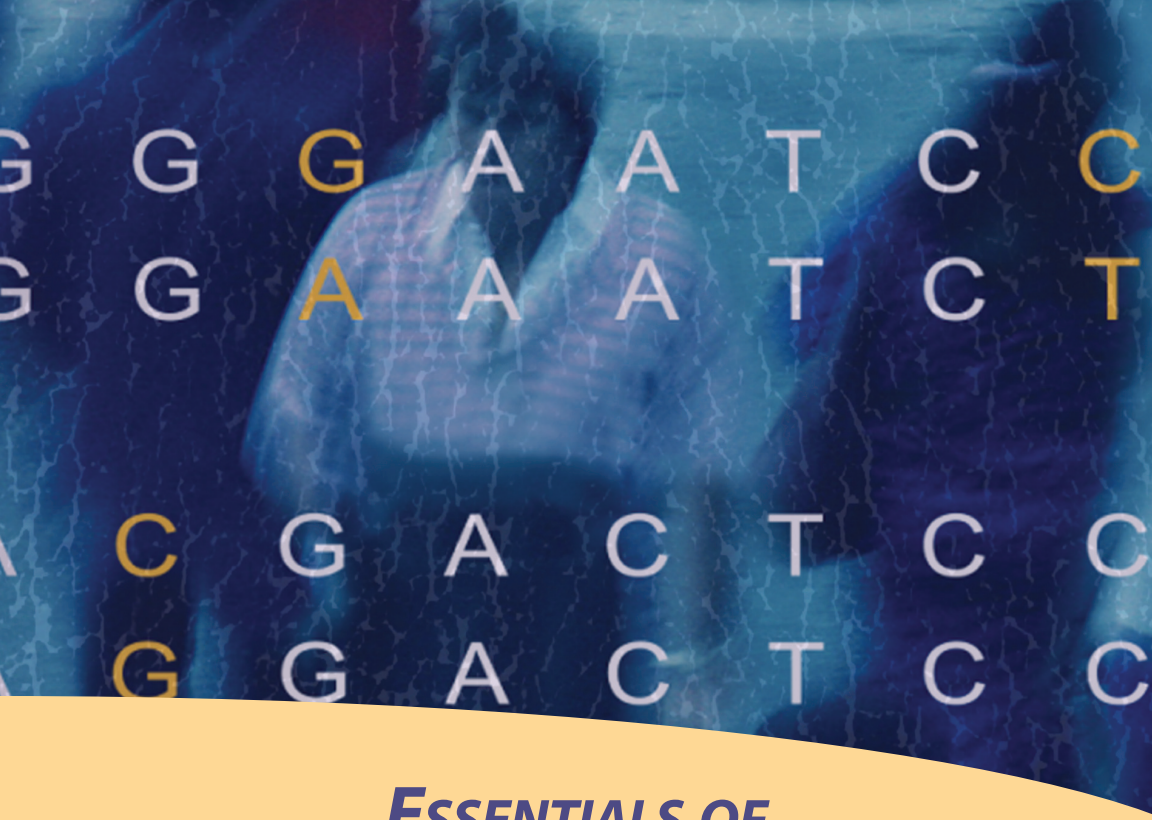

Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators, 2nd Edition

First edition—
Competencies and Curricula Guidelines established by Consensus Panel, September 21–22, 2005 and published by the American Nurses Association, Silver Spring, Maryland 2006

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This publication — *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators, 2nd Edition* — 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 *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators, 2nd Edition* guides nurses in the application of their professional skills and responsibilities.

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Table of Contents

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 Academy of Nursing

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American Association of Neuroscience Nurses

