

Abstract: In this age of international biobanking involving populations, are current legal and ethical approaches sufficient? This book of selected papers covers population research and banking as well as accompanying confidentiality, and governance concerns. Possible commercialization, patents, benefit sharing, discrimination, and the role of patient organizations and of developing countries are also discussed. New perspectives and models are provided. The book concludes with a *Statement of Principles on the Ethical Conduct of Human Genetic Research Involving Populations*.

ARTICLES

Avard D. *Knowledge Transfer and HumGen*, GELS, (Winter 2004) Vol. 2, No. 2: 3.

Abstract : Genetics play an increasingly central role in our lives, from its use in medicine to determine disease risk or potential for efficacious drugs. With this knowledge comes legal, social-ethical, economic and environmental implications. At the Centre de recherche en droit public of the University of Montreal (CRDP) we have undertaken the Genetics and Society Project (GSP). The goal of the GSP project is to provide a diverse public, systematic, international access to policies as well as to prepare comparative analyses of the legal, social, and ethical implications of human genetics.

Godard B., Kääriäinen H., Kristoffersson U., Tranebjaerg L., Coviello D., Aymé S., "Provision of genetic services in Europe: current practices and issues", *European Journal of Human Genetics* (2003) 11, S13 - S48.

Abstract: This paper examines the professional and scientific views on the social, ethical and legal issues that impact on the provision of genetic services in Europe. Many aspects have been considered, such as the definition and the aims of genetic services, their organization, the quality assessment, public education, as well as the partnership with patients support groups and the multicultural aspects.

Godard B., Schmidtke J., Cassiman JJ., Aymé S., "Data storage and DNA banking for biomedical research: informed consent, confidentiality, quality issues, ownership, return of benefits. A professional perspective" *European Journal of Human Genetics*

(2003) 11, S88 - S122.

Abstract: The purpose of this paper is to formulate a professional and scientific view on the social, ethical, and legal issues that impact on data storage and DNA banking practices for biomedical research in Europe. Many aspects have been considered, such as the requirements for data storage and DNA banking in the public and private sectors in Europe and the issues relating to DNA banking, that is to say the consent requirements for the banking and further uses of DNA samples, their control and ownership, and the return of benefit derived from DNA exploitation to the community.

Godard B., ten Kate L., Evers-Kiebooms G., Aymé S., "Population genetic screening programmes: principles, techniques, practices, and policies" *European Journal of Human Genetics* (2003) 11, S49 - S87

Abstract: This paper examines the professional and scientific views on the principles, techniques, practices, and policies that impact on the population genetic screening programmes in Europe. This paper focuses on the issues surrounding potential screening programmes, which require further discussion before their introduction. It aims to increase, among the health-care professions and health policy-makers, awareness of the potential screening programmes as an issue of increasing concern to public health.

Godard B., Raeburn S., Pembrey M., Bobrow M., Farndon P., Aymé S. "Genetic information and testing in insurance and employment: technical, social and ethical issues" *European Journal of Human Genetics* (2003) 11, S123 - S142

Abstract: The present paper examines the professional and scientific views on the social, ethical and legal issues that impact on genetic information and testing in insurance and employment in Europe. For this purpose, many aspects have been considered, such as the concerns of medical geneticists, of the insurers and employers, of the public, as well as the regulatory frameworks and unresolved issues.

Sallée C. *Pushing back the boundaries of the genome: the international challenge of the P3G consortium*, GELS, (Winter 2004) Vol. 2, No. 2: 1.

Abstract: For the past several years, researchers in genetics and genomics have been tracking the boundaries of the human genome, gene by gene, SNP by SNP, and haplotype by haplotype. Driven by the desire to identify factors underlying the appearance of disease, and to comprehend the mechanisms in order to better grasp prevention methods, diagnosis and treatment, and benefiting from perfected analytical instruments, investigators today have come to rely extensively on "biobanks": organized storehouses of biological samples and data. These genetic databases are diverse not only due to their nature, their scientific *raison d'être*, and their philosophy and structure, but also due to their sample size. Over the past few years, several projects have been conducted with the aim to the study of genetic variations of entire populations or communities.

EDITORIALS

Mbulu H, Sur "Réflexions sur la philosophie du droit" dans *Les Presses de l'Université Laval, Les Cahiers de Droit*, (2003) Vol. 44, No. 3 : 557-564.



GENEDIT

The primary focus of the editorial GenEdit, which is exclusively written for HumGen, is to enhance our current understanding of policy statements related to human genetics through comparative legal, social and ethical analysis.

