



***ESSENTIAL NURSING COMPETENCIES
AND CURRICULA GUIDELINES
FOR GENETICS AND
GENOMICS***

**Established by Consensus Panel,
September 21–22, 2005**

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This publication — *Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics* — reflects the thinking of the nursing profession on various issues and should be reviewed in conjunction with state board of nursing policies and practices. State law, rules, and regulations govern the practice of nursing, while *Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics* guides nurses in the application of their professional skills and responsibilities.

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PREAMBLE

Genomics is a central science for all nursing practice because essentially all diseases and conditions have a genetic or genomic component. Health care for all persons will increasingly include genetic and genomic information along the pathways of prevention, screening, diagnostics, prognostics, selection of treatment, and monitoring of treatment effectiveness.

The essential competencies were developed by an independent panel of nurse leaders from clinical, research, and academic settings (identified on the next page) whose goal was to establish the minimum basis by which to prepare the nursing workforce to deliver competent genetic- and genomic-focused nursing care. *These competencies are not intended to replace or recreate existing standards of practice, but are intended to incorporate the genetic and genomic perspective into all nursing education and practice.*

The competencies were developed on the basis of:

- The results of a review of peer-reviewed published work reporting practice-based genetic and genomic competencies, guidelines, and recommendations.
- Input from nurse representatives to the National Coalition for Health Professional Education in Genetics (NCHPEG) meeting in January, 2005.
- Public comment from the nursing community at large.
- Statements from conference attendees during open comment periods during a two-day meeting of key stakeholders (listed on pages 3 and 4) held September 21 and 22, 2005.

The competencies are based on the state of the evidence available at the time they were developed and reflect the **MINIMAL** amount of genetic and genomic competency expected by every nurse. These competencies reflect a consensus and are **NOT** from any federal agency or single nursing organization, and they are applicable to the practice of all registered nurses regardless of academic preparation, practice setting, role, or specialty.

The nursing organizations that have endorsed the competencies (see pages 5 and 6) agree with the content, and they support and promote initiatives within their own organization to implement the competencies.

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American Nephrology Nurses Association	National Association of Hispanic Nurses
American Nurses Association	National Association of Neonatal Nurses
American Nurses Credentialing Center	National Association of Orthopedic Nurses
American Psychiatric Nurses Association	National Association of Pediatric Nurse Practitioners
American Radiological Nurses Association	National Coalition of Ethnic Minority Nurse Associations
American Society of Pain Management Nursing	National Conference of Gerontological Nurse Practitioners
American Society of Plastic Surgical Nurses	National Gerontological Nursing Association
Association of Pediatric Oncology Nurses	National League for Nursing
Association of periOperative Registered Nurses	National League for Nursing Accrediting Commission
Association of Women's Health, Obstetric and Neonatal Nurses	National Nursing Staff Development Organization
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BACKGROUND AND CONTEXT OF THE COMPETENCIES

Genetic and genomic science is redefining the understanding of the continuum of human health and illness. Therefore, recognition of genomics as a central science for health professional knowledge is essential. Because essentially all diseases and conditions have a genetic or genomic component, options for care for all persons will increasingly include genetic and genomic information along the pathways of prevention, screening, diagnostics, prognostics, selection of treatment, and monitoring of treatment effectiveness. The clinical application of genetic and genomic knowledge has major implications for the entire nursing profession regardless of academic preparation, role, or practice setting.

The public will increasingly expect that the registered nurse (RN) will use genetic and genomic information and technology when providing care. These expectations have direct implications for RN preparatory curricula, as well as for the 2.9 million practicing nurses. The rate of progress for applying a genomic approach throughout the continuum of care depends not only on technologic advances, but also on nursing expertise. In its report on genetics and nursing in 2000, an expert Health Resources and Services Administration (HRSA) panel emphasized the importance of integrating genetics content into nursing curricula in order to provide an adequately prepared nursing workforce now and for the future.¹ To care for persons/families/communities and/or populations throughout the life span, registered nurses will need to demonstrate proficiency with incorporating genetic and genomic information into their practice. For example:

- Understand the genetic and genomic basis of health and/or an illness for which the person is seeking care and the variables that impact his or her response.
- Recognize a newborn at risk for morbidity or mortality resulting from genetic metabolism errors.
- Identify an asymptomatic adolescent who is at high risk for hereditary colon cancer.
- Identify a couple at risk for having a child with a genetic condition.
- Guide interventions for the prevention of cardiovascular disease in young adults.

- Facilitate drug selection or dosage in treatment of an adult with cancer based on molecular markers.
- Promote informed consent that includes the risks, benefits, and limitations of participation in genetic research.
- Assist anyone having questions about genetic and genomic information or services.
- Identify Caucasians of northern European descent (a population at risk for hemochromatosis) who have joint disease, severe and continuing fatigue, heart disease, elevated liver enzymes, impotence, and diabetes, because they are candidates for hemochromatosis *HFE* genetic testing.

Purpose

The primary purpose of this document is to define essential genetic and genomic competencies for all registered nurses. This document is intended to guide nurse educators in the design and implementation of learning experiences that help students/learners/practicing nurses achieve these genetic and genomic competencies. These competencies are not intended to replace or recreate existing standards of practice but are intended to incorporate the genetic and genomic perspective into all nursing education and practice. The goal is to prepare the nursing workforce to deliver competent genetic- and genomic-focused nursing care.

Applicability

The genetic and genomic competencies are integral to the practice of all registered nurses regardless of academic preparation, practice setting, role, or specialty.

Definitions

The first two definitions of two central and somewhat overlapping terms remain a work in progress, because the new knowledge produced by genome research will create an ongoing need to assess and revise our understanding of the influence of both genetic and genomic factors for health outcomes. For the purpose of this document, both genetic and genomic information will be used as the context for defining required competencies.