American Association of Occupational Health Nurses

American Nephrology Nurses Association

American Nurses Association

American Nurses Credentialing Center

American Psychiatric Nurses Association

American Radiological Nurses Association

American Society of Pain Management Nursing

American Society of Plastic Surgical Nurses

Association of Pediatric Oncology Nurses

Association of periOperative Registered Nurses

Association of Women's Health, Obstetric and Neonatal Nurses

Council of Cardiovascular Nursing of the American Heart Association

Council of International Neonatal Nurses

Dermatology Nurses Association

Developmental Disabilities Nurses Association

Genetic Alliance

Hospice and Palliative Nurses Association

International Society of Nurses in Genetics

March of Dimes

National Association of Clinical Nurse Specialists

National Association of Hispanic Nurses

National Association of Neonatal Nurses

National Association of Orthopedic Nurses

National Association of Pediatric Nurse Practitioners

National Coalition for Health Professional Education in Genetics

National Coalition of Ethnic Minority Nurse Associations

National Conference of Gerontological Nurse Practitioners

National Gerontological Nursing Association

National League for Nursing

National League for Nursing Accrediting Commission

National Nursing Staff Development Organization

National Organization of Nurse Practitioner Faculties

Oncology Nursing Society

Pediatric Endocrinology Nursing Society

Philippine Nurses Association of America

Sigma Theta Tau International

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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 hemachromatosis) 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 micoarray 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 Salveson[13] 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.

Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics: Outcome Indicators

Introduction

The Outcome Indicators are an adjunct to the Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics and are intended to define for each competency the knowledge and practice indicators. The knowledge and practice indicators are not intended to be prescriptive but provide a guide to the user of essential knowledge elements and suggested practice indicators. To be consistent with the Competencies, definitions will be identical between the two documents. Genetic and genomic information will be used as the context for defining knowledge and practice indicators for each competency.

Definitions

Genetics – Study of individual genes and their impact on relatively rare single gene disorders

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.

Clients/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.

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).

Outcome Indicators

Domain: Professional Responsibilities	
Recognize when one's own attitudes and values related to genetic and genomic science may affect care provided to clients.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Values, attitudes and beliefs that influence genetic and genomic services (e.g., views on pregnancy termination). Impact of personal values, attitudes and beliefs on genetic and genomic health care.	Engage in reflective practice about one's own beliefs and values related to client care that integrates genetics and genomics. Articulate one's attitudes, values and beliefs that influence one's perspective about difficult genetic or genomic healthcare decisions.

Advocate for clients' access to desired genetic/genomic services and/or resources including support groups.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Resources for healthcare professionals and lay public about: disease susceptibility; genetic/genomic conditions, treatment, and prognosis (e.g., nursing literature, evidence-based websites sites such as the National Human Genome Research Institute http://www.genome.gov/ and the Centers for Disease Control National Office of Public Health Genomics http://www.cdc.gov/genomics/). Resources for genetic and/or genomic referrals within one's community.	Demonstrate appropriate care and concern for all clients throughout their referral, provision of direct care and follow-up to genetic services. Demonstrate knowledge about accessing local/regional genetic and/or genomic resources. Include genetic healthcare professionals in team building and collaborative strategies to optimize client outcomes. Help client negotiate system barriers that limit access to genetic/genomic services including access to clinical trials. Identify strategies that could be used to facilitate reimbursement for access to genetic/genomic services and/or tests.

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.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Scope of nursing practice in relation to genetics/genomics. Role of specialist genetic/genomic services and other agencies in providing competent client care. Interprofessional resources that contribute to evidence based care of clients needing genetic/genomic resources or services.	Identify relevance of genetics/genomics to nursing practice. Demonstrate awareness of the boundaries of one's own professional practice in relation to genetics/genomics. Perform regular self assessments to identify knowledge and skills deficits that could impact the quality of nursing care one provides to clients in need of genetic/genomic guidance, referral and resources. Take action to meet identified knowledge and skills deficits related to genetics and genomics.

Incorporate genetic and genomic technologies and information into registered nurse practice.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Technology and information systems for clinical care and clinical decision-making including: • Electronic health and medical records • Client monitoring systems, medication administration • Genetic and genomic testing technologies • Other technologies that support genetic and genomic based client care	Evaluate genetic and genomic technologies used in client care. Demonstrate use of genetic and genomic technology and client data for clinical decision-making in providing safe client care. Identify the credibility, reliability and limitations of genetic and genomic information. Identify ethical, legal, and social issues associated with genetic/genomic information.

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.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Cultural, social, ethnic and religious perspectives and literacy that may influence client's access and/or ability to use genetic and genomic information and services. Economic and health disparities related to genetics and genomics.	Incorporate client's cultural, social, ethnic and religious perspective and literacy level when delivering genetic and genomic care. Integrate knowledge from psychology, history, politics, sociology and culture when delivering genetic and genomic care.

