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

Second edition—
Outcome Indicators established by Consensus,
June 2008
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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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CEHR/Genetics_1.aspx

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# TABLE OF CONTENTS

Preamble ................................................................................................................................................. 1

Contributors, Consensus Panel, and Endorsing Organizations .............................................................. 2

Background and Context of the Competencies .......................................................................................... 7
   Purpose .................................................................................................................................................. 8
   Applicability ......................................................................................................................................... 8
   Definitions ............................................................................................................................................ 8
   Development of the Competencies and Process of Consensus ............................................................. 9
      Resource/Reference Documents ....................................................................................................... 9
      Competency Development ............................................................................................................... 10
      Process of Consensus ...................................................................................................................... 10

Essential Competencies ............................................................................................................................. 11
   Professional Responsibilities .............................................................................................................. 11
   Professional Practice Domain ........................................................................................................... 11
      Nursing Assessment: Applying/Integrating Genetic and Genomic Knowledge .............................. 11
      Identification .................................................................................................................................. 12
      Referral Activities ......................................................................................................................... 12
      Provision of Education, Care, and Support ..................................................................................... 13

Outcome Indicators ................................................................................................................................... 15
   Introduction ......................................................................................................................................... 15
   Definitions ........................................................................................................................................... 15
   Domain: Professional Responsibilities ................................................................................................. 16
   Domain: Professional Practice ........................................................................................................... 19
      Nursing Assessment ....................................................................................................................... 19
      Identification .................................................................................................................................. 26
      Referral Activities ......................................................................................................................... 30
      Provision of Education, Care, and Support ..................................................................................... 31

Implementation Strategies ......................................................................................................................... 37
   Key Strategies ..................................................................................................................................... 37
   Incorporation of Competencies, Content, and Teaching Strategies into the Curriculum ..................... 38

References Cited in Text ............................................................................................................................. 41
Appendix A. Resources to Support the Genetics and Genomics Competencies ......................................................... 45

Books and Monographs ......................................................................................................................... 46
Career Development: Continuing Education ................................................................. 49
Career Development: Post-Graduate Programs ............................................................ 51
Clinical Genetics ............................................................................................................................... 53
Consumer/Client: General Information ............................................................................. 54
Consumer/Client: Support and Advocacy Groups ...................................................... 56
ELSI (Ethical, Legal, and Social Implications),
  Policy, and Legislation ............................................................................................................. 57
Family History Tools ....................................................................................................................... 60
Genome Research ............................................................................................................................ 61
Health Professional Practice and Education ................................................................. 63
Internal Review Boards (IRBs) .............................................................................................. 66
News Sites Specializing in Genetics and Genomics ................................................... 67
Professional Organizations: Genetics ............................................................................. 68
Professional Organizations: Nursing Practice ............................................................... 69
Risk Assessment ......................................................................................................................... 71
Search Engines Specializing in Genetics and Genomics ........................................ 72
United States Government Agencies .................................................................................. 73
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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Essentials of Genetic and Genomic Nursing, 2nd Edition
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Academy of Medical-Surgical Nurses
Academy of Neonatal Nurses LLC
American Academy of Ambulatory Care Nursing
American Academy of Nursing
American Association of Colleges of Nursing
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 Society for Vascular Nursing
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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.
• 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](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. 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.
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.

<table>
<thead>
<tr>
<th>Specific Areas of Knowledge</th>
<th>Clinical Performance Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
<td>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.</td>
</tr>
</tbody>
</table>

Advocate for clients’ access to desired genetic/genomic services and/or resources including support groups.

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<tr>
<th>Specific Areas of Knowledge</th>
<th>Clinical Performance Indicators</th>
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<tbody>
<tr>
<td>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 <a href="http://www.genome.gov/">http://www.genome.gov/</a> and the Centers for Disease Control National Office of Public Health Genomics [<a href="http://www.cdc.gov/genomics/">http://www.cdc.gov/genomics/</a>]). Resources for genetic and/or genomic referrals within one’s community.</td>
<td>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.</td>
</tr>
</tbody>
</table>
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.

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<thead>
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</thead>
<tbody>
<tr>
<td>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.</td>
<td>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.</td>
</tr>
</tbody>
</table>

Incorporate genetic and genomic technologies and information into registered nurse practice.

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<thead>
<tr>
<th>Specific Areas of Knowledge</th>
<th>Clinical Performance Indicators</th>
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<tbody>
<tr>
<td>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</td>
<td>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.</td>
</tr>
</tbody>
</table>
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**  
- 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.

<table>
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<tr>
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| 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**  
- 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

<table>
<thead>
<tr>
<th>Clinical Performance Indicators</th>
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| 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 health-care 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.

