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How American Nurses Association Code of Ethics informs genetic/genomic nursing

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Abstract

Members of the Ethics and Public Policy Committee of the International Society of Nurses in Genetics prepared this article to assist nurses in interpreting the American Nurses Association (2015) Code of Ethics for Nurses with Interpretive Statements (Code) within the context of genetics/genomics. The Code explicates the nursing profession's norms and responsibilities in managing ethical issues. The nearly ubiquitous application of genetic/genomic technologies in healthcare poses unique ethical challenges for nursing. Therefore, authors conducted literature searches that drew from various professional resources to elucidate implications of the code in genetic/genomic nursing practice, education, research, and public policy. We contend that the revised Code coupled with the application of genomic technologies to healthcare creates moral obligations for nurses to continually refresh their knowledge and capacities to translate genetic/genomic research into evidence-based practice, assure the ethical conduct of scientific

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inquiry, and continually develop or revise national/international guidelines that protect the rights of individuals and populations within the context of genetics/genomics. Thus, nurses have an ethical responsibility to remain knowledgeable about advances in genetics/genomics and incorporate emergent evidence into their work.

Keywords
Code of Ethics, genetic/genomic nursing, nursing education, nursing practice, nursing research, public policy

Introduction

A code of ethics articulates the values of a profession, sets the standards for professional conduct, and provides guidelines for decision-making. A code signifies a profession's recognition of the trust and responsibility with which it has been vested by society. The American Nurses Association (ANA) *Code of Ethics for Nurses with Interpretive Statements* (Code)[1] functions as a resource for individual nurses, the nursing profession, and society by explicating the profession's norms, individuals' responsibilities, and requirements in managing ethical issues that nurses may encounter across various contexts. Specifically, the Code serves to (1) delineate ethical obligations and duties, (2) constitute the profession's ethical standard, and (3) articulate the profession's commitment to society. Although the Code was developed for nurses within the United States, it shares many values and obligations endorsed by international nursing and health organizations, including the International Council of Nurses *Code of Ethics for Nurses*,[2] the United Nations *Millennium Development Goals*,[3] and the World Medical Association *Declaration of Helsinki*.[4] A view only copy of the Code's provisions and interpretive statements is available at http://www.nursingworld.org/code-of-ethics.

Genetics is "the study of individual genes and their impact on single-gene disorders."[5] Genomics refers to "the study of all genes in the human genome together or as a subset, including their interaction with each other, the environment, and the influence of other psychosocial and cultural factors."[5] A human genome describes the entire genetic composition of an individual including his or her chromosomes, genes, and other DNA sequences. Genes, once thought of in association with rare single-gene-inherited disorders, are now understood to be a component of all common diseases including heart disease and stroke,[6] diabetes,[7] cancers,[8,9] altered coagulation,[10,11] seizure disorders,[12] autoimmune conditions,[13] emphysema,[14] and Alzheimer's disease,[15] as well as the body's responses to infectious diseases[16] and drug metabolism.[17] Genomic technologies are now routinely used in population screening panels (e.g. newborn screening),[18] screening subpopulations for cancer (e.g. cervical),[19] or for the likelihood of genetic syndromes (e.g. Lynch syndrome).[20,21] Pharmacogenetics is a recently developed branch of pharmacology that investigates a wide range of drugs recognized to respond differentially in patients with certain genetic variants (e.g. warfarin),[22] codeine,[23] and tamoxifen.[24]

Precision medicine is "an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person."[25] The application of genetic technologies, science, and informatics has become nearly ubiquitous in healthcare. New applications continue to evolve at a remarkably rapid pace. Although such contemporary advancements offer great promise for improving the quality of healthcare and health outcomes, they also pose novel ethical challenges and questions for nursing. Therefore, as the Code is for all nurses, so too is the incorporation of genetics/genomics into nursing. As members of the Ethics and Public Policy Committee of the International Society of Nurses in Genetics (ISONG), we developed this article to assist nurses in interpreting the Code of Ethics as revised in 2015, in the context of genetics/genomics.