PAST ISSUES

Volume II No.1

Protecting Genetic Information: A Comparison of Normative Approaches
Patricia Kosseim, Martin Letendre and Bartha Maria Knoppers

Volume I No.1

Stem Cells in a Pluralistic Society: Consequences of Proposed Canadian Legislation
Dorothy C. Wertz, Marie-Hélène Régner and Bartha Maria Knoppers

NEXT ISSUE

***** Available April, 2004 *****

Volume II No.2

Genetic and Life Insurance : Comparative Analysis of Favored Approaches at the International Level
Trudo Lemmens, Yann Joly, Bartha M. Knoppers

The debate surrounding the role of life insurance, the necessity of risk rating, and the notion of "acceptable discrimination" has raised questions about the larger social role of insurance. This debate has been exacerbated by the availability of an increasing number of genetic tests, allowing insurers to make use of genetic results as a new underwriting tool. The article presents a comparative study of approaches adopted by different countries or organization when faced with the genetics and life insurance dilemma. We analyze the position of 44 countries with regards to their potential for ensuring equitable access to life insurance.



NEW LAWS & POLICIES

The following section contains new policy (legal, ethical) statements on human genetics from international, regional and national sources.

We are constantly searching for documents to enrich our data bank. If your organisation has published policy statements relating to genetics, or if you are aware of such new publications, please be kind enough to send us the relevant information and we will consider including them in the data bank.

National Bioethics Commission, *Recommendation on the Patentability of Biotechnology Applications*, Athens, September 2003, http://www.bioethics.gr/mod.php?mod=userpage&menu=1106&page_id=39 (date accessed: February 20, 2004).

The National Bioethics Commission was convened by the President on 15.11.2002, 20.12.2002, 17.01.2003, 18.04.2003, 16.05.2003, 20.06.2003 and 19.09.2003 in order to consider the ethical and social issues within its jurisdiction with regard to the patentability of biotechnology applications and draft a related proposal pursuant to article 10, Act 2667/1998.

The Commission recognizes that patents on biotechnology applications currently constitute a powerful motive for raising funds in a field of costly research with a high failure rate, which nevertheless promises significant improvements in the quality of modern life.

The question of patents is primarily a matter of law. In view of the peculiarity of biotechnology applications, however, it raises fundamental questions of ethical-social evaluation in order to harmonize patents with freedom of research in particular. It is worth noting that European Union law already includes Directive 98/44/EU on the subject which has been transposed in Greek law (by p.d. 321/2001).

The present recommendation aims, first, at facilitating the interpretation of this Directive by the relevant authorities. At any rate, the recommendation is not bound by this legislation. By adopting a different view to certain aspects it urges our country to take initiatives to modify this legislation in the future.

ALelle FREquency Database (ALFRED), *ALFRED Ethics Statement*, New Haven, January 2, 2004, <http://alfred.med.yale.edu/alfred/ethics.asp> (date accessed: February 24, 2004).

ALFRED (the ALelle FREquency Database) is designed to store and disseminate frequencies of alleles at human polymorphic sites for multiple populations, primarily for the population genetics and molecular anthropology communities.

[ALFRED is] cognizant that historically, biological and genetic data have been misused to stigmatize or rationalize discrimination against specific, identifiable ethnic groups, or individuals. Use of the allele frequency data in ALFRED for such purposes would not be ethically or scientifically justified. The data contained in ALFRED represent normal genetic variants common to the majority of populations in the world.

ALFRED is intended to enhance basic scientific research and education and is a resource available for public use. It is important however, to be aware that analytical results from ALFRED frequencies will reflect the worldview and science-based perspective of the analysts and they must be sensitive to the possibility that the donating populations may view the world differently.

European Organization for Research and Treatment of Cancer (EORTC), *EORTC Tissue Research Policy*, Brussels, November 2003, <http://www.eortc.be/Services/Doc/policies/POL015.pdf> (date accessed: February 24, 2004).

The European Organization for Research and Treatment of Cancer (EORTC) in Brussels recently published a tissue research policy which summarizes the minimum legal requirements that fulfill the various national regulations. In any case, researchers who plan to work with samples should make sure that donors provide consent to the use of their tissues.

[This report] outlines the general principles of EORTC Tissue research, aims of the EORTC Tumor Bank to support histology review and translational research, and rules on material use for histology review and translational research.