Advocate for the rights of all clients for autonomous, informed genetic- and genomic- related decision-making and voluntary action.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Potential benefits, risks and limitations of genetic/genomic testing and accessing genetic/genomic information. Ethical, legal and social issues surrounding access to and use of genetic and genomic information. Impact of genetic and genomic information on individuals, family members, communities and/or populations. Components of informed decision-making including: • Types of information needed • Barriers to making an informed decision • Autonomous decision-making as appropriate	Ensure privacy when discussing genetic and genomic information. Maintain confidentiality when recording genetic and genomic information. Demonstrate awareness of the potential impact of genetic/genomic information on the individual and other family members. Respond appropriately to inquiries about genetic and genomic healthcare concerns.

Domain: Professional Practice
Essential Competency: Nursing Assessment: Applying/Integrating Genetic and Genomic Knowledge

Demonstrates an understanding of the relationship of genetics and genomics to health, prevention, screening, diagnostics, prognostics, selection of treatment, and monitoring of treatment effectiveness.

Specific Areas of Knowledge	Clinical Performance Indicators
Relationship of genetics and genomics to health, prevention, screening, diagnostics, prognostics, selection of treatment, and monitoring of treatment effectiveness. Relationship of genetics and genomics to normal physiology and pathophysiology including: Basics of gene function and genetic mutations in individual and populations: • Germline mutations, somatic mutations, polymorphisms • Selected mutations associated with single gene disorders, chronic disease • Concept of genotype/phenotype • Selected genotype predictors for disease prognosis and treatment Basic principles of pharmacogenetics and pharmacogenomics: • Polymorphisms and drug metabolism • Selected examples (e.g., Warfarin and CYP polymorphisms) Patterns of disease associated with single gene and multifactorial inheritance.	Collect a client's personal and three generation family health history to assess for genomic factors that impact the client's health. Identify potentially significant information from a family history. Identify clients who might benefit from referral to genetic specialists and/or information resources. Facilitate appropriate referral to genetic specialists, accurately documenting and communicating relevant history and clinical data. Describe a typical client journey that might be experienced in the process of genetic counseling. Describe genetic/genomic factors that contribute to variability of response to pharmacologic agents. Incorporates genetic and genomic health assessment data into routinely collected biopsychosocial and environmental assessments of health and illness parameters in client, using culturally sensitive approaches. Identify resources available to assist clients seeking genetic and genomic information or services including the types of services available.

Demonstrates ability to elicit a minimum of three-generation family health history information.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Components of family history needed to identify disease susceptibility or genetic/genomic condition: • Standard pedigree nomenclature • Type of information that needs to be collected and recorded such as: ⇒ Disease and age of onset, ethnicity, both maternal and paternal lineages ⇒ Three generations ⇒ Existing family history tools	Demonstrate ability to elicit a complete three-generation family health history. Identify available family history tools to facilitate collection of family health history information.

Constructs a pedigree from collected family history information using standardized symbols and terminology.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Components of family history needed to identify disease susceptibility or genetic/genomic condition: • Standard pedigree nomenclature • Type of information that needs to be collected and recorded such as: ⇒ Disease and age of onset, ethnicity, both maternal and paternal lineages ⇒ Three generations ⇒ Existing family history tools	Demonstrate ability to elicit a complete three-generation family health history. Construct a pedigree from collected family history information using standardized symbols and terminology. Identify available family history tools to generate and document a pedigree (e.g., Surgeon General's Family Health Portrait).

Collects personal, health, and developmental histories that consider genetic, environmental, and genomic influences and risks.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Fundamentals of genetic and genomic focused health assessment. Basics of risk factors: • Indicators of disease susceptibility or a genetic condition: • Family history: ⇒ Red flags of genetic/genomic conditions such as: • disease found primarily in males • early age of onset for chronic adult onset disease • multiple cases of rare disease ⇒ Confounders: • race and ethnicity • Physical findings • Health history: ⇒ Environmental and lifestyle factors ⇒ Social and emotional status	Demonstrate ability to collect personal, medical and family history that includes genetic/genomic as well as environmental risks.

Conducts comprehensive health and physical assessments which incorporate knowledge about genetic, environmental, and genomic influences and risk factors.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Fundamentals of genetic and genomic focused health and physical assessment. Basics of risk factors: • Indicators of disease susceptibility or a genetic condition: • Family history: ⇒ Red flags of genetic/genomic conditions such as: • disease found primarily in males • early age of onset for chronic adult onset disease • multiple cases of rare disease ⇒ Confounders: • race and ethnicity • Physical findings • Health history: ⇒ Environmental and lifestyle factors ⇒ Multifactorial influence	Incorporate genetic and genomic health assessment data into routinely collected biopsychosocial and environmental assessments of health and illness parameters in client, using culturally sensitive approaches.

