



# Competency *focus*

UPDATING THE NURSING COMMUNITY ON THE IMPLEMENTATION OF  
THE ESSENTIAL NURSING COMPETENCIES AND CURRICULA  
GUIDELINES IN GENETICS AND GENOMICS.

## **Journal of Nursing Scholarship Genomic Special Issue Highlights Nurses' Role and Practical Considerations in Genomic Healthcare**

Ensuring that nurses play a central role in the application of genomics to clinical care is at the core of the 2013 Genomics Special Issue of the *Journal of Nursing Scholarship*. The publication, coordinated by National Institutes of Health researchers Jean Jenkins, Ph.D., RN, FAAN, and Kathleen Calzone, Ph.D., RN APNG, FAAN, explores genomic variation and its clinical implications for common diseases in pediatric and adult patients such as cardiovascular diseases, metabolic syndrome and cancer with the implications for nursing practice. The special issue spotlights the genomics of common health conditions, emerging genomic science and technology, and the ethical, legal, social and nursing research issues associated with the translation of genomics into healthcare. All articles included in this special issue are open access and freely available at <http://www.genome.gov/27552093>

### **Content of the Special Issue**

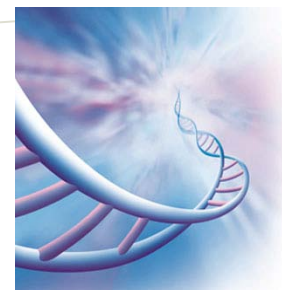
The issue begins with an editorial, **Relevance of Genomics to Healthcare and Nursing Practice**, which underscores the importance of nurses understanding the genomic science behind care decisions in order to improve patient outcomes. It was authored by Drs. Calzone and Jenkins, Dr. Nick Nicol, at the Universal College of Learning, New Zealand, Dr. Heather Skirton from Plymouth University in the United Kingdom, Dr. Greg Feero, a primary care physician formerly with the National Human Genome Research Institute (NHGRI), and Dr. Eric Green, NHGRI director.

Other articles include:

1. **Current and Emerging Approaches in Genomics** by Yvette Conley, Ph.D., et al., focuses on technologies for collecting, analyzing and interpreting genomic information. The authors summarize information about four approaches used in genomic research with implications for clinical application, including genome sequencing, genome-wide association studies, epigenomics and gene expression.
2. **Ethical, Legal and Social issues in the Translation of Genomics into Healthcare** by Laurie Badzek, LLM, J.D., MS, RN, FAAN, et al., reviews the ethical and legal foundations of genomic healthcare and highlights issues confronting nurses today such as confidentiality and privacy of genomic information, informed consent, genetic testing and the use of biorepositories.
3. **Integration of Genomics in Cancer Care** by Erika Santos, Ph.D., MS, RN, et al., reviews cancer etiology, hereditary cancer syndromes, epigenetics factors and the influence of genomics on cancer management. The authors use case studies to illustrate how rapidly developing genomic advances are changing cancer care.
4. **Genomics and Autism Spectrum Disorder (ASD)** by Norah Johnson, Ph.D., RN, CPNP, et al., examines ASD identification and diagnosis and its implications for the family. The authors review the genomic contributions to the risk for ASD and highlight how current research on ASD underscores the
5. **An Overview of the Genomics of Metabolic Syndrome** by Jacquelyn Taylor, PhD, PNP-BC, et al., analyzes diagnostic criteria for the components of metabolic syndrome (MetS). The contributions of cardiovascular, obesity, and diabetes genomic risk factors for MetS and the number of overlapping genes and polymorphisms associated with MetS are described with guidance for nurses of what this information means in practice.
6. **Cardiovascular Genomics** by Shu-Fen Wung Ph.D., RN, ACNP-BC, FAAN et al., centers on cardiovascular genomics using clinically relevant exemplars: myocardial infarction and coronary artery disease; stroke; and sudden cardiac death. The authors discuss the benefits and limitations of genetic testing for each of these case examples, describing specific implications for nurses.
7. **An Update of Childhood Genetic Disorders** by Cynthia Prows, MSN, CNS, FAAN, et al., spotlights nurses' important role in identifying children with genetic disorders and

complexity of genetic processes involved.