- **Genetics** – Study of individual genes and their impact on relatively rare single gene disorders.²

- **Genomics** – Study of all the genes in the human genome together, including their interactions with each other, the environment, and the influence of other psychosocial and cultural factors.²

The rest of the key definitions are more established, but are offered to clarify the use in this report of what can have more general meanings:

- **Clients** – Recipients of health care may include persons, families, communities, and/or populations from any race, ethnicity/ancestry, culture, or religious background. The term *clients* will be used throughout the document to reflect the focus of nursing care.
- **Pedigree** – A graphic illustration of a family health history using standardized symbols.³
- **Resources** – A collection of genetic and genomic tools and sites for healthcare referrals for delivery of nursing care.
- **Services** – The delivery of genetic and genomic health care.
- **Technology** – The use of tools and/or machines to perform tasks; in this case, the identification and assessment of genetic and genomic information (e.g., the use of microarray technology to assess the genetic features of a specific tumor).

Development of the Competencies and Process of Consensus

The development of this document and its underlying competencies are described below.

Resource/Reference Documents

The Steering Committee identified, reviewed, analyzed, and compared competencies recommended in existing published and peer-reviewed documents.⁴⁻¹² A pre-publication manuscript by Greco and Salveson¹³ reported on a qualitative analysis of published competency recommendations, including many of the above documents.^{4,5,8,9} In addition, a competence-based education framework developed in the United Kingdom was used as a resource document.¹⁴ Analysis of these documents and resources identified fundamental genetic and genomic competencies applicable for all registered nurses. A summary of available resources is provided in Appendix A.

Competency Development

Based on the review of earlier peer-reviewed published work reporting practice-based genetic and genomic competencies, guidelines, and recommendations, a group of nurse leaders from clinical, research, and academic settings developed these proposed competencies. The proposed competencies were approved by a steering committee of federal, academic, and national leaders in nursing. In addition, these competencies were reviewed by nurse representatives to the National Coalition for Health Professional Education in Genetics (NCHPEG) meeting in 2005 with subsequent revision to integrate their comments. To assist the development process, public comments, especially from the nursing community, were solicited.

Process of Consensus

The four-phase consensus process that guided the creation of this document is described below.

- *Phase I:* The Steering Committee reviewed and provided comments on the preliminary document. This revised draft document was shared with nursing representatives attending the National Coalition for Health Professional Education in Genetics meeting (January 2005) to further define and structure these recommended essential nursing competencies in genetics and genomics.
- *Phase II:* Additional review of the revised essentials document commenced with the posting for public comment at <http://NursingWorld.org/ethics/genetics> and announcement to the American Nurses Association (ANA) and its constituent members and organizational affiliates, the Nursing Organizations Alliance™, and other nursing organizations. All comments were carefully considered and appropriate revisions incorporated as indicated.
- *Phase III:* A meeting of key stakeholders was held September 21 and 22, 2005, to establish consensus on the final competency document by key stakeholders. This meeting's participants (consensus panel) are listed on pages 3 and 4. Strategies to integrate genetic and genomic information into education and practice were proposed and then discussed, with identification of steps to include in an action plan for integration of recommended genetic and genomic nursing competencies content into curricula, the NCLEX examination, specialty certification processes, and accreditation programs.
- *Phase IV:* Endorsement of the final document by all Nursing Organizations Alliance™ member organizations was requested by March 2006.

ESSENTIAL COMPETENCIES

Professional Responsibilities

All registered nurses are expected to engage in professional role activities that are consistent with *Nursing: Scope and Standards of Practice* (2004) by the American Nurses Association.¹⁵ In addition, competent nursing practice now requires the incorporation of genetic and genomic knowledge and skills in order to:

- Recognize when one's own attitudes and values related to genetic and genomic science may affect care provided to clients.
- Advocate for clients' access to desired genetic/genomic services and/or resources including support groups.
- Examine competency of practice on a regular basis, identifying areas of strength, as well as areas in which professional development related to genetics and genomics would be beneficial.
- Incorporate genetic and genomic technologies and information into registered nurse practice.
- Demonstrate in practice the importance of tailoring genetic and genomic information and services to clients based on their culture, religion, knowledge level, literacy, and preferred language.
- Advocate for the rights of all clients for autonomous, informed genetic- and genomic-related decision-making and voluntary action.

Professional Practice Domain

Nursing Assessment: Applying/Integrating Genetic and Genomic Knowledge

The registered nurse:

- Demonstrates an understanding of the relationship of genetics and genomics to health, prevention, screening, diagnostics, prognostics, selection of treatment, and monitoring of treatment effectiveness.
- Demonstrates ability to elicit a minimum of three-generation family health history information.

- Constructs a pedigree from collected family history information using standardized symbols and terminology.
- Collects personal, health, and developmental histories that consider genetic, environmental, and genomic influences and risks.
- Conducts comprehensive health and physical assessments which incorporate knowledge about genetic, environmental, and genomic influences and risk factors.
- Critically analyzes the history and physical assessment findings for genetic, environmental, and genomic influences and risk factors.
- Assesses clients' knowledge, perceptions, and responses to genetic and genomic information.
- Develops a plan of care that incorporates genetic and genomic assessment information.

Identification

The registered nurse:

- Identifies clients who may benefit from specific genetic and genomic information and/or services based on assessment data.
- Identifies credible, accurate, appropriate, and current genetic and genomic information, resources, services, and/or technologies specific to given clients.
- Identifies ethical, ethnic/ancestral, cultural, religious, legal, fiscal, and societal issues related to genetic and genomic information and technologies.
- Defines issues that undermine the rights of all clients for autonomous, informed genetic- and genomic-related decision-making and voluntary action.

Referral Activities

The registered nurse:

- Facilitates referrals for specialized genetic and genomic services for clients as needed.

