1. OVERVIEW

Good health is the bedrock on which social progress is built.
A nation of healthy people can do those things that make life worthwhile,
and as the level of health increases so does the potential for happiness.
Marc Lalonde
A New Perspective on the Health of Canadians

Maintaining good health goes far beyond reasonable access to competent medical care. And it goes beyond adequate nutrition and what is considered a "healthy" lifestyle. Many factors have an impact on how we feel and how we resist illness. In a significant way, our environment, family relationships, social, cultural, economic, and work conditions — even our self-esteem — determine who gets sick and who stays healthy.[1] The way all these factors interact is subtle, complex, and not fully understood, although scientific advances are constantly leading to better understanding of the nature and causes of specific diseases. Similarly, technological advances are leading to better methods of preventing, diagnosing, and treating particular diseases.

Numerous factors affect maintenance of good health.

This report is about the role of one factor — our genes — in health and disease, and the implications of genetic knowledge and technologies for personal and collective health and for delivery of health care in Canada.

Genes are one factor that affect health and cause some of our diseases.

We are in the early stages of a revolution in medical science. The application of new biotechnologies to human genetics is resulting in a quantum leap in our understanding of the nature and function of the human organism, and of the mechanisms of disease. The new genetic technologies are making it possible to recognize individuals with genetic diseases or at risk of developing them, and provide the basis for the development of effective prevention and treatment measures. Health services based on these technologies, when available for voluntary use by individuals and families, offer potential health benefits to Canadians.

New genetic technologies are providing the basis for development of effective prevention and treatment measures...

But along with the benefits, genetic technologies, and the information they produce, have the potential to be misused.[2] Inappropriate applications can result in harm to individuals and could adversely affect future generations.

...but also have the potential to be misused.

We are only beginning to develop genetic health care services based on the new technologies. But it is already evident that there is a need for changes in Canada's health care and education systems and for more research if we are to maximize the health benefits of genetic knowledge and technologies. There is an equally strong need to ensure that the development and application of genetic technologies proceed carefully. Clear objectives for the use of the technologies are required, along with guidelines and, where appropriate, controls. Potential technical and ethical problems must be identified and dealt with as research and development proceed.

To maximize the benefits and avoid misuse of genetic technologies, wise planning and changes in our health care and education systems are needed.

Role of Genes in Health and Disease

Genetic technologies are providing the opportunity to address the biological elements of health and disease.

It is generally accepted that maintenance of good health involves four interrelated factors: human biology, environment, lifestyle, and the health care system, all of which must be continually addressed in an integrated and balanced manner.[3] However, there are times when one or another of these factors offers a particular opportunity to understand and deal with specific health problems or improve general health status. Today, genetic technologies are providing the opportunity to address more fully the biological elements of human health and disease.

Information is accumulating on genes, the biological processes they encode, and the diseases they can cause.

The new recombinant DNA technologies provide the technical breakthrough that allows the isolation and analysis of genes, and thus enables the search for the genetic basis of disease to occur directly at the DNA level. These technologies are leading to a growing understanding of how genes contribute to our state of health and cause or make us susceptible to some diseases[4] (see Box 1). Because of these new technologies, information is accumulating on the specific DNA sequences of genes, the biological processes they encode, and the diseases and disease processes they can cause.

Individuals have a unique genetic make-up that influences their susceptibility to diseases.

Some genetic disorders are inherited, resulting from mutations in the DNA of previous generations. In other cases genetic disease is not inherited but results from mutations in the body cells of an individual; the subsequent disorder may or may not be transmitted to offspring. The combined processes of inheritance and mutation lead to genetic variation between individuals. One consequence of this variation is that individuals each have a unique genetic make-up that influences their diseases and disease susceptibilities.

Genes are implicated in many common diseases not usually thought of as genetic.

The ways in which genes contribute to disease vary. The general public, most patients, and many health care providers tend to think of genetic disease largely in terms of classic, often rare, single-gene disorders such as haemophilia, Huntington disease, or cystic fibrosis. In these single-gene disorders the presence of a specific gene will invariably lead to onset of the disease. However, genes are also implicated in many common diseases not usually thought of as genetic. These diseases are multifactorial; that is, genes make the individual susceptible to disease, but disease onset is triggered by some external environmental factor. Examples include some forms of arthritis, diabetes, Alzheimer disease, cancer, manic depressive illness, alcoholism, and heart disease. These diseases are more difficult to understand than the single-gene disorders.