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## Expanding RN Scope of Practice: A Method for Introducing a New Competency into Nursing Practice (MINC)

Sarah Caskey, MS

During the spring of 2012, nurses from 21 Magnet Hospitals from around the country were selected as participants in a first of its kind, year-long genomic nursing education initiative focused on incorporating the *Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics* into practice. Two other institutions were also selected to serve as controls, not participating in the educational intervention. Dyads, made up of one nursing educator and one nursing administrator, from each of the 21 participating institutions were established, serving as the project leads in each participating Magnet Hospital.



Participating nursing dyads in the MINC project. Photo by Laurie Badzek September 2012.

**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, 2009  
and published by the American Nurses Association,  
Silver Spring, Maryland  
2009

Second edition—  
Outcome Indicators established by Consensus,  
June 2008

**DO YOU NEED A  
COPY OF THE 2<sup>ND</sup>  
EDITION OF THE  
COMPETENCIES?  
DOWNLOAD AT:**

<http://www.genome.gov/27527634>

**OR EMAIL**

[CALZONE@MAIL.NIH.GOV](mailto:CALZONE@MAIL.NIH.GOV)

The *Expanding RN Scope of Practice: A Method for Introducing a New Competency into Nursing Practice (MINC)* project is led by Principle Investigator Dr. Laurie Badzek of the West Virginia University School of Nursing, and by Co-Investigators Drs. Kathy Calzone of the National Cancer Institute, NIH and Jean Jenkins of the National Human Genome Research Institute, NIH.

Over the last six months, the dyads have been very busy and a lot of progress has been made. The first step in the project was to evaluate institutional nursing workforce attitudes, practices, receptivity, confidence and competency in genomics of common disease and utilization of family history. A baseline online survey that was sent to all nurses working in the participating Magnet Hospitals and 7,306 RNs responded. Ninety percent considered genetics very important to nursing practice; however, 79% rated their understanding of the genetics of common diseases as poor or fair. In fact, most were receptive to learning more.

The survey data was also sent to each participating dyad to analyze. In September 2012, each nursing dyad from the participating institutions, along with the project team, exemplar speakers, and the MINC Advisory Group members convened at the MINC Kickoff Meeting, held in Herndon, VA. The successful two-day meeting was full of analysis of survey results for the whole study population, informative presentations from exemplar speakers and guests, a networking reception, and break-out session for team action plan development to carry out the educational intervention in their hospital over the course of the next year. The group also headed to the computer lab at the Uniformed Services University to explore the online genomic teaching tools including G2C2 <http://www.g-2-c-2.org> and G3C (<http://www.g-3-c.org/>).

Since the Kickoff Meeting, the dyads have been very busy carrying out their individually tailored educational interventions, as well as personal development by keeping up with the constant influx of new genomic information and literature – even influencing the amount of genetics and genomic resources available to staff in their hospital's library collection.



Co-Investigator Dr. Kathy Calzone and PI Dr. Laurie Badzek.



Dyads are also coming up with very creative ways to get their nursing and hospital staff aware of basic genetic and genomic information. For example, the dyad from Akron Children's Hospital hosted an informational booth for Family History Month to introduce the *Essentials of Genetic and Genomic Nursing: Competencies Curricula Guidelines, and Outcome Indicators* while creating a "jeans" theme.

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Members of the nursing dyads learning about the online genomic teaching tools G2C2 and G3C at the computer lab at the Uniformed Services University. Photo by Laurie Badzek.



The dyad from Fox Chase Cancer Center has been using very humorous, catchy emails and announcements to their nurses to stress the importance of taking family medical histories and announcing workshops and a webinar series going on throughout the year. The dyad from Jersey City Medical Center is using very creative ways to introduce their "Genomic Genie" in email blasts to nurses and on their hospital's intranet and social media outlets. While Hunterdon Healthcare System is offering "lunch and learn" sessions to discuss ways their staff can learn more about recording family histories in their EMR system.

