

# Recommendations of core competencies in genetics essential for all health professionals

*Core Competency Working Group of the National Coalition for Health Professional Education in Genetics*

Genetic scientific discoveries made throughout the last decade already have a tremendous influence on health care. Understanding the role genetics plays in health and disease provides the means to integrate such information into prevention, diagnosis, and treatment of many common diseases to improve the health of society. Genetic information and technologies are increasingly making their way into health care.<sup>1</sup> Yet, while patients are beginning to ask providers about—and even request—genetic services, primary care providers face economic and institutional barriers to incorporating genetic factors into management of patients.<sup>2</sup>

As outlined by the Institute of Medicine Report on the Future of Public Health,<sup>3</sup> public health agencies will have an increasing role in assessing the health needs of populations, working with the private sector in ensuring the quality of genetic tests and services, and evaluating the impact of interventions on medical, behavioral, and psychosocial outcomes. The Department of Health and Human Services Secretary's Advisory Committee on Genetic Testing (SACGT) is addressing the need to provide access to high-quality genetic testing when appropriate and effective.<sup>4</sup> Ultimately health professionals, regardless of specialty area, role, or practice setting, will face questions about the implications of genetics for their patients and communities. The fast pace of genetics research advances, the paucity of professional training in genetics, and the widespread underestimation of the value of genetics in medical decision-making leaves many providers without up-to-date answers.<sup>5</sup>

The National Coalition for Health Professional Education in Genetics (NCHPEG) was founded by the American Medical Association, the American Nurses Association, and the National Human Genome Research Institute in an attempt to bridge this gap in genetic knowledge. This coalition of organizations constitutes an interdisciplinary, collaborative, and national effort to promote health professional education about application of human genetics information.

NCHPEG members are representatives from more than 100 diverse organizations including consumer and voluntary groups, private industry, managed care organizations, government agencies, health professional societies, and genetics organizations (Appendix). Membership is voluntary, with representatives selected by their respective organizations. Read more about NCHPEG at the Web site (<http://www.nchpeg.org/>).

NCHPEG seeks to gain from the diverse expertise and experience of member organizations working toward mutually identified goals. NCHPEG solicits group members to work together to address several priorities, including the identification

of core competencies in genetics essential for all health professionals. Implicit goals of seeking consensus on basic genetics competencies among NCHPEG members were (1) to validate the importance of a basic foundation in genetics for health care, (2) to foster the use of common terminology, (3) to increase the consistency of genetics education efforts across the disciplines, (4) to facilitate active discourse about the relative role of the different professions in the provision of genetic services, and (5) to reduce duplication of effort. Achievement of each of these goals will require disciplines to recognize the need for genetics education, to integrate genetics concepts into their current educational resources, and to utilize these competencies to design new programs.

## Development of recommendations

The Core Competency Working Group of NCHPEG originally consisted of 27 volunteer members representing varied disciplines who convened in October 1997 after the NCHPEG annual meeting (see Acknowledgment). The actions of the Working Group were accomplished during meetings and conference calls. The initial contact of the Working Group determined the direction and necessary actions of the group to achieve the goal of basic awareness of all health professionals about genetics. In an effort to identify and build on work already completed by a number of professional groups, all NCHPEG members were asked to submit curriculum samples, workshop objectives, articles, guidelines, and any other materials that addressed genetics competency. The evidence for this consensus process was the more than 35 total programs, articles, and draft genetic education materials received for review by the Working Group in 1998. Although they represented only those materials known to NCHPEG members, these materials were felt to include the majority of genetics education resources available.

The chair of the Working Group (Jenkins) abstracted competencies and objectives from these materials and drafted a listing of NCHPEG core competency options. Themes were identified and content was grouped accordingly. The original wording of the identified source material was maintained. Draft competencies were formatted into a survey tool that, after content review by experts, was mailed to all Working Group members in July 1998. This survey asked all Working Group members to read through each competency grouping and to choose those items they felt were essential for each health care worker to know or be able to do. Working Group members were requested to suggest additional items or re-

wording of items already included. Finally, they were instructed to choose the five competency items that reflected their top priorities for genetics education.

Working Group members (68% response rate) selected those competencies felt to be essential and then prioritized items for inclusion. Eighteen themes for core competencies for genetics education were identified. Working Group members also suggested additional content items, including informed consent, cost/reimbursement issues, and documentation of genetic information. Responses from the Working Group members were presented at the NCHPEG annual meeting in October 1998, where it was recommended that a smaller subgroup then draft a document for consideration by the total Working Group that would recommend specific genetics competencies.

