

MINC Implementation in the Clinical Center: *Exemplar.* Implementation of clinical competencies

Georgie Cusack, MS, RN, AOCNS
Director of Education and Outcomes
National Heart, Lung and Blood Institute

Kathy Feigenbaum, MSN, CDE
Clinical Nurse Specialist
Clinical Center Nursing Department
National Institutes of Health

Disclosure

- ▶ We have nothing to disclose. The views in this presentation are that of the team and do not necessarily represent the view of the NIH or United States government.
- 



The National Institutes of Health

Office of the Director



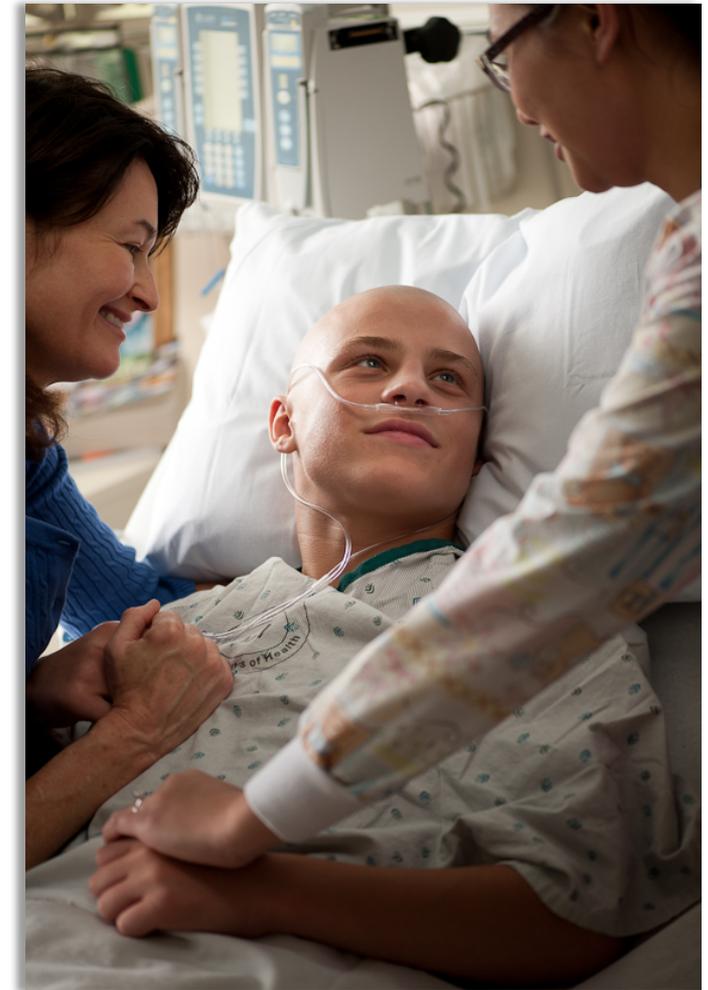
NIH Clinical Center: America's Research Hospital

- Supports intramural clinical research conducted by the Institutes and Centers of the NIH
- Creates and disseminates standards and innovations for conducting clinical research
- Creates and demonstrates models for clinical research training and career development for all disciplines



Nursing Practice at the NIH Clinical Center

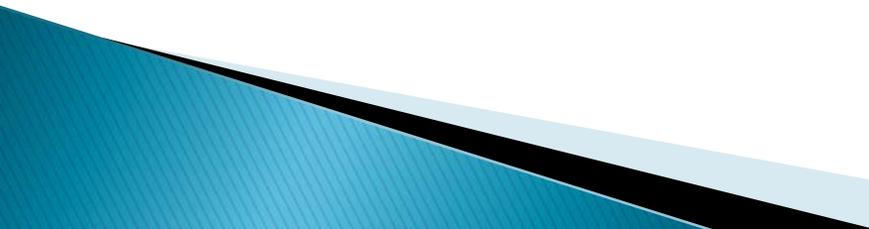
- Acute care hospital and ambulatory care center with over 650 direct care CRNs
- An additional 275 RNs work with investigators as research nurse coordinators
- 200 NP's/PA's provide direct care
- Staffed at a level to support precision in patient care and data collection
- Clinical care requirements are protocol-driven



Method of Introducing a New Competency

- ▶ Personal Development
 - ▶ Staff Genetic/Genomic Knowledge Needs Assessment
 - ▶ Genetics/Genomics in Practice Assessment
 - ▶ Policy Genetic/Genomic Content Assessment
 - ▶ Staff Development
 - ▶ Plans for Genetic/Genomic Integration
 - ▶ Anticipated Obstacles and Challenges
- 

Personal Development

- ▶ Identified Core Staff to serve as experts for CCND and Institutes
 - ▶ Performed initial knowledge self-assessment
 - Identified key questions from survey
 - ▶ Examined own beliefs and attitudes regarding Genetics/Genomics
 - Book club
- 

Genetics and Genomics Competency and Nursing Education Workgroup

- ▶ Kathy Calzone, RN, PhD, APNG, FAAN
- ▶ Georgie Cusack, RN, MS, AOCNS®
- ▶ Ellen Eckes, RN, MSN, ARNP, FNP-BC, CCRN
- ▶ Kathy Feigenbaum, RN, MSN, CDE, CGRN
- ▶ Sharon Flynn, RN, MS, ANP-BC, AOCNS®, BMTCN®
- ▶ Jean Jenkins, RN, PhD, FAAN
- ▶ Julie Kohn-Godbout, RN, MSN, PMHCNS-BC
- ▶ Gwen Wallen, RN, PhD

