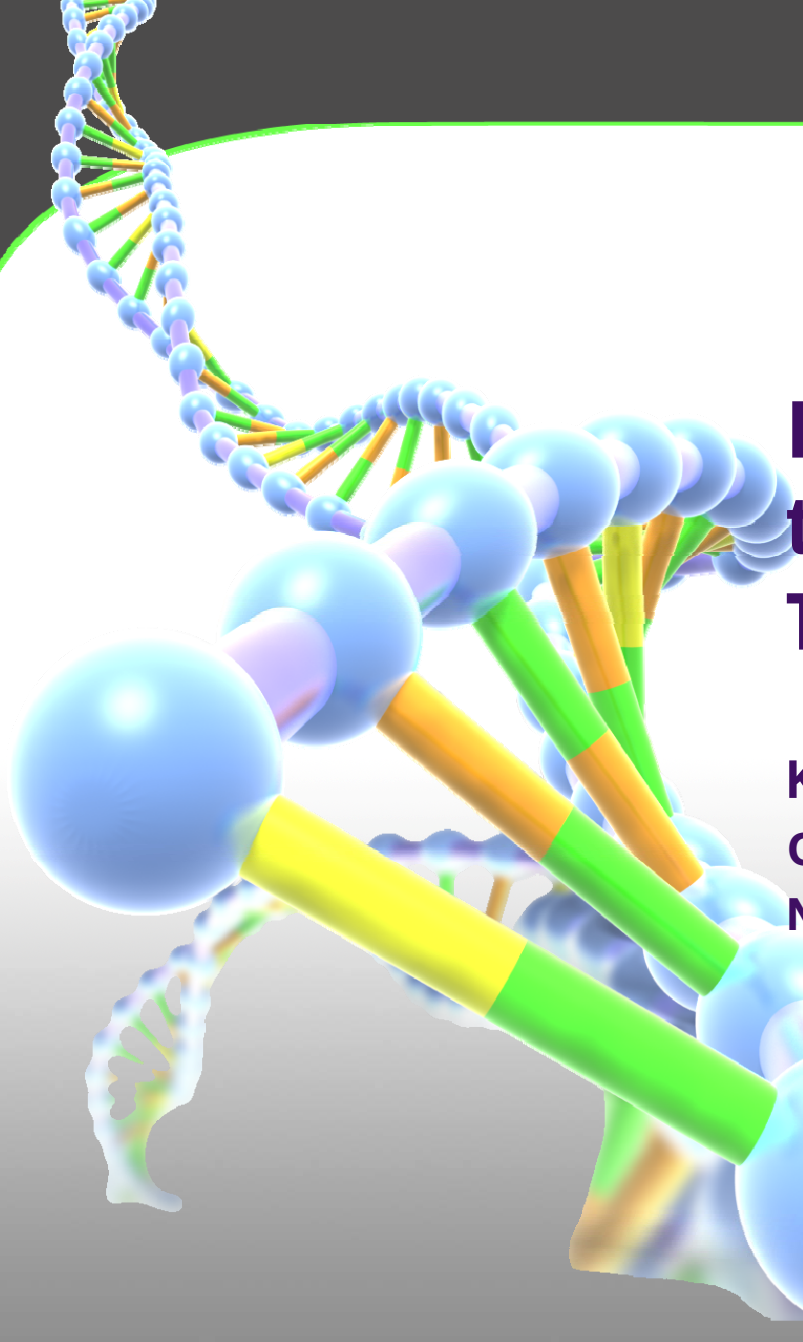


Nurses Essential to Closing the Genetics/Genomics Translation to Practice Gap

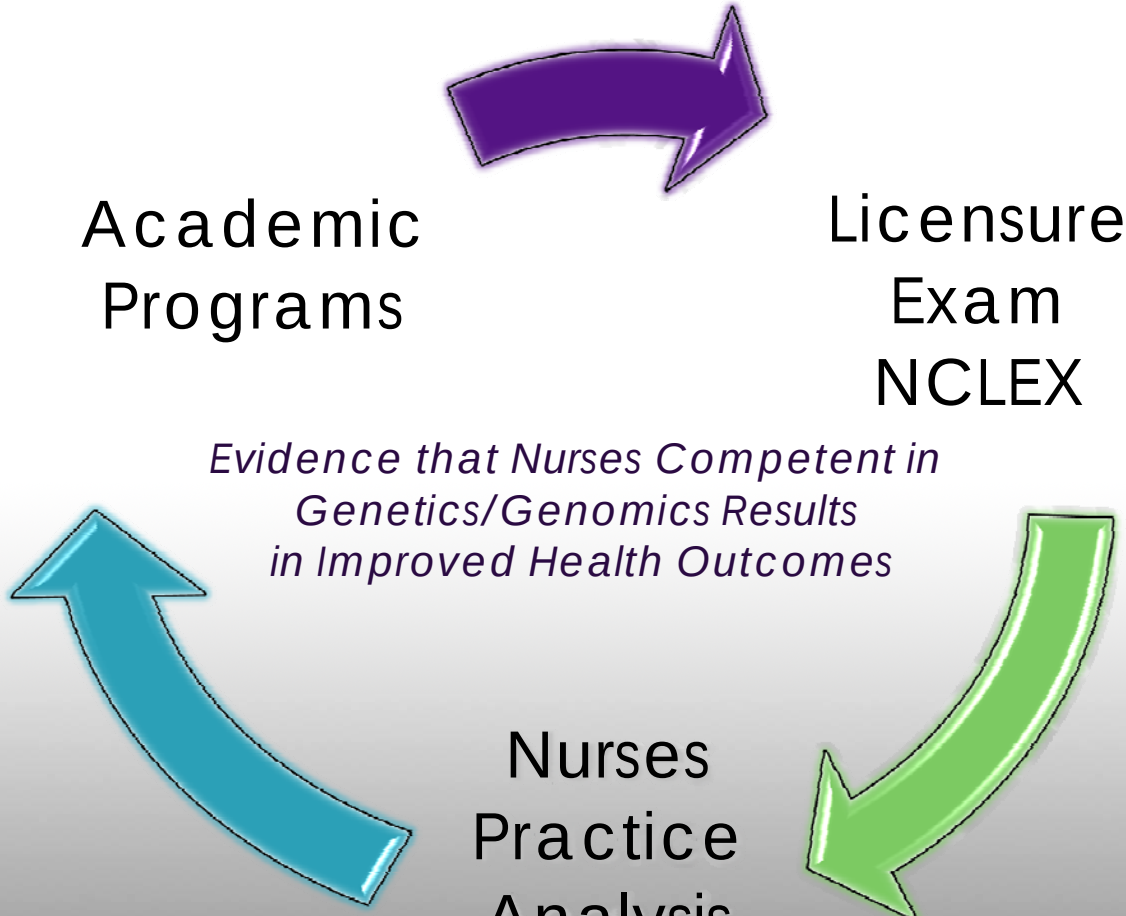
Kathleen Calzone, PhD, RN, APNG, FAAN
Center for Cancer Research, Genetics Branch
National Cancer Institute

Nursing Population

- There are more than 3,000,000 nurses as of March 2008
  - 3,063,162 current licenses to practice as registered nurses
  - 2,596,399 (84.4%) employed in nursing
    - Highest rate of nursing employment since 1977
    - 62.2% practice in a hospital setting
    - 63.2% work full time
      - First increase in full time employment since 1998
  - 250,527 work as an advanced practice nurse
  - 40.9% graduated 1984 or earlier
- Genomic content is not consistently incorporated into 2010 NCLEX-RN® Detailed Test Plan