A subgroup of eight members from the Working Group met in February 1999 to utilize survey data and their own expertise to draft such a document. This subgroup consisted of volunteers, representative of diverse disciplines, who were committed to draft a document and able to participate actively. This subgroup utilized the 18 themes identified from the survey to guide discussion, ensure priority of items included, and add items of importance to the draft document. Total Working Group member feedback on this draft was solicited via e-mail and the NCHPEG Web page in March 1999. Suggested format, wording, length, and content modifications were reviewed with NCHPEG Executive Committee members. This revised draft was sent to the Working Group members and to Steering Committee members in July 1999. The subgroup considered Working Group and NCHPEG Steering Committee member responses in the final revision of the Core Competencies at a December 1999 conference call (62% response rate).

Although diversity of opinions existed, members of the Working Group approved the final document. Main concerns throughout the development process were as follows: specialist versus generalist competency, “bare bones” versus inclusive competency, and competencies for today versus the future. After much input, discussion, revision, and compromise, the NCHPEG Steering Committee formally approved the draft document in February 2000 without any dissenting votes.

The NCHPEG Core Competency Working Group recommends that all health professionals possess the following core competencies in genetics, to enable them to integrate genetics effectively and responsibly into their practice. Competency in these areas represents the minimum knowledge, skills, and attitudes necessary for health professionals from all disciplines (medicine, nursing, allied health, public health, dentistry, psychology, social work, etc.) to provide care to their patients that involves awareness of genetic issues and concerns.

This document is a work in progress, since the knowledge produced by the Human Genome Project and related activities will create an ongoing need to assess and revise expectations. While the list is extensive, NCHPEG believes that the recommendations provide a useful tool for organizing the teaching of basic genetics in many educational settings and can be modified for particular disciplines. Those health care professionals

involved in the *direct* provision of genetic services will require additional training to achieve an appropriately higher level of competency (see competencies 2.9–2.17). Higher level competencies for disciplines that require specialized knowledge of genetics have been identified previously.<sup>6–15</sup>

### Objective

It should be noted that the impetus for developing this list of ideal genetics competencies was to encourage health care providers to acquire updated genetics education and integrate genetics knowledge, skills, and attitudes into routine practice in order to provide effective health care to individuals, families, and communities.

At a minimum, NCHPEG recommends all health professionals should be able to (1) appreciate the limitations of their own genetic expertise, (2) understand the social and psychological implications of genetic services, and (3) know how and when to make a referral to a genetics professional.

### Recommendations

Core Competencies (Please note: throughout this document, the term “clients” includes individuals and their social and biological families.)

## KNOWLEDGE

*All health professionals should understand:*

- 1.1 Basic human genetics terminology
- 1.2 The basic patterns of biological inheritance and variation, both within families and within populations
- 1.3 How identification of disease-associated genetic variations facilitates development of prevention, diagnosis, and treatment options
- 1.4 The importance of family history (minimum three generations) in assessing predisposition to disease
- 1.5 The role of genetic factors in maintaining health and preventing disease
- 1.6 The difference between clinical diagnosis of disease and identification of genetic predisposition to disease (genetic variation is not strictly correlated with disease manifestation)
- 1.7 The role of behavioral, social, and environmental factors (lifestyle, socioeconomic factors, pollutants, etc.) to modify or influence genetics in the manifestation of disease
- 1.8 The influence of ethnoculture and economics in the prevalence and diagnosis of genetic disease
- 1.9 The influence of ethnicity, culture, related health beliefs, and economics in the client’s ability to utilize genetic information and services
- 1.10 The potential physical and/or psychosocial benefits, limitations, and risks of genetic information for individuals, family members, and communities
- 1.11 The range of genetic approaches to treatment of disease (prevention, pharmacogenomics/prescription of drugs

- to match individual genetic profiles, gene-based drugs, gene therapy)
- 1.12 The resources available to assist clients seeking genetic information or services, including the types of genetics professionals available and their diverse responsibilities
  - 1.13 The components of the genetic counseling process and the indications for referral to genetic specialists
  - 1.14 The indications for genetic testing and/or gene-based interventions
  - 1.15 The ethical, legal, and social issues related to genetic testing and recording of genetic information (e.g., privacy, the potential for genetic discrimination in health insurance and employment)
  - 1.16 The history of misuse of human genetic information (e.g., eugenics)
  - 1.17 One's own professional role in the referral to genetic services, or provision, follow-up, and quality review of genetic services

## SKILLS

*All health professionals should be able to:*

- 2.1 Gather genetic family history information, including an appropriate multigenerational family history
- 2.2 Identify clients who would benefit from genetic services
- 2.3 Explain basic concepts of probability and disease susceptibility and the influence of genetic factors in maintenance of health and development of disease
- 2.4 Seek assistance from and refer to appropriate genetics experts and peer support resources
- 2.5 Obtain credible, current information about genetics, for self, clients, and colleagues
- 2.6 Effectively use new information technologies to obtain current information about genetics
- 2.7 Educate others about client-focused policy issues
- 2.8 Participate in professional and public education about genetics