Core Team Book Club

▶ **Francis Collins**

- The Language of Life
- The Language of God

▶ **Bryan Sykes**

- The Seven Daughters of Eve
- Adam's Curse

▶ **James Watson**

- Double Helix

▶ **Brenda Maddox**

- Rosalind Franklin: The Dark Lady of DNA

▶ **Rebecca Skloot**

- The Immortal Life of Henrietta Lacks

Staff Genetic/Genomic Knowledge Needs Assessment

- ▶ Assessed attitudes, practices, receptivity, confidence, and competency in genetics and genomics
 - ▶ Gathered test/re-test validation data to further refine Genetics and Genomics in Nursing Practice Survey instrument
- 

Genetics / Genomics Nursing Survey

	CCND Nurses n (%)	Institute Nurses n (%)
Important to become more educated about genetics/genomics	141 (93)	175 (98)
Initiated discussion about genetics in last three months	21 (15)	66 (50)
Complete family history in last 3 months often or always	13 (11)	52 (39)
Updated family history in last 3 months often or always	15 (13)	41 (31)
Heard of essential comp's for genetics/genomics	56 (42)	44 (32)
Attended a course on genetics since graduation	36 (26)	68 (48)
Intend to learn more about genetics/genomics	56 (41)	117 (82)

CCND = 158 RR=26%
Institute=192 RR=50%

Genetics / Genomics in Practice Assessment

- ▶ Identified current practice across all environments (inpatient, day hospital, ambulatory)
 - Established Genetics / Genomics Special Interest Group (SIG)
 - Kick-off meeting in March 2013 to introduce results of OHSRP-approved Genetic / Genomic Survey
 - Clinical Nurse Specialists conducted focus groups in 2014 with inpatient and outpatient representatives from each practice environment (medical-surgical, behavioral health, oncology, and critical care)
- 

Focus Group Discussions

- ▶ How would you want educational information about genetics/genomics presented to you?
 - ▶ What resources do you feel you need to feel more competent about genetics and genomics in your practice?
 - ▶ What are your barriers to knowing/understanding educational material being presented to you?
 - ▶ What do you recommend to increase genetics/genomics understanding/education in our practice?
- 

Policy Genetic/Genomic Content Assessment

- ▶ Reviewed current policies within NIH
 - Evaluated current NIH policies for gaps in Genetic/Genomics
 - Assessed the potential for standardization of Genetic/Genomic language in Informed Consent document across Institutes
 - Assessed the potential of standardization of incidental findings across NIH
- 

Staff Development

Increased Knowledge of Genetics/Genomics for nursing staff working at the NIH, Clinical Center

- Designed and distributed monthly posters to announce specific genetics/genomics competency initiatives
 - Special Interest Group Meetings
 - Gene Splash Documents
 - Education Flyers
- Presented preliminary results of Pre-Survey and Retest Validation to NIH, CC staff and Institute staff
- Developed, implemented and evaluated Introductory and Intermediate Genetics/Genomics Courses
- Developed and Implemented Introductory and Intermediate Genetics/Genomics Competencies at NIH, Clinical Center

Staff Development

Increased knowledge of Genetics/Genomics for nursing staff working at the NIH, Clinical Center

- Incorporated genetics education into core courses and protocol education sessions
 - Encouraged staff to provide Genetic/Genomic in-services at unit level– core team, research nurses and clinical educators
 - Developed and implemented a website for Genetics/Genomics education
- 

Marketing Initiatives

Genetics/Genomics Special Interest Group Meeting

NIH Clinical Studies in Whole Genome Analysis

Kathleen Calzone, PhD, RN, APNG, FAAN
Senior Nurse Specialist, Research
Center for Cancer Research, Genetics Branch
National Cancer Institute

Steve Gonsalves, RN, BC-FNP
Nurse Practitioner and Research Associate
Medical Genomics and Metabolic Genetics Branch
National Human Genome Research Institute

Wednesday, October 15, 2014
3-4pm
B1C205 Room 4



 National Institutes of Health
Clinical Center

Genetics and Genomics Courses for Clinical Research Nurses & Research Nurse Coordinators

Introduction to Genetics and Genomics in HealthCare:

August 28, 2015	May 27, 2016
September 11, 2015	June 9, 2016
November 5, 2015	July 7, 2016
December 4, 2015	September 13, 2016
February 10, 2016	October 5, 2016
March 22, 2016	November 2, 2016

Intermediate Genetics and Genomics in HealthCare*:

October 8-9, 2015	March 23-24, 2016
January 13-14, 2016	September 22-23, 2016
February 4-5, 2016	November 29-30, 2016

*Participants must have completed the Intro to Genetics and Genomics in HealthCare course prior to attending the Intermediate course

Please Register on the Nursing Department's online course registration site:
<http://ccieprod.cc.nih.gov/nursing/nursingclassreg.nsf/index>

