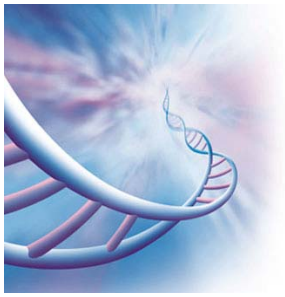
ISSUE 4 | VOLUME 3 | YEAR 2009

Competency focus

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



In September 2008, the Genetics/Genomics Nursing Competency Initiative finalized Outcome Indicators for each of the individual competencies. They are being published this month with the release of the 2nd Edition of the Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics.

Outcome Indicators Published with Competency Second Edition

After a year long consensus process, we are pleased to announce the availability of the Outcome Indicators that accompany the Essential Competencies. The Outcome Indicators are an adjunct to the Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics. They define the specific areas of knowledge and suggested clinical performance indicators for each specific competency. The Outcome Indicators are not intended to be prescriptive but provide a guide for the user. To be consistent with the Competencies, the definitions utilized are identical to the Essential Competencies. Genetic and genomic information is used as the context for defining knowledge and practice indicators for each competency.

An exerpt of the Outcome Indicators for a portion of the Professional Responsibilities Competencies is included here to demonstrate how the Outcome Indicators are structured.

A copy of the 2nd Edition of the Competencies which include the Outcome Indicators can be found: http://www.genome.gov/27527634 Or by emailing calzonek@mail.nih.gov to request a copy.

Domain: Professional Responsibilities	
Recognize when one's own attitudes and values related to genetic and genomic science may affect care provided to clients.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Values, attitudes and beliefs that influence genetic and genomic services e.g. views on pregnancy termination. Impact of personal values, attitudes and beliefs on genetic and genomic health care.	Engage in reflective practice about one's own beliefs and values related to client care that integrates genetics and genomics. Articulate one's attitudes, values and beliefs that influence one's perspective about difficult genetic or genomic health care decisions.
Advocate for clients' access to desired genetic/genomic services and/or resources including support groups.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Resources for healthcare professionals and lay public about: disease susceptibility; genetic/genomic conditions, treatment, and prognoses e.g. nursing literature, evidence-based websites sites such as the National Human Genome Research Institute http://www.genome.gov/ and the Centers for Disease Control National Office of Public Health Genomics http://www.cdc.gov/genomics/default.htm . Resources for genetic and/or genomic referrals within one's community.	Demonstrate appropriate care and concern for all clients throughout their referral, provision of direct care and follow-up to genetic services. Demonstrate knowledge about accessing local/regional genetic and/or genomic resources. Include genetic healthcare professionals in team building and collaborative strategies to optimize client outcomes. Help client negotiate system barriers that limit access to genetic/genomic services including access to clinical trials. Identify strategies that could be used to facilitate reimbursement for access to genetic/genomic services and/or tests.

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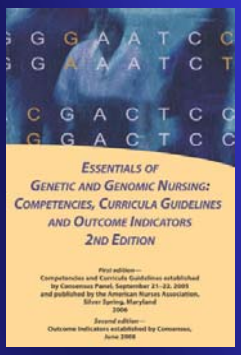


DO YOU NEED A COPY OF THE 2ND EDITION OF THE COMPETENCIES?

DOWNLOAD AT:

http://www.genome.gov/27527634

OR EMAIL

CALZONEK@MAIL.NIH.GOV

SPOTLIGHT

Online Genetics Courses for Nurses at The University of Iowa

For the past three years, The University of Iowa College of Nursing has offered online genetics courses for nurses in undergraduate or graduate degree programs as well as nurses or other health care professionals taking courses for professional improvement. Three courses are in the online program. The first, Introduction to Human Genetics course [96:116] is a 3 credit hour course, offered in the fall semester each year. This course provides an introduction to the organization of the human genome and basic principles of inheritance in humans. Course content includes an overview of cells and development, organization of the human genome, chromosome structure and function, gene structure and function, genes in pedigrees and populations, and the implications of genetic variation on health. This course was designed for upper level undergraduate and/or graduate students. Students with backgrounds in nursing and other healthcare professions as well as students preparing for roles in a healthcare profession - have taken this course.