Self-determination

Interpretive statement 1.4 addresses the patient's right to self-determination and articulates the belief that this right is predicated upon "accurate, complete, and understandable information" which will enable the patient to make an informed decision regarding care.[1] Cutilli and Bennett[26] report that about one-third of the people living in the United States have limited health literacy. Johnson et al.[27] suggest that those with limited health literacy will have even more difficulty understanding genetic/genomic influences on health. A review of the literature[28] offers evidence that while people in the general public have some familiarity with genetic terms, they also have gaps in their genetic knowledge regarding health. Thus, there is a heightened challenge to ensure that patients are able to make truly informed healthcare decisions that involve genetic information. For example, during the process of obtaining informed consent for a genetic test, nurses must be able to describe the nature of the test, explain how the test results will inform patients' treatment, explain the limitations of the test, discuss potential implications of the test results for family members as well as the patient, and locate additional resources for the patient as required.

The protection of human participants in research, adhering to interpretive statement 3.2 of the Code, requires assurance that autonomy and respect for persons are preserved.[1] Respecting an individual's autonomy means that consent to participate in research must be both informed and voluntary. Without appropriate informed consent, neither respect for persons nor generation of knowledge is ethically possible. However, assuring potential participants' understanding of genetic/genomic research can be challenging because the science of genetics is often fraught with esoteric terminology and complicated concepts, for example, DNA, mutation, autosomal recessive or dominant, heterozygote, and homozygote. In the informed consent process, investigators must therefore use plain language and clearly define terms while addressing each element of the consent process.

Two ethical issues, unique to genetic/genomic research, also need to be addressed during the consent process. Genetic results can include findings that have implications for health risks among the participant's family members as well as the participant. In addition, in some research genetic results can include incidental or unintended findings that may or may not be medically actionable, for example, genetic predisposition for serious health conditions with no cure. It is important for researchers to be clear with participants about how their protocols will address such issues.

Other essential elements of the consent process include explaining why particular participants were selected or invited, procedures participants will undergo, risks and benefits associated with any genetic information gained, alternatives to participating in the research, voluntary nature of participation, confidentiality assurances, any costs associated with participation, and who to contact with questions or concerns. The limitations of the *Genetic Information Nondiscrimination Act* (GINA; US Equal Employment Opportunity Commission, 2008)[29] should also be explained. Although GINA prevents discrimination on the basis of genetic information regarding health insurance and employment, protection is not extended to life or long-term care insurance. In addition, businesses with fewer than 15 employees are exempt from GINA protections.

If incidental findings or mutations of unknown clinical significance could be part of the research findings, potential participants should receive counseling from a qualified genetics professional regarding the potential implications for themselves and their families. Additional precautions may be required for vulnerable groups for whom informed, voluntary consent might be compromised. Such populations may include, but are not limited to, children, incarcerated persons, and individuals with low literacy.

Although the right not-to-know seems contrary to the patient's right to self-determination, discussion regarding this seeming dilemma is occurring with regard to genetic testing. The right not-to-know paradigm gained legitimacy when early discussions were centered on Huntington's disease and Alzheimer's disease, both extremely debilitating adult-onset disorders with no known treatment. The right not-to-know is recognized as an extension of the patient's right to self-determination.[30] Currently, however, the scope

of genetic information generated by innovative sequencing tests continues to broaden and the knowledge of how, exactly, the individual's health will be impacted is imperfect. Recent discussions reflect the practical and philosophical concerns arising from the use of innovative technologies.[31,32] Nurses need to remain aware of evolving ethical issues so that they can contribute nursing perspectives to ongoing debates about genetic/genomic testing in research and practice.

Some individuals use direct-to-consumer genetic testing to enhance their knowledge of health risks. Nurses are further challenged in the roles of patient educator and counselor to guide patients to companies with approved laboratories and genetic counseling services. Nurses will also be asked to explain the relevance of this genetic information to guide their healthcare decision-making.[33] This can be a daunting task and nurses should be familiar with the genetic services available to the patient.

