

• **RESOLUTION OF THE
SECRETARY'S ADVISORY COMMITTEE ON GENETICS, HEALTH, AND SOCIETY
ON
GENETICS EDUCATION AND TRAINING OF HEALTH PROFESSIONALS
June 2004**

Whereas the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) was established to advise the Secretary of Health and Human Services (HHS) on the range of complex and sensitive medical, ethical, legal and social issues raised by new technological developments in human genetics;

Whereas advances in genetics and genomics¹ will lead to a more precise understanding of disease processes and will provide better guidance on the application of therapeutic and preventive strategies that will make significant improvements in health status and outcomes;

Whereas insufficient education and training in genetics and genomics has led, and may continue to lead, to inaccurate or delayed disease diagnoses, misguided disease management, inadequate family planning counseling, an exacerbation of health disparities, and unnecessary costs;

Whereas appropriate and adequate training and education in genetics and genomics is crucial for all health care and public health professionals to assure the appropriate, effective and efficient integration of genetic and genomic technologies and services throughout the entire health care system;

Whereas appropriate education in genetics and genomics is crucial for the general public to take advantage of the benefits of genetics and genomic advances;

Whereas education of health care and public health professionals and the public is a necessary component of assuring equitable access to genetic and genomic technologies;

Whereas education of health care and public health professionals and the public is a necessary component of the application of evidence-based medicine related to genetics and genomics;

¹ The term "genomics" is a relatively recent addition to the lexicon and represents a broad and comprehensive way of looking at the role and function of genes and their interactions. Though genomic tools are used to address similar questions asked in genetics, SACGHS believes that it is necessary and important to use the term in its deliberations and documents given the growing part genomics is beginning to play in health and health care. Although new and distinct from "genetics," the two fields also overlap, and there is a lack of consensus on their definitions. In the Committee's view, the fields actually differ more in emphasis (i.e., single traits vs. whole genomes) than in scope [what they each encompass]. Genetics is the study of inherited traits, of inherited variability, and the mechanisms of transmission revealed by patterns of inheritance. Genetic diseases addressed by clinical practice (and specifically the specialty of medical genetics) include single gene disorders, chromosomal disorders (such as rearrangements or trisomy) and multifactorial disorders (such as heart disease or diabetes) in which the role of genes is apparent. Genomics is the study of the structure and function of whole genomes, and science related to genomes, including expression patterns that result from the interaction of the whole genomic complement. Genomic medicine refers to the application of the principles of genomics for the prevention, diagnosis and treatment of disease as well as determining the probability of future disease and, in general, deals with the combinatorial effect of many genes, rather than the effect of single genes.

Whereas through a survey of selected Federal agencies on their role and activities in genetics and genomics education, training, and health workforce analysis, it was found that Federal efforts are appropriately focused on the translation and appropriate integration of new genetics and genomics technologies into health care and public health;

Whereas a solicitation of information from educational and professional organizations² identified the following urgent needs in genetics and genomics education and training:

- A broadening of the focus of genetics education and training to incorporate both genetics and genomics;
- Greater diversity in the health care and public health workforce and cultural competence of its members;
- An inventory or catalogue of widely relevant clinical and public health applications stemming from advances in genetics and genomics;
- Educational models that use such applications to clarify how genetics and genomics should be integrated into practice through the use of family history tools, information technologies and web-based practice tools, among others;
- Training programs that address the interface of, and interaction between, genetics and genomics, their ethical, legal, and social implications, and public policy;
- Growth in the number of faculty appropriately trained in genetics and genomics; and
- National accreditation and re-accreditation standards that incorporate genetics and genomic competencies.

As such and in light of the importance of ensuring that the benefits of the genetics and genomics revolution are accessible to all Americans, SACGHS urges the Secretary to take the following steps to ensure the adequacy of genetics and genomics education and training of all health care and public health professionals:

Promote and actively incorporate into Departmental policies and programs the philosophy that genetic information, which includes family history information, should be treated as part of the spectrum of health information and viewed as an integral part of the practice of all health care and public health professionals.

Incorporate genetics and genomics, including family history tools and point of care educational support, into relevant initiatives of HHS, including the Secretary's Health Information Technology Initiative, and engage in the dissemination of this knowledge to health care and public health professionals.

Promote and support initiatives that address the integration of genetics and genomics into the education and training of all health care and public health professionals.

² American Academy of Pediatrics, American Association of Colleges of Nursing, American Association of Colleges of Pharmacy, American Board of Genetic Counseling, American College of Physicians, American Dental Education Association, American Medical Association, American Nurses Association, American Society of Human Genetics, Association of American Medical Colleges, Association of Professors of Human and Medical Genetics, Association of Schools of Allied Health Professions, Association of Schools of Public Health, International Society of Nurses in Genetics, National Coalition for Health Professional Education in Genetics, National Medical Association, National Organization of Nurse Practitioner Faculty, and National Society of Genetic Counselors.

In order to facilitate the integration of genetics and genomics into health care and public health now, develop a plan for HHS agencies to work collaboratively and with State, Federal and private organizations (such as the National Coalition for Health Professional Education in Genetics) to support the development, cataloguing and dissemination of case studies and practice models that demonstrate the current relevance and applicability of genetics and genomics to health care and public health.

Support Federal programs that provide for faculty training in the implementation and dissemination of clinical application-based genomics educational models, particularly models that incorporate the ethical, legal, and social implications of genetics and genomics.

Work with the Association of State and Territorial Health Officers and other relevant organizations to address issues associated with incorporating knowledge of human genetics and genomics into accreditation, licensure and certification processes.

Provide support for K-12 and undergraduate education programs that serve as “pipelines” for health professionals to incorporate a genetics and genomics focus into their curricula.

Encourage, support and facilitate programs that promote the diversity and cultural competency, including issues associated with disability rights, of the health care and public health workforce.

Promote sensitive and culturally appropriate public education to equip consumers with the knowledge and skills they need to participate effectively in health care decisions which increasingly are informed by genetic and genomic perspectives.