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<tr>
<td>Relationship of genetics and genomics to health, prevention, screening, diagnostics, prognostics, selection of treatment, and monitoring of treatment effectiveness.</td>
<td>Collect a client’s personal and three generation family health history to assess for genomic factors that impact the client’s health.</td>
</tr>
<tr>
<td>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</td>
<td>Identify potentially significant information from a family history.</td>
</tr>
<tr>
<td>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.</td>
<td>Identify clients who might benefit from referral to genetic specialists and/or information resources.</td>
</tr>
<tr>
<td></td>
<td>Facilitate appropriate referral to genetic specialists, accurately documenting and communicating relevant history and clinical data.</td>
</tr>
<tr>
<td></td>
<td>Describe a typical client journey that might be experienced in the process of genetic counseling.</td>
</tr>
<tr>
<td></td>
<td>Describe genetic/genomic factors that contribute to variability of response to pharmacologic agents.</td>
</tr>
<tr>
<td></td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>Identify resources available to assist clients seeking genetic and genomic information or services including the types of services available.</td>
</tr>
</tbody>
</table>
Demonstrates ability to elicit a minimum of three-generation family health history information.

<table>
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</table>
| 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.

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  • 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.

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<thead>
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</table>
| 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.

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| 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.

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

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<tr>
<td>Cultural, social, ethnic and religious perspectives may influence client’s ability to use genetic and genomic information and services.</td>
<td>Demonstrate the ability to assess clients cultural, religious and ethnic perspectives with regards to genetics and genomics.</td>
</tr>
<tr>
<td>Social and psychological implications of accessing genetic services and information.</td>
<td>Demonstrate an awareness of the client’s background in facilitating communication about genetic and genomic issues.</td>
</tr>
<tr>
<td>Ethical and legal issues surrounding genetic and genomic information and services.</td>
<td>Demonstrate the ability to use resources to facilitate effective communication and access to genetic services.</td>
</tr>
<tr>
<td>Principles of autonomous decision-making in genetic counseling.</td>
<td>Use communication skills to promote and check the clients’ understanding of genetic and genomic information.</td>
</tr>
<tr>
<td>Principles of client genetic/genomic education and counseling.</td>
<td>Demonstrate an awareness of client’s needs, showing fairness and sensitivity when exploring the rationale for seeking specialist genetic advice/referral.</td>
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<td></td>
<td>Identify situations when the nurse’s own beliefs and values may have potential to influence the genetic and genomic care given to clients.</td>
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<td></td>
<td>Identify situations where clients’ own beliefs and/or values influence genetic and genomic care choices.</td>
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<td></td>
<td>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.</td>
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<td></td>
<td>Display a non-judgmental attitude at all times.</td>
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<td></td>
<td>Demonstrate use of language appropriate to the client’s level of understanding and developmental age when explaining genetic and genomic information.</td>
</tr>
<tr>
<td></td>
<td>Demonstrate assessment of the clients’ understanding of genetic and genomic information.</td>
</tr>
<tr>
<td></td>
<td>Demonstrate assessment of social and psychological responses to genetic/genomic information.</td>
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</tbody>
</table>
Develops a plan of care that incorporates genetic and genomic assessment information.

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| 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.

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

<table>
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<tbody>
<tr>
<td>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 <a href="http://www.genome.gov/">http://www.genome.gov/</a> and the Centers for Disease Control National Office of Public Health Genomics <a href="http://www.cdc.gov/genomics/">http://www.cdc.gov/genomics/</a>.</td>
<td>Evaluate strengths, limitations, and best use of genetic and/or genomic resource for a client or group of clients.</td>
</tr>
<tr>
<td>Resources for referral within one’s community.</td>
<td>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.</td>
</tr>
<tr>
<td>Roles of genetic/genomic healthcare professionals.</td>
<td>Discuss the ways in which nurses can meet the knowledge, psychosocial and resource needs of clients and families affected by genetic/genomic technology.</td>
</tr>
<tr>
<td>Interprofessional resources that contribute to evidence based care of clients needing genetic/genomic resources or services (i.e., EGAPP; AHRQ).</td>
<td>Identify resources available to assist clients seeking genetic and genomic information or services including the types of services available.</td>
</tr>
<tr>
<td>Developing a list of contacts for a genetic/genomic referral resource in one’s community or within one’s respective healthcare setting.</td>
<td>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.</td>
</tr>
</tbody>
</table>
Identifies ethical, ethnic/ancestral, cultural, religious, legal, fiscal, and societal issues related to genetic and genomic information and technologies.

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<tbody>
<tr>
<td>Cultural, ethnic, family values, traditions, health beliefs and religious perspectives that influence access and use of genetic/genomic information and services. &lt;br&gt;The components of informed decision-making including: &lt;br&gt;• Types of information needed &lt;br&gt;• Barriers to making an informed decision &lt;br&gt;Sources of genetic information. &lt;br&gt;Capabilities and limitations of current genetic/genomic technologies. &lt;br&gt;Ethical issues related to genetic/genomic information and technology (such as confidentiality, privacy, disclosure, duty to warn). &lt;br&gt;Psychosocial issues and impact of genetic/genomic information on individual and the family (such as emotional distress, discrimination). &lt;br&gt;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.</td>
<td>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. &lt;br&gt;Identify cultural, language, family values, traditions, health beliefs and religious perspectives that impact access and use of genetic/genomic information, technology and services. &lt;br&gt;Identify psychosocial issues and impact of genetic/genomic information, technology and services on individual and the family. &lt;br&gt;Use ethical principles when deliberating genetic/genomic issues of decision-making, privacy, confidentiality, informed consent, disclosure, access, and personal impact. &lt;br&gt;List action steps to address genetic/genomic ethical issues in practice, (e.g., discuss with nursing team or supervisor, present to ethics committee). &lt;br&gt;Describes the influence of insurance or other methods of reimbursement for services on access to genetic and genomic information and technologies.</td>
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</table>
Defines issues that undermine the rights of all clients for autonomous, informed genetic- and genomic-related decision-making and voluntary action.