Privacy and confidentiality

Interpretive statement 3.1 reinforces the obligation to protect patients' privacy. It defines privacy as "the right to control access to, and disclosure or non-disclosure of, information pertaining to oneself, and to control the circumstances, timing and extent to which information may be disclosed."[1] Confidentiality refers to the "measures taken to protect private information."[34] However, in the era of electronic health records, insurer demands, and increasing use of genetic testing to determine susceptibility to disease or treatment options, the boundaries of privacy and confidentiality become blurred. Thus, it is important to explore patients' concerns about genetic test results being placed in medical/health records. Genetic discrimination in the workplace and insurance industry is of concern to some despite the enactment of the *Patient Protection and Affordable Care Act* (2010)[35] and the *GINA* (2008).[29] Nurses need to be able to explain how genetic information is recorded and stored, identify the information released to third parties, and otherwise respond to patients' concerns regarding the privacy and confidentiality of genetic information.

Furthermore, the registered nurse should be knowledgeable about the local regulations related to genetic/genomic information and technologies. Many states have laws regulating the disclosure of genetic information that may be more restrictive than those imposed by the *Health Information Portability and Accountability Act* (1996).[36] The scope of applicability, restrictions, and statuary penalties varies. Information by state can be found in a report by Foley & Lardner, LLP (2014).[37]

Although genetic information is like other physiological information in that it informs intervention, genetic data can also elicit unique concerns and produce unanticipated consequences. Health information gleaned from genetic testing reveals information pertinent to an individual's health but it also has implications for other family members. Therefore, when patients receive genetic test results, they might feel burdened with the responsibility of communicating complicated genetic information to other relatives. The challenge of such a task can be amplified when family relationships are strained. Nurses can help patients explore strategies to share such sensitive information with other family members in ways that can be mutually beneficial.

Nursing obligations

Provision 2 states that the nurse's primary commitment is to the patient, whether an individual, family, group, community, or population.[1] Provision 3 stipulates that all nurses have a duty to "advocate" for the health and well-being of their patients.[1] Provision 4 asserts that nurses are accountable for nursing care and must act to provide optimal care.[1] As genetic/genomic information expands, and technologies become available, nurses in all areas of practice are being challenged to translate genetic/genomic knowledge into evidence-based practice as they educate, counsel, and support patients through the delivery of care. To effectively do so, nurses entering the workforce must be adequately informed about genetic/genomic concepts and emerging technologies. Therefore, nurse educators have a duty to include these concepts in required coursework

(e.g. readings, online resources, class lectures/discussion, case studies, and assignments) along with illustrating the application of the concepts during clinical practicums. These concepts can be threaded throughout the curriculum in courses, such as pathophysiology, pharmacology, medical-surgical, obstetrics, pediatrics, gerontology, as well as concentrated in stand-alone genetic/genomic courses. Genetic/genomic knowledge is recognized as an integral part of basic nursing education in the *Essentials of Baccalaureate Education for Professional Nursing Practice*.[38] An excellent resource available to nurse educators is the *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators*[39] which was established by consensus of nursing representatives from many national nursing organizations and endorsed by 49 organizations including the National League of Nursing Accrediting Commission and the *American Association of Colleges of Nursing* (AACN). This document includes clinical performance indicators that identify specific behaviors nurses should consider during a self-assessment.

Guidelines for genetic/genomic content for curriculum development in advanced degree nursing programs are available in the *Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees*.[40] The AACN mentions genetics in the first essential of the *Essentials of Master's Education in Nursing*[41] and genomics in the *Essentials of Doctoral Education for Advanced Nursing Practice*.[42] Moreover, genetics, genomics, and pharmacogenomics are frequently included on the test content outlines for advanced practice nurse certification examinations, such as the American Nurses Credentialing Center (ANCC).[43,44]

Interpretive statement 5.5 of the Code focuses on the need for maintaining competence and continuing professional growth among practicing nurses at all levels.[1] Nurses may examine their own understanding of genetics/genomics and abilities to recognize the implications of such information on the health of their patients. A variety of professional educational venues are available to help nurses fulfill this competency obligation (e.g. specialty certification, professional reading, self-study, professional conferences, and networking with professional colleagues). In addition, a recent initiative associated with ANCC Magnet-recognized hospitals promotes efforts to increase nurses' understanding and knowledge of genetics and genomics using trained nurse dyads.[45] Entry-level nursing education must prepare nurses with skill sets that enable them to educate, counsel, and advocate for patients and families who face challenging genetic choices. There is a need for continuing education programs that teach nurses how to apply ethical assessment frameworks to effectively support patients through their genetic decision-making processes.[46]