Starting in 2009, nurses, and other health care professionals, will have more flexibility in registering for the content in the clinical practice courses by selecting content modules that meet their individual education needs. Students have said *"I have never learned as much information in one class"* and *"Dr Daack-Hirsch was a terrific on line instructor. She was organized, provided appropriate and informative feedback, and was available during her office hours for telephone contact. Thank you for making this wonderful learning opportunity available to those of us across the country who do not have such access otherwise!"*

The Advanced Practice in Genetic Nursing I (96:228) and Advanced Practice in Genetic Nursing II (96:230) courses are offered in the fall semester odd years [next 96:228 course in fall 2009] and spring semester even years [next 96:230 course 2010]. Students can now select up to 3 content modules from 96:228 and up to 3 modules from 96:230 Advanced Practice in Genetic Nursing II. Each module is equivalent to one credit hour. Topics for the modules include:

96:228
Module 1 Basic Risk Assessment (pedigree construction and interpretation)
96:228
Module 1 Basic Risk Assessment (pedigree construction and interpretation)
Module 2 Advance Risk Assessment (Baysian analysis, nontraditional inheritance and dysmorphology)
Module 3 Molecular Genetics-implications for testing and ELSI
96:230
Module 4 Genomics and Healthcare delivery (primary care and public health)
Module 5 Common Genetic Disorders (Childhood onset)
Module 6 Common Genetic Disorders (Adult onset)

To register for these courses, offered through *The University of Iowa's Center for Credit Programs*, call 1-800-272-6430, or complete the online registration form at http://www.continuetolearn.uIowa.edu/ccp/de/regform.htm
To learn more about the courses, please contact Dr. Sandra Daack-Hirsch, at 319-335- 9967 [sandra-daack-hirsch@uiowa.edu]; to learn more about undergraduate, genetics education opportunities, and the T32 postdoctoral clinical genetics research fellowship at The University of Iowa, please contact Dr. Janet Williams, at 319-335-7046 [janet-williams@uiowa.edu].

Publication Update

Dudley-Brown S, Freivogel M. (2009). Hereditary colorectal cancer in the gastroenterology clinic: how common are at-risk patients and how do we find them? *Gastroenterol Nurs.* 32(1):8-16.

Feero, W. et al. (2008). New standards and enhanced utility for family health history information in the electronic health record: an update from the American health information community's family health history multi-stakeholder workgroup. *J of the Amer Med Informatics Assoc*, 15(6): 723-728.

Hinton, R. (2008). The family history: Reemergence of an established tool. *Crit Care Nurs Clin N Am.* 20: 149-158.

Pestka, E.L. and Wolf, C. (2009). Is genomics relevant for perioperative nurses? *OR Nurse*, January, 40-45.

COMPETENCY WATCH

At the American Association of Colleges of Nursing (AACN) Fall Semiannual Meeting held October 20, 2008, deans and directors from the nation's senior schools of nursing voted to endorse The Essentials of Baccalaureate Education for Professional Nursing Practice, a re-envisioning of the previous Baccalaureate Essentials issued in 1998. The revised document was developed through a national consensus-building process and will have a significant impact on how professional nurses are prepared for contemporary nursing practice. The new set of competency standards includes the integration of genetics and genomics throughout as illustrated in one the introductory statements:
"Scientific advances, particularly in the areas of genetics and genomics, have had and will continue to have a growing and significant impact on prevention, diagnosis, and treatment of diseases, illnesses, and conditions."
The Essentials of Baccalaureate Education for Professional Nursing Practice may be downloaded online at http://www.aacn.nche.edu/Education/pdf/BaccEssentials08.pdf. These Essentials form the foundation for the accreditation of baccalaureate nursing programs starting in 2010.