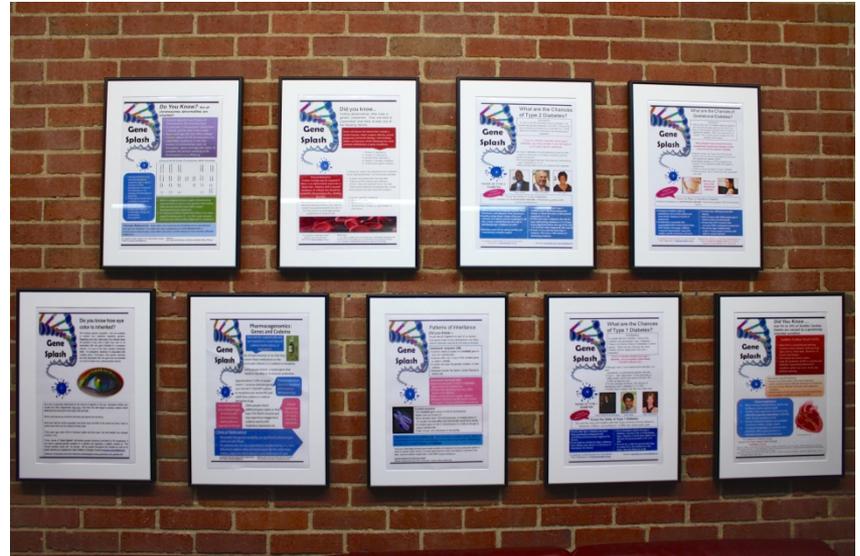
Both courses are sponsored by the Genetics and Genomics Workgroup:
Dr. Gwen Wallen, Dr. Kathy Calzone, George Cusack, Ellen Eckes, Kathy Feigenbaum, Sharon Flynn and Dr. Jean Jenkins

Discover What's Next in Nursing.
The NIH Clinical Center Nursing Department



Gene Splashes

- #1: Patterns of Inheritance
- #2: Pharmacogenomics
- #3: Eye Color
- #4: What are the Chances of Type 1 Diabetes
- #5: What are the Chances of Type 2 Diabetes
- #6: What are the Chances of Gestational Diabetes
- #7: Chromosome Abnormalities
- #8: Sudden Cardiac Death
- #9: Clotting Abnormalities
- #10 Pheochromocytoma



Adapted from South Shore Hospital in Boston, Mass

Course Content

Introduction to Genetics/Genomics in HealthCare

- ❖ Video: Welcome to the Genome Era
- ❖ Cells to Genes
- ❖ From Genes to Proteins
- ❖ How Genes Work
- ❖ Mutations and Health
- ❖ Inherited Genetic Conditions: Inheritance Patterns and Understanding Risk
- ❖ Pedigree Activity
- ❖ Genetic Testing
- ❖ Genetics and Genomics Resources
- ❖ Genetics and Genomics in Current Practice
- ❖ Jeopardy

Intermediate Genetics/Genomics in Healthcare

- ❖ Welcome and Pre-Course Learning Assessment
- ❖ Review Key Concepts from Introduction Course
- ❖ Integration of Genomics into Nursing Practice
- ❖ Incidental Findings
- ❖ Ethical, Legal, and Social Implications of Genetics and Genomics
- ❖ Gene Therapy
- ❖ Genetics and Genomic Case Studies
- ❖ Epigenetics
- ❖ Pharmacogenomics
- ❖ Genetic Consultation
- ❖ Assessing the Research Participant's Knowledge of Genetics and Genomics

Competency

NIH CLINICAL CENTER NURSING DEPARTMENT CRN COMPETENCY VALIDATION

Name: _____ Manager or Designee: _____
 Work Area: _____ Hire Date: _____ Competency Date: Met _____ Not Met: _____

Reason for validation: Orientation Re-validation PIFollow-up Other _____

Key: 1 = No knowledge/Experience 3 = Knowledge/Done with assistance Method used for validation: D = Demonstration DR = Documentation Review V = Verbalization
 2 = Knowledge/No experience 4 = Knowledge/Done independently T = Test/Quiz O = Activity in Class

Competency: Genetics/ Genomics – Integration of genetics/ genomics into the Nursing Professional Practice Domain related to nursing assessment, education, care and support.

Behavioral Indicators	Self-Evaluation				Assessment Method	Validator's Initials/Date		Comments
	1	2	3	4		Met	Not Met*	
BEGINNER LEVEL (All CRNs/Research Nurses)								
1. Demonstrates ability to define basic genetics and genomics terminology.	1	2	3	4	T			
2. Recognizes one's own attitudes and values related to genetic and genomic science and how it may affect care provided to clients.	1	2	3	4	V			
3. Demonstrates an understanding of the relationship of genetics and genomics to health, prevention, screening and diagnostics.	1	2	3	4	T, O			
4. Demonstrates the ability: a. To elicit a minimum of a three-generation family health history information. b. Constructs pedigree from collected family history information using basic standardized symbols and terminology.	1	2	3	4	O			
5. Demonstrates ability to recognize how to maintain privacy and confidentiality when discussing genetic and genomic information.	1	2	3	4	T, V			
6. Discuss scope of legislative protections and possible limitations a. GINA (Genetic Information Nondiscrimination Act) b. State laws c. ADA	1	2	3	4	T			

Key: 1 = No knowledge/Experience 3 = Knowledge/Done with assistance Circle method used for validation: D = Demonstration DR = Documentation Review V = Verbalization
 2 = Knowledge/No experience 4 = Knowledge/Done independently T = Test/Quiz O = Other (specify)

Competency: Genetics/ Genomics – Integration of genetics/ genomics into the Nursing Professional Practice Domain related to nursing assessment, education, care and support.

Genetics Competency: Beginner

1. Demonstrates ability to define basic genetics and genomics terminology.

 2. Recognizes one's own attitudes and values related to genetic and genomic science and how it may affect care provided to clients.