Continuing education activities focusing on genetic/genomic topics are available through many professional organizations, universities, and federal programs. The National Human Genome Research Institute (NHGRI) provides the annual Short Course in Genomics for nursing faculty and free, online information on a variety of genetic topics. The Genetics/Genomics Competency Center is another repository of genetic/genomic information accessible to nurses. The Global Genetics and Genomics Community[47] offers genomic healthcare case studies and simulations. The section of Clinical Pharmacology in the Department of Medicine at Indiana University—Purdue University Indianapolis[48] provides a helpful table focusing on P450 drug interactions. The ISONG offers webinars and annual conferences that focus on new developments in genetics/genomics as they apply to nursing (see Table 1 for additional information).

Nursing research

Interpretive statement 7.1, which refers to the generation and development of knowledge through research, states, "All nurses must participate in the advancement of the profession through knowledge development, evaluation, dissemination, and application to practice."[1] It is consistent with the principles of respect for persons, beneficence, and justice as articulated in the Belmont Report[49] and is congruent with recommendations from the National Institutes of Health.[25]

Recent nursing research supports the contributions of genetics to health outcomes in certain conditions.[50–52] In 2012, the National Institutes of Health convened a Genomic Nursing State of the Science

Table 1. Education/training resources for nurses on genetics/genomics.

Resource	Format	URL
NINR Summer Genetics Institute	Face-to-face	https://www.ninr.nih.gov/training/trainingopportunitiesintramural/summergeneticsinstitute#.V8CVhZgrKM8
NHGRI Short Course in Genomics	Face-to-face	https://www.genome.gov/27564236/nhgri-short-course-in-genomics-nurse-physician-assistant-and-faculty-track-/
National Human Genome Research Institute	Website	https://www.genome.gov/
Genetics/Genomics Competency Center	Website	http://www.g-2-c-2.org
Global Genetics and Genomics Community	Online interactive case study simulations	http://g-3-c.org/en/
International Society of Nurses in Nursing (ISONG)	Website and annual conference	http://www.isong.org/

NINR: National Institute of Nursing Research; NHGRI: National Human Genome Research Institute.

Advisory Panel to identify critical genomic health issues that could be addressed through nursing research.[53] The resulting "blueprint" identified a need for "biologic plausibility" and intervention research designed to improve health, environmental, and economic outcomes of diverse populations across settings. The National Institute of Nursing Research is dedicated to supporting nursing science that advances precision medicine which considers the health implications of one's genes, environment, and lifestyle.

The societal benefits of the genetic findings from any study need to outweigh the potential risks to individual participants or participant communities. Obtaining approval from an institutional ethics board is one way to assure adherence to this principle while complying with interpretive statement 7.1. Institutional review boards (IRBs) are charged with conducting review of proposed studies for congruence with accepted ethical principles.[54] Additional approvals may be required in cross-cultural and international genetic research. Maintaining close collaborative relationships with community leaders should continue throughout the implementation of the study and dissemination of results. The principle of beneficence also suggests that the qualifications of study team members must match their responsibilities in the research, in order to assure that harm is minimized and benefit maximized.[55,56]

Reasonable remuneration for participation in research can prevent undue influence on individual's decision to take part in research. Genetic research can lead to financial gains for investigators or their institutions, particularly in the area of biotechnology development. From the onset of designing a study, it is important for researchers to consider how they might give back to communities that support their empirical work. Researchers also need to remain cognizant of potential conflicts of interest and develop appropriate management plans when or if such conflicts arise.

In addition to the aforementioned considerations for ethical research, research involving genetics poses other unique concerns. When the study involves genetic testing of members of a particular racial/ethnic group, such as among Native American tribal groups or international populations, the impact of findings may extend well beyond research participants; entire communities can be affected. Therefore, it is critical for investigators to partner with community leaders when planning the study to assure the relevance of the study to the needs of the community. Furthermore, the development of the consent process may also need to include leadership of those communities in order to assure culturally competent consent processes. It is of paramount importance that researchers avoid therapeutic misconception by clearly differentiating between

genetic testing done for research, which is intended to gain generalizable knowledge, and testing performed for clinical purposes that may directly benefit individual patients and families.