European Parliament, *European Parliament legislative resolution on the Council common position adopting a European Parliament and Council Directive on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells (10133/3/2003 - C5-0416/2003 - 2002/0128(COD))*, Strasbourg, December 16 2003, http://www3.europarl.eu.int/omk/omnsapir.so/pv2?PRG=CALDOC&FILE=20031216&LANGUE=EN&TPV=PROV&LASTCHAP=20&SDOCTA=18&TXTLST=1&Type_Doc=FIRST&POS=1 (date accessed: February 12, 2004)

The European Parliament voted through the first EU level safety rules for handling human cells and tissues, marking the end of the legislative process. The Parliament voted on a compromise text that had been pre-agreed by the EU Council, Commission and Parliament. Once the new rules have been approved by the Council of Ministers, they are expected to come into force in the coming months and Member States will have then two years to transpose the Directive into national law.

Specifically the new rules focus on the quality and safety aspects of cells and tissues being donated for human applications, excluding cells and tissues used in research. The principle of unpaid donations while allowing for compensation is guaranteed. On specific cell types to be covered by the Directive, the Parliament has agreed to leave this to Member States to decide whilst ensuring that such cells are subject to appropriate provisions protecting public health. The Directive also permits public and private sector tissue banks to operate along side each other under the same set of rules.

The rules will now cover final manufactured products as far as processing, storage, and distribution is concerned. New legislation is being prepared by the Commission to cover market authorisation and will be in place by the time this Directive becomes law.

United Kingdom/Department of Health, *Genetics and Insurance Committee (GAIC) Second Report from September 2002 to December 2003*, London, January 20, 2004, <http://www.doh.gov.uk/genetics/gaic/gaicsecondreport.pdf> (date accessed: February 12, 2004)

This report provides a summary of the main work of the Genetics and Insurance Committee over the specified period.

In March 2001, the House of Commons Science and Technology Committee Report on Genetics and Insurance was published. [It] made 32 recommendations including one that the (GAIC) should be reconstituted with an extended remit, which the Government agreed to do in October 2001. The new GAIC held its first meeting in September 2002.

GAIC brings together individuals from a range of backgrounds and with expertise to make decisions on the validity of using predictive genetic test results in determining insurance premiums for a range of insurance products. The insurance products GAIC expects to look at are life, critical illness, income protection, long term care, and possibly private medical insurance. These are all products for which people may be paying premiums for many decades. GAIC has therefore been working to establish improved criteria for assessment of the technical, clinical, and actuarial relevance of specific genetic tests in insurance underwriting.

GAIC has also been keen to start carrying out its two important new roles. The first is to monitor the insurance industry's compliance with the moratorium (to November 2006) on the use of predictive genetic test results in setting insurance premiums. The second is to consider complaints from individuals who feel that they may not have been treated fairly by an insurance company for reasons to do with their genes.

One of the things we have been trying to do as a Committee is to demystify what insurance actually is, partly for educational purposes, but mostly because genetic predisposition to disease is likely to have different impacts on the affordability and viability of different insurance products. As part of this work we have included a detailed annex on all five insurance products mentioned above.

American College of Medicine Genetics, *ACMG Statement on Direct-to-Consumer Genetic Testing*, (2004) 6: 1 *Medicine in Genetics*, 60, <http://ipsapp002.lwwonline.com/content/getfile/4140/20/9/fulltext.htm> (date accessed: February 12, 2004)

At a time when genetic tests for breast cancer and other inherited diseases are being marketed directly to the public, the American College of Medical Genetics (ACMG) has issued a statement recommending that such tests be provided "only through the services of an appropriately qualified health professional."

The official statement appears in the January/February issue of *Genetics in Medicine*, official publication of the ACMG. It is accompanied by a commentary from Linda L. McCabe, Ph.D., and Edward R.B. McCabe, M.D., Ph.D., of the David Geffen School of Medicine at UCLA.

A medical geneticist or other health professional should always be responsible for ordering and interpreting genetic tests and for patient counseling before and after testing, the ACMG Board of Directors maintains. Without professional guidance, using genetic "home testing" kits carries potential risks of harm, including inappropriate test use, misinterpretation of test results, and inadequate medical follow-up.

The ACMG Board of Directors hopes that their new Statement will help to educate the public and medical professionals about direct-to-consumer genetic testing, and particularly the importance of professional genetic counseling. The statement will promote further discussion of this increasingly important medical and policy issue.