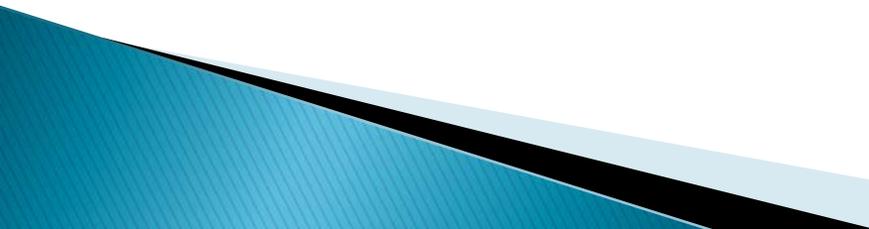
 3. Demonstrates an understanding of the relationship of genetics and genomics to health, prevention, screening and diagnostics.

 4. Demonstrates the ability:
 - a. To elicit a minimum of a three-generation family health history information.
 - b. Constructs pedigree from collected family history information using basic standardized symbols and terminology.

 5. Demonstrates ability to recognize how to maintain privacy and confidentiality when discussing genetic and genomic information.

 6. Discuss scope of legislative protections and possible limitations
 - a. GINA (Genetic Information Nondiscrimination Act)
 - b. State laws
 - c. ADA

 7. Identify 1 medical condition that has a genetic/genomic component within your program of care.

 8. Describe genetic and genomic resources within the Clinical Center
- 

Genetics Competency: Intermediate

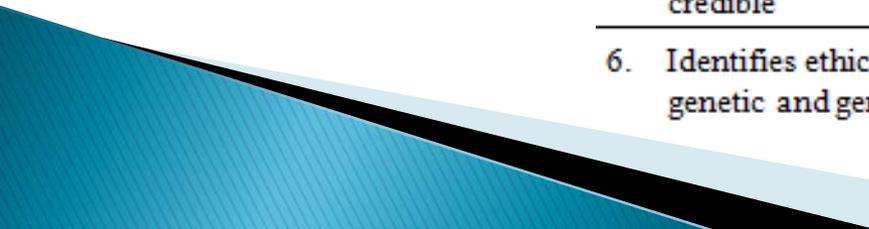
1. Demonstrates an understanding of the relationship of genetics and genomics within program of care as relates to:
 - a. Health promotion
 - b. Disease prevention
 - c. Risk factors
 - d. Therapeutics/ Selection of Treatment
 - e. Prognostics

 2. Demonstrates assessment of research participant's and family's baseline knowledge and perception of genetic/genomic information.

 3. Demonstrates the ability to identify and facilitate referrals for specialized genetic and genomic services for research participants as needed within defined program of care

 4. Provides education to research participant and family taking into consideration their personal environment and other risk factors.

 5. Provides research participant and family genetic and genomic resources that are accurate, appropriate and credible

 6. Identifies ethical, legal, and societal issues related to genetic and genomic information and technologies.
- 

Facilitators Guide





Nursing

Genetics and Genomics

- » [Nursing Intranet Home](#)
- » [Clinical Research Nursing Domain of Practice](#)
- » [Competencies](#)
- » [Education and Training](#)
- » [Evidence Based Practice](#)
- » [Genetics and Genomics](#)
- » [INSPIRE Committee](#)
- » [Nursing Research](#)
- » [Orientation](#)
- » [Practice Areas](#)
- » [Policies, Procedures, SOPs](#)
- » [Professional Opportunities](#)
- » [Recognition and Retention](#)
- » [Resources](#)
- » [Shared Governance](#)

Purpose

The primary purpose of the Genetics and Genomics Competency is to define the essential genetic and genomic competencies needed for all Clinical Research Nurses (CRNs) in the Clinical Center Nursing Department (CCND). The goal is to prepare the CCND CRN workforce to deliver competent genetic and genomic focused nursing care.

Genetics is the study of individual genes and their role in single gene disorder inheritance. **Genomics** is the study of all the genes including their interactions with each other, the environment, and the influence of other psychosocial and cultural factors.

Competency

- » [Genetics and Genomics Competency](#) (234 KB)

Resources

- » [Facilitator's Guide](#) (1.04 MB)
- » [Participant's Guide](#) (1.03 MB)

Articles

1. Badzek, L, Henaghan, M, Turner, M, and Monsen, R. 2013. Ethical, legal, and social issues in the translation of genomics into health care. *Journal of Nursing Scholarship*; 45 (1): 15-24.
2. B. Chan, F. Facio, H. Eidem, S. Hull, L. Biesecker, and B. Berkman. 2012. Genomic Inheritances: Disclosing Individual Research Results from Whole-Exome Sequencing to Deceased Participants' Relatives. *The American Journal of Bioethics*; 12(10): 1-8.
3. A brochure entitled What Every Law Enforcement Officer Should Know About DNA Evidence (BC 000614) is available on the [NCJRS Website](#).
4. Bennett, R.L., French, L., S., Resta, R.G., Doyle, D.L. 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.
5. Does It Run In My Family? Toolkit from the Genetic Alliance
6. Understanding Genetics: A New York – Mid-Atlantic Guide for Patients and Health Professionals by Genetic Alliance
7. [Genetic Information Nondiscrimination Act \(GINA\)](#) [disclaimer]
8. Haga, S. et al. Public knowledge of and attitudes towards genetics and genetic testing. *Genetic Testing and Molecular Biomarkers*, 17 (4): 327-335.