Provision of Education, Care, and Support

The registered nurse:

- Provides clients with interpretation of selective genetic and genomic information or services.
- Provides clients with credible, accurate, appropriate, and current genetic and genomic information, resources, services, and/or technologies that facilitate decision-making.
- Uses health promotion/disease prevention practices that:
 - Consider genetic and genomic influences on personal and environmental risk factors.
 - Incorporate knowledge of genetic and/or genomic risk factors (e.g., a client with a genetic predisposition for high cholesterol who can benefit from a change in lifestyle that will decrease the likelihood that the genetic risk will be expressed).
- Uses genetic- and genomic-based interventions and information to improve clients' outcomes.
- Collaborates with healthcare providers in providing genetic and genomic health care.
- Collaborates with insurance providers/payers to facilitate reimbursement for genetic and genomic healthcare services.
- Performs interventions/treatments appropriate to clients' genetic and genomic healthcare needs.
- Evaluates impact and effectiveness of genetic and genomic technology, information, interventions, and treatments on clients' outcome.

IMPLEMENTATION STRATEGIES

Practice and curriculum change requires the commitment of nursing leaders and academic faculty to develop a long-term plan to incorporate genetic and genomic information in order to improve the public's health. Faculty and practicing nurses must be supported by their institutions to attend continuing education or academic courses to update their genetic and genomic knowledge. Collaboration with other disciplines is necessary to provide a strong foundation of knowledge of basic human genetics and current applications to practice.

Key Strategies

Some strategies to implement the competencies specified in this document are described briefly below.

- *NCLEX* – Participate in the NCLEX test development process to ensure inclusion of test items addressing genetic and genomic knowledge. Continue to include and participate in development of test items assessing integration of genetic and genomic knowledge. Work with the American Hospital Association and other regulatory agencies and organizations to incorporate genetics and genomics practice content on assessments of quality which will also influence NCLEX content.
- *Certification* – All certification exams should include test items measuring the knowledge of genetic and genomic information pertinent to the specialty for which a registered nurse is being certified.
- *Practicing Nurses* – Practicing nurses should be encouraged to pursue genetic and genomic continuing education. Consider establishing a United States National Genetics Education and Development Center modeled after the United Kingdom initiative which can serve as the central resource for genetics and genomic education initiatives. See <http://www.geneticseducation.nhs.uk>
- *Accreditation of Programs* – The standards for accreditation should evaluate whether the curriculum is designed to meet the essential core genetic and genomic competencies. See <http://www.nlnac.org/home.htm> for the most recent edition of the National League for Nursing Accrediting Commission's accreditation manual for these standards.

- *Curricula* – Each nursing curriculum preparing registered nurses for practice (at any and all levels) should include genetic and genomic learning experiences sufficient for all registered nurses to be proficient in the essential competencies. This can be accomplished by incorporating genetics and genomics learning experiences into existing classes. Refer to Appendix A for resources useful to faculty.

Incorporation of Competencies, Content, and Teaching Strategies into the Curriculum

Today's nursing curriculum is dense, and integrating new information is a challenge. Since genetic and genomic information is integral and critical to all areas of nursing practice, curricula must prepare graduates with this information.¹⁶ Nursing faculty from 171 nursing schools contributed to the development of a checklist which was created to help faculty integrate genetics content into nursing curricula.¹⁷ An important initial strategy noted in the checklist is to determine what content is already being taught in pre-nursing and nursing courses. Once content gaps are identified, many curriculum change strategies can be used to add genetic and genomic content to instructional resources.¹⁸ Potential solutions include incorporating genetics and genomics as a central science including the following:

- Add genetic and genomic content to existing lectures;
- Integrate assignments and test questions incorporating genetic and genomic knowledge into existing courses;
- Include genetic- and genomic-focused objectives in all nursing courses;
- Create a curriculum thread focused on genetics and genomics;
- Develop an elective genetics and genomics nursing course that can be transitioned into a required course; and
- Collaborate with interdisciplinary colleagues to design courses and curricula.

Outcomes associated with some of the curriculum options listed above have already been published.¹⁹ A theory-based approach to integrating genetics into one school's nursing curriculum is well described by Horner et al.²⁰ Integrative approaches in associate and baccalaureate programs have been published by Danz (2004), Zamerowski (2000), and Read et al. (2004).^{21, 22, 23}

Development of a single genetic and genomic nursing course incorporated into the curriculum has also been described.²⁴ The ability of faculty to effectively incorporate genetics and genomics content into the nursing curricula hinges on the availability of faculty with education or expertise in genetics and genomics.²⁵ Outcomes associated with faculty training initiatives addressing this need (including summer institutes and a web-based program^{26,27,28}) have also been described.

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APPENDIX A

RESOURCES TO SUPPORT THE GENETICS AND GENOMICS COMPETENCIES

This appendix brings together the following categories of available resources that are pertinent to the fundamental genetic and genomic competencies for RNs specified in this publication.

Books and Monographs

Career Development: Continuing Education

Career Development: Post-Graduate Programs

Clinical Genetics

Consumer/Client: General Information

Consumer/Client: Support and Advocacy Groups

ELSI (Ethical, Legal, and Social Implications), Policy, and
Legislation

Family History Tools

Genome Research

Health Professional Practice and Education

Internal Review Boards (IRBs)

News Sites Specializing in Genetics and Genomics

Professional Organizations: Genetics

Professional Organizations: Nursing Practice

Risk Assessment

Search Engines Specializing in Genetics and Genomics

United States Government Agencies

All online resources were current as of July 10, 2006. Listing of a book in this appendix does not indicate that it is still in print.