As the project continues, the participating dyads will continue to attend monthly webinars with all dyads, the MINC team and exemplar speakers/presenters to hear about a range of topics relevant to the project. Dyads are also updating their action plans and the status of the project strategies and deliverables each quarter to track progress.

At the end of the intervention year, a repeat of each of the baseline surveys will be completed at both intervention and controlled institutions. This includes the online participant survey to assess each dyad members current personal level of genomic competency; institutional status survey completed by the dyad together to assess institutional achievements, and the Genomics and Genetics Practicing Nurses Survey to assess institutional nursing staff progress related to

attitudes, practices, receptivity, confidence and competency in genomics of common disease and utilization of family history.

Institutional progress or success can be demonstrated as improvements in learners' skills and attitudes, and in itself, evidence of significant learning. The dyads, along with the MINC team and others are eager to see these results. They expect that at the end of the program, the intervention institutional nursing staff will demonstrate an increased use of family history in nursing practice, construction of a three-generation pedigree, and referral of patients who would benefit from further genetic evaluation.

For more information about the MINC project visit: <http://nursing.hsc.wvu.edu/MINC/Home>



The Akron Children's Hospital dyad members Dana Nelson and Suzanne Nicholas (right) and nursing staff at Family History Month table outside their hospital's cafeteria.

## Summer Genetics Institute (SGI)

Sponsored by the  
National Institute of Nursing Research  
**CALL FOR APPLICANTS**

The SGI is an intensive one month program offered at no tuition cost to participants (travel and accommodations are not provided). SGI provides participants with a foundation in molecular genetics appropriate for use in research and clinical practice. The program seeks to increase the research capability among graduate students and faculty and to develop and expand clinical practice in genetics among clinicians.

### SGI Program Objectives

Participants in the SGI will increase their knowledge of molecular genetics for use in research, teaching, and clinical practice. Specifically, they will be able to:

- Use molecular genetics methods in biobehavioral research in a laboratory setting
- Analyze strategies used for genomic-based therapies and describe trends in the molecular therapeutics
- Identify the strengths, weaknesses, and applications of genetic tests
- Examine the ethical and legal issues related to genetic testing and genetic counseling and their implications for practice and research

**Application deadline is March 18, 2013.**

For more information about SGI visit the SGI website:  
<https://www.ninr.nih.gov/training/trainingopportunitiesinframural/summergeneticsinstitute>

To apply to SGI visit the application website at:  
<https://www.ninr.nih.gov/training/trainingopportunitiesinframural/summergeneticsinstitute/howtoapply>



## Educational Highlight

**The Genetic/Genomic Competency Center for Education (G2C2)**

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

**G2C2** provides a centralized repository for health professional education resources for use in genetics/genomics education.

Find websites, download PDFs, locate courses, enhance your class content with peer reviewed genetic/genomic resources.

Within this website you can:

- 1-search for resources from nursing as well as other disciplines including physician assistants, and genetic counselors;
- 2-submit resources to be included on the site
- 3-access competency guidelines
- 4-provide feedback on the site to improve its value to you

## International Society of Nurses in Genetics 25<sup>th</sup> Anniversary Conference

October 4-6, 2013

DoubleTree by Hilton  
Bethesda, Maryland USA

For more information: <http://www.isong.org>

## POTENTIAL NEW OPPORTUNITY

### The National Human Genome Research Institute invites nurse faculty to apply to the: ADVANCES IN GENOMICS RESEARCH SUMMER PROGRAM

#### Background

The National Human Genome Research Institute (NHGRI) led the National Institutes of Health's (NIH) contribution to the International Human Genome Project, which had as its primary goal the sequencing of the human genome. This project was successfully completed in April 2003. Now, the NHGRI's mission has expanded to improve health through an enhanced understanding of the function of the human genome. To that end, NHGRI supports the training of educators to integrate genomics into curriculum and improve the competency of a new generation of nurses.