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<tr>
<td>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.</td>
<td>Identify respective genetic state legislation.</td>
</tr>
<tr>
<td>The components of informed decision-making including types of information needed and barriers to make an informed decision.</td>
<td>Identify examples of misuse of genetic/genomic information and technology.</td>
</tr>
<tr>
<td>Past and potential for misuse of genetic/genomic information and technology.</td>
<td>Describe legal and social issues related to access and use of genetic information and technology.</td>
</tr>
<tr>
<td>Guidelines or policies regarding access to genetic/genomic information and technology (i.e., children, vulnerable populations, economics).</td>
<td>Access interprofessional ethical resources when trying to resolve ethical dilemmas.</td>
</tr>
</tbody>
</table>

*Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics*
**Domain: Professional Practice**  
**Essential Competency: Referral Activities**

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

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<tr>
<td>Professional roles of providers delivering genetic and genomic services.</td>
<td>Develop an interprofessional plan of care in collaboration with the client that incorporates genetics and genomics.</td>
</tr>
<tr>
<td>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 <a href="http://www.genome.gov/">http://www.genome.gov/</a> and the Centers for Disease Control National Office of Public Health Genomics <a href="http://www.cdc.gov/genomics/">http://www.cdc.gov/genomics/</a>.</td>
<td>Uses genetic and genomic indicators as rationale for clients who may benefit from further evaluation or other risk management interventions.</td>
</tr>
<tr>
<td>Resources for genetic and genomic referrals within the community.</td>
<td>Develop a list of contacts for a genetic/genomic referral resource in one’s community or within one’s respective healthcare setting.</td>
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<td></td>
<td>Develop a plan for follow-up of a client post genetics/genomic referral.</td>
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</table>
## Domain: Professional Practice
### Essential Competency: Provision of Education, Care and Support

Provides clients with interpretation of selective genetic and genomic information or services.

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</table>
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  • 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.

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<td>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 <a href="http://www.genome.gov/">http://www.genome.gov/</a> and the Centers for Disease Control National Office of Public Health Genomics [<a href="http://www.cdc.gov/genomics/">http://www.cdc.gov/genomics/</a>]).</td>
<td>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.</td>
</tr>
<tr>
<td>Referral resources for genetic and genomic services within one's community.</td>
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<tr>
<td>Roles of genetic/genomic healthcare professionals.</td>
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</tbody>
</table>

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).

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<td>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.</td>
<td>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.</td>
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</table>
Uses genetic- and genomic-based interventions and information to improve clients' outcomes.

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| Pharmacogenetics, pharmaco- genomics.  
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.

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| 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.

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<td>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.</td>
<td>Identify strategies that could be used 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).</td>
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Performs interventions/treatments appropriate to clients’ genetic and genomic healthcare needs.

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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.

<table>
<thead>
<tr>
<th>Specific Areas of Knowledge</th>
<th>Clinical Performance Indicators</th>
</tr>
</thead>
</table>
| Range of psychosocial responses to genetic and/or genomic test results, genetic diagnosis and prognosis.  
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. |
IM PLEM EN TATION S T RATEGIES

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](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](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. 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. 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. 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. A theory-based approach to integrating genetics into one school’s nursing curriculum is well described by Horner et al. Integrative approaches in associate and baccalaureate programs have been published by Danz (2004), Zamerowski (2000), and Read et al. (2004).
Development of a single genetic and genomic nursing course incorporated into the curriculum has also been described. 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. Outcomes associated with faculty training initiatives addressing this need (including summer institutes and a web-based program) have also been described.
REFERENCES CITED IN TEXT

All URLs were accessed and confirmed December 22, 2008.


13. Greco, K. E. and Salveson, C. (In review process) An evidence-based qualitative analysis identifying fundamental undergraduate nursing competencies in genetics. (Submitted to Journal of Nursing Education for publication.)


