



Essential Genetic and Genomic Competencies

Established by Consensus Panel
September 2011

for Nurses with Graduate Degrees

ESSENTIAL GENETIC AND GENOMIC COMPETENCIES FOR NURSES WITH GRADUATE DEGREES

Karen E. Greco, PhD, RN, ANP-BC, FAAN

Susan Tinley, PhD, RN, CGC

Diane Seibert, PhD, CRNP, FAANP

Established by Consensus Panel

September 2011



Library of Congress Cataloging-in-Publication Data

Greco, Karen E.

Essential genetic and genomic competencies for nurses with graduate degrees / Karen E. Greco, Susan Tinley, Diane Seibert.

p. ; cm.

Includes bibliographical references.

Summary: "Describes and delineates the thirty-eight essential genetic and genomic competencies that inform the practice of all nurses functioning at the graduate level in nursing, summarizes the key documents and processes used to identify these competencies, and identifies the members of the Steering, Advisory, and Consensus Panel committees involved"--Provided by publisher.

ISBN 978-1-55810-437-2 -- ISBN 1-55810-437-2

I. Tinley, Susan. II. Seibert, Diane. III. American Nurses Association. IV. International Society of Nurses in Genetics. V. Title.

[DNLM: 1. Genetics, Medical--standards--United States. 2. Clinical Competence--United States. 3. Education, Nursing, Graduate--standards--United States. 4. Genomics--standards--United States. QZ 50]

616'.042--dc23

2011049764

This publication — Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees — reflects the thinking of the nursing profession on various issues and should be reviewed in conjunction with state board of nursing policies and practices. State law, rules, and regulations govern the practice of nursing, while Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees guides nurses in the application of their professional skills and responsibilities.

The opinions in this book reflect those of the authors and do not necessarily reflect positions or policies of the American Nurses Association or the International Society of Nurses in the Genetics and Genomics. Furthermore, the information in this book should not be construed as legal or other professional advice.

The PDF of this publication is available on the ANA website at <http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Genetics-1> and also on the ISONG website at <http://www.isong.org/>

©2012 American Nurses Association and International Society of Nurses in Genetics. All rights reserved. Any part of this book may be reproduced or utilized in any form or any means without permission in writing from the publisher. Please, however, cite this publication as the source:

Greco, K. E., Tinley, S. & Seibert, D. (2012) Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees. Silver Spring, MD: American Nurses Association and International Society of Nurses in Genetics.

ISBN-13: 978-1-55810-437-2

Published: March 2012

Table of Contents

Steering Committee, Advisory Panel, and Consensus Panel	iv
Executive Summary	1
Introduction and Background	2
Purpose and Applicability	3
Definitions.....	3
Development of the Competencies and Process of Consensus	5
Resource/Reference Documents	
Competency Development and Process of Consensus	
Endorsement Process	8
Development of Performance Indicators and Educational Resources	8
Summary	9
Essential Competencies in Genetics and Genomics for Nurses with Graduate Degrees	10
Professional Practice	10
Risk Assessment and Interpretation	
Genetic Education, Counseling, Testing, and Results Interpretation	
Clinical Management	
Ethical, Legal, and Social Implications (ELSI)	
Professional Responsibilities	12
Professional Role	
Leadership	
Research	
References	14
Endorsing Organizations.....	18
Genetic/Genomic Online Resources	19

Steering Committee, Advisory Committee, and Consensus Panel

<u>Steering Committee Members</u>	<u>Affiliations</u>
Karen E. Greco, PhD, RN, ANP-BC, FAAN	National Cancer Institute, Center for Cancer Research, Genetics Branch
Susan Tinley, PhD, RN, CGC	Creighton University
Diane Seibert, PhD, CRNP, FAANP	Uniformed Services University
<u>Advisory Committee Members</u>	<u>Affiliations</u>
Kathleen Calzone, PhD, RN, APNG, FAAN	National Cancer Institute, Center for Cancer Research, Genetics Branch
Jean F. Jenkins, PhD, RN, FAAN	National Human Genome Research Institute
Carol J. Bickford, PhD, RN-BC, CPHIMS	American Nurses Association
Quannetta Edwards, PhD, FNP, WHCNP, FAANP	American Academy of Nurse Practitioners
Suzanne Feetham, PhD, RN, FAAN	Children's National Medical Center & University of Wisconsin, Milwaukee
Tracy Klein, PhD, RN, FNP-BC, FAANP	Oregon State Board of Nursing
Kathy McGuinn, MSN, RN, CPHQ	American Association of Colleges of Nursing
Karen Pehrson, MS, PMHCNS-BC	Sigma Theta Tau International
Cynthia A. Prows, MSN, CNS, FAAN	Cincinnati Children's Hospital Medical Center
Jo Ellen Rust, MSN, RN, CNS	National Association of Clinical Nurse Specialists
Elizabeth Thomson, DNSc, MSN, RN, CGC, FAAN	National Human Genome Research Institute
Janet K. Williams, PhD, RN, PNP, FAAN	University of Iowa