Books and Monographs

Resource	Publisher	Description
<i>Clinical Genetics in Nursing Practice</i> , 3rd ed. (2005) By Felissa R. Lashley	Springer Publishing Company, Inc.	Nursing and genetics text
<i>Genetics in Nursing</i> (2004) Editors: Suzanne Feetham and Janet Williams	International Council of Nurses http://www.icn.ch/bookshop.htm	Monograph to provide direction for nursing leadership in genetics in global, scientific, practice, education, social, information, ethical and political contexts.
<i>Genetics in Oncology Practice: Cancer Risk Assessment</i> (2003) Editors Amy Strauss Tranin, Agnes Masny, and Jean Jenkins	Oncology Nursing Society Press	A detailed overview of genetics and the implications for cancer nursing practice.
<i>The Genetics Revolution: Implications for Nurses</i> (1997) Editor: Felissa Lashley	American Academy of Nursing	The first nursing monograph to be published on the profession's responses to the opportunities and challenges of the Human Genome Project and the advances in gene research.
<i>Applied Genetics in Healthcare</i> (2005) By Heather Skirton, Christine Patch, and Janet Williams	BIOS Scientific Publishers (New York; Abingdon [England]: Taylor and Francis Group)	Test for application of genetic and genomic principles by nurses who provide genetic and genomic health care as specialist practitioners and advanced practice nurses

<p><i>Nursing Care in the Genomic Era: A Case-Based Approach</i> (2005) By Jean F. Jenkins and Dale Halsey Lea</p>	<p>Jones and Bartlett Publishers</p>	<p>Provides nurses with up-to-date and accessible information on core competencies in genetics, interwoven with stories that highlight a particular condition and the related biological, personal, and psychosocial issues.</p>
<p><i>Genetics in Clinical Practice: New Directions for Nursing and Health Care</i> (1998) By Dale Halsey Lea, Jean F. Jenkins, and Clair A. Francomano</p>	<p>Jones and Bartlett Publishers</p>	<p>Provides a unique, understandable approach to the emerging science of genetics.</p>
<p><i>Genetic Nursing Portfolios: A New Model for the Profession</i> (2005) Editor: Rita Black Monson</p>	<p>American Nurses Association (Nursebooks.org)</p>	<p>Describes the development of the GNCC credentialing program. The book shows how to assemble and use a portfolio to verify competency in a specialty.</p>
<p><i>Statement on the Scope and Standards of Genetics Clinical Nursing Practice</i> (1998) By International Society of Nurses in Genetics, Inc.</p>	<p>American Nurses Association and ISONG (Nursesbooks.org)</p>	<p>Scope and standards of practice for nurses in genetics (A new edition has been published in 2006 as <i>Genetics/Genomics Nursing: Scope and Standards of Practice.</i>)</p>
<p><i>Genetics and the Perinatal and Women's Health Nurse</i> (2001) By Judith Lewis</p>	<p>Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN)</p>	<p>This practice monograph provides nurses with the basic information they need to provide patients with accurate information about genetic screening and testing.</p>

Genetic Issues for Perinatal Nurses (2003)
By Janet Williams and Dale Halsey Lea
Editor: Rita Reis Wieczorek

March of Dimes Birth Defects Foundation
Education Services Department

A nursing continuing education program that presents an update of genetics, principles of inheritance and ethical principles. Provides information on identification of actual or potential genetic conditions in the fetus, parent, or neonate.

The Nursing Clinics of North America: Clinical Genetics (2000). Editors: Sharon Olsen, Lynn Baxendale-Cox, and Victoria Mock

W.B. Saunders Company

The basics of genetics and genetic health care for the practice of every nurse and specialist.

Cancer Care: A Guide for Oncology Nurses (2002)
By Dale Halsey Lea, Kathleen Calzone, Agnes Masny, and Annette Parry Bush

Oncology Nursing Society Press

A tool kit to assist the nurse in becoming competent in cancer genetics.

Career Development: Continuing Education

Resource	Contact	Description
American Society of Clinical Oncology	ASCO Bookstore 1900 Duke Street, Suite 200 Alexandria, VA 22314 (703) 299-0150 http://www.asco.org	<i>Cancer Genetics and Cancer Predisposition Genetic Testing, 2nd Edition</i> : An ASCO Curriculum, including binders and CD-ROM slide set. ONCOSEP: Genetics: A tool for self-education and assessment in genetic testing, risk assessment, and specific areas of genetic disease.
Cincinnati Children's Hospital Medical Center	3333 Burnet Avenue Cincinnati, Ohio 45229-3039 (513) 636-4200 http://www.cincinnatichildrens.org/ed/clinical/gpnf	Genetics Education Program for Nurses: Web-Based Genetics Institute and Genetics Program for Nursing Faculty
City of Hope National Medical Center and Beckman Research Institute	1500 E. Duarte Road Duarte, CA 91010-3000 (800) 423-7119 http://cityofhope.org/CME/cmemainpg.htm	Intensive Course in Cancer Risk Assessment
Foundation for Blood Research	8 Nonesuch Road P.O. Box 190 Scarborough ME 04070-0190 (207) 883-4131 http://www.fbr.org/publications/pub_curic.html	Practice-based Genetics Curriculum For Nurse Educators (sample chapter available online)
Fox Chase Cancer Center	333 Cottman Avenue Philadelphia, PA 19111-2497 (215) 728-2892 or 1-888-369-2427 http://www.fccc.edu/nursing/education/	A Basic Course in Cancer Genetics: Familial Cancer Risk Assessment An Advanced Course for Nurses in Genetic Cancer Risk Counseling

International Society of Nurses in Genetics, Inc. (ISONG)	461 Cochran Road Box 246 Pittsburgh, PA 15228 412-344-1414 E-mail: isongHQ@msn.com http://www.isong.org/events/conference.cfm and http://www.isong.org/support/scope.cfm	Annual Nursing and Genetic Education Meeting Statement on the Scope and Standards of Genetics Clinical Nursing Practice
National Institute of Nursing Research (NINR)	Summer Genetics Institute Division of Intramural Research National Institute of Nursing Research National Institutes of Health 31 Center Drive, 5B-13 Bethesda, MD 20892-2178 (202) 255-6922 http://ninr.nih.gov/ninr/research/dir/sgi.html	Summer Genetics Institute program designed to provide training in molecular genetics for use in research and clinical practice
Oncology Nursing Society (ONS)	125 Enterprise Drive RIDC Park West Pittsburgh, PA 15275-1214 (866) 257-4ONS Email: customer.service@ONS.org http://www.ons.org/ceCentral/prevention/	Genetics Short Course for Cancer Nurses