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

<table>
<thead>
<tr>
<th>Resource</th>
<th>Publisher</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Genetics in Nursing</em> (2004)</td>
<td>International Council of Nurses</td>
<td>Monograph to provide direction for nursing leadership in genetics in global, scientific, practice, education, social, information, ethical and political contexts.</td>
</tr>
<tr>
<td><em>The Genetics Revolution: Implications for Nurses</em> (1997)</td>
<td>American Academy of Nursing</td>
<td>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.</td>
</tr>
<tr>
<td><em>Applied Genetics in Healthcare</em> (2005)</td>
<td>BIOS Scientific Publishers</td>
<td>Test for application of genetic and genomic principles by nurses who provide genetic and genomic health care as specialist practitioners and advanced practice nurses</td>
</tr>
<tr>
<td>Title</td>
<td>Publisher</td>
<td>Description</td>
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<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><em>Nursing Care in the Genomic Era: A Case-Based Approach</em> (2005)</td>
<td>Jones and Bartlett Publishers</td>
<td>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.</td>
</tr>
<tr>
<td><em>Genetics in Clinical Practice: New Directions for Nursing and Health Care</em> (1998)</td>
<td>Jones and Bartlett Publishers</td>
<td>Provides a unique, understandable approach to the emerging science of genetics.</td>
</tr>
<tr>
<td><em>Genetic Nursing Portfolios: A New Model for the Profession</em> (2005)</td>
<td>American Nurses Association (Nursesbooks.org)</td>
<td>Describes the development of the GNCC credentialing program. The book shows how to assemble and use a portfolio to verify competency in a specialty.</td>
</tr>
<tr>
<td><em>Genetics and the Perinatal and Women's Health Nurse</em> (2001)</td>
<td>Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN)</td>
<td>This practice monograph provides nurses with the basic information they need to provide patients with accurate information about genetic screening and testing.</td>
</tr>
</tbody>
</table>

Appendix A—Resources to Support Genetics and Genomics Competencies
<table>
<thead>
<tr>
<th>Title</th>
<th>Publisher</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic Issues for Perinatal Nurses (2003)</td>
<td>March of Dimes Birth Defects Foundation</td>
<td>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.</td>
</tr>
</tbody>
</table>
## Career Development: Continuing Education

<table>
<thead>
<tr>
<th>Resource</th>
<th>Contact</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cincinnati Children's Hospital Medical Center</td>
<td>3333 Burnet Avenue&lt;br&gt;Cincinnati, Ohio 45229-3039&lt;br&gt;(513) 636-4200&lt;br&gt;<a href="http://www.cincinnatichildrens.org/ed/clinical/gpnf">http://www.cincinnatichildrens.org/ed/clinical/gpnf</a></td>
<td>Genetics Education Program for Nurses: Web-Based Genetics Institute and Genetics Program for Nursing Faculty</td>
</tr>
<tr>
<td>City of Hope National Medical Center and Beckman Research Institute</td>
<td>1500 E. Duarte Road&lt;br&gt;Duarte, CA 91010-3000&lt;br&gt;(800) 423-7119&lt;br&gt;<a href="http://www.infosci.coh.org/ccgp/ic/course09.aspx">http://www.infosci.coh.org/ccgp/ic/course09.aspx</a></td>
<td>Intensive Course in Cancer Risk Assessment</td>
</tr>
<tr>
<td>Foundation for Blood Research</td>
<td>8 Nonesuch Road&lt;br&gt;P.O. Box 190&lt;br&gt;Scarborough ME 04070-0190&lt;br&gt;(207) 883-4131&lt;br&gt;<a href="http://www.fbr.org/publications/pub_curic.html">http://www.fbr.org/publications/pub_curic.html</a></td>
<td>Practice-based Genetics Curriculum For Nurse Educators (sample chapter available online)</td>
</tr>
<tr>
<td>Fox Chase Cancer Center</td>
<td>333 Cottman Avenue&lt;br&gt;Philadelphia, PA 19111-2497&lt;br&gt;(215) 728-2892 or 1-888-369-2427&lt;br&gt;<a href="http://www.fccc.edu/healthProfessionals/continuingNursing">http://www.fccc.edu/healthProfessionals/continuingNursing</a></td>
<td>A Basic Course in Cancer Genetics: Familial Cancer Risk Assessment An Advanced Course for Nurses in Genetic Cancer Risk Counseling</td>
</tr>
</tbody>
</table>
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

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/Training Opportunities/Intramural/
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

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

University of Washington  
School of Nursing  
Box 357260  
Seattle, WA 98195  
(206) 221-2458  
http://www.son.washington.edu/eo/apgn

Master's and doctoral degree programs in Genomics

Master's degree program with a minor in genetics nursing (advanced practice genetics nursing)
### Clinical Genetics

<table>
<thead>
<tr>
<th>Resource</th>
<th>Contact</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Human Genome Epidemiology Network (HuGENet™)</td>
<td><a href="http://www.cdc.gov/genomics/hugenet/default.htm">http://www.cdc.gov/genomics/hugenet/default.htm</a></td>
<td>Network for sharing population-based human genome epidemiologic information</td>
</tr>
<tr>
<td>National Newborn Screening &amp; Genetics Resource Center</td>
<td><a href="http://genes-r-us.uthscsa.edu/">http://genes-r-us.uthscsa.edu/</a></td>
<td>Information and resources nationally available on newborn screening and genetics</td>
</tr>
</tbody>
</table>
**Consumer/Client: General Information**