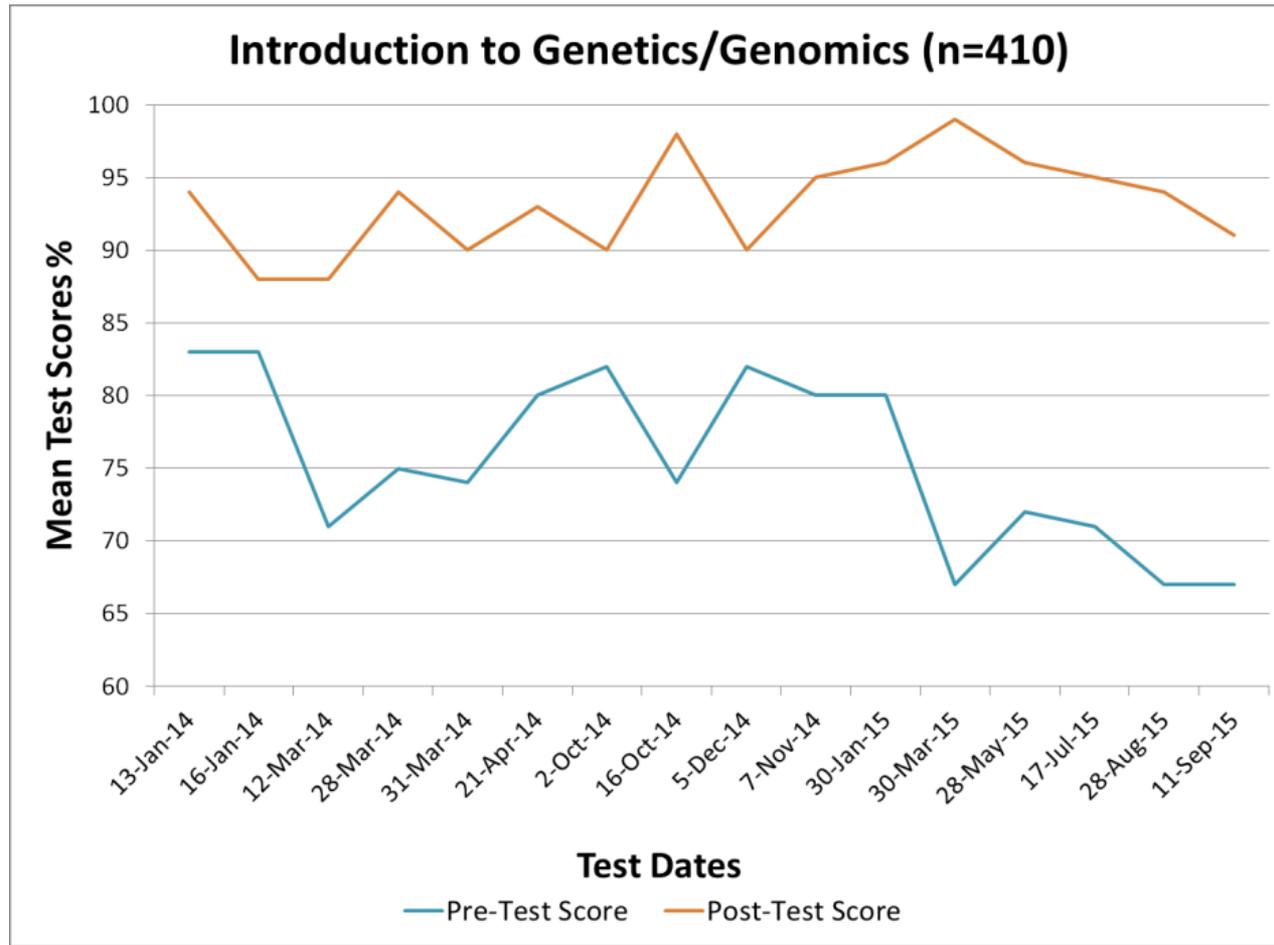
Websites

- » [National Human Genome Research Institute](#)
- » [Global Genetics/Genomics Community - Interactive Case Studies](#) [disclaimer]
- » [Genetics Home Reference Handbook](#)