Career Development: Post-Graduate Programs

Organization	Contact	Program/Resources
Columbia University	Columbia University School of Nursing 617 West 168th Street New York, NY 10032 (212) 305-6761 http://www.cumc.columbia.edu/dept/nursing/programs/cg.html	Master's degree program with a clinical genetics sub-specialty
University of Iowa	University of Iowa College of Nursing 50 Newton Rd. Iowa City, IA 52242 (319)335-7046 or 335-7018 Attention: Janet Williams, PhD, RN http://www.nursing.uiowa.edu/academprog/msn/geneticsindex.htm	Master's and PhD degree programs in Genetics Nursing
University of Pittsburgh	University of Pittsburgh School of Nursing 239 Victoria Building Pittsburgh, PA 15261 (412) 624-4586 or 1-888-747-0794 http://www.pitt.edu/~nursing/academicprograms/certificates/post_bacc_genetics.html and http://www.pitt.edu/~nursing/academicprograms/certificates/post_masters_cert_genetics.html	Post-Baccalaureate Certificate in Genetics Post-Master's Certificate in Health Care Genetics

University of California, San Francisco	University of California, San Francisco Department of Physiological Nursing 2 Koret Way, Suite N-631 San Francisco, CA 94143- 0610 (415) 476-0984 Attention: Mary B. Engler, PhD, RN, MS http://nurseweb.ucsf.edu /www/genomic.htm	Master's and doctoral degree programs in Genomics
University of Washington	University of Washington School of Nursing Box 357260 Seattle, WA 98195 (206) 221-2458 http://www.son.washington.edu/eo/apgn	Master's degree pro- gram with a minor in genetics nursing (advanced practice genetics nursing)

Clinical Genetics

Resource	Contact	Description
GeneTests	http://www.genetests.org/	Information for health professionals about hundreds of genetic tests and the laboratories performing those tests
Human Genome Epidemiology Network (HuGENet™)	http://www.cdc.gov/genomics/hugenet/default.htm	Network for sharing population-based human genome epidemiologic information
INFOGENETICS©	http://www.infogenetics.org/	Clinical practice tools
National Birth Defects Prevention Network	http://www.nbdpn.org	Network of resources for surveillance, research, and prevention of birth defects care
National Newborn Screening & Genetics Resource Center	http://genes-r-us.uthscsa.edu/	Information and resources nationally available on newborn screening and genetics
Online Mendelian Inheritance in Man (OMIM™)	http://www.ncbi.nlm.nih.gov/Omim/	Catalog of human genes and genetic disorders

Consumer/Client: General Information

Resource	Contact	Description
Building and Understanding Your Medical Family History	http://jamesline.com/patientsandvisitors/prevention/cancergenetics/	Information on collecting family health history and assessing cancer risk
The DNA Files	http://www.dnfiles.org/	A series of 14 one-hour public radio documentaries and related information (10 more to come out in 2006)
Dolan DNA Learning Center	http://vector.cshl.org/	A variety of educational resources, including an interactive DNA timeline
Ethics and Genetic Testing for Nurses	http://www.nursing.uiowa.edu/areas/parentchild/cdrom.htm	CD-ROM modules on ethics, ethics of genetic testing, and case studies
Foundations of Classical Genetics	http://www.esp.org/foundations/genetics/classical	Complete versions of classic genetics works written between 350 B.C. and 1965
Generational Health	http://209.61.158.31:8287/	Tool to help trace a family's medical history and provide information on common diseases
Genetic Science Learning Center	http://gslc.genetics.utah.edu/	Basic genetics, genetic disorders, genetics in society, and several thematic units
Genetics and Rare Diseases Information Center	http://www.genome.gov/10000409	Information service for the general public, including patients and their families, as well as healthcare professionals and biomedical researchers

Genetics Education Center	http://www.kumc.edu/gec/	Material for educators
Genetics Home Reference—National Library of Medicine	http://ghr.nlm.nih.gov/	Consumer information about genetic conditions and the genes responsible for those conditions
The Human Genome Project: Exploring Our Molecular Selves	http://www.genome.gov/Pages/EducationKit/	Download modules and online viewing about Human Genome Project, timeline about genetics, talking glossary, classroom activities, 3-D animation of cell
MendelWeb	http://www.mendelweb.org/	Mendel's papers in English (with annotations) and German and related materials
National Society of Genetic Counselors—Your Family History	http://www.nsgc.org/consumer/familytree/index.cfm	Information on collecting family health history
The New Genetics: A Resource for Students and Teachers	http://www4.umdj.edu/camlbweb/teachgen.html	Links to genetic education resources
Understanding Gene Testing (from the National Cancer Institute, NIH)	http://www.cancer.gov/cancertopics/UnderstandingCancer/genetesting	Primer on genetic testing

Consumer/Client: Support and Advocacy Groups

Resource	Contact	Description
Coalition for Genetic Fairness	http://www.geneticfairness.org/	Advocacy group for federal legislation regarding genetics discrimination
Family Village	http://www.familyvillage.wisc.edu/index.htmlx	Disability-related resources
Genetic Alliance	http://www.geneticalliance.org/	Wide array of genetic-related information
National Organization for Rare Disorders (NORD)	http://www.rarediseases.org/	Rare diseases database and index of organizations

ELSI (Ethical, Legal, and Social Implications), Policy, and Legislation

Resource	Contact	Description
American Academy of Pediatrics: Ethical Issues With Genetic Testing in Pediatrics	http://aappolicy.aappublications.org/ and enter the article title in the Title search window.	Recommendations on newborn screening and genetic testing in children
Bioethics Resources on the Web (NIH)	http://www.nih.gov/sigs/bioethics/	Links to bioethics resources
bioethics.net	http://www.bioethics.net	Links to articles on bioethics and genetics
Council for Responsible Genetics	http://www.genewatch.org/	Information on the social, ethical, and environmental implications of genetic technologies
DNA Patent Database	http://dnapatents.georgetown.edu	Searchable database of U.S. DNA-based patents issued by the U.S. Patent and Trademark Office
Ethical, Legal, and Social Issues (from the Human Genome Project)	http://www.ornl.gov/hgmis/elsi/elsi.html	Information, articles, and links on a wide range of issues
Foundation for Genetic Medicine, Inc.	http://www.genome.gov/10001754	Links to information on the science of genetic medicine, genetic and genomic research, and ethical, legal, and social dimensions and implications
Genethics.ca	http://www.geneticmedicine.org/	Information on the social, ethical, and policy issues associated with genetic and genomic knowledge and technology