<u>*Consensus Panel Members</u>	<u>Affiliations</u>
Michelle Beauchesne, DNSc, RN, CPNP, FNAP, FAANP	National Association of Pediatric Nurse Practitioners
Linda Callahan, PhD, CRNA, PMHNP	American Association of Nurse Anesthetists
Duck-Hee Kang, PhD, RN, FAAN	Asian American/Pacific Islander Nurses Association
Carole Kenner, PhD, NNP, RNC-NIC, FAAN	Council of International Neonatal Nurses
Elizabeth A. Kostas-Polston, PhD, APRN, WHNP-BC	National Association of Nurse Practitioners in Women's Health
Ann Maradiegue, PhD, FNP-BC, FAANP	National Organization of Nurse Practitioner Faculties
Carrie Merkle, PhD, RN, FAAN	American Academy of Nursing, Genetic Health Care Expert Panel
Carmen T. Paniagua, EdD, RN, CPC, ACNP-BC, APNG, FAANP	National Association of Hispanic Nurses
Nancy Roehnel, PhD, NP-BC	Oncology Nursing Society
Barbara M. Raudonis, PhD, RN, FNGNA, FPCN	National Gerontological Nursing Association
Lynnece Rooney, MSN, CNM, RNC-OB	American College of Nurse-Midwives
Catherine Ruhl, MS, CNM	Association of Women's Health, Obstetric and Neonatal Nurses
Kathleen Sparbel, PhD, RN, FNP-BC	International Society of Nurses in Genetics
Ida Johnson-Spruill, PhD, RN, LISW, FAAN	National Black Nurses Association
Lois A. Tully, PhD	National Institute of Nursing Research
Mary Weber, PhD, APRN, PMHNP-BC	International Society of Psychiatric-Mental Health Nurses

*The Consensus Panel also includes the Steering Committee and Advisory Board members

Executive Summary

Genetic and genomic scientific advances are redefining our understanding of health and illness, necessitating a concomitant shift in graduate nursing education and practice. The primary purpose of this document is to identify essential genetic and genomic competencies for individuals prepared at the graduate level in nursing. These competencies apply to anyone functioning at the graduate level in nursing, including but not limited to advanced practice registered nurses (APRNs), clinical nurse leaders, nurse educators, nurse administrators, and nurse scientists. These competencies complement existing nursing competencies and standards of practice and are intended to incorporate genetics and genomics into all clinical and non-clinical nursing roles. They build on the *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines and Outcome Indicators* (Consensus Panel, 2009) and assume that nurses with graduate degrees have already achieved those core competencies. Because the APRN role has a different legal scope of practice than that of other nurses with graduate degrees, some competencies have been identified as unique to APRNs.

The 38 competencies are organized under the following major categories:

1. Risk Assessment and Interpretation
2. Genetic Education, Counseling, Testing, and Results Interpretation
3. Clinical Management
4. Ethical, Legal, and Social Implications (ELSI)
5. Professional Role
6. Leadership
7. Research

Introduction and Background

Genetic and genomic scientific advances are redefining our understanding of health and illness. Many common health conditions have been identified as having a genetic and/or genomic component, and mounting evidence supports that these multifactorial conditions result from the interactions of multiple genes and environmental, lifestyle, and other factors (Guttmacher, Collins, & Drazen, 2004).

Hundreds of genetic tests are now available which can identify individuals who carry one or more gene mutations associated with an increased risk of developing common health conditions. Increased availability of genetic testing and consumer access to this testing over the internet are moving genetic testing away from trained genetics health professionals and into the hands of primary care providers and consumers (Greco & Mahon, in press). This increased access to genetic information and technology brings with it a host of ethical challenges, including maintaining genetic privacy, facilitating ethical decision-making concerning whether to undergo genetic testing, and protecting the confidentiality of genetic/genomic information.

Nurses prepared at the master's and doctoral levels are at the interface of translating these genetic and genomic advances into client care, integrating genomic health care into health care systems, and addressing the ethical challenges associated with genetic information and technology. As the public continues to become more aware of genetic and genomic contributions to health and disease, nurses will be even more on the front lines, addressing genetics/genomics questions and the ethical issues that go with them (Greco, 2009).

Nurses with graduate degrees are also increasingly asked to provide leadership in caring for clients who have genetic conditions, concerns, or potential genetic components to their health and disease. Advances in genetics and genomics necessitate the integration of the appropriate content in nursing curricula to provide the knowledge and skills needed for graduate-level nursing practice, education, and research. Genetic and genomic competencies are integral to the practice of nurses prepared at any graduate level, regardless of academic preparation, practice setting, role, or specialty. This need is evidenced by the 2011 revision of the American Association of Colleges of Nursing's (AACN) *Essentials of*

Master's Education in Nursing, which includes several references to genetics and genomics distributed across three discreet essentials (AACN, 2011).

These graduate nursing competencies build upon the *Essentials of Genetics and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators* (Consensus Panel, 2009), which has been endorsed by over 40 nursing organizations and assumes that nurses with graduate degrees have already achieved the core competencies therein. These graduate-level genetic/genomic nursing competencies are complementary to existing nursing competencies and standards of practice and are intended to provide structure as graduate-level nurses incorporate genetics and genomics into clinical and non-clinical roles.

