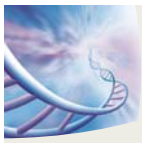
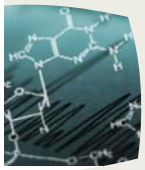
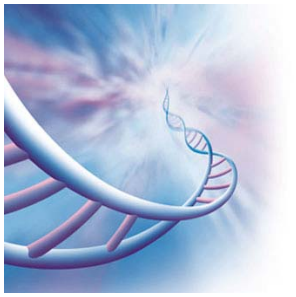




ISSUE 4 | VOLUME 1 | YEAR 2010

Competency focus

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

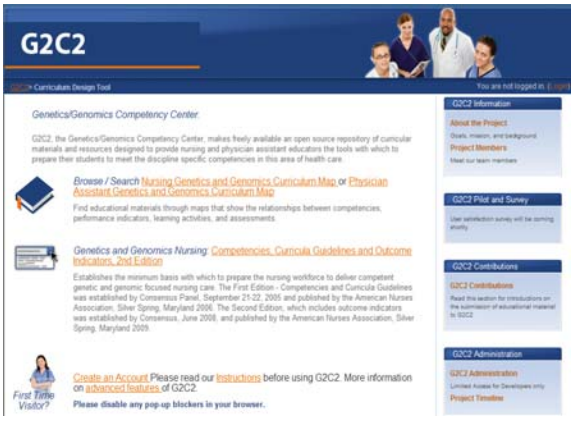


In January 2010, the Genetics/Genomics Nursing Competency Initiative in collaboration with the Physician Assistance Genetic/Genomic Competency Initiative finalized a repository of curricular materials and resources to provide educators with ready access to the tools to teach genetics and genomics.

Genetic/Genomic Competency Center (G2C2) Launching

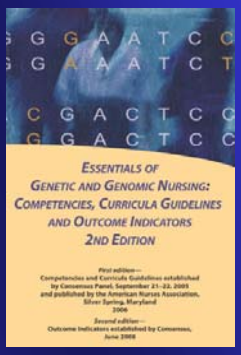
Establishing genetic and genomic literacy is a pressing concern for health professional educators. Sponsored by the National Human Genome Research Institute through a contract to the University of Virginia, and created with an advisory group made up of representatives from nursing and physician assistant educator communities, a resource tool was developed to meet these needs. G2C2 (Genetic/Genomic Competency Center), a free open-source web-based repository for describing, organizing, hosting and disseminating competency-based curricular materials for genetics/genomics education has been created to promote access to already available educational materials. G2C2 contains a four column map of the relevant professional competencies necessary for effective nursing and physician assistant practice as described by the *Genetics and Genomics Nursing: Competencies, Curricula Guidelines and Outcome Indicators, 2nd Edition* and analogous competencies developed by representatives of the physician assistant educator community.

Currently available is a web repository platform containing both nursing and physician assistant genetics/genomics competency maps. These maps express the relationships identified by each professional community between competencies, outcome indicators, learning activities, and assessments. G2C2 provides educators with the ability to browse or search (keyword based) the web repository for material they can subsequently download for their instructional use. The competency repository also has the capacity to allow educators to upload resource material and an iterative review process by an editorial board will be implemented to assure quality control. The site is currently available at: http://www.g-2-c-2.com/



http://www.g-2-c-2.com/

We owe thanks for the work and time that has been provided to this initiative by the following nursing representatives: Kathleen Calzone, National Cancer Institute; Linda Howe, National League for Nursing; Jean Jenkins, National Human Genome Research Institute; Bonnie Jerome-D'Emilia, University of Virginia; Karen Pearson, Sigma Theta Tau, Cathy Read, American Association of Colleges of Nursing.



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

United Kingdom NHS National Genetics Education and Development Centre

SPOTLIGHT

Since the 2003 publication of the United Kingdom (UK) National Health Service (NHS) Genetics White Paper, Our Inheritance, Our Future, the NHS has supported the National Genetics Education and Development Centre, whose mission is to work with all healthcare disciplines throughout the UK to facilitate the integration of genetics education into all levels of healthcare professional education and training. The key aims of the Centre are to:

1. Provide leadership in genetics education
2. Help to raise awareness
3. Involve patients and their families in informing all aspects of the work
4. Identify the genetics knowledge, skills and attitudes which are useful for clinical role
5. Develop a framework for competences in genetics
6. Facilitate the integration of genetics into curricula and courses
7. Identify and develop resources appropriate to the needs of health professionals (and their trainers)
8. Support and disseminate learning from service development initiatives in genetics