Genetic Disease and Its Implications in Canada

The relative significance of "genetic" disease has increased.

Genetic disease contributes in a substantial way to the burden of ill health in Canada. With improvements in social conditions and public health and medical practices we have experienced a relative decline in the incidence of diseases caused by infection and nutritional deficiencies. As a result, the relative importance of "genetic" disease has increased.[5] Today, even based on our current limited knowledge of gene-disease links, it is estimated that at least one in 20 Canadians will experience a gene-related impairment, disability, or handicap by age 25[6] and that during their lifetime more than half the population will have a disease that in some cases has a genetic component to its cause.[7] For example, many of the chronic diseases of middle and old age appear to be multifactorial and have a genetic component.[8] Up to half the admissions to

paediatric hospitals[9] and 12 per cent of adult admissions to general hospitals[10] are for "genetic" diseases. And an important but undetermined share of psychiatric admissions have some genetic link.[11]

In recent years, the number of diseases for which genetic causes have been identified has increased exponentially. Genes are now known to contribute to several thousand diseases. In addition, some diseases and mutations occur at higher incidence in specific regions of Canada or subgroups of the population. This clustering of disease reflects biological, cultural, and environmental factors. As we learn more and more about the causes and clustering of diseases, we can increasingly use the knowledge to develop prevention and treatment measures.[12]

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Strategies for Dealing with Genetic Disease

The growing understanding of the role of genes in all aspects of health and disease has broad implications for health care delivery. Genetic knowledge and technologies have applications in diagnosis of disease and in strategies for fighting disease through prevention, treatment, avoidance, and gene therapy.

Genetic technologies offer potential strategies to fight disease.

Diagnosis of individuals with or at risk for genetic disease is a critical first step in providing prevention or treatment options. Now, in addition to diagnostic technologies based on clinical signs and indirect methods of detecting genetic disease, recombinant DNA technologies can be used to analyse DNA and detect genes that cause or are associated with disease.

Prevention of disease is the ideal strategy. Genetic technologies are contributing to prevention of disease through identification of environmental risk factors and healthier lifestyle options for individuals at risk. Measures that reduce the mutation rate constitute primary prevention, and include control of exposure to ionizing radiation and chemical mutagens. Where a mutation has already occurred or been inherited, secondary prevention addresses the interacting risk factors for genetically susceptible individuals — for example, controlling diet for those at risk for heart disease.

Genetic technologies are helping to prevent disease.

Where prevention is not possible, the strategies include treatment to address the consequences of the mutation, avoidance of the birth of children with serious genetic diseases, and gene therapy to offset or correct the mutation.

Where prevention is not possible, strategies include treatment, avoidance, and gene therapy.

An improved ability to identify individuals at genetic risk can lead to earlier diagnosis and treatment, and thus a better prognosis (as in the case of some familial cancers). In addition, understanding the underlying genetic causes of a disease and the metabolic processes under way in the course of the disease can help in the development of effective treatments, including medications.

A number of avoidance strategies are available for families that are at risk of having children with serious genetic disorders. Avoidance-based strategies include deciding not to have a family, prenatal diagnosis (with the option of pregnancy termination if the fetus is affected), and alternative avenues to parenthood. Alternatives include adoption, artificial insemination, and other reproductive technologies.

Gene therapy involves correcting the intrinsic defect in the genetic material. No proven gene therapies are available to cure genetic disease at this time, but

Box 1:
Genes, Mutation, and Disease

Modern human genetics evolved from centuries of scientific exploration into the causes and treatment of inherited diseases. In 1953, James Watson and Francis Crick's landmark work[1] on the nature of deoxyribonucleic acid (DNA) provided the key to understanding the complex links between genes and disease. It is now understood that:

- DNA molecules are made up of chains of nucleotides bound together in a double helix. DNA molecules and the information they carry on some 50 000 to 100 000 genes control the structure, organization, and function of cells.
- A gene is a specific stretch of the DNA molecule and codes information for production of a specific protein. It is the specific nucleotide sequence of the gene that provides the code.
- Genes are transmitted from parent to offspring and are the mechanism for inheritance. An important feature of genes is their ability to be replicated identically and transmitted from generation to generation. But genes can also be altered: the nucleotide sequences along a DNA molecule are susceptible to change through a process known as mutation.
- Mutations may occur during the process of cell division to produce eggs and sperm, through exposure to specific environmental factors that cause mutation, or as a consequence of spontaneous change.
- In many cases a change in the DNA sequence of a gene will result in malfunction of the gene and disease in the organism.
- An individual's full complement of DNA is referred to as his or her genome and is normally identical in the nucleus of every cell in the body.

research will undoubtedly yield gene therapy for some disorders. There are two forms of gene therapy, one involving germ line cells, which can be inherited, the other somatic (i.e., body) cells, which affect the health of the individual but are not transmitted to the next generation. In September 1990 a four-year-old American girl became the first person to undergo somatic cell gene therapy in an attempt to treat a genetic disorder (severe combined immune deficiency disease), and research involving such treatment is under consideration for a number of other disorders. But gene therapy is complex and bears risks as well as potential benefits, both to the individual being treated and, in the case of germ line therapy, to future generations. It is therefore imperative to proceed very carefully.

Although genetic technologies are already being used to prevent, treat, and avoid diseases, we are still in the early stages of acquiring genetic knowledge and developing related health care applications. In most cases we do not yet fully understand the role our genes play in either single-gene or multifactorial disorders and have not yet identified specific mutations that allow accurate identification of individuals with or at risk for specific disorders. Moreover, at present our ability to identify an individual at risk for genetic diseases exceeds our ability to prevent or treat the disease.

We are still in the early stages of acquiring genetic knowledge and applying it to health care.

If we knew the specific mutations resulting in single-gene disorders we would be closer to developing effective treatments and even gene therapy solutions. Similarly, if we knew which genes make us susceptible to particular multifactorial disorders, we could determine what external factors are required to trigger onset of disease. We could then use the information to prevent or delay onset and to develop more effective treatments.

Despite their potential benefits, genetic technologies must be developed and used cautiously. Research related to human genetics should be subject to guidelines and review procedures that incorporate ethical and safety considerations to protect the human participants and the environment. Similarly, the introduction of any new genetic tests or treatments for clinical purposes should conform to appropriate guidelines, and should proceed only after a comprehensive technology assessment that incorporates technical, safety, ethical, societal, legal, and economic considerations.

Despite their potential benefits, the technologies must be developed and used with caution.

Delivery of Genetic Health Care Services

For over half a century genetic services, including screening and testing, counselling, and follow-up treatment programs, have had a place in Canadian health care systems. In fact, Canada has been a pioneer in the development and delivery of genetic health services. Thanks to genetic technologies and services, some single-gene diseases have become virtual "non-diseases" for the affected patients. For example, individuals with phenylketonuria can now grow up and lead normal lives, whereas only 30 years ago they would probably have been confined for life to institutions for the mentally retarded. Yet, despite such successes, genetic technologies and services are not well integrated into Canadian health care.

Canada has been a pioneer in developing genetic health services but overall, genetic technologies and services are not well integrated into Canadian health care.

There are two important, interrelated approaches to delivering genetic services. One approach involves the delivery of specialized services (usually targeted to single-gene disorders) through genetic centres. The second approach involves the integration of genetic knowledge and technologies into the routine

There are two approaches to delivering genetic services.

practice of all aspects of medicine. For example, many of the common multifactorial diseases require solutions that involve prevention as well as treatment; genetics has a role to play in understanding these disorders and in contributing to solutions.[13]

Genetic centres cannot meet even the current demand for services.

In Canada, there are eight major centres accredited by the Canadian College of Medical Geneticists for genetics training and comprehensive service delivery. In addition, there are twice as many centres offering some specific genetic health services. A survey of 10 Canadian genetic centres in 1986-87 indicated that eight of the centres could not meet the current demand for services, let alone the increased demand anticipated as a result of new DNA-based technologies and growing public awareness of the benefits of genetic services.

Funding is the principal limitation. The centres experience particular difficulty in obtaining funds to deliver new technologies, even those that can be demonstrated to be beneficial and cost effective.

Moreover, health care practitioners are not incorporating genetic knowledge and tools into their practices.