Purpose and Applicability

The primary purpose of this document is to identify essential genetic and genomic competencies for individuals prepared at the graduate level in nursing. These competencies apply to anyone functioning at the nursing graduate level, including but not limited to APRNs, nurse educators, nurse administrators, and nurse scientists.

Definitions

Nurses with graduate degrees: Any nurse prepared at the master's and/or doctoral level practicing in a clinical or non-clinical role. This includes registered nurses with master's and/or doctorates in other fields functioning in graduate nursing roles.

Advanced Practice Registered Nurse (APRN): An umbrella term appropriate for a licensed registered nurse prepared at the graduate degree level as a Certified Nurse Anesthetist, Certified Nurse-Midwife, Clinical Nurse Specialist, or Certified Nurse Practitioner (American Nurses Association [ANA], 2009).

Client: Used throughout the document to reflect the recipient of nursing care, including individuals, families, communities, and populations. In the education setting, *client* includes the student being taught; in research, *client* includes the participant in the research setting.

Competency: An observable, measurable, performance-based outcome that indicates the achievement of a particular knowledge component, application, or demonstration of a psychomotor behavior or skill.

Genetic predisposition: A genetic factor that alters an individual's chances of developing a disease or condition.

Genetic testing: The use of a laboratory test to look for genetic variations associated with a disease (<http://www.genome.gov/glossary/index.cfm?id=88>). Genetic testing may also be used for other purposes.

Genetics: The study of individual genes and their impact on relatively rare single-gene disorders (Guttmacher, Collins, & Drazen, 2004).

Genomics: The study of a subset or all the genes in the human genome together, including their interactions with each other, the environment, and other psychosocial and cultural factors (Guttmacher, Collins, & Drazen, 2004).

Genotype: An individual's collection of genes. The genotype is expressed when information encoded in the gene's DNA is used to make protein and RNA molecules. Expression of the genotype contributes to an individual's observable traits, called the *phenotype* (<http://www.genome.gov/glossary/index.cfm?id=93>).

Pedigree: A graphic illustration of a family health history using standardized symbols (Bennett et al., 2008).

Pharmacogenomics: The study of genomic variations associated with drug response. This term is often used interchangeably with pharmacogenetics, the study of allelic differences of single genes associated with individual variability in drug response.

Development of the Competencies and Process of Consensus

Resource/Reference Documents

Articles and other documents published in the United States in the English language between May 1997 and May 2009 were identified through searching standard medical and nursing databases, consultation with a reference librarian, and reviewing professional organizations' websites. Key words included *genetic(s) competencies*, *genomic(s) competencies*, *genetic(s) curriculum*, *genomic(s) curriculum*, *genetic(s) education*, and *genomic(s) education*. These were cross-referenced with nursing and advanced practice nursing/nurses. Searches were performed in MEDLINE, CINAHL, Web of Science, Google, Google Scholar, and websites for health-professional organizations. Bibliographies for relevant articles were reviewed. Documents obtained were reviewed by the Steering Committee to identify:

1. key published nursing articles addressing what nurses with graduate degrees should know about genetics/genomics (Berry & Hern, 2004; Calzone, Jenkins, & Masny, 2002; Edwards, Maradiegue, Seibert, Macri, & Sitzler, 2006; Horner, 2004; Lea, Feetham, & Monsen, 2002; Lea, Jenkins, & Monsen, 1999; Maradiegue, Edwards, Seibert, D., Macri, & Sitzler, 2005);
2. published genetic/genomic competencies that included but were not specific to nurses with graduate degrees (CDC, 2001; NCHPEG, 2001; NCHPEG, 2007);
3. published genetic/genomic competencies from similar graduate-level health professionals that require master's or doctoral entry to practice have some overlap with a graduate nursing scope of practice and have published genetic/genomic competencies; i.e., family practice physicians, physician assistants, social workers, optometrists, speech-language pathologists, and audiologists (American Academy of Family Physicians, 2008; Association of Professors of Human and Medical Genetics/American Society of Human Genetics, 2001; National Association of Social Workers, 2003; Rackover, Goldgar, Wolpert, Healy, Feiger, & Jenkins, 2007).

Published formal genetic/genomic competencies were not found for the following health professional groups: chiropractors, dentists, naturopaths, nutritionists, physical therapists, podiatrists, psychologists, or occupational therapists. Most of these professional groups have published on the importance of genetics and genomics;

4. Eleven exam guidelines from six graduate-nursing certification bodies were reviewed for genetic/genomic content:
 - American Nurses Credentialing Commission: (Family Nurse Practitioner [NP], Adult NP, Pediatric NP, Gerontological NP, & Clinical Nurse Specialist [CNS] “Core” exam) <http://www.nursecredentialing.org/>
 - National Certification Corporation: Women’s Health Care NP and Neonatal NP <http://www.nccwebsite.org/>
 - American Academy of Nurse Practitioners: Family NP <http://www.aanp.org/Certification>
 - Pediatric Nursing Certification Board: Primary Care Pediatric NP <http://www.pncb.org/ptistore/control/index>
 - American Midwifery Certification Board: Midwifery <http://www.amcbmidwife.org/index.php>
 - Council of Certification of Nurse Anesthetists: Nurse Anesthetist <http://cms2.aana.com/>