Critically analyzes the history and physical assessment findings for genetic, environmental, and genomic influences and risk factors.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Pathophysiological, medical and nursing evaluation of common acute and chronic disease. • Indicators of disease susceptibility or a genetic condition • Family history: ⇒ Red flags of genetic/genomic conditions such as: • disease found primarily in males • early age of onset for chronic adult onset disease • multiple cases of rare disease ⇒ Confounders: • race and ethnicity • Physical findings • Health history: ⇒ Environmental and lifestyle factors ⇒ Multifactorial influence Assessment and diagnosis of acute and chronic disease including predisposition to disease based on genetic and genomic risk factors.	Identify genetic and genomic factors within collected history and physical assessment data that contribute to disease and/or health risks. Demonstrate ability to incorporate family history as part of the nursing assessment. • Documents family history information on three-generations on both maternal and paternal side, when available • Documents key genetic and genomic assessment information Identify components of assessment data that contribute to disease and/or health risks to establish a plan of care.

Assesses clients' knowledge, perceptions, and responses to genetic and genomic information.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Cultural, social, ethnic and religious perspectives may influence client's ability to use genetic and genomic information and services. Social and psychological implications of accessing genetic services and information. Ethical and legal issues surrounding genetic and genomic information and services. Principles of autonomous decision-making in genetic counseling. Principles of client genetic/genomic education and counseling.	Demonstrate the ability to assess clients cultural, religious and ethnic perspectives with regards to genetics and genomics. Demonstrate an awareness of the client's background in facilitating communication about genetic and genomic issues. Demonstrate the ability to use resources to facilitate effective communication and access to genetic services. Use communication skills to promote and check the clients' understanding of genetic and genomic information. Demonstrate an awareness of client's needs, showing fairness and sensitivity when exploring the rationale for seeking specialist genetic advice/referral. Identify situations when the nurse's own beliefs and values may have potential to influence the genetic and genomic care given to clients. Identify situations where clients' own beliefs and/or values influence genetic and genomic care choices. Use communication skills to enable the client to express his or her own wishes, or to pursue a chosen course of action for genetic and genomic services. Display a non-judgmental attitude at all times. Demonstrate use of language appropriate to the client's level of understanding and developmental age when explaining genetic and genomic information. Demonstrate assessment of the clients' understanding of genetic and genomic information. Demonstrate assessment of social and psychological responses to genetic/genomic information.

Develops a plan of care that incorporates genetic and genomic assessment information.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Interprofessional plan of care: • Assessment, diagnosis and care planning from a genetic and genomic perspective • Client goals • Expected outcomes • Genetic and genomic resources • Implications for both the individual and their family	Develop, in partnership with the client, a healthcare plan that takes into account genetic and genomic determinants of health, available resources, and range of activities that contribute to health and prevention of illness, injury, disability and premature death. Integrate best evidence, clinical judgment, client preferences, and family implications in planning genetic and genomic focused individualized care.

Domain: Professional Practice
Essential Competency: Identification

Identifies clients who may benefit from specific genetic and genomic information and/or services based on assessment data.

Specific Areas of Knowledge	Clinical Performance Indicators
Components of family history needed to identify disease susceptibility or genetic/genomic condition. • Standard pedigree nomenclature • Type of information that needs to be collected and recorded such as: ⇒ Disease and age of onset, ethnicity, both maternal and paternal lineages ⇒ Three generations ⇒ Existing family history tools Inheritance patterns: • Single gene • Multifactorial Indicators of disease susceptibility or a genetic condition: • Family history ⇒ Red flags of genetic/genomic conditions such as: • disease found primarily in males, • early age of onset for chronic adult onset disease, • multiple cases of rare disease ⇒ Confounders: • race and ethnicity • Physical findings • Health history: ⇒ Environmental and lifestyle factors ⇒ Multifactorial influence Common health conditions with a genetic/genomic component to disease susceptibility, screening and detection, diagnosis, treatment, and prognosis. Indicators of need for targeted treatment selection • known targeted interventions available • genetic tests available • adverse drug reaction • altered response to intervention	Demonstrate ability to elicit a complete three-generation family health history. Construct a pedigree from collected family history information using standardized symbols and terminology. Identify factors in a family and health history that contribute to: disease susceptibility; disease characteristics, treatment, prognosis; or genetic/genomic condition. Identify clients who may benefit from further evaluation of the identified disease susceptibility or genetic/genomic condition. Demonstrate assessment of client concerns or understanding about information received from specialty genetic services (i.e., on-line genetic testing results). Demonstrate ability to incorporate family history as part of the nursing assessment. • Documents family history information on three-generations on both maternal and paternal side, when available. • Documents key genetic and genomic assessment information. • Uses genetic and genomic indicators as rationale for clients who may benefit from further evaluation or other risk management interventions. • Incorporate into the interprofessional plan of care the need for further genetic/genomic evaluation or other risk management interventions in collaboration with the client.