<table>
<thead>
<tr>
<th>Resource</th>
<th>Contact</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family History Cancer Risk Assessment:</td>
<td><a href="http://jamesline.com/patientsandvisitors/prevention/cancergenetics/">http://jamesline.com/patientsandvisitors/prevention/cancergenetics/</a></td>
<td>Information on collecting family health history and assessing cancer risk</td>
</tr>
<tr>
<td>James Link</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The DNA Files</td>
<td><a href="http://www.dnafiles.org/">http://www.dnafiles.org/</a></td>
<td>A series of 14 one-hour public radio documentaries and related information (10 more to come out in 2006)</td>
</tr>
<tr>
<td>Dolan DNA Learning Center</td>
<td><a href="http://www.dnalc.org/">http://www.dnalc.org/</a></td>
<td>A variety of educational resources, including an interactive DNA timeline</td>
</tr>
<tr>
<td>Foundations of Classical Genetics</td>
<td><a href="http://www.esp.org/foundations/genetics/classical">http://www.esp.org/foundations/genetics/classical</a></td>
<td>Complete versions of classic genetics works written between 350 B.C. and 1965</td>
</tr>
<tr>
<td>Genetic Science Learning Center</td>
<td><a href="http://learn.genetics.utah.edu">http://learn.genetics.utah.edu</a></td>
<td>Basic genetics, genetic disorders, genetics in society, and several thematic units</td>
</tr>
<tr>
<td>Genetics and Rare Diseases Information Center</td>
<td><a href="http://www.genome.gov/10000409">http://www.genome.gov/10000409</a></td>
<td>Information service for the general public, including patients and their families, as well as healthcare professionals and biomedical researchers</td>
</tr>
<tr>
<td>Genetics Education Center</td>
<td><a href="http://www.kumc.edu/gec/">http://www.kumc.edu/gec/</a></td>
<td>Material for educators</td>
</tr>
<tr>
<td>Resource</td>
<td>URL</td>
<td>Description</td>
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</tr>
<tr>
<td>The Human Genome Project: Exploring Our Molecular Selves</td>
<td><a href="http://www.genome.gov/Pages/EducationKit/">http://www.genome.gov/Pages/EducationKit/</a></td>
<td>Download modules and online viewing about Human Genome Project, timeline about genetics, talking glossary, classroom activities, 3-D animation of cell</td>
</tr>
<tr>
<td>MendelWeb</td>
<td><a href="http://www.mendelweb.org/">http://www.mendelweb.org/</a></td>
<td>Mendel's papers in English (with annotations) and German and related materials</td>
</tr>
<tr>
<td>The New Genetics: A Resource for Students and Teachers</td>
<td><a href="http://www4.umdnj.edu/camlbweb/teachgen.html">http://www4.umdnj.edu/camlbweb/teachgen.html</a></td>
<td>Links to genetic education resources</td>
</tr>
<tr>
<td>Understanding Genetics (from the Genetic Alliance)</td>
<td><a href="http://geneticalliance.org/understanding.genetics">http://geneticalliance.org/understanding.genetics</a></td>
<td>A guide for patients and professionals</td>
</tr>
</tbody>
</table>
## Consumer/Client: Support and Advocacy Groups

<table>
<thead>
<tr>
<th>Resource</th>
<th>Contact</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coalition for Genetic Fairness</td>
<td><a href="http://www.geneticfairness.org/">http://www.geneticfairness.org/</a></td>
<td>Advocacy group for federal legislation regarding genetics discrimination</td>
</tr>
<tr>
<td>Family Village</td>
<td><a href="http://www.familyvillage.wisc.edu/index.htmlx">http://www.familyvillage.wisc.edu/index.htmlx</a></td>
<td>Disability-related resources</td>
</tr>
<tr>
<td>National Organization for Rare Disorders (NORD)</td>
<td><a href="http://www.rarediseases.org/">http://www.rarediseases.org/</a></td>
<td>Rare diseases database and index of organizations</td>
</tr>
</tbody>
</table>
## ELSI (Ethical, Legal, and Social Implications), Policy, and Legislation