5. The following documents were also reviewed:
 - *Nurses Transforming Health Care Using Genetics and Genomics* (American Academy of Nursing, 2009)
 - *The Essentials of Doctoral Education for Advanced Nursing Practice* (American Association of Colleges of Nursing, 2006)
 - *The Essentials of Master’s Education for Advanced Nursing Practice* (American Association of Colleges of Nursing, 1996).
 - *Genetics and Genomics Nursing: Scope and Standards of Practice* (International Society of Nurses in Genetics/American Nurses Association, 2007)
 - *Nurse Practitioner Primary Care Competencies in Specialty Areas: Adult, Family, Gerontological, and Women’s Health* (National Organization of Nurse Practitioner Faculties in partnership with the American Association of Colleges of Nursing, 2002)

Competency Development and Process of Consensus

Phase I: Steering Committee and Competency Draft Document

A Steering Committee was created in the spring of 2009 to provide leadership for the development of genetic and genomic competencies for nurses prepared at the graduate level (Greco, Tinley, & Seibert, in press). This committee reviewed and analyzed documents obtained from the resource and reference materials listed above. Competency themes were identified from published genetic/genomic competencies applicable to graduate-level health professionals and from the seven nursing manuscripts. A similar thematic analysis was conducted for documents in each of the other four categories. From these analyses, the initial competency draft document was created. Because the APRN role has a different legal scope of practice than that of other nurses with graduate degrees, some competencies have been identified as unique to APRNs.

Phase II: Advisory Board

An Advisory Board consisting of a broad representation of nursing leaders and genetics experts was created in the fall of 2009. The draft competency document was sent out to the advisory board for comment and review. Several advisory board meetings were held via conference call to discuss the document and proposed revisions. Based on this and email feedback, the graduate competencies document was revised and returned to the board for further review after each conference call.

Phase III: Consensus Panel

Advisory board members helped identify individuals from across a broad representation of different APRN and nursing organizations to serve on a Consensus Panel. The consensus panel helped review the relevance and comprehensiveness of the draft competency document and provided feedback through email and via conference calls. Comments were circulated to the entire consensus panel for discussion, and the steering committee also held regular conference calls to discuss feedback and update the document before it was sent back out for further review.

Phase IV: Public Comment

The revised competency document was posted for public comment on the American Nurses Association (ANA) website for 45 days in the fall

of 2010. Comments received during the public comment period were reviewed and summarized by the steering committee and discussed by the consensus panel. The competencies were revised based on those comments.

Phase V: Consensus Surveys

A consensus survey using Survey Monkey was sent out in December 2010 to all consensus panel members to test each competency for consensus. Competencies for which consensus was not achieved in the initial survey were discussed, additional revisions were made, and a second consensus survey was sent to all consensus panel members in May 2011. Consensus was achieved in September 2011 after all survey responses were received.

Endorsement Process

Endorsement from a wide variety of nursing organizations is currently being sought. At the time of publication of this document, 19 nursing and professional organizations have endorsed the competencies (see Appendix). Additional information about the development of these competencies can be found in Greco, Tinley, & Seibert (in press).

Development of Performance Indicators and Educational Resources

Achieving consensus on *Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees* is the first step toward ensuring that nurses with graduate degrees are prepared to deliver competent genomic care. A list of genetics and genomics resources can be found in the appendix. The next major effort is to develop performance indicators and identify additional educational resources to assist educators in teaching competency concepts. Performance indicators will be developed using a process similar to the one used to develop performance indicators for *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines and Outcome Indicators* (Calzone, Jenkins, Prows, & Masny, 2011; Consensus Panel, 2009).

Summary

Genomic discoveries and technology are improving our ability to predict disease susceptibility, provide individualized preventive screening

and risk reduction interventions, and target disease treatment. Nurses educated at the graduate level need to be prepared to assume clinical and leadership roles in translating these genetic and genomic advances into effective health care.

Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees establishes baseline genetic and genomic competencies for all nurses functioning at the graduate level in nursing. These competencies were developed using a structured, methodical approach and validated by a diverse panel of 31 nursing leaders and genetics experts representing professional nursing organizations, academic institutions, regulatory bodies, and government agencies, using a consensus model. *Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees* provides the foundation for the genomic competence of graduate nursing practice.

Essential Competencies in Genetics and Genomics for Nurses with Graduate Degrees

I. Professional Practice

A. Risk Assessment and Interpretation

The nurse with a graduate degree engages in a more active role in risk assessment and interpretation than the registered nurse without a graduate degree.

APRNs perform a more detailed evaluation, gather an expanded history, assess for modifiers of risk, confirm reported family health histories, ensure that histories are updated, integrate psychosocial aspects of the family history, and assess for other complex variables (e.g., consanguinity within a family pedigree).