Not only are the genetic centres constrained in their ability to deliver services, but physicians and other health care practitioners are not effectively incorporating available genetic knowledge and tools into their practices. The integration of genetic technologies into routine health care practice is limited partly by the scarcity of knowledge and technologies and partly by a general lack of awareness regarding available technologies and their applications and benefits.[14] Genetics has implications for all aspects of health care, beginning with an understanding of why a patient has a particular disease. If the Canadian public is to reap the benefits of genetic knowledge and technologies, all health care practitioners must become, to some degree, "geneticists."

Some progress toward integration is being made...

Some progress toward better integration of genetics into health care delivery is being made. Several provinces have established provincial advisory committees on genetic services. The committees raise awareness and assist in the efficient allocation of services. In addition, non-governmental organizations — such as the Canadian Cystic Fibrosis Foundation and the Huntington Society of Canada — provide research funding, maintain a strong advocacy role in their dealings with health ministries and professional organizations, and offer services relevant to specific disorders.

...but improvements are needed.

Despite these efforts, improvements are needed in how genetic health services are integrated into health care. These improvements will require diverse changes in public policy, in medical practice, and in education of the public as well as health care planners and providers; and thorough evaluation of the effectiveness, reliability, costs, and benefits of specific genetic services. All these improvements and indeed all planning for both current and future genetic health services must include ethical considerations.

An Ethical Context

Ethical issues associated with genetics are of particular concern.

If not used properly, genetic technologies and the information they provide could result in harm. The ethical issues associated with genetics are of particular concern because in the past, serious abuses of human rights occurred in the name of eugenics; for example, genetics has been used to justify claims of racial superiority or inferiority and to discriminate against individuals.[15] Care and planning are required to prevent any recurrence of such abuses and to

ensure that the full range of ethical issues associated with genetic research, technologies, service delivery, and information are satisfactorily addressed.

Diagnostic testing (which identifies individuals with or at risk of disease), population screening (to identify carriers of harmful genes), prenatal diagnosis, gene therapy, DNA banks, and disease registries raise a variety of concerns. Among them are the possibility that individual choice in health care decisions will be lost, or that the confidentiality of health records and information will not be maintained. In addition, there are ethical concerns associated with the general issue of tampering with our essential "humanness."

There is a concern that individual choice will be lost or that the confidentiality of health records will not be maintained.

Non-medical applications of genetic technologies also raise concerns. Potential non-medical uses include fetal sex selection, exclusion of individuals from employment or insurance coverage, proof of kinship or paternity for legal or immigration purposes, and development of agents for biological warfare.

All of these concerns point to a need for open, ongoing discussion of the ethical issues surrounding genetic technologies and applications. Many of these issues are complex and evoke a wide range of opinions among Canadians. Different perceptions of what is good for the individual and what is good for a society that has universal health insurance are likely to drive vigorous debate. Such debate is necessary to set suitable goals, to identify and deal with conflicts, and to generate appropriate objectives, standards, guidelines, and controls.

Open, ongoing discussion of the ethical issues is necessary to set goals and establish appropriate guidelines, standards, and controls.

A major component of a compassionate health care system is its understanding, care, and support for individuals who are either sick or at risk of developing a disease. It is the view of the Science Council that:

- Genetic technologies and services are, and should continue to be, evaluated and delivered in the context of a caring society. Individual choice (autonomy), counselling, informed consent, and confidentiality are the cornerstones of the ethical delivery of genetic services.

Autonomy, counselling, informed consent, and confidentiality are the cornerstones of ethical delivery of genetic services.

- The primary objective of genetic applications in health care is to treat or prevent genetic disorders; the technologies should not be used with the primary goal of reducing the costs of health care or improving the human species. Genetic services should be initiated only if there are benefits to the recipient such as disease prevention or treatment, or lifestyle or reproductive choices.

- Individuals and families should have access to beneficial technologies in order to make informed decisions about their own health care and reproductive options. The decisions should be based on reliable technical information and accurate, non-directive counselling.

Individuals and families should have access to beneficial technologies.

- Participation in genetic services should be a matter of free choice. Individual and family decisions must be respected and supported. Individuals should not be penalized (through reduced medical or social services, for example) for their reproductive or personal health care decisions.

- Genetic technologies should be used in a manner consistent with acceptance of human diversity and disability. We must ensure that availability of genetic services does not decrease our acceptance of the disabled.

The availability of genetic services must not decrease our acceptance of human diversity and disability.