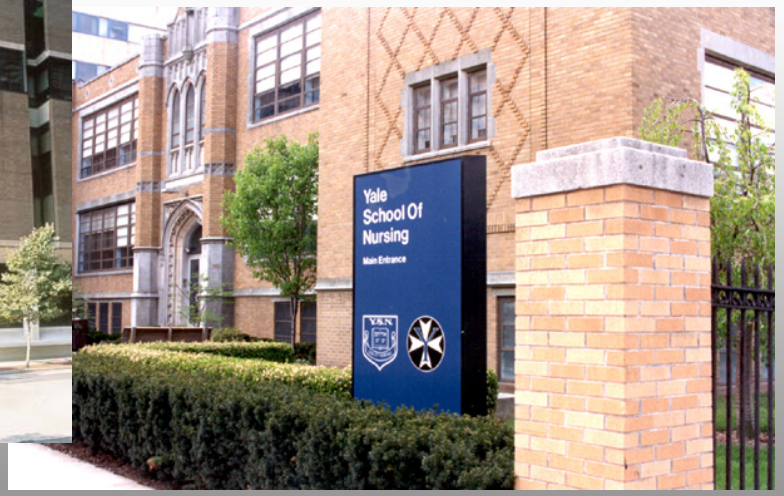
National Council State Boards of Nursing. (2010). 2010 NCLEX-RN® Detailed Test Plan. https://www.ncsbn.org/2010_NCLEX_RN_Detailed_Test_Plan_Candidate.pdf
U.S. DHHS (2010). The Registered Nurse Population: Preliminary Findings from the National Sample Survey Of Registered Nurses. September 2010, HRSA, Bureau of Health Professions, Division of Nursing.

National Council State Boards of Nursing



Nursing Academic Landscape

- More than 3000 schools of nursing accredited by either the Commission on Collegiate Nursing Education and/or the National League for Nursing Accrediting Commission or State Boards of Nursing



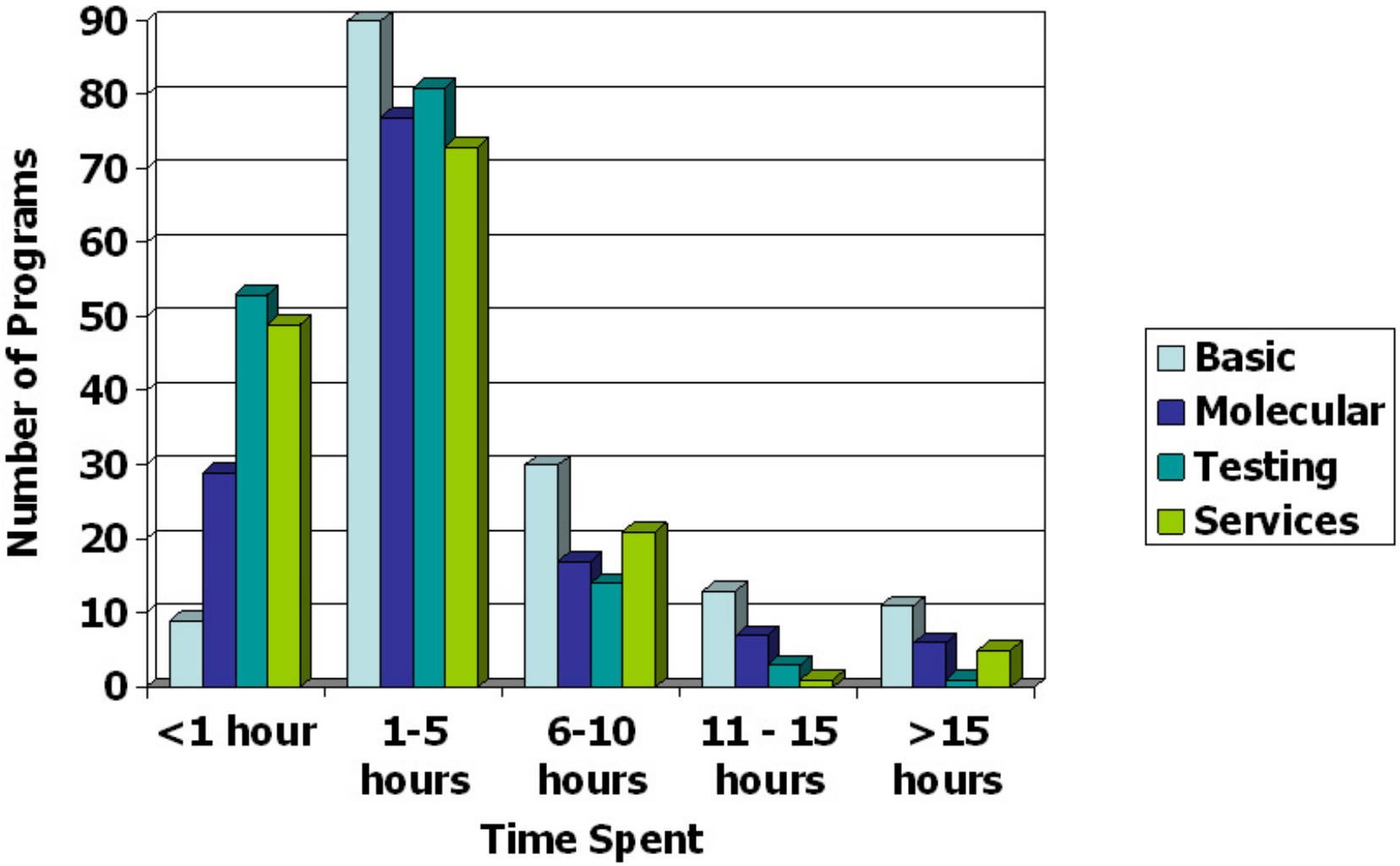
Barriers to Incorporating Genomics into Nursing Curricula