All nurses with graduate degrees in nursing

1. identify clients with inherited predispositions to diseases as appropriate to the nurse's practice setting.

Nurses with graduate degrees functioning in APRN roles also

2. analyze a pedigree to identify potential inherited predisposition to disease;
3. estimate risks for Mendelian and multifactorial disorders in affected families as appropriate;
4. use family history and pedigree information to plan and conduct a targeted physical assessment;
5. interpret the findings from the physical assessment, family history, laboratory findings, diagnostic tests, and/or radiology results that may indicate genetic/genomic disease, disease risk, or the need for a genetics/genomics referral;
6. refer at-risk family members for assessment of inherited predisposition to disease.

B. Genetic Education, Counseling, Testing, and Results Interpretation

Nurses with graduate degrees provide genetic/genomic education, counseling and testing, and client support throughout the lifespan

within their licensure, scope of practice, and clinical setting, and seek consultation as appropriate.

All nurses with graduate degrees in nursing

1. incorporate clients' attitudes, values, and beliefs rooted in varying ethnic, cultural, social, and religious backgrounds when communicating genetic/genomic information;
2. provide genetic/genomic information that is appropriate to client's level of health literacy and numeracy;
3. educate clients about possible risks, benefits, and limitations of genetic testing and/or therapy;
4. provide anticipatory guidance to assist clients in the decision-making process related to genetics/genomics;
5. obtain informed consent for genetic testing and/or therapy;
6. assess the influence of genetic/genomic risk and disease on family communication and functioning;
7. assess the clinical and psychosocial outcomes, including benefits, limitations, and risks of genetic/genomic information and/or therapies, for clients;
8. support client coping and client use of genetic/genomic information in promoting health, reducing risk, managing symptoms, and/or preventing illness.

Nurses with graduate degrees functioning in APRN roles also

9. provide genetic/genomic education and counseling appropriate to practice setting;
10. select appropriate genetic/genomic tests and/or studies;
11. communicate results of genetic/genomic screening and/or testing at a level that clients can understand.

C. Clinical Management

Nurses with graduate degrees need to be able to provide personalized care and/or care coordination that incorporates genetic/genomic-based technology into client care.

All nurses with graduate degrees in nursing

1. apply knowledge about the interaction of genetic/genomic and environmental factors to the care of clients;
2. make appropriate referrals to genetic professionals or other health care resources;
3. evaluate effectiveness of prevention, risk reduction, health

promotion, and disease management interventions related to genetics/genomics.

Nurses with graduate degrees functioning in APRN roles also

4. manage care of clients, incorporating genetic/genomic information and technology (e.g., risk-based genetic screening and testing, prescription of pharmacogenomic-based drugs, gene-targeted therapy, and use of genetic/genomic information in symptom management);
5. collaborate with genetic specialists, health professionals, and those in relevant disciplines to develop a comprehensive plan to evaluate and manage clients with genetic/genomic disease or risk.

D. Ethical, Legal, and Social Implications (ELSI)

Nurses with graduate degrees need to recognize the significance of ethical, legal, and social implications in genetics and genomics. Genetic testing is a component of health care where ethical issues may be most apparent, although ethical, legal, and social implications apply across all areas of practice.

All nurses with graduate degrees in nursing

1. facilitate ethical decision-making related to genetics/genomics congruent with the client's values and beliefs;
2. inform health care and research policy related to ELSI issues in genetics/genomics;
3. implement effective strategies to resolve ELSI issues related to genetics/genomics;
4. apply ethical principles when making decisions regarding management of genetic/genomic information identified through clinical or research technologies.

II. Professional Responsibilities

A. Professional Role

Nurses with graduate degrees need to maintain a solid foundation in genetics/genomics to provide safe and competent care to clients.

All nurses with graduate degrees in nursing

1. integrate best genetic/genomic evidence into practice that incorporates client values and clinical judgment;

2. mentor other nurses in the application of genetics/genomics to nursing care within their practice setting;
3. identify genetic/genomic learning needs of other health professionals and disciplines;
4. conduct educational interventions to address the genetic/genomic learning needs of health professionals and clients;
5. participate in the development of professional practice guidelines related to genetics/genomics.

B. Leadership

Nurses with graduate degrees assume an active role in genetic/genomic policies at the local, state, national, and international levels in nursing and other health care organizations.

All nurses with graduate degrees in nursing

1. contribute a nursing perspective to genetic/genomic clinical and policy discussions;
2. facilitate an organizational climate that is responsive to genetic/genomic discoveries;
3. use care delivery strategies which incorporate genetic/genomics;
4. influence health policy at the local, state, national, and international levels related to genetics/genomics.

C. Research

Nurses with graduate degrees must understand how genetic/genomic research can provide insight into human biology and disease pathogenesis, leading to improved health outcomes. Nurses prepared at the doctoral level are expected to provide leadership in the conduct of research and translation of genetic/genomic findings into practice.