<table>
<thead>
<tr>
<th>Resource</th>
<th>Contact</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bioethics Resources on the Web (NIH)</td>
<td><a href="http://www.nih.gov/sigs/bioethics/">http://www.nih.gov/sigs/bioethics/</a></td>
<td>Links to bioethics resources</td>
</tr>
<tr>
<td>bioethics.net</td>
<td><a href="http://www.bioethics.net/genetics/genetics.php">http://www.bioethics.net/genetics/genetics.php</a></td>
<td>Links to articles on bioethics and genetics</td>
</tr>
<tr>
<td>Ethical, Legal, and Social Issues (from the Human Genome Project)</td>
<td><a href="http://www.ornl.gov/hgmi/elsi/elsi.html">http://www.ornl.gov/hgmi/elsi/elsi.html</a></td>
<td>Information, articles, and links on a wide range of issues</td>
</tr>
<tr>
<td>Organization</td>
<td>Website</td>
<td>Description</td>
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<tr>
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</tr>
<tr>
<td>The Genetics and Public Policy Center</td>
<td><a href="http://www.dnapolicy.org">http://www.dnapolicy.org</a></td>
<td>Information on public policy related to human genetic technologies for the public, media, and policymakers</td>
</tr>
<tr>
<td>Genome Technology and Reproduction: Values and Public Policy and The Communities of Color and Genetics Policy Project</td>
<td><a href="http://www.sph.umich.edu/genpolicy/">http://www.sph.umich.edu/genpolicy/</a></td>
<td>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.</td>
</tr>
<tr>
<td>HumGen</td>
<td><a href="http://www.humgen.umontreal.ca/en/">http://www.humgen.umontreal.ca/en/</a></td>
<td>Access to a comprehensive international database on the legal, social, and ethical aspects of human genetics</td>
</tr>
<tr>
<td>National Information Resource on Ethics and Human Genetics</td>
<td><a href="http://bioethics.georgetown.edu/nirehg/">http://bioethics.georgetown.edu/nirehg/</a></td>
<td>Links to resources and databases on ethics and human genetics</td>
</tr>
<tr>
<td>NCSL (National Conference of State Legislatures) Genetic Technologies Project</td>
<td><a href="http://www.ncsl.org/programs/health/genetics.htm">http://www.ncsl.org/programs/health/genetics.htm</a></td>
<td>Status of legislative actions and access to policy briefs on genetic issues of concern to state legislators</td>
</tr>
<tr>
<td>The President’s Council on Bioethics</td>
<td><a href="http://www.bioethics.gov/">http://www.bioethics.gov/</a></td>
<td>Information on current bioethical issues</td>
</tr>
<tr>
<td>Scope Note Series (Kennedy Institute of Ethics/Georgetown University)</td>
<td><a href="http://bioethics.georgetown.edu/publications">http://bioethics.georgetown.edu/publications</a> scopenotes/</td>
<td>Annotated bibliographies on various aspects of genetics and ethics</td>
</tr>
<tr>
<td>THOMAS Legislative Information (from Library of Congress)</td>
<td><a href="http://thomas.loc.gov/">http://thomas.loc.gov/</a></td>
<td>Searchable database of U.S. legislation (current and previous)</td>
</tr>
</tbody>
</table>
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

<table>
<thead>
<tr>
<th><strong>Resource</strong></th>
<th><strong>Contact</strong></th>
<th><strong>Description</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Centers for Disease Control and Prevention</td>
<td><a href="http://www.cdc.gov/genomics/fhix.htm">http://www.cdc.gov/genomics/fhix.htm</a></td>
<td>Family history resources and tools</td>
</tr>
<tr>
<td>Cyrillic</td>
<td><a href="http://www.cyrillicsoftware.com">http://www.cyrillicsoftware.com</a></td>
<td>Pedigree drawing software for genetic counselors and clinicians; links to genetic sites</td>
</tr>
<tr>
<td>Progeny</td>
<td><a href="http://www.progenygenetics.com">http://www.progenygenetics.com</a></td>
<td>Genetic data management and pedigree drawing software</td>
</tr>
</tbody>
</table>
## Genome Research

<table>
<thead>
<tr>
<th><strong>Resource</strong></th>
<th><strong>Contact</strong></th>
<th><strong>Description</strong></th>
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</thead>
<tbody>
<tr>
<td>BLAST Search (part of Ensembl; see below)</td>
<td><a href="http://www.ensembl.org/Multi/blastview">http://www.ensembl.org/ Multi/blastview</a></td>
<td>Provides data sets from an annotated genome analysis and annotation process; searches of protein or DNA sequence against metazoan genomes</td>
</tr>
<tr>
<td>Ensembl (Joint software project between the European Bioinformatics Institute and the Sanger Institute)</td>
<td><a href="http://www.Ensembl.org/index.html">http://www.Ensembl.org/ index.html</a></td>
<td>Access to DNA and protein sequences with automatic baseline annotation</td>
</tr>
<tr>
<td>Genome Sequencing Center: Human genome maps</td>
<td><a href="http://genome.wustl.edu/">http://genome.wustl.edu/</a></td>
<td>Links to clone and accession maps of the human genome</td>
</tr>
<tr>
<td>Oak Ridge Genome Channel</td>
<td><a href="http://compbio.ornl.gov/channel/">http://compbio.ornl.gov/ channel/</a></td>
<td>Java viewers for human genome data</td>
</tr>
<tr>
<td>The SNP (Single Nucleotide Polymorphisms) Consortium</td>
<td><a href="http://www.hapmap.org">http://www.hapmap.org</a></td>
<td>A variety of ways to query for SNPs in the human genome</td>
</tr>
</tbody>
</table>
UCSC Genome Bioinformatics

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

[http://genome.cse.ucsc.edu/](http://genome.cse.ucsc.edu/)
# Health Professional Practice and Education