Identifies credible, accurate, appropriate, and current genetic and genomic information, resources, services, and/or technologies specific to given clients.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Resources for healthcare professionals and lay public about: disease susceptibility; genetic/genomic conditions, treatment, and prognosis (e.g., nursing literature, evidence-based websites sites such as the National Human Genome Research Institute http://www.genome.gov/ and the Centers for Disease Control National Office of Public Health Genomics http://www.cdc.gov/genomics/). Resources for referral within one's community. Roles of genetic/genomic healthcare professionals. Interprofessional resources that contribute to evidence based care of clients needing genetic/genomic resources or services (i.e., EGAPP; AHRQ).	Evaluate strengths, limitations, and best use of genetic and/or genomic resource for a client or group of clients. Discuss the ways in which nurses can meet the educational, psychosocial and resource needs of clients and families affected by a genetic or genomic condition. Discuss the ways in which nurses can meet the knowledge, psychosocial and resource needs of clients and families affected by genetic/genomic technology. Identify resources available to assist clients seeking genetic and genomic information or services including the types of services available. Develop a list of contacts for a genetic/genomic referral resource in one's community or within one's respective healthcare setting. Evaluate sources of evidence and clinical practice guidelines for a client whose care involves genetic and/or genomic healthcare. Use continuous quality improvement initiatives to update practice guidelines as necessary.

Identifies ethical, ethnic/ancestral, cultural, religious, legal, fiscal, and societal issues related to genetic and genomic information and technologies.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Cultural, ethnic, family values, traditions, health beliefs and religious perspectives that influence access and use of genetic/genomic information and services. The components of informed decision-making including: • Types of information needed • Barriers to making an informed decision Sources of genetic information. Capabilities and limitations of current genetic/genomic technologies. Ethical issues related to genetic/genomic information and technology (such as confidentiality, privacy, disclosure, duty to warn). Psychosocial issues and impact of genetic/genomic information on individual and the family (such as emotional distress, discrimination). Current state, federal, and military policies that impact genetic/genomic privacy, health, life, long term care and disability insurance, employment, and other forms of genetic discrimination.	Demonstrate the ability to assess cultural, language, family values, traditions, health beliefs and religious perspectives that influence access to and use of genetic/genomic information, technology, and services. Identify cultural, language, family values, traditions, health beliefs and religious perspectives that impact access and use of genetic/genomic information, technology and services. Identify psychosocial issues and impact of genetic/genomic information, technology and services on individual and the family. Use ethical principles when deliberating genetic/genomic issues of decision-making, privacy, confidentiality, informed consent, disclosure, access, and personal impact. List action steps to address genetic/genomic ethical issues in practice, (e.g., discuss with nursing team or supervisor, present to ethics committee). Describes the influence of insurance or other methods of reimbursement for services on access 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.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Current state, federal, and military policies that impact genetic/genomic privacy, health, life, long term care and disability insurance, employment and other forms of genetic discrimination. The components of informed decision-making including types of information needed and barriers to make an informed decision. Past and potential for misuse of genetic/genomic information and technology. Guidelines or policies regarding access to genetic/genomic information and technology (i.e., children, vulnerable populations, economics).	Identify respective genetic state legislation. Identify examples of misuse of genetic/genomic information and technology. Describe legal and social issues related to access and use of genetic information and technology. Access interprofessional ethical resources when trying to resolve ethical dilemmas.