Skills 2.9–2.17 delineate the components of the genetic counseling process and **are not** expected of all health care professionals. However, health professionals should be able to facilitate the genetic counseling process and prepare clients and families for what to expect, communicate relevant information to the genetics team, and follow up with the client after genetic services have been provided. **For those health professionals with additional training who choose to provide genetic counseling services to their clients, all components of the process, as delineated in 2.9–2.17, should be performed.**

- 2.9 Educate clients about availability of genetic testing and/or treatment for conditions seen frequently in practice
- 2.10 Provide appropriate information about the potential risks, benefits, and limitations of genetic testing
- 2.11 Provide clients with an appropriate informed consent process to facilitate genetic testing decision-making

- 2.12 Provide, and encourage use of, culturally appropriate, user-friendly materials/media to convey information about genetic concepts
- 2.13 Educate clients about the range of emotional effects they and/or family members may experience as a result of receiving genetic information
- 2.14 Explain potential physical and psychosocial benefits and limitations of gene-based therapeutics for clients
- 2.15 Discuss costs of genetic services, benefits and potential risks of using health insurance for payment of genetic services, and potential risks of discrimination
- 2.16 Safeguard privacy and confidentiality of genetic information of clients to the extent possible
- 2.17 Inform clients of potential limitations to maintaining privacy and confidentiality of genetic information

## ATTITUDES

*All health professionals should:*

- 3.1 Recognize philosophical, theological, cultural, and ethical perspectives influencing utilization of genetic information and services
- 3.2 Appreciate the sensitivity of genetic information and the need for privacy and confidentiality
- 3.3 Recognize the importance of delivering genetic education and counseling fairly, accurately, and without coercion or personal bias
- 3.4 Appreciate the importance of sensitivity in tailoring information and services to client's culture, knowledge, and language level
- 3.5 Seek coordination and collaboration with interdisciplinary team of health professionals
- 3.6 Speak out on issues which undermine clients' rights to informed decision-making and voluntary action
- 3.7 Recognize the limitations of their own genetics expertise
- 3.8 Demonstrate willingness to update genetics knowledge at frequent intervals
- 3.9 Recognize when personal values and biases with regard to ethical, social, cultural, religious, and ethnic issues may impact or interfere with care provided to clients
- 3.10 Support client-focused policies

## CONCLUSIONS

The accelerating pace of genetic research and its application in the clinical setting make it essential that persons/groups responsible for continuing education, curriculum development, licensing, certification, and accreditation for all health-related disciplines adopt these or similar recommendations and integrate genetics content into ongoing education. These competencies provide direction for curriculum content that can be utilized in the design of seminars, workshops, Web-based education, and academic preparation. There is a need for commitment on the part of all educators to incorporate genetic

information into all levels of education for all health professionals. The representatives to NCHPEG from each member organization are being encouraged to identify how their organization might utilize these recommendations to enhance genetics education of their members. NCHPEG member organizations will be asked to identify whether future NCHPEG goals should include development of specific educational materials, courses, or resources based on these competencies.

Enhanced genetics competency will help meet changing health care system demands and promote human benefit as a result of genetic scientific discoveries. These identified core competencies in genetics essential for all health professionals are recommendations representative of the beliefs, values, and opinions of those contributing to the final document. This document is only a point of beginning, as each professional organization must now decide how it will support genetics education, how it will utilize this tool to begin to address the needs of its membership, and whether adequate educational resources are available. Although this list of recommended competencies may appear challenging, it is important to prepare not only for the needs of today, but also for utilization of genetic advances in the health care of tomorrow.

#### Acknowledgment

This document has been endorsed by the National Coalition for Health Professional Education in Genetics, a consortium of more than a hundred organizations involved in health care. Working Group members who contributed to the development, review, and finalization of recommended competencies in addition to the authors of this manuscript include Charles G. Atkins, PhD (American Osteopathic Association); Michelle A. Beauchesne, DNSc, RN, PNP (National Organization of Nurse Practitioner Faculties); Judith Benkendorf, MS, CGC (American Board of Genetic Counseling); Richard E. Braun, MD (American Academy of Insurance Medicine); Jessica G. Davis, MD (American College of Medical Genetics); Sue K. Donaldson, PhD, RN (American Academy of Nursing); Louis J. Elsas, MD, FFACMG (Association of Professors of Human and Medical Genetics); Ronald Katz, DMD, PhD (American Association of Dental Research and American Association of Dental Schools); Carole Kenner, DNS, RNC (National Association of Neonatal Nurses); Penny Kyler, MA, OTR/L (American Occupational Therapy Association); Michelle A. Lloyd-Puryear, MD, PhD (Health Resources and Services Administration); Kenneth Miller, PhD (American Association of Colleges of Pharmacy); Robert Smith, PhD (American Can-