<table>
<thead>
<tr>
<th><strong>Resource</strong></th>
<th><strong>Contact</strong></th>
<th><strong>Description</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Centre for Education in Medical Genetics</td>
<td><a href="http://www.bwhct.nhs.uk/genetics-cemg-home.htm">http://www.bwhct.nhs.uk/genetics-cemg-home.htm</a></td>
<td>Develops, provides, and evaluates genetics education opportunities and resources</td>
</tr>
<tr>
<td>Dolan DNA Learning Center</td>
<td><a href="http://www.dnalc.org/">http://www.dnalc.org/</a></td>
<td>Interactive, multimedia genetics education resources</td>
</tr>
<tr>
<td>Foundation for Genetic Education and Counseling</td>
<td><a href="http://www.fgec.org">http://www.fgec.org</a></td>
<td>Educational resources on genetics and common diseases, especially psychiatric disorders (bipolar disorder and schizophrenia)</td>
</tr>
<tr>
<td>GenEd Project</td>
<td><a href="http://www.medicine.man.ac.uk/GenEd/">http://www.medicine.man.ac.uk/GenEd/</a></td>
<td>Education and research links related to European aspects of genetic services</td>
</tr>
<tr>
<td>Genetics and Your Practice</td>
<td><a href="http://www.marchofdimes.com/gyponline/index.bm2">http://www.marchofdimes.com/gyponline/index.bm2</a></td>
<td>Online modules for healthcare professionals designed for exploration of a topic rather than sequential presentation of material...Many excellent factsheets and sample clinical forms</td>
</tr>
<tr>
<td>Genetics in Clinical Practice: A Team Approach</td>
<td><a href="http://iml.dartmouth.edu/education/cme/Genetics/">http://iml.dartmouth.edu/education/cme/Genetics/</a> or <a href="http://www.acmg.net/resources/cd-rom-01/intro.asp">http://www.acmg.net/resources/cd-rom-01/intro.asp</a></td>
<td>Takes healthcare provider into a Virtual Genetics Clinic...Interactive virtual genetics clinic with case scenarios and case discussions...Target audience is primary care professionals</td>
</tr>
<tr>
<td>Genetics in Primary Care</td>
<td><a href="http://genes-r-us.uthscsa.edu/resources/genetics/primary_care.htm">http://genes-r-us.uthscsa.edu/resources/genetics/primary_care.htm</a></td>
<td>Training program curriculum materials</td>
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<tr>
<td>Genetics in Psychology</td>
<td><a href="http://www.apa.org/science/genetics/homepage.html">http://www.apa.org/science/genetics/homepage.html</a></td>
<td>American Psychological Association’s genetics site</td>
</tr>
<tr>
<td>Genetics Education Program for Nurses (GEPN) curriculum resources</td>
<td><a href="http://www.cincinnatichildrens.org/ed/clinical/gpnf/default.htm">http://www.cincinnatichildrens.org/ed/clinical/gpnf/default.htm</a></td>
<td>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)</td>
</tr>
<tr>
<td>Genetics: Educational Information</td>
<td><a href="http://www.ashg.org/pages/pubs_curriculum.shtml">http://www.ashg.org/pages/pubs_curriculum.shtml</a></td>
<td>Medical school course competencies, skills, knowledge, and behaviors which should be covered in genetics</td>
</tr>
<tr>
<td>Kansas Genetics Education Center</td>
<td><a href="http://www.kumc.edu/gec/">http://www.kumc.edu/gec/</a></td>
<td>An ever-growing list of available resources, lesson plans, etc.</td>
</tr>
<tr>
<td>National Cancer Institute's CancerNet</td>
<td><a href="http://www.cancer.gov/cancerinfo/prevention">http://www.cancer.gov/cancerinfo/prevention</a> genetics-causes</td>
<td>Authoritative information about cancer genetics</td>
</tr>
<tr>
<td>National Coalition for Health Professional Education in Genetics (NCHPEG)</td>
<td><a href="http://nchpeg.org/">http://nchpeg.org/</a></td>
<td>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</td>
</tr>
<tr>
<td>Resource</td>
<td>Link</td>
<td>Description</td>
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<tr>
<td>Practice-Based Genetics Curricula for Nurse Educators</td>
<td><a href="http://www.fbr.org/publications/pub_curic.html">http://www.fbr.org/publications/pub_curic.html</a></td>
<td>Bound instructional modules with accompanying CD or PowerPoint presentations (sample chapter available online)</td>
</tr>
<tr>
<td>Six Weeks to Genomic Awareness</td>
<td><a href="http://www.cdc.gov/genomics/training/sixwks.htm">http://www.cdc.gov/genomics/training/sixwks.htm</a></td>
<td>Webcast of 12 segments of genomic topics for public health professionals</td>
</tr>
</tbody>
</table>
## Internal Review Boards (IRBs)