#### Program Overview

The Advances in Genomics Research Summer Program is offered by the NHGRI at the NIH and is an intensive, five-day course for nursing faculty at colleges and universities with substantial under-represented minority, rural and/or disadvantaged student enrollment. Nursing faculty will join other science faculty and grad students to attend seminars presented by leading NHGRI research investigators and educators. Seminars will provide updates on the latest advances in genomics research, focus on the most current understanding of the genetic/genomic basis of disease, examine the ethical, legal and social implications of genomics research, and provide potential strategies for nursing education. Class size is limited.

#### Course Dates

The 2013 Advances in Genomics Research Summer Program will potentially be held **August 5-9: Application deadline is set for 5 pm ET on March 25, 2013.** However, funding for the 2013 NHGRI Advances in Genomics Research Summer Program is still pending the Department of Health and Human Services (DHHS)/ National Institutes of Health (NIH) approval. We will update the website as soon as more information is made available.

#### Scope of Support

For Faculty participants, NHGRI will pay for room and board; participant schools must be willing to pay travel costs for faculty, both to and from the NIH in Bethesda, Maryland.

#### Application Process

Applicants must complete an online application describing their personal and teaching goals for attending this course. In addition, applicants are asked to submit a curriculum vitae and a supporting letter from their department head (or equivalent). To be eligible, candidates must also be U.S. citizens or permanent residents. Minorities are encouraged to apply. Contact Jean Jenkins ([jean.jenkins@nih.gov](mailto:jean.jenkins@nih.gov)) for more information.

**For Further information about previous Advances in Genomics Research Summer Programs, visit:**  
<http://www.genome.gov/10000217>.

## Smithsonian Genome Exhibit

To celebrate the 10th anniversary of researchers producing the first complete human genome sequence - the genetic blueprint of the human body - the Smithsonian Institution in Washington, D.C., will open a high-tech, high-intensity exhibition in 2013. The exhibition will result from a collaboration of the Smithsonian's National Museum of Natural History (NMNH) and the National Human Genome Research Institute. The NMNH exhibition, now in development, will be organized around several themes, including the genome and you, the natural world, health, and humanity. The exhibition will present key insights about the human genome to the museum's approximately 7 million annual visitors. It will provide museum goers with new ways to look at themselves as individuals, as members of a family, and as a species that is part of the diversity of life on the planet. They will discover how scientists use genomics to establish links between genes and specific diseases and traits, as well as the latest advances in genomic medicine, prenatal testing and genomically guided drug therapy. The exhibition will attempt to dispel common misconceptions about genetics and genomics, and challenge visitors to think more deeply about the complex ethical, legal, social and environmental issues raised by genomic advances.

The approximately 2,500-square-foot exhibition will occupy NMNH's Hall 23, the exhibition hall that typically houses temporary exhibitions, but an appropriate venue since humans have 23 pairs of chromosomes. After at least a year at the museum, the exhibition will travel to venues around the nation and the world. The exhibition will be accompanied by free educational resources and programs on genetics and genomics.

### Publication Update

Goldsmith L, Jackson L, O'Connor A, Skirton H. (2013). Direct-to-consumer genomic testing from the perspective of the health professional: a systematic review of the literature. J Community Genet. [Epub ahead of print]

Aiello-Laws, L.B. (2013). Genetics and genomics nursing has arrived! *Oncol Nurs Forum.* 40(1):20-1.

Downing NR, Williams JK, Daack-Hirsch S, Driessnack M, Simon CM. (2013). Genetics specialists' perspectives on disclosure of genomic incidental findings in the clinical setting. *Patient Educ Couns.* 90(1):133-8.

Giarelli E, Reiff M. (2012). Genomic literacy and competent practice: call for research on genetics in nursing education. *Nurs Clin North Am.* 47(4):529-45.



DNA day was created to educate students, teachers, and the public about genetics and genomics. This day commemorates the unearthing of DNA's double helix and the completion of the Human Genome Project in April 2003.

The next National DNA day will occur, April 25, 2013. To learn more about National DNA day visit <http://www.genome.gov/10506367>.