The work associated with the Nursing Professions arm of the Centre is under the direction of Prof. Maggie Kirk, and serves as the Lead Professional Specialist. She is assisted by the Education Development Officer Dr. Emma Tonkin. Together with the Centre staff they have worked to develop a wealth of resources that are available not only to academic and health professionals in the UK but also to the international healthcare and academic communities. Some of the resources especially helpful in genetic/genomic education include:

Telling Stories: Understanding Real Life Genetics

This is a free site that provides real stories in both written and video formats. The stories are a mechanism to promote understanding among all health professionals of the impact genetics has on real life, and its relevance to healthcare practice. The website draws on stories that cover a range of genetic conditions including single-gene disorders (with autosomal dominant, autosomal recessive and X-linked inheritance patterns), chromosomal abnormalities and multifactorial conditions such as cancer and heart disease. New stories continue to be added. Every story includes activities, points for reflection and links to further sources of information.

Telling Stories is the winner of the Association of Healthcare Communicators Best Use of New Media Award 2009! Telling Stories can be accessed at:
http://www.tellingstories.nhs.uk

Supporting Educators

The Centre has developed a network of university educators who act as a named link between their University and the Centre. The educators work with the Centre to highlight their institutions' teaching needs and thus help direct the nursing professions programme of work including resource development. They also disseminate information about the Centre's activities to colleagues.

In addition, the Centre works with Regional Genetic Centres throughout the UK and has created a number of new job roles for practicing genetic counselors. As well as providing counselling, they also act as Genetics Education Facilitators (GEF). The GEFs work with the National Genetics Education and Development Centre to provide support and training opportunities for nurse faculty, students and practitioners in their local area.

[left to right]
Dr. Emma Tonkin and Prof. Maggie Kirk

The NHS National Genetics Education and Development Centre has a wealth of resources that can be useful in both learning and teaching genetics and genomics. Take the time to explore their website and be sure to delve into not only the nursing professions section but those of the other healthcare disciplines as well.
http://www.geneticseducation.nhs.uk/

Publication Update

Cashion A. (2009). The importance of genetics education for undergraduate and graduate nursing programs. *J Nurs Educ*, 48(10):535-6

Greco KE, Salveson C. (2009). Identifying genetics and genomics nursing competencies among published recommendations. *J Nurs Educ*, 30:1-9 [Epub ahead of print]

Hamilton R. (2009). Nursing advocacy in a postgenomic age. *Nurs Clin North Am*, 44(4):435-46

Kirk M, Tonkin E. (2009). Understanding the role of genetics and genomic in health 1: Background. *Nurs Times*, 105(45):18-22

Kirk M, Tonkin E. (2009). Understanding the role of genetics and genomic in health 2: Implications for practice. *Nurs Times*, 105(46):19-23

Pestka, E.L. (2009). Genetics and genomics to general nursing practice: an exemplar. *Am Nurse*, 41(5):2

Family History State of the Science

A State of the Science Conference sponsored by the NIH "Family History and Improving Health" was held Aug. 26, 2009. The Planning Committee narrowed the scope of the review to family history for common diseases as seen by clinicians in primary care, specifying a review to assess the available scientific evidence regarding six questions. It is important to emphasize that the review covers only a small portion of the evidence that might generally link family history to improved health. Questions addressed included:

- What are the key elements of a family history in a primary care setting for the purposes of risk assessment for common diseases?
- What is the accuracy of the family history, and under what conditions does the accuracy vary?
- What is the direct evidence that getting a family history will improve health outcomes for the patient and/or family?
- What is the direct evidence that getting a family history will result in adverse outcomes for the patient and/or family?
- What are the factors that encourage or discourage obtaining and using a family history?
- What are future research directions for assessing the value of family history for common diseases in the primary care setting?

It was recognized that family history has an important role in the practice of medicine and may motivate positive lifestyle changes, enhance individual empowerment, and influence clinical interventions. The panel found that it is unclear how this information can be effectively gathered and used in the primary care setting for common diseases. Twenty-five recommendations were delineated for future research. Research recommendations can be grouped into three categories: (1) structure or characteristics of a family history, (2) the process of acquiring a family history, and (3) outcomes of family history acquisition, interpretation, and application.

The Evidence Report prepared for this conference by the Agency for Healthcare Research and Quality is available on the Web via http://www.ahrq.gov/clinic/tp/famhimptp.htm. Printed copies of the Evidence Report may be ordered from the AHRQ Publications Clearinghouse by calling **1-800-358-9295**.