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**Appendix**

National Coalition for Health Professional Education in Genetics  
Member Organizations: April 2000

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Agency for Healthcare Research and Quality	Council of Medical Speciality Societies
American Academy of Family Physicians	<i>Council on Social Work Education</i>
American Academy of Insurance Medicine	Dana Alliance for Brain Initiatives
<i>American Academy of Nursing</i>	<i>Department of Veterans Affairs</i>
American Academy of Oral Medicine	Federation of Special Care Organizations
American Academy of Pediatric Dentistry	Foundation for Blood Research
<i>American Academy of Pediatrics</i>	<i>Genetic Alliance</i>
American Academy of Physician Assistants	<i>Glaxo Wellcome R&amp;D</i>
<i>American Association of Colleges of Nursing</i>	<i>Health Resources and Services Administration</i>
American Association of Colleges of Osteopathic Medicine	Howard Hughes Medical Institute
American Association of Colleges of Pharmacy	Human Genome Education Model Project
American Association of Critical Care Nurses	International Patient Advocacy Association
American Association for Dental Research	<i>International Society of Nurses in Genetics</i>
American Association of Dental Schools	Joint Commission on Accreditation of Health Care Organizations
American Association on Mental Retardation	<i>March of Dimes</i>
American Association of Occupational Health Nurses, Inc.	National Association of Neonatal Nurses
American Association of Orthodontists	National Association of Pediatric Nurse Associates & Practitioners
American Board of Genetic Counseling	<i>National Association of School Nurses</i>
American Board of Medical Specialties	National Association of Social Workers
American Cancer Society	<i>National Board of Medical Examiners</i>
American Cleft Palate Craniofacial Association	<i>National Cancer Institute</i>
<i>American College of Medical Genetics</i>	National Center for Genome Resources
American College of Obstetricians & Gynecologists	National Heart, Lung, and Blood Institute
American College of Physicians	<i>National Human Genome Research Institute</i>
American College of Preventive Medicine	National Institute of Child Health and Human Development
American Dental Hygienists Association	National Institute of Dental Research
American Dietetic Association	National Institute of Diabetes and Digestive and Kidney Diseases
American Federation for Medical Research	National Institute of Environmental Health Services
<i>American Medical Association</i>	National Institute of General Medical Sciences
American Medical Informatics Association	National Institute of Mental Health
<i>American Nurses Association</i>	National Institute of Neurological Disorders and Stroke
American Occupational Therapy Association, Inc.	<i>National Institute of Nursing Research</i>
<i>American Osteopathic Association</i>	National Institute on Aging
American Pediatric Society	National Institute on Alcohol Abuse and Alcoholism
<i>American Psychological Association</i>	National Institute on Deafness and Other Communication Disorders
American Society for Clinical Laboratory Science	National Institute on Drug Abuse
American Society of Clinical Oncology	National Marfan Foundation
American Society of Health-System Pharmacists	National Medical Association
<i>American Society of Human Genetics</i>	<i>National Organization for Rare Disorders, Inc.</i>
Armed Forces Institute of Pathology	National Organization of Nurse Practitioner Faculty
<i>Association of American Medical Colleges</i>	<i>National Society of Genetic Counselors</i>
Association of Asian Pacific Community Health Organizations	<i>Nursing Organization Liaison Forum</i>
Association of Genetic Technologists	<i>Office of Rare Diseases</i>
<i>Association of Professors of Human and Medical Genetics</i>	Office of Woman's Health
Association of Professors of Medicine	<i>Oncology Nursing Society</i>
<i>Association of Schools of Allied Health Professions</i>	<i>Pharmaceutical Research &amp; Manufacturers of America</i>
<i>Association of Schools of Public Health</i>	Sigma Theta Tau International
Association of State and Territorial Health Officials	Society of General Internal Medicine
Association of Teachers of Preventive Medicine	Society of Gynecologic Oncologists
Association of Women's Health, Obstetric and Neonatal Nurses	<i>Society of Pediatric Nurses</i>
<i>Biotechnology Industry Organization</i>	Society for Academic Continuing Medical Education
<i>Centers for Disease Control and Prevention</i>	Society for Inherited Metabolic Disorders
College of American Pathologists	Uniformed Services Academy of Family Physicians

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Italics = Steering Committee member organizations.