While much more research is needed to understand the extent of the influence of genetics/genomics on health outcomes, nurses must be proactive in recognizing inequities in the generation of genetic/genomic knowledge. Rotimi[57] observed that people of European ancestry have been the focus of over 90% of all genome-wide association studies. Easton et al. [58] acknowledge that almost all genetic studies related to predictive risk of breast cancer relate to women of European ancestry.

Nursing and health policy

Interpretive statement 7.3 of the Code articulates the obligation of nurses, both individually and through professional organizations, to respond to health needs with the development of nursing and health policies that reflect respect for human rights and are informed by the principle of social justice.[1] Policy can guide the integration of genetics into healthcare procedures and programs. Policy development may focus on the accessibility and appropriate use of genetic technologies, the assurance of confidentiality in the storage of genetic data, and quality of genetic services. It takes place at many levels, from institutional and community, to national and international. Population-based genetic information can guide policy development to improve interventions. Public health policies can inform about genetic technologies and thus empower the public in making decisions regarding the uptake of these technologies. Nursing is uniquely positioned within healthcare systems to identify such integration opportunities. The development of both nursing and health policy as mandatory areas for nursing effort is affirmed within the code.

Particularly relevant to nursing, social justice aims to ensure an equitable distribution of both wealth and burden in society. Social justice affirms health as a universal right and obligates citizens to create an environment where that right can be realized. Social justice requires nurses to address health disparities and demands health diplomacy to be conducted in a manner that respects the right of individual.

"Health is a Universal Right" is stated in interpretive statement 8.1. While this interpretive statement recognizes direct healthcare, it also acknowledges political, social, and economic pressures that impact health, including food security and safe water. Interpretive statements 8.2–8.3 define one leadership obligation as the expectation that nurses address local, national, and global health needs.[1] Although nursing continues to focus mainly on the healthcare needs of individual patients, the profession is also prepared to embrace challenges contributing to the creation of a social environment that is compatible with equitable distribution of health-related resources, including genetic resources.

Health disparity

Interpretive statement 8.3 asserts that the reduction in health disparities is a nursing obligation.[1] The National Institute of Allergy and Infectious Disease[59] defines health disparities as

> Gaps in the quality of health and healthcare that mirror differences in socioeconomic status, racial and ethnic background, and education level. These disparities may stem from many factors, including accessibility of healthcare, increased risk of disease from occupational exposure, and increased risk of disease from underlying genetic, ethnic, or familial factors. (What are Health Disparities? Section 1, para. 1)

The World Health Organization (WHO)[60] found in 2000 about 80% of investments in genomics occurred in the United States and about 80% of DNA patents in genomics between 1980 and 1993 were held by US companies. In a 2010 report, *Community Genetics in Low- and Middle-Income Countries*,[61] the WHO identified the cost, complexity of genomic technologies, lack of professionals trained in genetics, cultural beliefs, and fear of stigmatization as barriers for utilization of genetic services in developing countries.

These barriers also exist in many underserved areas within developed countries. Furthermore, the nature of genetics, the fears of genetic discrimination, issues of confidentiality, concerns regarding misuse of genetic information, issues of intellectual property, availability of drug being tested once the research is concluded and the cost of the drug becomes unaffordable, and misinformation regarding the goals of genetic healthcare may foster a degree of discomfort for individuals, organizations, and governments.

Article 19 of the *Universal Declaration on the Human Genome and Human Rights*[62] specifically addresses the responsibility of developed countries to provide developing countries access to genomic healthcare. The document identifies important ethical considerations for those developing genetic healthcare strategies. Because there is a potential that the availability of genetic tests and subsequent treatments for select population groups may contribute to an increase in health disparity, Fullerton et al.[63] call for a new approach to genomic research. They urge a reformation of the research question to ask "how genomic information could be better used to direct population-scale health interventions" (p. 160). Such innovative solutions are required to align genetic discovery with public health priorities and to facilitate translation of genomic information into practice in many underserved areas. Interpretive statement 8.3 requires nurses to examine and address barriers to genetic/genomic testing and related healthcare that perpetuate health disparities.[1] It also highlights the expanding role of nursing in the global arena propelled by communication technologies. In addition, it aligns with the International Council of Nurses *Mission Statement*,[2] the Sigma Theta Tau International Nursing Honor Society *Mission Statement*,[64] the *AACN Essentials for Baccalaureate Nursing Education*,[38] *Master's Education in Nursing*,[41] and *Doctoral Education for Advanced Nursing Practice*,[42] and the United Nation's *Universal Declaration of Human Rights*.[65] While reaffirming the nursing profession's commitment to human rights, the Code thus guides nursing into emerging healthcare arenas and challenges the profession to respond as equal partners with other professionals and the public to promote health diplomacy and thereby to reduce health disparities.