<table>
<thead>
<tr>
<th>Resource</th>
<th>Contact</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td><strong>Genetic Testing and Screening in the Age of Genomic Medicine.</strong> New York State Task Force on Life and Law (2001)</td>
<td><a href="http://www.health.state.ny.us/nysdoh/taskfce/screening.htm">http://www.health.state.ny.us/nysdoh/taskfce/screening.htm</a></td>
<td>Includes general and state-specific information in a bulleted report that is relatively easy to scan by topic.</td>
</tr>
<tr>
<td><strong>Human Subjects Protection Resource Book.</strong> U.S. Department of Energy (2006)</td>
<td><a href="http://humansubjects.energy.gov/doe-resources/humsubj-resourcebook.htm">http://humansubjects.energy.gov/doe-resources/humsubj-resourcebook.htm</a></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Resource</strong></td>
<td><strong>Contact</strong></td>
<td><strong>Description</strong></td>
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<tr>
<td>Genetics and Molecular Medicine (American Medical Association)</td>
<td><a href="http://www.ama-assn.org/ama/pub/category/1799.html">http://www.ama-assn.org/ama/pub/category/1799.html</a></td>
<td>Links to current articles, new educational programs and initiatives, and other resources</td>
</tr>
<tr>
<td>Genome News Network (Center for the Advancement of Genomics)</td>
<td><a href="http://www.genomenewsnetwork.org/">http://www.genomenewsnetwork.org/</a></td>
<td>Original articles and links</td>
</tr>
<tr>
<td>Science News Presented by BIO, the Biotechnology Industry Organization</td>
<td><a href="http://science.bio.org/genomics.news.html">http://science.bio.org/genomics.news.html</a></td>
<td>Links to current articles</td>
</tr>
</tbody>
</table>
### Professional Organizations: Genetics

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

<table>
<thead>
<tr>
<th>Organization</th>
<th>Contact</th>
<th>Description</th>
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</table>
| American Nurses Association | [http://www.nursingworld.org](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 |
| Association of Women’s Health, Obstetric and Neonatal Nurses | [http://www.awhonn.org](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](http://www.isong.org/support/scope.cfm) and [http://www.isong.org/about/position.cfm](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](http://www.nchpeg.org) | Recommendations of core competencies in genetics for all health professionals |

Position statements on:
- The role of the oncology nurse in cancer genetic counseling
- Cancer predisposition genetic testing and risk assessment counseling
## Risk Assessment

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<tr>
<th>Resource</th>
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## Search Engines Specializing in Genetics and Genomics

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<tr>
<th>Resource</th>
<th>Contact</th>
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<tbody>
<tr>
<td>Centers for Disease Control: Genomics and Disease Prevention GDP InfoSearch</td>
<td><a href="http://www.cdc.gov/genomics/">http://www.cdc.gov/genomics/</a></td>
<td>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.</td>
</tr>
<tr>
<td>Genetics Resources on the Web (GROW)</td>
<td><a href="http://www.geneticsresources.org/">http://www.geneticsresources.org/</a></td>
<td>Provides health professionals and the public with high quality information related to human genetics, with a particular focus on genetic medicine and health.</td>
</tr>
</tbody>
</table>
# United States Government Agencies

<table>
<thead>
<tr>
<th>Resource</th>
<th>Contact</th>
<th>Description</th>
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<tbody>
<tr>
<td>Center for Disease Control and Prevention: Office of Genomics and Disease Prevention</td>
<td><a href="http://www.cdc.gov/genomics/">http://www.cdc.gov/genomics/</a></td>
<td>Information about human genetic discoveries and how to use to improve health and prevent disease, including links to many resources</td>
</tr>
<tr>
<td>Department of Energy Office of Science (DOEgenomes.org)</td>
<td><a href="http://www.doegenomes.org/">http://www.doegenomes.org/</a></td>
<td>Multiple genomics educational resources</td>
</tr>
<tr>
<td>Genetic Modification Clinical Research Information System (GeMCRIS®)</td>
<td><a href="http://www.gemcris.od.nih.gov/">http://www.gemcris.od.nih.gov/</a></td>
<td>Access to an array of information about human gene transfer trials registered with the NIH</td>
</tr>
<tr>
<td>National Human Genome Research Institute</td>
<td><a href="http://www.genome.gov">http://www.genome.gov</a></td>
<td>Research, policy, ethics, education, and training information and resources about genetic and rare diseases</td>
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<tr>
<td>National Institutes of Health Obesity Research</td>
<td><a href="http://obesityresearch.nih.gov/">http://obesityresearch.nih.gov/</a></td>
<td>Information about NIH-supported research that seeks to identify genetic, behavioral, and environmental causes of obesity and to develop prevention and treatment strategies</td>
</tr>
<tr>
<td>Secretary's Advisory Committee on Genetic Testing</td>
<td><a href="http://www4.od.nih.gov/oba/sacgt/aboutsacgt.htm">http://www4.od.nih.gov/oba/sacgt/aboutsacgt.htm</a></td>
<td>Public policy issues regarding genetic testing (archival)</td>
</tr>
<tr>
<td>Secretary's Advisory Committee on Genetics, Health, and Society</td>
<td><a href="http://www4.od.nih.gov/oba/sacghs/reports/reports.html">http://www4.od.nih.gov/oba/sacghs/reports/reports.html</a></td>
<td>Reports on public policy issues regarding the impact of genetic technologies on society</td>
</tr>
</tbody>
</table>
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.