ISONG 2009 ANNUAL CONFERENCE: GENOMIC PIPELINE: FROM BENCH TO PRACTICE

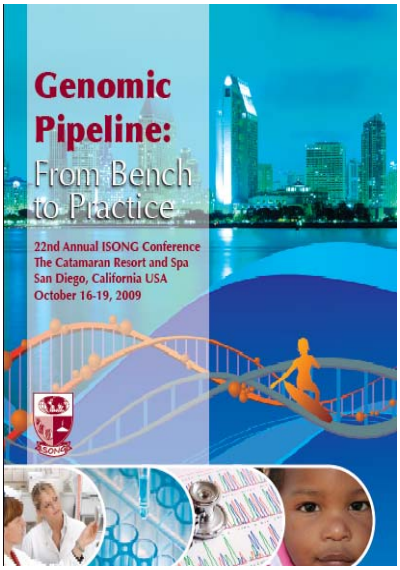
The 2009 International Society of Nurses in Genetics 22nd Annual Conference will focus on clinical translation of genetics and genomics to nursing practice.

LOGISTICS

October 16-19, 2009
The Catamaran Resort and Spa
San Diego, California

FOR MORE INFORMATION

http://www.isong.org/events/futureconference.cfm



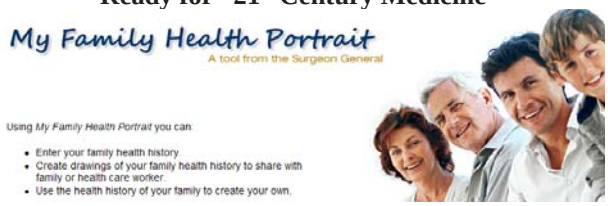
Outcome Indicators: Continued from Page 1

Examine competency of practice on a regular basis, identifying areas of strength, as well as areas in which professional development related to genetics and genomics would be beneficial.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Scope of nursing practice in relation to genetics/genomics. Role of specialist genetic/genomic services and other agencies in providing competent client care. Interprofessional resources that contribute to evidence based care of clients needing genetic/genomic resources or services.	Identify relevance of genetics/genomics to nursing practice. Demonstrate awareness of the boundaries of one's own professional practice in relation to genetics/genomics. Perform regular self assessments to identify knowledge and skills deficits that could impact the quality of nursing care one provides to clients in need of genetic/genomic guidance, referral and resources. Take action to meet identified knowledge and skills deficits related to genetics and genomics.
Incorporate genetic and genomic technologies and information into registered nurse practice.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Technology and information systems for clinical care and clinical decision-making including: • Electronic health and medical records, • Client monitoring systems, medication administration • Genetic and genomic testing technologies • Other technologies that support genetic and genomic based client care.	Evaluate genetic and genomic technologies used in client care. Demonstrate use of genetic and genomic technology and client data for clinical decision-making in providing safe client care. Identify the credibility, reliability and limitations of genetic and genomic information. Identify ethical, legal, and social issues associated with genetic/genomic information.
Demonstrate in practice the importance of tailoring genetic and genomic information and services to clients based on their culture, religion, knowledge level, literacy, and preferred language.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Cultural, social, ethnic and religious perspectives and literacy that may influence client's access and/or ability to use genetic and genomic information and services. Economic and health disparities related to genetics and genomics.	Incorporate client's cultural, social, ethnic and religious perspective and literacy level when delivering genetic and genomic care. Integrate knowledge from psychology, history, politics, sociology and culture when delivering genetic and genomic care.
Advocate for the rights of all clients for autonomous, informed genetic- and genomic- related decision-making and voluntary action.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Potential benefits, risks and limitations of genetic/genomic testing and accessing genetic/genomic information. Ethical, legal and social issues surrounding access to and use of genetic and genomic information. Impact of genetic and genomic information on individuals, family members, communities and/or populations. Components of informed decision-making including: • types of information needed • barriers to making an informed decision. • autonomous decision-making as appropriate.	Ensure privacy when discussing genetic and genomic information. Maintain confidentiality when recording genetic and genomic information. Demonstrate awareness of the potential impact of genetic/genomic information on the individual and other family members. Respond appropriately to inquiries about genetic and genomic healthcare concerns.
Collaborates with insurance providers/payers to facilitate reimbursement for genetic and genomic healthcare services.	
Specific Areas of Knowledge	**Clinical Performance Indicators**
Determinants of clinical utility of genetic/genomic tests e.g. Test specificity, sensitivity, positive predictive value Test cost – benefit information Economic impact of new genetic / genomic based therapies • Can be life long therapy once started • Consideration of individual / family maximum lifetime benefit Influence of predisposition gene variants, genetic disease/disorder on access to health, life, disability, long term care insurances and military benefits.	Identify strategies that could be 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).