Genetics and the Law (from CRG—Council for Responsible Genetics)	http://www.genethics.ca/index.html	A searchable online clearinghouse of information on emerging legal developments in human genetics
The Genetics and Public Policy Center	http://www.genelaw.info/	Information on public policy related to human genetic technologies for the public, media, and policymakers
Genome Technology and Reproduction: Values and Public Policy and The Communities of Color and Genetics Policy Project	http://www.sph.umich.edu/genpolicy/	Two subprojects combined to form a five-year project designed to provide policy recommendations based on public perceptions and responses to the explosion of genetic information and technology.
HumGen	http://www.humgen.umontreal.ca/en/	Access to a comprehensive international database on the legal, social, and ethical aspects of human genetics
National Information Resource on Ethics and Human Genetics	http://www.georgetown.edu/research/nrcbl/nirehg/index.htm	Links to resources and databases on ethics and human genetics
NCSL (National Conference of State Legislatures) Genetic Technologies Project	http://www.ncsl.org/programs/health/genetics.htm	Status of legislative actions and access to policy briefs on genetic issues of concern to state legislators
The President's Council on Bioethics	http://www.bioethics.gov/	Information on current bioethical issues

Scope Note Series (Kennedy Institute of Ethics/ Georgetown University)	http://www.georgetown.edu/research/nrcbl/nirehg/scope.htm	Annotated bibliographies on various aspects of genetics and ethics
THOMAS Legislative Information (from Library of Congress)	http://thomas.loc.gov/	Searchable database of U.S. legislation (current and previous)
Your Genes, Your Choices	http://ehrweb.aaas.org/ehr/books/index.html	Describes the Human Genome Project, the science behind it, and the ethical, legal, and social issues that are raised by the project

Family History Tools

Resource	Contact	Description
American Medical Association: Family History Tools	http://www.ama-assn.org/ama/pub/category/2380.html	Tools for gathering family history and links to resources
Cyrillic	http://www.cyrillicsoftware.com	Pedigree drawing software for genetic counselors and clinicians; links to genetic sites
Pedigree-Draw	http://www.pedigree-draw.com	Pedigree drawing software for Macintosh
Progeny	http://www.progeny2000.com	Genetic data management and pedigree drawing software
U.S. Surgeon General's Family History Initiative: "My Family Health Portrait"	http://www.hhs.gov/familyhistory/	Patient-completed pedigree drawing software

Genome Research

Resource	Contact	Description
BLAST Search (part of Ensembl; see below)	http://www.ensembl.org/Data/blast.html	Provides data sets from an annotated genome analysis and annotation process; searches of protein or DNA sequence against metazoan genomes
The Cancer Genome Anatomy Project	http://cgap.nci.nih.gov	Access to all CGAP data and biological resources
Chromosomal Variation in Man	http://www.wiley.com/legacy/products/subject/life/borgaonkar/	A catalog of chromosomal variants and anomalies
Ensembl (Joint software project between the European Bioinformatics Institute and the Sanger Institute)	http://www.ensembl.org	Access to DNA and protein sequences with automatic baseline annotation
Genome Sequencing Center: Human genome maps	http://genome.wustl.edu/	Links to clone and accession maps of the human genome
National Center for Biotechnology Information: Genomic Biology	http://www.ncbi.nlm.nih.gov/genome/guide/	Views of chromosomes, maps, and loci; links to other NCBI resources
Oak Ridge Genome Channel	http://compbio.ornl.gov/channel/	Java viewers for human genome data
Online Mendelian Inheritance in Man (OMIM™)	http://www.ncbi.nlm.nih.gov/Omim/	Catalog of human genes and genetic disorders
The SNP (Single Nucleotide Polymorphisms) Consortium	http://snp.cshl.org/	A variety of ways to query for SNPs in the human genome

UCSC Genome
Bioinformatics

<http://genome.cse.ucsc.edu/>

Reference sequence for the human and *C. elegans* genomes and working drafts for the mouse, rat, Fugu, *Drosophila*, *C. briggsae*, yeast, and SARS genomes

Health Professional Practice and Education

Resource	Contact	Description
Centre for Education in Medical Genetics	http://www.bwhct.nhs.uk/genetics-cemg-home.htm	Develops, provides, and evaluates genetics education opportunities and resources
Centre for Genetics Education	http://www.genetics.com.au/	Education and service resources for patients and professionals
Dolan DNA Learning Center	http://www.dnalc.org/	Interactive, multimedia genetics education resources
Foundation for Genetic Education and Counseling	http://www.fgec.org	Educational resources on genetics and common diseases, especially psychiatric disorders (bipolar disorder and schizophrenia)
GenEd Project	http://www.medicine.man.ac.uk/GenEd/	Education and research links related to European aspects of genetic services
Genetics and Your Practice	http://www.marchofdimes.com/gyponline/index.bm2	Online modules for healthcare professionals designed for exploration of a topic rather than sequential presentation of material... Many excellent fact sheets and sample clinical forms
Genetics in Clinical Practice: A Team Approach	http://iml.dartmouth.edu/education/cme/Genetics/ or http://www.acmg.net/resources/cd-rom-01/intro.asp	Takes healthcare provider into a Virtual Genetics Clinic... Interactive virtual genetics clinic with case scenarios and case discussions... Target audience is primary care professionals