An Economic Context

Canada has a national health insurance that reflects fundamental social values. Our health care system* is not perfect, but it is probably as good as any in the world. It is a good compromise of quality, affordability, equity, and humanity.[16] But rising health care costs are increasingly stressing this balance.

Rising health care costs have resulted in cost-containment measures.

The cost of health care in Canada in 1987 amounted to 9.0 per cent of our gross national product[17] and accounted for 25-35 per cent of government expenditures at the provincial level.[18] The rising cost of health care has resulted in cost-containment measures and increasing competition for existing resources. This is the health-economics environment facing proponents of genetic health services.

Cost concerns are preventing delivery of proven services.

It is not possible to predict what genetic technologies and health services will become available or whether, overall, they will save health care dollars. What is certain is that the improved understanding of the role of genes in health and disease is resulting in the development of some health care applications that offer effective and efficient use of health care dollars.[19] But lack of resources is hampering delivery of some cost-effective genetic services of proven health benefit. The funding limitations reflect both the competition for resources and the relatively low priority genetic programs are generally accorded by the medical profession, health administrators, and health ministries.

Failure to integrate effective new services into publicly funded health care compromises the objectives of our health care system.

The difficulty in obtaining funds for genetic health services exemplifies the problems inherent in integrating any new technology into health care systems and suggests there is a need to look at the larger issues surrounding delivery and funding of health care in Canada. Universal access to comprehensive, publicly funded health care is an important Canadian objective that reflects fundamental social values. Failure to include effective new services — such as some genetic services — into publicly funded health care compromises this objective, and might also foster the development of privately offered services. The result could be a two-tier health care system based on ability to pay. This would run counter to the objectives of the Canadian health care system and to the stated wishes of the Canadian public.

An effective health care system must remain flexible. As scientific knowledge advances and consumer needs change, policy makers must continually reorder their priorities for health care delivery and ensure the incorporation of new knowledge and technologies.

An Educational Context

Better health education is required so that Canadians can make informed decisions about their health.

To better realize the benefits of genetic knowledge and technologies, and to avoid their misuse, the Canadian public, health care professionals, and health policy makers must become more aware of the current contributions and future potential of genetics in both preventing and treating disease. Education is key, and should begin in the elementary schools and be carried on through our secondary schools, universities, and training programs for health care professionals. But education is a life-long process and must also reach those in

* The 12 provincial and territorial health care systems, which reflect the principles of the Canada Health Act, are here collectively considered to be the Canadian health care "system."

the general public and health care community who have already completed their formal schooling.

At present, the majority of students in elementary and secondary schools receive little instruction in genetics. To reach all students, the role genes play in health and disease should be taught in elementary school and be part of the core curriculum in junior high school. Students should be introduced to both the health applications of genetic knowledge and the related social and ethical issues.

Even the providers of health care are not receiving an adequate education in genetics.[20] For example, genetics needs to be better integrated into the education of physicians at the undergraduate, postgraduate, and continuing education levels and should be taught in three different ways: as a basic science underlying all aspects of health and health care, as a specific course on medical genetics, and as an integral component of all other courses.

Genetics should be better incorporated into the education of health care providers.

An understanding of genetic predisposition to disease is also important in other health care fields, including dentistry, dietetics, nursing, pharmacy, rehabilitation therapy, and social work. At present, genetics is not well incorporated into the education and practice of any of these disciplines.

Finally, in a democratic society, an informed public is essential for individuals to make informed personal decisions and participate effectively in public policy making. To this end, Canadians need information that will improve their understanding of genetic health care technologies and services in particular, and the Canadian health care system in general.

Research Required

The research required to understand the role of genes and to develop health care applications is formidable and is likely to be a focus of national and international activity for a long time to come. Canadians are involved in genetics research not only to advance a body of knowledge with important health implications, but also to address specific mutations and diseases that are common, or cluster, in Canadian populations, and to foster the development of Canada's biotechnology sector.

As well as contributing to the growing knowledge base, Canadian research is developing solutions to health problems that cluster in Canadian populations.

Canada has proven expertise in certain areas of genetics research and Canadian researchers are at the forefront in the investigation of genetic diseases such as Duchenne muscular dystrophy, cystic fibrosis, and hypercholesterol-aemia. Canadian research is contributing to the growing international information base on genes and their role in health and disease. The Canadian government recently recognized the importance of genetics research and researchers by establishing a genetics research network in the National Networks of Centres of Excellence Program.