Resource Highlight: Gene Journey

'Illumination Educational Software' is dedicated to the development of innovative teaching and learning resources on genetics, aimed at students ranging from high school to undergraduate level. The latest addition to their flagship online learning resource, 'Gene Journey', comprises a series of interviews with people whose work involves genetics: fruit fly scientist Kevin Moffat, cytogeneticist Angela Douglas, specialist midwife for inherited blood disorders, Dorcas Akeju OBE, and Nobel Prize winner, John Sulston, who played a leading role in the Human Genome Project. They discuss their childhood and the influences that have lead them to choose their careers, as well as their work and the many ethical issues raised by it. Visit the website for more information and to register for a free 21-day trial. http://www.illumination-ed.co.uk/GeneJourney

Surgeon General's New Family Health History Tool Is Released, Ready for "21st Century Medicine"



The U.S. Department of Health and Human Services has released an updated and improved version of the Surgeon General's Internet-based family health history tool. The new tool makes it easier for consumers to assemble and share family health history information. It can also help practitioners make better use of health history information so they can provide more informed and personalized care for their patients.

Key features of the new version of the Surgeon General's My Family Health Portrait include:

Convenience – Consumers can access the tool easily on the Web. Completing the family health history profile typically takes 15-20 minutes. Consumers should not have to keep filling out different health history forms for different practitioners. Information is easily updated or amended.

Consumer control and privacy – The family health history tool gives consumers access to software that builds a family health tree. But the personal information entered during the use of the tool is not kept by a government or other site. Consumers download their information to their own computer. From there, they have control over how the information is used.

Sharing – Because the information is in electronic form, it can be easily shared with relatives or with practitioners. Relatives can add to the information, and a special re-indexing feature helps relatives easily start their own history based on data in a history they received. Practitioners can help consumers understand and use their information.

EHR-ready, Decision support-ready – Because the new tool is based on commonly used standards, the information it generates is ready for use in electronic health records and personal health records. It can be used in developing clinical decision software, which helps the practitioner understand and make the most use of family health information.

Personalization of care – Family history information can help alert practitioners and patients to patient-specific susceptibilities.

Downloadable, customizable – The code for the new tool is openly available for others to adopt. Health organizations are invited to download and customize, using the tool under their own brand and adding features that serve their needs. Developers may also use the code to create new risk assessment software tools.

The Surgeon General's My Family Health Portrait was originally launched in 2004, but the first version was not standards-based. The new tool was developed under prior DHHS Secretary Leavitt's Initiative on Personalized Health Care. It will be hosted by the National Cancer Institute, where the caBIG® initiative is pioneering health IT networks and software sharing. A ready process for organizations to download the family health history code is at https://gforge.nci.nih.gov/projects/fhh. The Surgeon General's new My Family Health Portrait tool is located at https://familyhistory.hhs.gov.

American Academy of Nursing Publishes White Paper

"Nurses Transforming Health Care Using Genetics and Genomics"

The purpose of the White Paper is to **e**ducate policymakers, the media, and other professional health organizations. Nursing's role in the evolving field of genetics and genomics

- Illustrate improved health outcomes via nurses who are competent in genetics and genomics. Include one or two concrete examples.
- Describe nursing's role in genetics and genomics.
- Provide an overview and comparison of what the U.S. and other countries are doing in this area.
- Highlight relevant points from the international perspective that can be used to inform U.S. policy issues.
- What are the current and future policy issues.

The White paper can be located at: http://www.aannet.org/files/public/Genetic_White_Paper_1.22.09_FINAL2.pdf