Genetics in Primary Care	http://genes-r-us.uthscsa.edu/resources/genetics/primary_care.htm	Training program curriculum materials
Genetics in Psychology	http://www.apa.org/science/genetics/homepage.html	American Psychological Association's genetics site
Genetics Education Program for Nurses (GEPN) curriculum resources	www.gepn.cchmc.org or http://www.cincinnatichildrens.org/ed/clinical/gpnf/default.htm	Sample genetics nursing course syllabi and other genetics educational opportunities and resources for nurses, as well as links to instructional resources used in GSI (Genetics Summer Institute) and WBG I (Web-based Genetic Institute)
Genetics: Educational Information	http://genetics.faseb.org/genetics/ashg/policy/rep-01.htm	Medical school course competencies, skills, knowledge, and behaviors which should be covered in genetics
Kansas Genetics Education Center	http://www.kumc.edu/gec/	An ever-growing list of available resources, lesson plans, etc.
National Cancer Institute's CancerNet	http://www.cancer.gov/cancerinfo/prevention-genetics-causes	Authoritative information about cancer genetics
National Coalition for Health Professional Education in Genetics (NCHPEG)	http://www.nchpeg.org/	Core competencies in genetics and reviews of education programs... Descriptions of available instructional resources, courses, institutes... All have been submitted by developers and some have accompanying peer reviews

Physician's Database Query (PDQ®) Cancer Information Summaries	http://www.cancer.gov/cancerinfo/pdq/genetics	PDQ® cancer information summaries in genetics
Practice-Based Genetics Curricula for Nurse Educators	http://www.fbr.org/publications/pub_curic.html	Bound instructional modules with accompanying CD or PowerPoint presentations (sample chapter available online)
Six Weeks to Genomic Awareness	http://www.cdc.gov/genomics/training/sixwks.htm	Webcast of 12 segments of genomic topics for public health professionals

Institutional Review Boards (IRBs)

Resource	Contact	Description
<i>Genetic Testing and Screening in the Age of Genomic Medicine</i> . New York State Task Force on Life and Law (2001)	http://www.health.state.ny.us/nysdoh/taskforce/screening.htm	Includes general and state-specific information in a bulleted report that is relatively easy to scan by topic
<i>Human Subjects Protection Resource Book</i> . U.S. Department of Energy (2006)	http://www.science.doe.gov/ober/humsubj/resourcebook.html	Synthesizes the current information on protecting human research subjects, its application to new fields, and the underlying rules, regulations, and guidance... Includes chapters specific to given types of research (including genetics and gene therapy) and specific research populations
<i>My Very Own Medicine: What Must I know? Information Policy for Pharmacogenetics</i> . Public Health Genetics Unit, National Health Service, UK - D. Melzer et al. (2003)	http://www.phgu.org.uk/pages/work/pgx.html	General information and background, looking ahead to future needs, including guidance for IRBs
<i>Protecting Human Research Subjects Institutional Review Board Guidebook, Chapter H: Human Genetic Research</i> . Office for Human Research Protections (1993)	http://www.hhs.gov/ohrp/irb/irb_chapter5ii.htm#h12	Discusses many issues that continue to challenge IRBs and investigators (and policymakers) today
<i>Pharmacogenetics: Ethical Issues</i> . Nuffield Council on Bioethics (2003)	http://www.nuffieldbioethics.org/go/ourwork/pharmacogenetics/publication_314.html	Includes a section discussing the use of pharmacogenetics in clinical trials

News Sites Specializing in Genetics and Genomics

Resource	Contact	Description
Genetics and Molecular Medicine (American Medical Association)	http://www.ama-assn.org/ama/pub/category/1799.html	Links to current articles, new educational programs and initiatives, and other resources
Genome News Network (Center for the Advancement of Genomics)	http://www.genome-newsnetwork.org/	Original articles and links
Science News Presented by BIO, the Biotechnology Industry Organization	http://science.bio.org/genomics.news.html	Links to current articles

Professional Organizations: Genetics

Resource	Contact	Description
American Board of Genetic Counseling (ABGC)	http://www.faseb.org/genetics/abgc/abgcmenu.htm	Information about certification of genetic counselors
American Board of Medical Genetics (ABMG)	http://www.faseb.org/genetics/abmg/abmgmenu.htm	Information about medical genetic training programs and certification of geneticists
American College of Medical Genetics (ACMG)	http://www.acmg.net/	Resources, policy statements, and practice guidelines about medical genetics
American Society for Human Genetics (ASHG)	http://www.ashg.org/	Resources, projects, and policies concerning human genetics
Genetics Nursing Credentialing Commission (GNCC)	http://www.geneticnurse.org	Information about credentialing of genetics nurses
Genetics Society of America (GSA)	http://www.faseb.org/genetics/gsa/gsamenu.htm	Links to teaching websites, general educational courses, and journals and publications about genetics
International Society of Nurses in Genetics (ISONG)	http://www.isong.org/	Resources to help nurses incorporate new knowledge about human genetics into practice, education, and research
National Society of Genetic Counselors (NSGC)	http://www.nsgc.org/	Information about genetic counseling; practice guidelines, links to genetic counselors, genetic discrimination resources
Society for the Study of Inborn Errors of Metabolism (SSIEM)	http://www.ssiem.org/	Links to websites and resources about inherited metabolic disorders

Professional Organizations: Nursing Practice

Organization	Contact	Description
American Nurses Association	http://www.nursingworld.org	Code of Ethics for Nurses Policy statements on: <ul style="list-style-type: none"> • Genetics and nursing • Cloning and therapeutic and reproductive application of genetics • Human cloning: human rights, discriminations and privacy and confidentiality
American Society of Clinical Oncology	http://www.asco.org	Policy statement update Genetic testing for cancer susceptibility
Association of Women's Health, Obstetric and Neonatal Nurses	http://www.awhonn.org	Position statement on the role of the registered nurse as related to genetic testing
International Society of Nurses in Genetics, Inc. (ISONG)	http://www.isong.org/support/scope.cfm * and http://www.isong.org/about/position.cfm (* The currency of this <i>Statement</i> document will be superseded by the end of 2006 with an updated and expanded document on the scope and standards of genetic and genomic nursing practice.)	Statement on the scope and standards of genetics clinical nursing practice. Policy statements on the roles of nurses and/or nursing in: <ul style="list-style-type: none"> • Access to genomic health care • Privacy and confidentiality of genetic information • Genetic counseling for vulnerable populations • Informed decision-making and consent
National Coalition for Health Professional Education in Genetics (NCHPEG)	http://www.nchpeg.org	Recommendations of core competencies in genetics for all health professionals