Domain: Professional Practice Essential Competency: Referral Activities	
Facilitates referrals for specialized genetic and genomic services for clients as needed.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Professional roles of providers delivering genetic and genomic services. Resources for healthcare professionals and lay public about: disease susceptibility; genetic/genomic conditions, treatment, and prognosis (e.g., nursing literature, evidence-based websites sites such as the National Human Genome Research Institute http://www.genome.gov/ and the Centers for Disease Control National Office of Public Health Genomics http://www.cdc.gov/genomics/). Resources for genetic and genomic referrals within the community.	Develop an interprofessional plan of care in collaboration with the client that incorporates genetics and genomics. Uses genetic and genomic indicators as rationale for clients who may benefit from further evaluation or other risk management interventions. Develop a list of contacts for a genetic/genomic referral resource in one's community or within one's respective healthcare setting. Develop a plan for follow-up of a client post genetics/genomic referral.

Domain: Professional Practice **Essential Competency: Provision of Education, Care and Support**	
Provides clients with interpretation of selective genetic and genomic information or services.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Components of family history needed to identify disease susceptibility or genetic/genomic condition: • Standard pedigree nomenclature • Type of information that needs to be collected and recorded such as: ⇒ Disease and age of onset, ethnicity, both maternal and paternal lineages ⇒ Three generations ⇒ Existing family history tools Inheritance patterns • Single gene • Multifactorial Role of environmental and psychosocial factors involved in penetrance of predisposition gene variants. Informed consent procedures and essential elements.	Discuss factors in a family and health history that contribute to: disease susceptibility; disease characteristics, treatment, prognosis; or a genetic/genomic condition. Use family history information to inform health education. Discuss the role of genetic, genomic, environmental and psychosocial factors in maintaining health and preventing disease. Discuss the role of genetic, genomic, environmental and psychosocial factors in the manifestation of disease. Reinforce/clarify information provided by genetic professional to client (i.e., genetic test interpretation; informed consent).

Provides clients with credible, accurate, appropriate, and current genetic and genomic information, resources, services, and/or technologies that facilitate decision-making.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Resources for healthcare professionals and lay public about: disease susceptibility; genetic/genomic conditions, treatment, and prognosis (e.g., nursing literature, evidence-based websites sites such as the National Human Genome Research Institute http://www.genome.gov/ and the Centers for Disease Control National Office of Public Health Genomics http://www.cdc.gov/genomics/). Referral resources for genetic and genomic services within one's community. Roles of genetic/genomic healthcare professionals.	Evaluate strengths, limitations, and best use of one genetic and/or genomic resource for a client or group of clients. Help clients interpret and understand genetic and genomic information. Develop a list of contacts for a genetic/genomic referral resource in one's community or within one's respective healthcare setting.

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)	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Role of environmental and psychosocial factors involved in penetrance of predisposition gene variants. Fundamentals of epidemiology, biostatistics, (distribution, incidence, prevalence rates, risk factors, health status indicators, and control of disease in populations). Ongoing research contributing to improved understanding of the genetic/genomic influences on health.	Incorporate genetic and genomic health assessment data into routinely collected biopsychosocial and environmental assessments of health and illness parameters in client, using culturally sensitive approaches. Use evaluation results to influence delivery of care and deployment of resources to promote health and prevent disease.

Uses genetic- and genomic-based interventions and information to improve clients' outcomes.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Pharmacogenetics, pharmacogenomics. Gene or gene product targeted therapy (e.g., HER2 and Herceptin BCR/ABL and imatinib). Protein replacement therapy (e.g., enzyme therapy for lysosomal diseases). Chaperone therapy.	Demonstrate ability to incorporate family history as part of the nursing assessment. • Document family history information on three-generations on both maternal and paternal side, when available • Documents key genetic and genomic assessment information • Uses genetic and genomic indicators as rationale for clients who may benefit from further evaluation or other risk management interventions • Incorporate into the interprofessional plan of care the need for further genetic/genomic evaluation or other risk management interventions in collaboration with the client Monitor client response to genetic/genomic based interventions. Intervene when client has an unintended response to genetic/genomic based interventions to ensure client safety.

Collaborates with healthcare providers in providing genetic and genomic health care.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Roles of genetic/genomic healthcare professionals. Roles of other specialists in which genetic/genomic information and technology are integral to their care delivery.	Use interprofessional communication and collaboration skills to deliver safe, evidence-based, client-centered care. Demonstrate team building and collaborative strategies when working with interprofessional teams. Adopt a range of interpersonal skills whilst communicating with clients and colleagues about genetic/genomic issues.