New Jersey Legislature, *An Act concerning human stem cell research and supplementing Title 26 of the Revised Statutes and Title 2C of the New Jersey Statutes(A2840, S1909)*, United-States, January 2, 2004, <http://www.njleg.state.nj.us/bills/BillView.asp> (date accessed: February 19, 2004)

New Jersey has become the second state, after California, to legalize stem cell research.

The New Jersey Assembly narrowly approved a bill banning human reproductive cloning but allowing "therapeutic cloning" for the purpose of obtaining embryonic stem cells for research and, eventually, medical treatments.

The state Senate unanimously approved the bill in December 2002, but anti-cloning activists were successful in stalling it in the lower house last February. Supporters mustered the 41 votes needed for passage Dec. 15, 2003. Gov. James E. McGreevey signed the bill into law.

The New Jersey bill will allow the state's research institutions, universities, and pharmaceutical and biotech industries to utilize excess fertilized eggs discarded from fertility clinics for stem cell and therapeutic cloning research. It will also require clinics to inform patients of the option to donate their excess eggs for the research. The bill would outlaw human reproductive cloning and establishes strict penalties for violators.

Le New Jersey, après la Californie est devenu le 2eme état américain à légaliser la recherche sur les cellules souches d'embryons humains. Cette loi autorise la recherche sur les cellules souches embryonnaires mais aussi le clonage d'embryons humains à des fins de recherche.

Italian Government, *Assisted Human Reproduction Act*, Italy, December 11, 2003.

Italy's Senate approved a contentious law on reproductive rights on Thursday, December 11, banning the use of donor sperm, eggs or surrogate mothers and restricting assisted fertilization to "stable" heterosexual couples. Under the bill, only infertile couples can obtain assisted reproduction, and they cannot use the sperm or eggs of a donor or use a surrogate mother. The couple must be married or provide evidence of having a "stable" relationship.

Embryos resulting from artificial insemination cannot be frozen or used for research purposes. Doctors can only create up to three embryos during each attempt at insemination, and all of them must be implanted in the potential mother's womb.

Le Parlement italien a approuvé mardi dernier, un projet de loi visant à interdire le recours aux donneurs de sperme ou d'ovocytes ainsi qu'aux mères porteuses. Il restreint aussi la procréation médicalement assistée aux couples hétérosexuels "stables". Le projet final a été adopté à une large majorité.

American College of Medical Genetics, *Standards and Guidelines for Clinical Genetics Laboratories (Latest Edition)*, Bethesda, 2003, http://www.acmg.net/Pages/ACMG_Activities/stds-2002/stdsmenu-n.htm (date accessed: February 19, 2004).

These voluntary standards have been established as an educational resource to assist medical geneticists in providing accurate and reliable diagnostic genetic laboratory testing consistent with currently available technology and procedures in the areas of clinical cytogenetics, biochemical genetics and molecular diagnostics.

These standards establish minimal criteria for clinical genetics laboratories. Many laboratories will exceed these minimal standards.

Adherence to these Standards and Guidelines is completely voluntary and does not necessarily ensure a successful outcome. The Standards and Guidelines should not be considered inclusive of all proper procedures and tests or exclusive of other procedures and tests that are reasonably directed to obtaining the same results.

It is acknowledged that numerous acceptable variations exist in genetic testing methodologies. The accuracy and dependability of all procedures should be documented in each laboratory. This should include in-house validation and/or references to appropriate published literature.

Canadian Government/Health Canada, *Health Protection Legislative Renewal*, Ottawa, Fall 2003, <http://www2.itssti.hc-sc.gc.ca/HPCB/Policy/LegislativeRenewal.nsf/WebHome/575087A768EAEFD185256D3A0058E5D6?opendocument&L=E&> (date accessed: February 19, 2004)

Health Canada will be conducting public consultations this fall on proposed new legislation in the area of health protection.

The new legislative framework would be centred on a new Canada Health Protection Act that would replace the *Quarantine Act* (1872), the *Food and Drugs Act* (1953), most of the *Hazardous Products Act* (1969), and the *Radiation Emitting Devices Act* (1969). Existing laws that would remain in force, such as the *Tobacco Act* and the *Pest Control Products Act*, would work together with the new Canada Health Protection Act to produce a stronger legislative framework for health protection.