Oncology Nursing
Society

[http://www.ons.org/
publications/positions/](http://www.ons.org/publications/positions/)

Position statements on:

- The role of the oncology nurse in cancer genetic counseling
- Cancer predisposition genetic testing and risk assessment counseling

Risk Assessment

Resource

Harvard Center for
Cancer Prevention: Your
Disease Risk

Contact

[http://www.yourcancer
risk.harvard.edu/](http://www.yourcancer
risk.harvard.edu/)

Description

Personalized estimation
of cancer risk and tips for
prevention

National Cancer Institute:
Breast Cancer Risk
Assessment Tool

[http://bcra.nci.nih.gov/
brc/](http://bcra.nci.nih.gov/
brc/)

Interactive tool for health
professionals to measure
a woman's risk of invasive
breast cancer

Search Engines Specializing in Genetics and Genomics

Resource	Contact	Description
Centers for Disease Control: Genomics and Disease Prevention GDP InfoSearch	http://apps.nccd.cdc.gov/genomics/GDPquerytool/searchbygene.asp	Provides access to information and resources for guiding public health research, policy, and practice on using genetic information to improve health and prevent disease... Includes core competencies for public health genetics
Genetics Resources on the Web (GROW)	http://www.geneticsresources.org/	Provides health professionals and the public with high quality information related to human genetics, with a particular focus on genetic medicine and health
Georgetown University: National Information Resource on Ethics & Human Genetics	http://www.georgetown.edu/research/nrcbl/nirehg/index.htm	Search engine for literature on specific issues related to ethics and human genetics
National Newborn Screening and Genetics Resource Center: Genetic Education Materials (GEM) Database	http://www.gemdatabase.org/GEMDatabase/index.asp	Search engine for policy documents and clinical issues

United States Government Agencies

Resource	Contact	Description
Center for Disease Control and Prevention: National Office of Public Health Genomics (NOPHG), formerly the Office of Genomics and Disease Prevention	http://www.cdc.gov/genomics/	Information about human genetic discoveries and how to use to improve health and prevent disease, including links to many resources
Department of Energy Office of Science (DOEgenomes.org)	http://www.doegenomes.org/	Multiple genomics educational resources
Genetic Modification Clinical Research Information System (GeMCRIS®)	http://www.gemcris.od.nih.gov/	Access to an array of information about human gene transfer trials registered with the NIH
Department of Health and Human Services	http://ask.hrsa.gov/ProfessionalPublications.cfm?start=72	Report of the expert panel on genetics and nursing; includes implications for education and practice
Health Resources and Services Administration (HRSA): Genetics Services Branch of Maternal and Child Health Bureau	http://www.mchb.hrsa.gov/	To support newborn screening and increase knowledge of how genetic disorders affect health
National Cancer Institute's Cancer.gov	http://www.cancer.gov/cancertopics/prevention-genetics-causes/genetics	Authoritative information about cancer genetics
National Human Genome Research Institute	http://www.genome.gov	Research, policy, ethics, education, and training information and resources about genetic and rare diseases

National Institute of Environmental Health Sciences (NIEHS): Environmental Genome Project	http://www.niehs.nih.gov/envgenom/home.htm	Project to improve understanding of human genetic susceptibility to environmental exposures
National Institutes of Health Obesity Research	http://obesityresearch.nih.gov/	Information about NIH-supported research that seeks to identify genetic, behavioral, and environmental causes of obesity and to develop prevention and treatment strategies
National Institutes of Health	http://www.nih.gov/	Research, health policy, ethics, education, and training information and resources
National Institute of Nursing Research: Summer Genetics Institute	nintr.nih.gov/research/	Summer Genetics Institute program designed to provide training in molecular genetics for use in research and clinical practice
Office of Rare Diseases, National Institutes of Health	http://rarediseases.info.nih.gov/	Information on thousands of rare and genetic diseases
Secretary's Advisory Committee on Genetic Testing	http://www4.od.nih.gov/oba/sacgt/aboutsacgt.htm	Public policy issues regarding genetic testing (archival)
Secretary's Advisory Committee on Genetics, Health, and Society	http://www4.od.nih.gov/oba/sacghs/reports/reports.html	Reports on public policy issues regarding the impact of genetic technologies on society



ESSENTIAL NURSING COMPETENCIES AND CURRICULA GUIDELINES FOR GENETICS AND GENOMICS

Central to contemporary health care is that all diseases and health conditions have some genetic or genomic component. Nursing practice, then, increasingly includes genetics and genomics along its pathways of prevention, screening, diagnostics, prognostics, selection of treatment, and monitoring of treatment effectiveness. This monograph succinctly addresses and articulates the competencies essential for all nursing practice, as well as the subsequent curricular guidelines for all nursing education.

Developed by an independent panel of nurse leaders from clinical, research, and academic settings, this monograph reflects their goal: to establish the minimum basis for preparing the nursing workforce to deliver competent genetic- and genomic-focused nursing care. While neither replacing nor recreating existing standards of practice, these essential competencies do incorporate the genetic and genomic perspective into all nursing education and practice.

Based on the panel's review of peer-reviewed published work, input from nurse representatives at a stakeholders' meeting in September 2005, and public comment from the nursing community at large, this monograph reflects nursing's consensus on the minimal amount of genetic and genomic competency expected by every registered nurse, regardless of academic preparation, practice setting, role, or specialty.

To supplement its primary content, this monograph also includes a comprehensive selection of resources—primarily those available online—that pertain directly to the competencies and guidelines. As a result, *Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics*, will prove to be an essential volume for nursing professional development at all levels.