Collaborates with insurance providers/payers to facilitate reimbursement for genetic and genomic healthcare services.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Determinants of clinical utility of genetic/genomic tests (e.g., test specificity, sensitivity, positive predictive value; test cost-benefit information). Economic impact of new genetic/genomic based therapies: • Can be life-long therapy once started • Consideration of individual/family maximum lifetime benefit Influence of predisposition gene variants, genetic disease/disorder on access to health, life, disability, long term care insurances and military benefits.	Identify strategies that could be use to facilitate reimbursement for genetic/genomic services and/or tests. Describe other methods of payment for genetic/genomic healthcare services (i.e., laboratory indigent assistance programs).

Performs interventions/treatments appropriate to clients' genetic and genomic healthcare needs.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Pharmacogenetics, pharmacogenomics Gene or gene product targeted therapy (e.g., HER2 and Herceptin BCR/ABL and imatinib). Protein replacement therapy (e.g., enzyme therapy for lysosomal diseases). Chaperone therapy (small molecules that specifically bind to and stabilize a misfolded protein in the endoplasmic reticulum of a cell).	Administer medications safely with consideration of pharmacogenetic test results if available. Administer prescribed genetic/genomic based therapies safely as allowed per State Practice Act. Monitor client response to genetic/genomic based interventions. Intervene when client has an unintended response to genetic/genomic based interventions to assure client safety. Teach client about purpose, expected benefits, limitations and potential risks of genetic/genomic based interventions.

Evaluates impact and effectiveness of genetic and genomic technology, information, interventions, and treatments on clients' outcome.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Range of psychosocial responses to genetic and/or genomic test results, genetic diagnosis and prognosis. Expected outcomes of various genetic/genomic based interventions.	Assess client response to genetic/genomic information. Assess client response to genetic/genomic based interventions. Assess client response to genetic/genomic services. Use evaluation of genetic/genomic technology, information and interventions to modify client's plan of care.

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 January 29, 2009. Listing of a book in this appendix does not indicate that it is still in print.

Books and Monographs

Resource	*Publisher*	*Description*
Clinical Genetics in Nursing Practice, 3rd ed. (2005) By Felissa R. Lashley	Springer Publishing Company, Inc.	Nursing and genetics text
Genetics in Nursing (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.
Genetics in Oncology Practice: Cancer Risk Assessment (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.
The Genetics Revolution: Implications for Nurses (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.
Applied Genetics in Healthcare (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

Nursing Care in the Genomic Era: A Case-Based Approach (2005) By Jean F. Jenkins and Dale Halsey Lea	Jones and Bartlett Publishers	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.
Genetics in Clinical Practice: New Directions for Nursing and Health Care (1998) By Dale Halsey Lea, Jean F. Jenkins, and Clair A. Francomano	Jones and Bartlett Publishers	Provides a unique, understandable approach to the emerging science of genetics.
Genetic Nursing Portfolios: A New Model for the Profession (2005) Editor: Rita Black Monson	American Nurses Association (Nursesbooks.org)	Describes the development of the GNCC credentialing program. The book shows how to assemble and use a portfolio to verify competency in a specialty.
Genetics/Genomics Nursing: Scope and Standards of Practice. (2006) by International Society of Nurses in Genetics, Inc. (ISONG) and American Nurses Association	American Nurses Association and ISONG (Nursesbooks.org)	Scope and standards of practice for nurses in genetics
Genetics and the Perinatal and Women's Health Nurse (2001) By Judith Lewis	Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN)	This practice monograph provides nurses with the basic information they need to provide patients with accurate information about genetic screening and testing.