Health diplomacy

Interpretive statement 9.4 demands participation with the global nursing community and health organizations and collaboration with others in advancing health. This interpretive statement also obligates nursing organizations to actively engage in the political process on issues related to the advancement of the nursing profession and the health of the public.[1] Global health "places a priority on improving health and achieving equity in health for all people worldwide."[66] Diplomacy is a skill of negotiating "between and among nations to resolve disputes and enact formal agreements."[67] Since health diplomacy is an evolving field it has been defined in various ways.[68] The Code[1] defines health diplomacy as

> prioritizing global issues and concerns within the context of international diplomacy and practices. Bringing together public health, international affairs, management, law, economics, foreign policy, and trade, it focuses on negotiations that shape and manage the global policy environment for health.

Interpretive statement 8.2 addresses the responsibility to collaborate for health diplomacy. The interpretive statement declares "Ethics, human rights and nursing converge as a formidable instrument for social justice and health diplomacy that can be amplified by collaboration with other health professionals."[1] As the economies of developing countries improve and the goals of mitigating infectious disease become successful, there will be more people who are suffering from chronic illnesses such as diabetes, heart disease, and cancer. Ensuring the inclusion of genetic technologies in present and future initiatives will improve the health of populations.

Although health diplomacy can be understood as forming binding agreements between or among nations, it can also occur among government officials, public health professionals, nongovernmental

organizations (NGOs), private companies, and the public.[67] The early years of the 21st century have already witnessed the ease with which infectious diseases (e.g. AIDS, SARS, H5N1, Ebola, and Zika viruses) have spread. News headlines frequently report large numbers of people suffering from poor nutrition and living conditions due to poverty, natural disaster, or conflict. The challenge is to respond to these immediate dire needs and to create an environment in which all advances in medicine, including genetic technologies, are accessible. Outward looking, creative nurses are needed to participate in discussions concerning the delivery of healthcare services to include genetic/genomic technologies and to be at the forefront of identifying ways to educate local nursing groups to deliver such care.

Although nurses have participated for centuries in providing care internationally, and at times, also participated in policy development, the role of nurses as global health diplomats has not yet been clearly defined. In an effort to identify global health competencies for nursing, Wilson et al.[69] identified six categories of competence for nurses in global health: (1) global burden of disease; (2) health implications of migration, travel, and displacement; (3) social and environmental determinants of health; (4) globalization of health and healthcare; (5) healthcare in low-resource settings; and (6) health as a human right and development resource. However, none of the skills in any of the competencies specifically identify genetics. Hunter et al.[70] suggest that the skills of health diplomats include those of negotiation, research, collaboration, and conflict resolution. Knowledge of the economics, politics, laws, health concerns, and culture of the population are also essential. The role of the genetic nurse in health diplomacy may be even more complicated since the genetic nurse health diplomat will be further challenged to create an environment in which health inequities between and within countries can be reduced by incorporating genetic/genomic modalities into the healthcare delivery plan.

Conclusion

The 2015 ANA Code of Ethics for Nurses with Interpretive Statements coupled with the ubiquitous application of genetic/genomic technologies to healthcare identify moral obligations for nurses to continually refresh their knowledge and capacities to translate genetic/genomic research into evidence-based practice. Nurse researchers involved in genetic/genomic studies must assure the ethical conduct of scientific inquiry by continually monitoring for and remediating potential threats to informed consent and participant privacy. There is also a critical need for nursing forums that bring together policymakers, clinicians, researchers, and educators in reciprocal exchanges of information that may identify genetic/genomic ethical issues as they emerge. Finally, the nursing profession must demonstrate leadership in inter-professional initiatives charged with the responsibility of establishing national/international guidelines that assure the well-being and protect the rights of individuals and populations within the context of genetics/genomics.

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Conflict of interest

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