The NIH State-of-the-Science Conference: Family History and Improving Health was webcast live August 24-26, 2009. The webcast is archived and available for viewing free of charge at http://videocast.nih.gov. The written report with recommendations can be ordered from http://consensus.nih.gov/2009/familyhistory.htm .

The general consumer community, the Genetic Alliance, provided a response to the NIH Family History State-of-the-Science Conference summary. For their perspective visit:
http://www.geneticalliance.org/ws_display.asp?filter=fhh.programs.response

ISONG 2010 Annual Conference: Genomic Pipeline: From Bench to Practice

The 2010 International Society of Nurses in Genetics 23rd Annual Conference will focus on ethics and genetic/genomic healthcare.

Logistics

October 16-19, 2010
Fairmont Dallas
Dallas, Texas

For More Information

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

The Faculty Champion Initiative

The American Association of Colleges of Nursing (AACN) Baccalaureate Essentials http://www.aacn.nche.edu/Education/pdf/BaccEssentials08.pdf now include genetics and genomics as important content for the educational preparation of nurses. The Faculty Champion Initiative, launched on Sept. 25, 2009 with an inaugural meeting, is designed to support faculty from schools of nursing undergoing accreditation in 2010/2011 to be able to meet these new requirements.

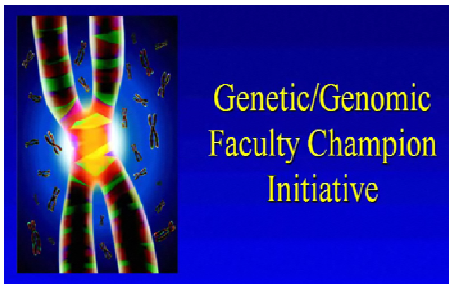
Twenty Faculty Champions were selected from a competitive application pool to participate in this year long initiative. Faculty Champions are expected to provide leadership at their schools of nursing and more broadly throughout the profession of nursing as leadership opportunities arise, and share expertise throughout their schools of nursing to plan for curriculum integration of genetics and genomics by:

- Informing colleagues about the relevancy and need to include genetics and genomics in the curriculum
- Consult with individual faculty to provide assistance in integrating genetics/genomics into existing coursework
- Serve as a faculty resource
- Determine opportunities to accelerate the change process

The Faculty Champions represent academic nursing programs from across the country and are of varying sizes. A list of the champions can be found at: http://www.genome.gov/27535175 .

The inaugural Sept. 25, 2009 meeting included presentations to provide a starting point for all nursing faculty to begin to explore the implications of genetics and genomics for nursing education and practice. The presentations are available for viewing via a webinar as well as in transcript form at http://www.genome.gov/27535172 and included the following topics:

Introductions and Purpose of the Meeting
Kathleen Calzone, MSN, RN, APNG, FAAN
Senior Nurse Specialist (Research)
National Cancer Institute, Center for Cancer Research/Genetics Branch, National Institutes of Health



Key Note Address: Bridging the Gap Between Genome Research and Clinical Care
Alan Guttmacher, MD
Acting Director, National Human Genome Research Institute, NIH

Basic Genetic and Genomic Concepts: What do Nursing Faculty Really Need to Know?
Julie Eggert, PhD, GNP-BC, AOCN®
Associate Professor and Healthcare Genetics Doctoral Program Coordinator

Genetic/Genomic Implications for Nursing Practice and Education
Kathleen Calzone, MSN, RN, APNG, FAAN
Senior Nurse Specialist (Research)
National Cancer Institute, Center for Cancer Research/Genetics Branch, National Institutes of Health

Resources for Evaluating your Nursing Curriculum
Cindy Prows, MSN, RN, FAAN
Clinical Nurse Specialist, Genetics
Children's Hospital Medical Center

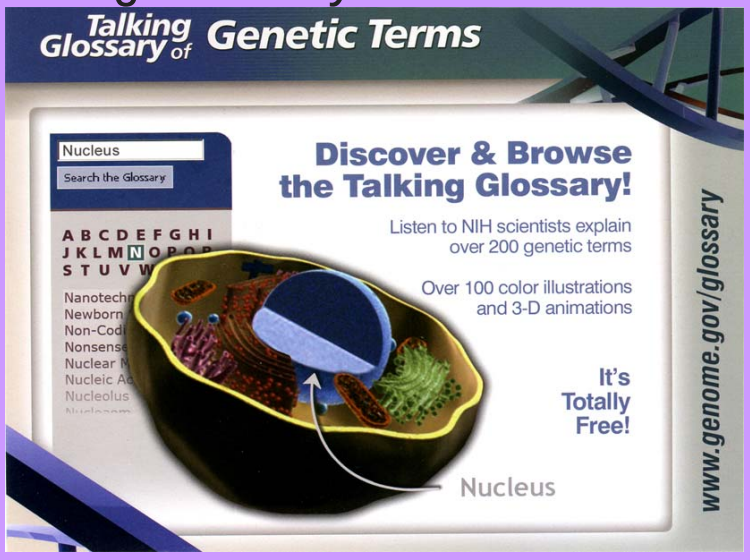
Catherine Yetter Read, PhD, RN
Associate Dean, Undergraduate Program
Associate Professor
Boston College, William F. Connell School of Nursing