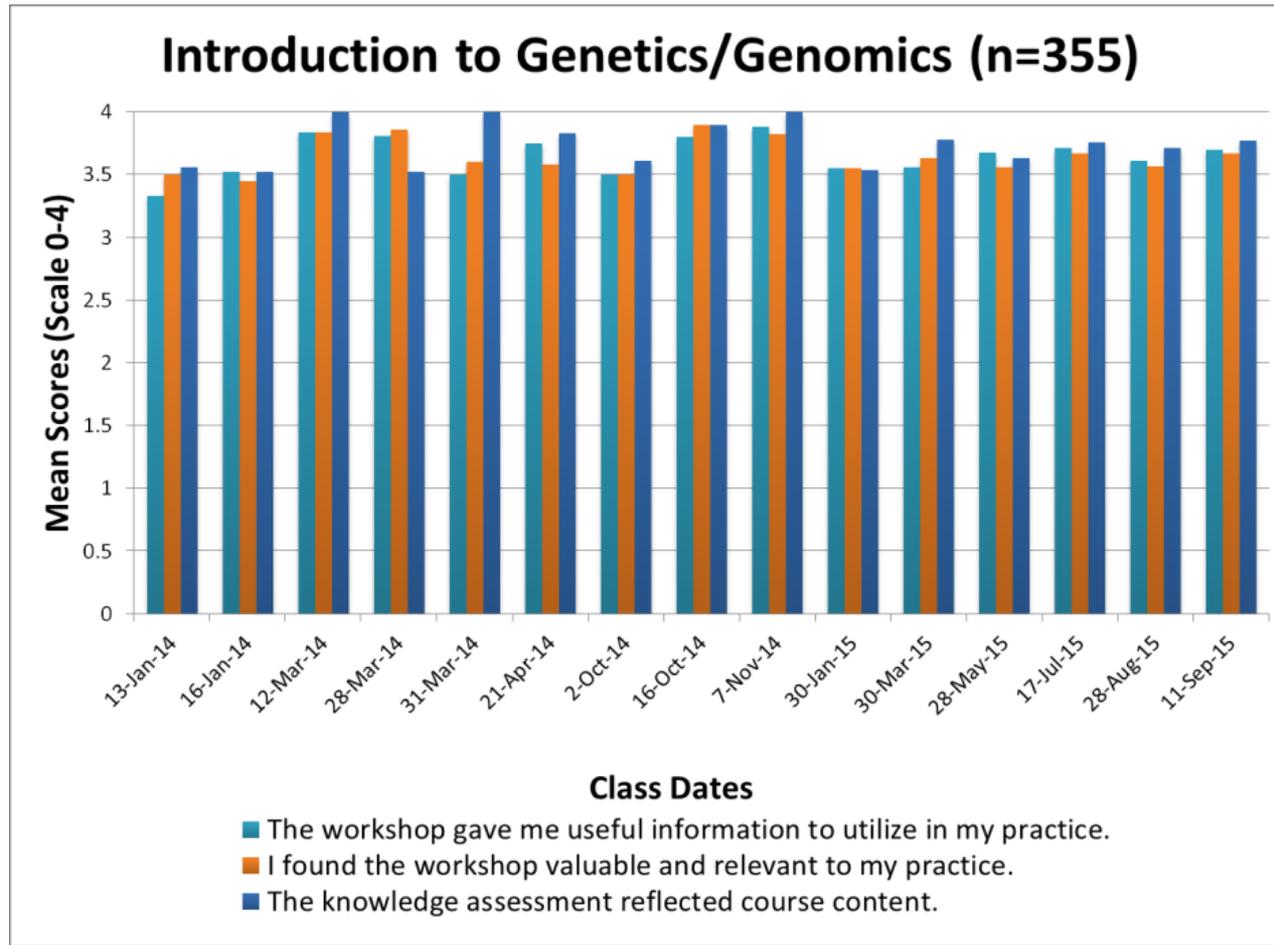
Evaluation Components

- Test Scores
 - Course Evaluations
 - Facilitator Guide Feedback
- 

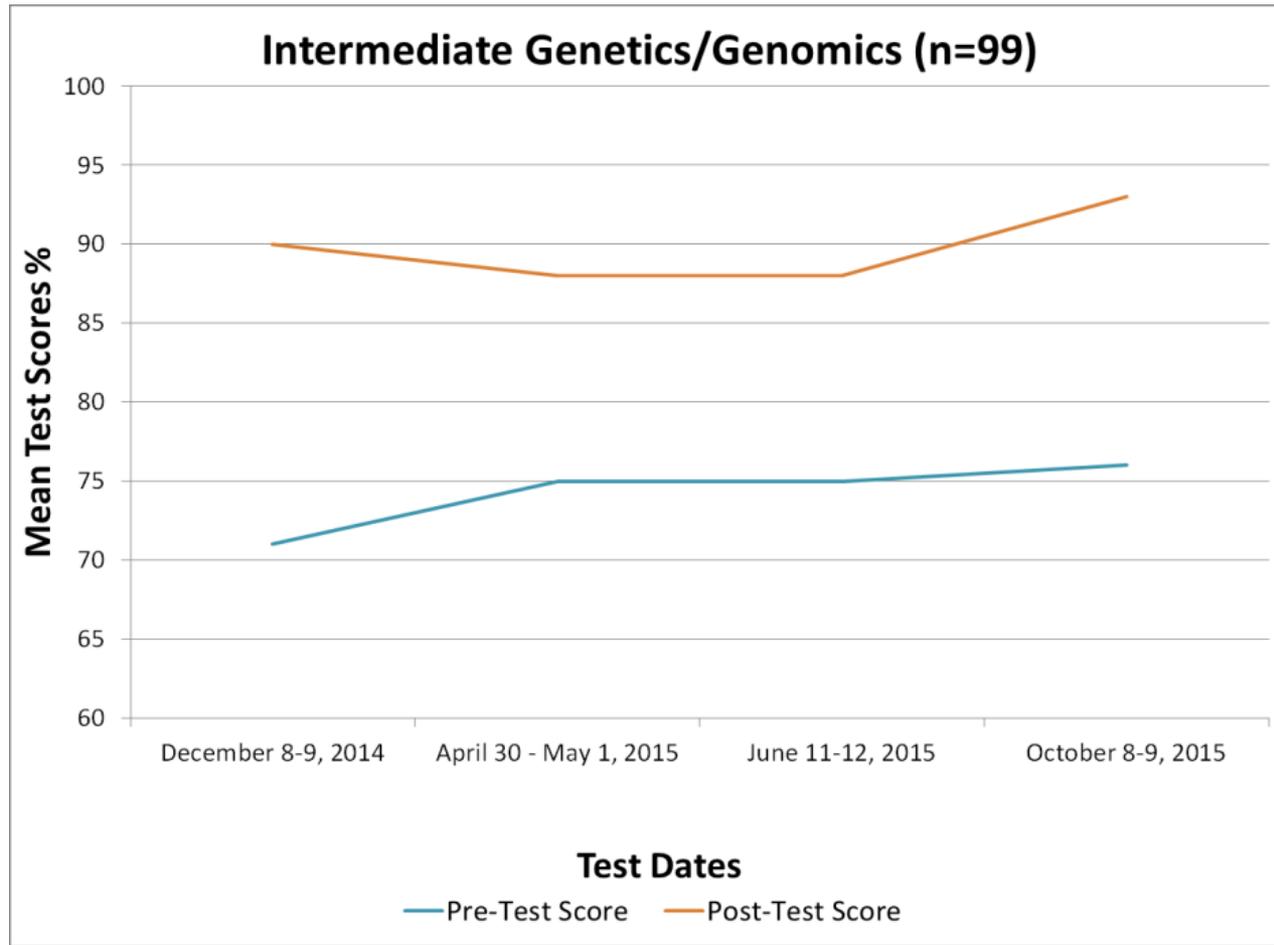
Course Evaluations



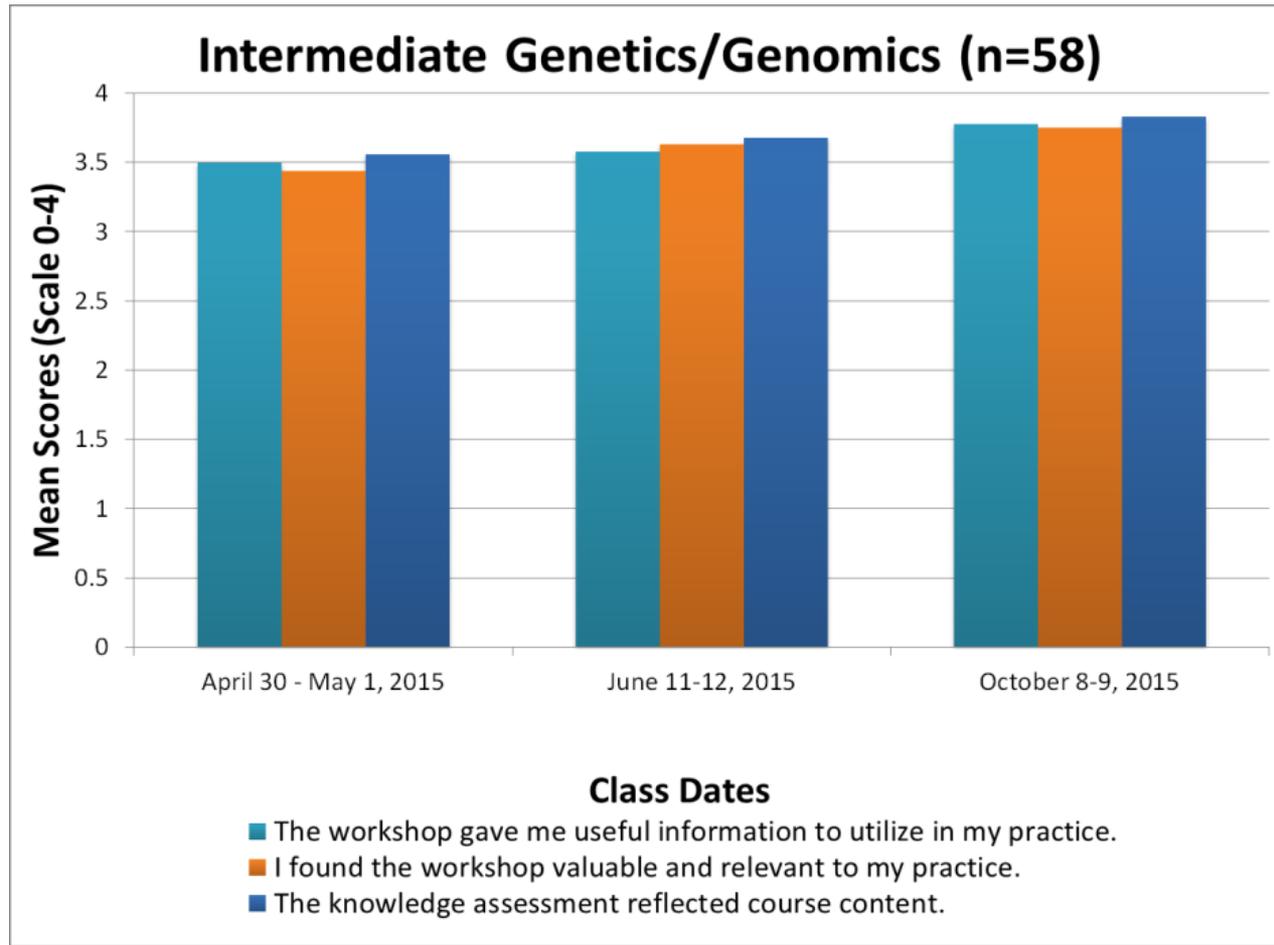
Course Evaluations



Course Evaluations



Course Evaluations



Plans for Genetic/Genomic Integration

Incorporated genetics and genomics information into registered nurse practice

- Core team attended educational sessions to increase knowledge awareness of genetics and genomics and to identify strengths and areas of improvement
 - Genetics Short Course
 - MINC Kick-Off Meeting
 - Pharmacogenomics in Clinical Practice Seminar
 - Explored Online education websites to validate own knowledge and competency in using sites
 - G2C2 website
 - G3C website