All nurses with graduate degrees in nursing

1. participate in the application and translation of genetic/genomic research in nursing practice and/or education;
2. identify genetic/genomic health care methods and outcomes that can be influenced by nursing;
3. collaborate with researchers in relevant disciplines in the conduct, dissemination, and/or translation of genomic inquiry and research.

References

- American Association of Colleges of Nursing (2006). *The Essentials of Doctoral Education for Advanced Nursing Practice*. Retrieved from <http://www.aacn.nche.edu/DNP/pdf/Essentials.pdf>
- American Association of Colleges of Nursing (2011). *The Essentials of Master's Education in Nursing*. Retrieved from <http://www.aacn.nche.edu/education-resources/MastersEssentials11.pdf>
- American Association of Colleges of Nursing (1996). *The Essentials of Master's Education for Advanced Nursing Practice*. Retrieved from <http://www.aacn.nche.edu/Education/pdf/MasEssentials96.pdf>
- American Academy of Nursing (2009). *Nurses Transforming Health Care Using Genetics and Genomics*. Retrieved from http://www.aannet.org/files/public/Genetic_White_Paper_1.22.09_2.pdf
- American Nurses Association (2009). *Consensus Model for APRN Regulation: Licensure, Accreditation, Certification and Education*. Retrieved from <http://www.nursingworld.org/cmissuebrief>
- American Academy of Family Physicians (2008). *Recommended Curriculum Guidelines for Family Medicine Residents (3d ed.)*. Retrieved from http://www.aafp.org/online/etc/medialib/aafp_org/documents/about/rap/curriculum/medical_genetics.Par.0001.File.tmp/medicalgenetics.pdf
- American Speech-Language-Hearing Association (2011). *What Does the Speech-language Pathologist or Audiologist Need to Know about Genetics When Conducting Assessments?* Retrieved from <http://www.asha.org/academic/questions/Genetics-Education.htm>
- Association of Professors of Human and Medical Genetics/American Society of Human Genetics (2001). *Medical School Core Curriculum in Genetics*. Available at http://www.meddean.luc.edu/lumen/MedEd/genetics/core_curric.htm and also <http://www.ashg.org/pdf/Medical%20School%20Core%20Curriculum%20in%20Genetics.pdf>

- Association of Schools & Colleges of Optometry (2008). *Core Competencies in Genetics*. Available at <http://www.opted.org/i4a/pages/index.cfm?pageid=3366>
- Beery, T., & Hern, M. (2004). Genetic practice, education, and research: an overview for advanced practice nurses. *Clinical Nurse Specialist: The Journal for Advanced Nursing Practice*, 18(3), 126-134.
- Bennett, R. L., Steinhaus French, K. A., Resta, R. G., & Lochner Doyle, D. (2008). Standardized human pedigree nomenclature. *Update and assessment of the recommendations of the National Society of Genetic Counselors. Journal of Genetic Counseling*, 17, 424-433.
- Calzone, K. A., Jenkins, J., & Masny, A. (2002). Core competencies in cancer genetics for advanced practice oncology nurses. *Oncology Nursing Forum*, 29(9), 1327-1333.
- Center for Disease Control and Prevention (2001). *Genomic Competencies for All Public Health Professionals*. Retrieved from <http://www.cdc.gov/genomics/translation/competencies/index.htm>
- Consensus Panel on Genetic/Genomic Nursing Competencies (2009). *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators (2nd ed.)*. Silver Spring, MD: American Nurses Association. Retrieved from http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Genetics_1/EssentialNursingCompetenciesandCurriculaGuidelines-forGeneticsandGenomics.aspx
- Edwards, Q. T., Maradiegue, A., Seibert, D., Macri, C., & Sitzer, L. (2006). Faculty members' perceptions of medical genetics and its integration into nurse practitioner curricula. *Journal of Nursing Education*, 45(3), 124-130.
- Greco, K. E., Tinley, S., & Seibert, D. (2012). Development of the essential genetic and genomic competencies for nurses with graduate degrees. *Annual Review of Nursing Research (Vol. 29)*. New York: Springer Publishing Co.

- Greco, K. E. (2009). Scope and standards of genomics nursing practice and the interface with ethics. In Monsen, R. B. (Ed.) *Genetics and Ethics in Health Care: New Questions in the Age of Genomic Health*. Silver Spring, MD: Nursesbooks.org.
- Greco, K. E. & Mahon, S. (2012) The state of genomic healthcare and cancer: Are we going two steps forward and one step backward? *Annual Review of Nursing Research (Vol. 29)*. New York: Springer Publishing Co.
- Guttmacher, A. E., Collins, F. S., & Drazen, J. M. (2004). *Genomic Medicine*. Baltimore: Johns Hopkins University Press.
- Horner, S. (2004). A genetics course for advanced clinical nursing practice. *Clinical Nurse Specialist: The Journal for Advanced Nursing Practice*, 18(4), 194-199.
- International Society of Nurses in Genetics & American Nurses Association (2007). *Genetics and Genomics Nursing: Scope and Standards of Practice*. Silver Spring, MD: Nursesbooks.org.
- Lea, D. H., Feetham, S. L., & Monsen, R. B. (2002). Genomic-based health care in nursing: A bidirectional approach to bringing genetics into nursing's body of knowledge. *Journal of Professional Nursing*, 18(3), 120-129.
- Lea, D. H., Jenkins, J., & Monsen, R. B. (1999). Incorporating genetics into nursing practice. *Nurse Educator*, 24(5), 4-5.
- Maradiegue, A., Edwards, Q., Seibert, D., Macri, C., & Sitzler, L. (2005). Knowledge, perceptions, and attitudes of advanced practice nursing students regarding medical genetics. *Journal of the American Academy of Nurse Practitioners*, 17(11), 472-479.
- National Association of Social Workers (NASW) Genetics & Practice Standards Working Group (2003). *NASW Standards for Integrating Genetics into Social Work Practice*. Retrieved from <http://www.naswdc.org/practice/standards/GeneticsStd4112003.pdf>