Models of Curriculum Integration
Panel Presentation:
Jean Jenkins, PhD, RN, FAAN-Moderator
Senior Clinical Advisor, National Human Genome Research Institute, National Institutes of Health
Panelists:
Integrated
Janet Williams, PhD, RN, FAAN
Kelting Professor of Nursing and Director Clinical Genetics Research Postdoctoral Fellowship
The University of Iowa
Shared Courseware
Lorraine Frazier, DSN, MS, RN, NP, FAAN
Associate Professor
University of Texas Health Science Center at Houston School of Nursing, Director CCTS and TexGen BioBanks
Senior Nurse Scientist THI and St. Luke's Episcopal Hospital
Stand Alone
Judith Lewis, PhD, RN, WHNP-BC, FAAN
Professor Emerita
School of Nursing, Virginia Commonwealth University
Interdisciplinary Model
Yvette Conley, PhD
Associate Professor
School of Nursing, University of Pittsburgh

This project has been funded by the National Human Genome Research Institute, the Health Resources Services Administration, Bureau of Health Professions, Division of Nursing and the National Cancer Institute.

Resource Highlight:
The National Human Genome Research Institute
Talking Glossary of Genetic Terms

- Designed to help learners at any level better understand genetic terms
- Guided by national science standards
- Explained by scientists at the NIH



- Specialists in genetics share their descriptions of terms
- Many terms include images, animation and links to related terms.

http://www.genome.gov/Glossary/

The Talking Glossary includes:

- Over 125 illustrations in color that can be downloaded as power point slides or PDF's.
- All illustrations are copyright-free.
- 30 NHGRI professionals voiced the audio definitions.
- Nearly 30 3-D animations, all are new and created by NHGRI.
- A "Test Your Gene Knowledge" quiz that randomly chooses 10 terms from the Glossary. Users can print a certificate at completion that states their name, score, and the date.
- You can send any term to a friend, suggest a term be added, and every term is pronounced as well.
- Spanish version is under development.

Physician Meeting Held at NIH

A "Developing a Blueprint for Primary Care Physician Education in Genomic Medicine" meeting was held on June 8-9, 2009 at the National Institutes of Health. Co-sponsored by multiple federal agencies and coordinated by the Genomic Healthcare Branch of the National Human Genome Research Institute, this meeting was convened for representatives from various government organizations, physicians' groups, and genomics/genetics groups and provided an opportunity for primary care physician leadership to discuss implications of genetics/genomics discoveries for their practice and education needs. Invited speakers, Kathleen Calzone and Michael Rackover, presented information about the previous work within the Nursing and Physician Assistant communities related to genetic/genomic competencies and resources under development (G2C2). Meeting participants identified core genetics/genomics education needs for primary care physicians and specialty-specific needs; laid out concrete steps for genetics/genomics education for physicians at various levels of training; and identified barriers and facilitators of primary care education in genetics. For more information visit: http://www.genome.gov/Pages/Careers/HealthProfessionalEducation/Feero-CreatingAnEducationalBlueprint.pdf

Genomic Applications in Practice and Prevention Network (GAPPNet)

GAPPNet is a collaborative initiative involving partners including nursing from across the public health sector who are working together to realize the promise of genomics in healthcare and disease prevention. GAPPNet was established in 2009 by the CDC's Office of Public Health Genomics, NCI's Division of Cancer Control and Population Sciences, and other stakeholders.

http://www.cdc.gov/genomics/translation/GAPPNet/index.htm/

Mission:

GAPPNet aims to accelerate and streamline effective and responsible use of validated and useful genomic knowledge and applications, such as genetic tests, technologies, and family history, into clinical and public health practice.

The GAPPNet Inaugural Meeting was held on October 29-30, 2009 in Ann Arbor, Michigan. More than 100 people attended, including researchers, practitioners, policy makers, educators, and professionals from academia, government, health care, public health, industry, and community and consumer groups.