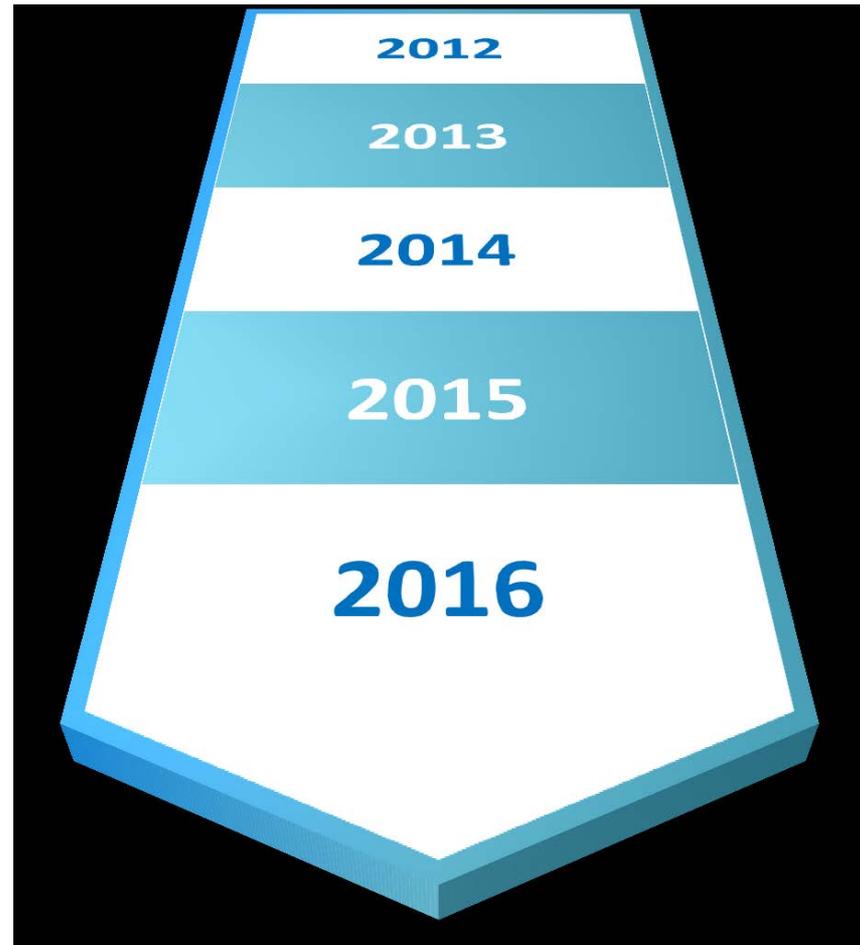
Plans for Genetic/Genomic Integration

- ▶ **Incorporated genetics and genomics technologies into registered nurse practice**
 - Core team introduced websites to SIG to identify best resources for education
- ▶ **Established culture of inquiry around Genetics and Genomics**
 - Identified staff to participate in Genetics/Genomics initiatives
 - Genetics Short Course
 - G2C2 Beta Site Testing
 - G3C Beta Site Testing
 - Mentorship in teaching courses

Anticipated Obstacles and Challenges

- ▶ Competing CRN competency priority
 - Marketing, communication at Nursing Practice Council and at Nursing Leadership forums
- ▶ Dedicated time for initiative
 - Establish set dates and times for meetings
- ▶ Administrative support of activities
 - Dedicate staff from Research and Practice Development—average 2–4 hours/week for meeting minutes, virtual community support

Project Timeline



Program Implementation

Fall 2012

- Core Team attended Method for Introducing a New Competency (MINC) Kick off Meeting
- Developed MINC Action Plan



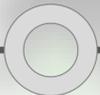
2013

- Core team training
- Genetics Survey
- Genetics Special Interest Group
- Introduction of Marketing Initiatives
- Introductory Genetic/Genomics Course Development
- MINC Action Plan Update



2014

- Introductory Genetics Course Implementation
- Focus groups conducted by CNS and Educators
- Introductory Competency Development
- Intermediate Course Development



Program Implementation

2015

- Introductory Genetics Competency Implementation (Mandatory)
- Intermediate Genetics Course Implementation
- Intermediate Genetics Competency Development
- NIH Policy Discussions



2016

- Intermediate Genetics Competency Implementation
- Advanced Genetics Course Development



2017

- Repeat Genetics/Genomics Survey
- Advanced Genetics Course Implementation



Future Implications

- ▶ Educate and validate all nurses in Introductory Genetics/Genomics Competencies by end of 2016
 - ▶ Repeat Genetics/Genomics Survey in 2017
 - ▶ Educate and validate select nurses in Intermediate Genetics/Genomics Competencies by end of 2017
 - ▶ Incorporate Advanced Genetics/Genomics Education Series in 2017
- 

References

- ▶ Calzone, K., Jenkins, J., Culp, S., Caskey, S., & Badzek, L. (2014). Expanding RN Scope of Practice: A Method for Introducing a New Competency into Nursing Practice. *Journal of Nursing Regulation*, 5(1), 40–47.
- ▶ Jenkins, J., Calzone, K., Caskey, S., Culp, S., Weiner, M., & Badzek, L. (2015). Methods of Genomic Competency Integration in Practice. *Journal of Nursing Scholarship*, 47(3), 200–210.