National Coalition for Health Professional Education in Genetics

(2001). Recommendations of core competencies in genetics essential for all health professionals. *Genetics in Medicine*, 3(2), 155-159.

National Coalition for Health Professional Education in Genetics (2007). *Core Competencies in Genetics Essential for all Health Care Professionals* (3rd ed.). Retrieved from <http://www.nchpeg.org/>

National Organization of Nurse Practitioner Faculties in partnership with the American Association of Colleges of Nursing (2002). *Nurse Practitioner Primary Care Competencies in Specialty Areas: Adult, Family, Gerontological, and Women's Health*, published by HRSA, division of nursing. Retrieved from <http://www.aanp.org/NR/rdonlyres/E1B37354-2195-401D-8027-A5A2763E3006/0/finalaug2002.pdf>

Rackover, M., Goldgar, C., Wolpert, C., Healy, K., Feiger, J., & Jenkins, J. (2007). Establishing essential physician assistant clinical competencies guidelines for genetics and genomics. *Journal of Physician Assistant Education*, 18(2), 47-48. Available at <http://www.paeaonline.org/index.php?ht=a/GetDocumentAction/i/25416>

Endorsing Organizations

American Academy of Nursing
American Association of Colleges of Nursing
American College of Nurse-Midwives
American Nurses Association
Asian American/Pacific Islander Nurses Association
Association of Women's Health, Obstetric and Neonatal Nurses
Council of International Neonatal Nurses
International Society of Nurses in Genetics
International Society of Psychiatric-Mental Health Nurses
National Association of Hispanic Nurses
National Association of Clinical Nurse Specialists
National Association of Nurse Practitioners in Women's Health
National Association of Pediatric Nurse Practitioners
National Black Nurses Association
National Coalition for Health Professional Education in Genetics
National Gerontological Nursing Association
National Organization of Nurse Practitioner Faculties
Oncology Nursing Society
Sigma Theta Tau International

Genetic/Genomic Online Resources

Risk Assessment and Interpretation

American Medical Association Family History Resources

Available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-science/genetics-molecular-medicine/family-history.page?>:

- Family history forms for prenatal, pediatric, and adult populations

Centers for Disease Control and Prevention: Public Health Genomics

Available at <http://www.cdc.gov/genomics/default.htm>:

- Family Health History

National Cancer Institute

Available at <http://www.cancer.gov/bcrisktool/>:

- Breast Cancer Risk Assessment Tool
Available at <http://www.cancer.gov/colorectalcancerrisk/>:
- Colorectal Cancer Risk Assessment Tool

National Cancer Institute

Available at <http://www.cancer.gov/cancertopics/pdq/genetics/risk-assessment-and-counseling/HealthProfessional/page3>:

- Components of the Cancer Risk Assessment Process

National Coalition of Health Professionals in Genetics

Available at <http://www.nchpeg.org/>:

- Family History Tool: Family history collection information and form
- Genetic Red Flags: Six genetic red flags that indicate there might be increased genetic risk in an individual or family

U.S. Department of Health and Human Services

Surgeon General's Family Health History Initiative

Available at www.hhs.gov/familyhistory:

- Online and paper-based family history collection tool in both English and Spanish

Genetic Education, Counseling, Testing, and Results Interpretation

Genetics Home Reference

Available at <http://ghr.nlm.nih.gov/handbook/testing/interpretin-gresults>:

- What do the results of genetic tests mean?

National Coalition of Health Professionals in Genetics

Available at <http://www.nchpeg.org/>:

- Communicating Risk Fact Sheet
- Gene Facts: Concise, accurate fact sheets on genetic conditions to provide decision support for non-geneticist clinicians at the point-of-care

U.S. National Library of Medicine: Genes and Disease

Available at <http://www.ncbi.nlm.nih.gov/books/nbk22183>:

- Articles on genetic disorders, arranged by body systems

U.S. Department of Energy Office of Science: Human Genome Project Information

Available at http://www.ornl.gov/sci/techresources/Human_Ge-nome/medicine/genetest.shtml:

- Gene Testing information and resources

Clinical Management

Gene Tests/Gene Reviews

Available at <http://www.genetests.org/>:

- Expert authored disease reviews for clinicians
- Database of clinical and research genetic testing laboratories
- Links to genetic services and providers