We have added seven new unfolding case scenarios to the G3C site (<http://g-3-c.org>). Learn more about patient concerns from those with male or female breast cancer risk; colon cancer risk; receiving targeted lung cancer treatment; having questions about a baby's CF risk; or considering pharmacogenomics testing for arrhythmia treatment. Let us know what you think about the cases and their usefulness to you.

## Resource Update GAPP Knowledge Base

<http://www.hugenavigator.net/GAPPKB/home.do>

The **GAPP Knowledge Base (GAPP KB)** is an online resource providing access to information on applications of genomic research for use in public health and healthcare. GAPP KB features

- GAPP Finder-a continuously updated, searchable database of genetic tests in transition to practice;
- Evidence Aggregator-an application that facilitates searching for evidence reports, systematic reviews, guidelines related to the use of genetic tests and other genomic applications;
- Project Locator-an online database with brief information about ongoing and completed genomic research translation projects.

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facilitating their access to services and resources. This article illustrates genomic concepts of relevance to nurses who care for infants, children and adolescents and provides resources.

8. **Physical, Psychological, & Ethical Issues in Caring for Individuals with Genetic Skin Disease** by Diane Seibert, Ph.D., ARNP, FAANP, and Thomas Darling M.D, Ph.D., examines five genetic skin disorders, their inheritance patterns, genomics and treatments. The authors discuss issues and concerns important for nurses caring for patients with genetic skin diseases.
9. **Implications of Newborn Screening for Nurses** article by Jane DeLuca, Ph.D., RN, CPNP, APNG, et al., surveys newborn screening activities, current controversies and ethical considerations. It also describes nurses' roles in the newborn screening process with suggestions for nursing education and research and a summary of expected future developments in newborn screening (i.e., genome sequencing) with implications for policy, practice, education and research.
10. **The Implications of Genomics on the Nursing Care of Adults with Neuropsychiatric Conditions** by Debra Schutte, Ph.D., RN et al., concentrates on the genomic contributions to adult conditions, including irreversible dementias, Alzheimer's disease and Huntington's Disease. The authors examine implications for nursing practice and research when caring for these challenging patients.

The Genomic Special Issue culminates with an article, **A Blueprint for Genomic Nursing Science** by Dr. Calzone, et al., which summarizes recommendations of a 2012 Genomic Nursing State of Science Advisory Panel for furthering genomic nursing science to improve health outcomes. This Federal wide initiative including the National Institute of Nursing Research has identified a blueprint of targeted research topics based on evidence gaps which provide guidance for furthering genomic nursing science to improve health outcomes.

#### Genomic Special Issue Webinar Series

As an adjunct to the publication of this special issue, most of the authors have agreed to present more detailed information from their paper and answer questions as part of a series of live open access Webinars. This Webinar series will kick off on February 5, 2013 at 4PM EST. This kick-off event will include presentations from some of the editorial authors as well as a presentation by the *JNS* Editor Dr. Susan Gennaro. Visit <http://www.genome.gov/27552312> for log-in information or viewing archived webinars.

February 5, 2013 4:00PM EST-Relevance of Genomics to Healthcare and Nursing Practice

February 19, 2013 3:30PM EST-Current and Emerging Technology Approaches in Genomics

March 5, 2013 3:30PM EST-Cardiovascular Genomics

March 5, 2013 4:00PM EST-An Overview of the Genomics of Metabolic Syndrome

March 20, 2013 3:30PM EST-Implications of Newborn Screening for Nurses and Nursing Faculty

March 20, 2013 4:00PM EST-Ethical, Legal, and Social Issues in the Translation of Genomics into Healthcare

April 2, 2013 3:30PM EST-Integration of Genomics in Cancer Care

April 2, 2013 4:00PM EST-Physical, Psychological and Ethical issues in Caring for Individuals with Genetic Skin Disease

April 26, 2013 3:30PM EST-Genomics and Autism Spectrum Disorder

April 26, 2013 4:00PM EST-An Update of Childhood Genetic Disorders

May 7, 2013 3:30PM EST-A Blueprint for Genomic Nursing Science