Among other aspects, the proposal for a new Canada Health Protection Act includes the following elements:

- *Fundamental values, Guiding principles for risk decision-making, General safety requirement, Categorization of products, Review of novel products, Advertising of health products, Health- and safety-related activities, Communicable diseases, Passenger conveyances, Health surveillance and research, Confidentiality, Regulatory authority, Enforcement, Emergency response,*

Gouvernement du Canada/Santé Canada, *Renouveau de la législation sur la protection de la santé*, Ottawa, Automne 2003, <http://www2.itssti.hc-sc.gc.ca/HPCB/Policy/LegislativeRenewal.nsf/WebHome/575087A768EAEFD185256D3A0058E5D6?OpenDocument&L=F&> (page consultée le 19 février 2004)

Santé Canada entreprend des consultations publiques concernant le renouveau de la législation dans le domaine de la protection de la santé.

Au centre du nouveau cadre législatif proposé, on trouverait une nouvelle *Loi sur la protection de la santé du Canada* qui remplacerait la *Loi sur la quarantaine* (1872), la *Loi sur les aliments et drogues* (1953), l'essentiel de la *Loi sur les produits dangereux* (1969), et la *Loi sur les dispositifs émettant des radiations* (1970). Les lois existantes qui demeureraient en vigueur, comme la *Loi sur le tabac* et la *Loi sur les produits antiparasitaires*, pourraient être intégrées dans le nouveau cadre législatif dans le but de renforcer le cadre législatif de protection de la santé.

Parmi d'autres dispositions, la nouvelle *Loi sur la protection de la santé du Canada* qui est proposée comprendrait les éléments suivants :

- *Valeurs fondamentales, Principes guidant les décisions quant aux risques, Exigence générale en matière de sécurité, Catégorisation des produits, Évaluation des nouveaux produits, Activités liées à la santé et à la sécurité, Maladies transmissibles, Transporteurs communs, Surveillance et recherche dans le domaine de la santé, Confidentialité, Pouvoirs de réglementation, Mise en application de la loi, Intervention d'urgence*



DRAFTS

The President's Council on Bioethics, *Monitoring Stem Cell Research*, Washington, D.C., January 2004, <http://www.bioethics.gov/reports/stemcell/> (date accessed: February 12, 2004).

This monitoring report has its origins in President George W. Bush's remarks to the nation on August 9, 2001. In the speech, the President announced that after several months of deliberation he had decided to make federal funding available, for the first time, for research involving certain lines of embryo-derived stem cells. At the end of the speech the President declared his intention to name a President's Council to monitor stem cell research, to recommend appropriate guidelines and regulations, and to consider all of the medical and ethical ramifications of biomedical innovation. . . . to keep us apprised of new developments and give our nation a forum to continue to discuss and evaluate these important issues.

In keeping with the President's intention, the Council has been monitoring developments in stem cell research, as it proceeds under the implementation of the administration's policy. Our desire has been both to understand what is going on in the laboratory and to consider for ourselves the various arguments made in the ongoing debates about the ethics of stem cell research and the wisdom of the current policy. Although both the policy and the research are still in their infancy, the Council is now ready to give the President and the public an update on this important and dynamic area of research.

This report is very much an "update." It summarizes some of the more interesting and significant recent developments, both in the basic science and medical applications of stem cell research and in the related ethical, legal, and policy discussions. It does not attempt to be a definitive or comprehensive study of the whole topic. It contains no proposed guidelines and regulations, nor indeed any specific recommendations for policy change. Rather, it seeks to shed light on where we are now—ethically, legally, scientifically, and medically—in order that the President, the Congress, and the nation may be better informed as they consider where we should go in the future.



FAQ

The HumGen website will soon launch a "frequently asked questions" or FAQ section, which aims to provide accessible information on the ethical, legal and social implications of human genetics. In this issue of GenInfo, we present to you a sample of the questions that will be found in this section; the first discusses the notion of informed consent in research that involves human subjects, and the second handles the topic of population genetics.

Q Why obtain informed consent?

A Informed consent is needed for any research using a biological sample obtained from the participant. Informed consent is important because it protects the right and welfare of research participants as well as avoids unexplained interventions. The rule of informed consent recognizes that the individual has a right, and is free, to make choices whether or not to participate. The researcher has an obligation to obtain the individual's informed consent to participate in a research project. If such consent cannot be obtained directly, then the researcher should obtain it from the individual's legal guardian.

Q Are particular risks associated with population genetics research?

A Research using genetic information on a given population could give rise to stigmatization or discrimination. The influence of heredity itself may be perceived differently from one community to another. Given that genetic information may concern the population at large special considerations need to be taken. Care must be taken to consult the population as well as the individual. The conservation and use of genetic information stored in biobanks should be organized in a way that respects the privacy and the confidential nature of personal information.



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