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.
Individuals, Families and the New Era of Genetics (2006) by S, Miller, S. McDaniel, J. Rolland, and S. Feetham	W.W. Norton & Co. Inc.	Keeping the individual and family in focus during the era of 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	*Cancer Genetics and Cancer Predisposition Genetic Testing, 2nd Edition*: 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://www.infosci.coh.org/ccgp/ic/course09.aspx	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/healthProfessionals/continuingNursing	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)	Education/index.html 461 Cochran Road Box 246 Pittsburgh, PA 15228 412-344-1414 http://www.isong.org/ E-mail: isongHQ@msn.com	Annual Nursing and Genetic Education Meeting *Genetics/Genomics Nursing: Scope and Standards of Practice* (2006)
National Institute of Nursing Research (NINR)	Summer Genetics Institute Division of Intramural Research NINR National Institutes of Health 31 Center Drive, 5B-13 Bethesda, MD 20892-2178 (202) 255-6922 http://www.ninr.nih.gov/Training/TrainingOpportunitiesIntramural/SummerGeneticsInstitute/	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/excellence/genetics/index.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 program 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*
Family History Cancer Risk Assessment: James Link	http://jamesline.com/patientsandvisitors/prevention/cancergenetics/	Information on collecting family health history and assessing cancer risk
The DNA Files	http://www.dnafiles.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://www.dnalc.org/	A variety of educational resources, including an interactive DNA timeline
Ethics and Genetic Testing for Nurses	https://www.continuetolearn.uiowa.edu/ecomm/ccp/10Expand.asp?ProductCode=096cegenetic	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
Genetic Science Learning Center	http://learn.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.umdnj.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
Understanding Genetics (from the Genetic Alliance)	http://geneticalliance.org/understanding.genetics	A guide for patients and professionals

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/cgi/reprint/pediatrics;107/6/1451.pdf	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/genetics/genetics.php	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
Genethics.ca	http://www.Genethics.ca/	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.genelaw.info/	A searchable online clearinghouse of information on emerging legal developments in human genetics

The Genetics and Public Policy Center	http://www.dnapolicy.org	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://bioethics.georgetown.edu/nirehg/	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://bioethics.georgetown.edu/publications/scopenotes/	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
Centers for Disease Control and Prevention	http://www.cdc.gov/genomics/fhix.htm	Family history resources and tools
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.progenygenetics.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/Multi/blastview	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/index.html	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://www.hapmap.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	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 WBGI (Web-based Genetic Institute)
Genetics: Educational Information	http://www.ashg.org/pages/pubs_curriculum.shtml	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/preventiongenetics-causes	Authoritative information about cancer genetics
National Coalition for Health Professional Education in Genetics (NCHPEG)	http://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

Internal Review Boards (IRBs)

Resource	*Contact*	*Description*
Genetic Testing and Screening in the Age of Genomic Medicine. New York State Task Force on Life and Law (2001)	http://www.health.state.ny.us/nysdoh/taskfce/screening.htm	Includes general and state-specific information in a bulleted report that is relatively easy to scan by topic
Human Subjects Protection Resource Book. U.S. Department of Energy (2006)	http://humansubjects.energy.gov/doe-resources/humsubj-resourcebook.htm	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
My Very Own Medicine: What Must I know? Information Policy for Pharmacogenetics. Public Health Genetics Unit, National Health Service, UK - D. Melzer et al. (2003)	http://www.phpc.cam.ac.uk/epg/IPP.html	General information and background, looking ahead to future needs, including guidance for IRBs
Protecting Human Research Subjects Institutional Review Board Guidebook, Chapter H: Human Genetic Research. 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
Pharmacogenetics: Ethical Issues. 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.genomenewsnetwork.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.abgc.net	Information about certification of genetic counselors
American Board of Medical Genetics (ABMG)	http://www.abmg.org	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.genetics-gsa.org	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: • 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	Statement on the scope and standards of genetics/genomics nursing practice. Policy statements on the roles of nurses and/or nursing in: • 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/	Position statements on: • The role of the oncology nurse in cancer genetic counseling • Cancer predisposition genetic testing and risk assessment counseling

Risk Assessment

Resource	*Contact*	*Description*
Harvard Center for Cancer Prevention: Your Disease Risk	http://www.yourcancerrisk.harvard.edu/	Personalized estimation of cancer risk and tips for prevention
National Cancer Institute: Breast Cancer Risk Assessment Tool	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://www.cdc.gov/genomics/	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://bioethics.georgetown.edu/nirehg/	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://genes-r-us.uthscsa.edu/	Search engine for policy documents and clinical issues

United States Government Agencies

Resource	*Contact*	*Description*
Center for Disease Control and Prevention: 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/detail.cfm?PubID=BHP00177	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/research/supported/programs/egp/	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	http://www.ninr.nih.gov/Training/TrainingOpportunitiesIntramural/SummerGeneticsInstitute	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

Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators, 2nd Edition

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. The outcome indicators are an adjunct to the essential nursing competencies and curricula guidelines for genetics and genomics and are intended to define for each competency the knowledge and practice indicators.

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 that pertain directly to the competencies and guidelines. As a result, *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators, 2nd Edition*, will prove to be an essential volume for nursing professional development at all levels.

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