Canadian researchers are at the forefront of several genetic diseases.

In addition, more research is required to develop solutions to specific Canadian health problems. As a consequence of immigration and settlement patterns, Canadian populations have their own specific mutations and diseases. The integration of genetic knowledge and technologies into population health studies is enabling researchers to identify particular genes and risk factors associated with these diseases and to begin to find ways of anticipating and preventing them.

Genetics research also provides opportunities for Canada's biotechnology industry.

Genetics research also provides opportunities for Canada's biotechnology industry. There is currently little private sector activity in this area: a Science Council survey conducted in 1989 identified fewer than 10 firms active in development of specific gene-disease diagnostics or therapeutics. Mechanisms to enhance the level of private sector research include tax credits for investors, increased direct funding, tax credits for biotechnology firms, and better patent protection.

In spite of the opportunities, medical research in Canada is chronically underfunded compared to other developed countries, and the proportion of research funds spent on genetics research is relatively small.[21] Lack of resources is hampering progress in resolving important health problems.

The Need for Action: Goals and Initiatives

Canada's health care systems are not adequately delivering services based on existing genetic knowledge and technologies.

Canada's health care systems are not adequately delivering services based on existing genetic knowledge and technologies. Nor is our increasing understanding of the role of genes in health and disease being considered in health care planning. Existing genetic technologies and related services that are beneficial and cost effective should be better integrated into the publicly funded health care systems; new technologies and health services should be phased in as appropriate, based on evaluations of health benefits, health risks, and costs. We should proceed with the development of genetic technologies and the delivery of genetic health services, but with caution.

It is important to recognize that along with the health benefits associated with genetic technologies there is the potential for harm due to their misuse. The technical and ethical implications of genetic technologies and services must be carefully considered. Ethical considerations are critical to planning and decision making in all aspects of medical genetics including research, technology development, service delivery, and use of information. Genetic technologies and knowledge must be applied in the context of a caring society: a society that supports individual choice as well as advancement of knowledge.

Planning and action are required of policy makers, health care professionals, educators, and consumers.

To ensure effective and ethical development and delivery of genetic technologies and services, planning and action are needed now by health policy makers, health care providers and administrators, educators, and the public. To address this need, the Science Council has identified nine goals and recommends two initiatives.

Goals

Nine goals should guide future policies.

The Science Council believes that the following goals should guide future policies on genetic information and technologies. Together, they provide the basis for using genetic knowledge within an ethical and social framework that will reinforce Canada's health care values and contribute to improved health care delivery.

1. To improve delivery, within Canadian health care systems, of appropriately evaluated diagnostic, preventive, treatment, and counselling services based on existing genetic knowledge and technologies.

2. To continue to integrate new, beneficial genetic technologies and services into Canadian health care systems.

3. To ensure that any person with or susceptible to genetic disease, or at risk of having children affected by genetic disease, has equitable access to genetic health services within Canadian health care systems. The decision to use genetic services should remain with the individual.

4. To assess the safety and effectiveness of new genetic technologies. Assessments should encompass ethical, economic, and technical considerations.

5. To support more research on genetic factors in the origin, development, and effects of disease, and on the prevention and treatment of genetic disease.

6. To ensure that appropriate regulatory mechanisms and guidelines are in place and implemented for genetics-related research and health care, and for use of genetic health information.

7. To better incorporate genetics into the education and re-education of health care providers and into the examinations for graduation, licensing, and specialization.

8. To increase public awareness and understanding of human genetic diversity, genetic susceptibility to disease, and related social issues through improved science and health education in the schools and through public education programs.

9. To improve health information, data management, record linkage, and disease classification systems to accommodate genetic issues.

Initiatives

To meet the identified goals, the Science Council recommends that:

Two mechanisms are urgently needed to assist in the timely and efficient delivery of genetic services, and to address the full range of technical and ethical issues.

1. All provincial health ministries have in place committees mandated to advise on timely and efficient delivery of genetic services.

2. The federal and provincial health ministries establish a joint committee on genetic services and information to address the full range of technical and ethical issues associated with current and emerging genetic technologies and their applications. This committee should be multidisciplinary and represent the users of health care, as well as the planners and providers.