Evaluation of Genomic Applications in Practice and Prevention (EGAPP)

Available at <http://www.egappreviews.org/default.htm>:

- EGAPP evidence-based recommendations regarding the validity and utility of genetic tests for clinical practice for several health conditions, including cardiovascular health, breast cancer, colorectal cancer, and depression

Genetics/Genomics Competency Center for Education

Available at <http://www.g-2-c-2.org>:

- Searchable database with genetic/genomic resources and learning activities for educators of nurses, genetic counselors, and physician assistants

**National Human Genome Research Institute, NIH
Genetic and Rare Diseases Information Center**

Available at <http://www.genome.gov/12010957>:

- Information about genetic disorders for health professionals and the public
- Toll-free phone number staffed by an information specialist

U.S. Department of Energy Office of Science: Human Genome Project Information

Available at http://www.ornl.gov/sci/techresources/Human_Genome/medicine/pharma.shtml:

- Pharmacogenomics information and resources

The Future of Medicine, Pharmacogenomics: An Online Course

Available at http://www.lithiumstudios.com/fda/Sample_Home.htm

Ethical, Legal, and Social (ELSI) Issues

International Society of Nurses in Genetics

Available at http://www.isong.org/ISONG_PS_direct_consumer_marketing_genetic_tests.php:

- ELSI resources
Available at http://www.isong.org/ISONG_position_statements.php:
- Position Statements: *The Role of the Nurse in Informed Decision-Making, Privacy and Confidentiality of Genetic Information, Direct-to-Consumer Marketing of Genetic Tests, and Genetic Counseling for Vulnerable Populations*

Nature Education: Genetics and Society

Available at <http://www.nature.com/scitable/topic/genetics-and-society-11>:

- Article links for ELSI issues related to genetic advances and their applications

National Human Genome Research Institute, NIH

Available at <http://www.genome.gov/24519851>:

- Genetic Information Nondiscrimination Act (GINA) 2008 federal legislation

National Human Genome Research Institute, NIH

Available at <http://www.genome.gov/Issues/>:

- Policy, legal, and ethical issues in genetic research

U.S. Department of Energy Office of Science

Available at http://www.ornl.gov/sci/techresources/Human_Genome/elsi/elsi.shtml:

- Human Genome Project Information ELSI site

U.S. Department of Health and Human Services NIH: Ethics and Genetics

Available at <http://history.nih.gov/exhibits/genetics/sect6f.htm>:

- Prenatal & Adult Testing, Designing Your Children, Discrimination, Gene Therapy

World Health Organization

Available at <http://www.who.int/genomics/elsi/en/>:

- Human Genetics Programme ELSI site

Research

Centers for Disease Control and Prevention: Public Health Genomics

Available at <http://www.cdc.gov/genomics/famhistory/famhx.htm>:

- Family Healthware: Web-based research tool that can be used to assess a person's familial risk for coronary heart disease, stroke, diabetes, and colorectal, breast, and ovarian cancer

National Center for Biotechnology Information

Available at <http://www.ncbi.nlm.nih.gov/guide/all/#databases>:

- Genetic/genomic databases and data-mining tools

National Human Genome Research Institute, NIH

Available at <http://www.genome.gov/ResearchFunding/>:

- Research Funding, Grant Writing, Research Resources, and Funded Projects

Online Mendelian Inheritance in Man

Available at <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM> :

- Comprehensive database about genetic conditions reported in the literature



Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees

Advances in genetics and genomics are reshaping health care delivery and redefining how human health and disease are characterized and managed. Nurses prepared at the graduate level must be competent in their ability to translate these genetic and genomic advances into effective health care as educators, administrators, researchers, and advanced practice nurses. The *Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees* identifies essential graduate-level genetic and genomic nursing competencies.

Building upon the *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators (2nd edition)*, these competencies assume that nurses with graduate degrees have already achieved those core competencies for all nurses. These graduate-level genetic and genomic nursing competencies are complementary to existing nursing competencies and standards of practice and are intended to provide structure as graduate-level nurses incorporate genetics and genomics into clinical and non-clinical roles and graduate nursing education programs.

Development of these graduate-level nursing competencies began with a review and analysis of relevant nursing literature, published genetic and genomic competencies from comparable health professions, and genomic content on advanced practice nursing certification exam guidelines. After revision by a consensus panel of nursing leaders and genomics experts, the competencies were posted on the American Nurses Association website for public comment. Consensus on 38 competencies was ultimately achieved in September 2011.

The *Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees* provides a foundation for the genomic competence of graduate-level nursing practice and serves as a guide for nurse leaders as they help shape the future of genomic health care.

American Nurses Association

8515 Georgia Avenue, Suite 400
Silver Spring, MD 20910-3492
1-800-274-ANA4 (4262)
<http://www.nursingworld.org>

International Society of Nurses in Genetics

461 Cochran Road, Box 246
Pittsburgh, PA 15228
412-344-1414
<http://www.isong.org/>

ISBN 978-1-55810-437-2

©2012 American Nurses Association and
International Society of Nurses in Genetics