2005 Nursing Faculty Survey (N=224)

- 29% of schools reported no genetic or genomic curriculum content (no change from 1996)
- Barriers
  - Curriculum too full (92%)
  - Faculty not knowledgeable about genetics (59.4%)
  - Not high enough priority (34.4%)
  - Not covered in NCLEX (24.6%)
  - Not important for certification (10.3%)
  - Not essential to nursing care (9.4%)
  - Not applicable or relevant to nursing practice (2.2%)

Prows, C., Calzone, K., Jenkins, J. (2006). Genetics content in nursing curriculum. Proceedings of NCHPEG.

Estimated Curricular Time Spent on Genetic Content Categories



U.S. Genetic/Genomic Integration Efforts 1995-2002

Organizations

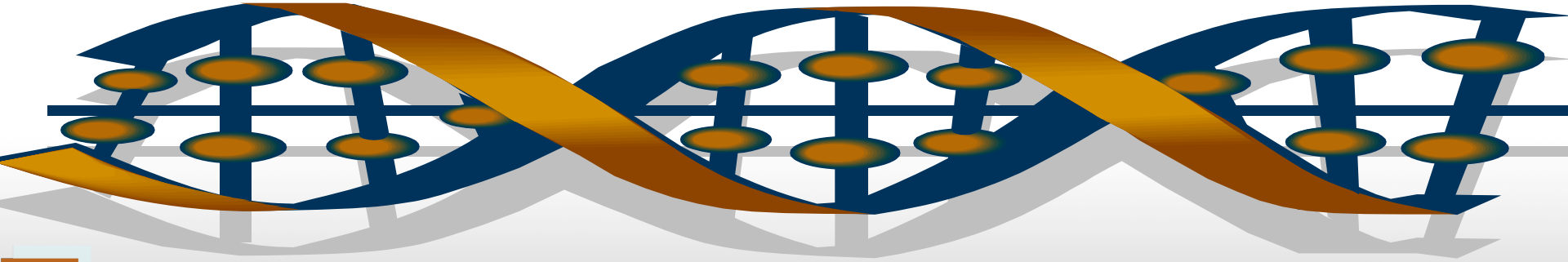
9/26/1995
Workshop for Genetics Education in Nursing

11/1996
ONS Genetic Think Tank

1998
American Society of Clinical Oncology Genetic Curriculum

11/2001
NIH Nursing Genetic Curriculum Recommendations

10/2002
Core Competencies in Cancer Genetics for Advanced Practice Oncology Nurses



Policy

1996
National Coalition of Health Professional Education in Genetics

1998
Secretary's Advisory Committee on Genetic Testing (SACGT) Established

9/28-29/2000
Health Resources Services Administration Expert Panel on Genetics and Nursing

2000
National Breast Cancer Coalition's Hereditary Susceptibility Working Group Knowledge Outline Established

2002
SACGT transitions to the Secretaries Advisory Committee on Genetics, Health, and Society with Administration change

Reasons for Limited Progress

- Relevance of genetics/genomics to nursing practice is not fully appreciated
- Top down approach does not engage the end user
  - absence of outcome evidence
- Previously existing competencies were long and not realistically achievable given packed curricula and busy professionals with limited time and educational resources
- Insufficient numbers of faculty/continuing ed educators prepared to teach this content
- Accrediting bodies did not consider genetics/genomics in their evaluations
- NCLEX and State Boards of Nursing do not require competency in genetics/genomics as part of licensure or re-licensure

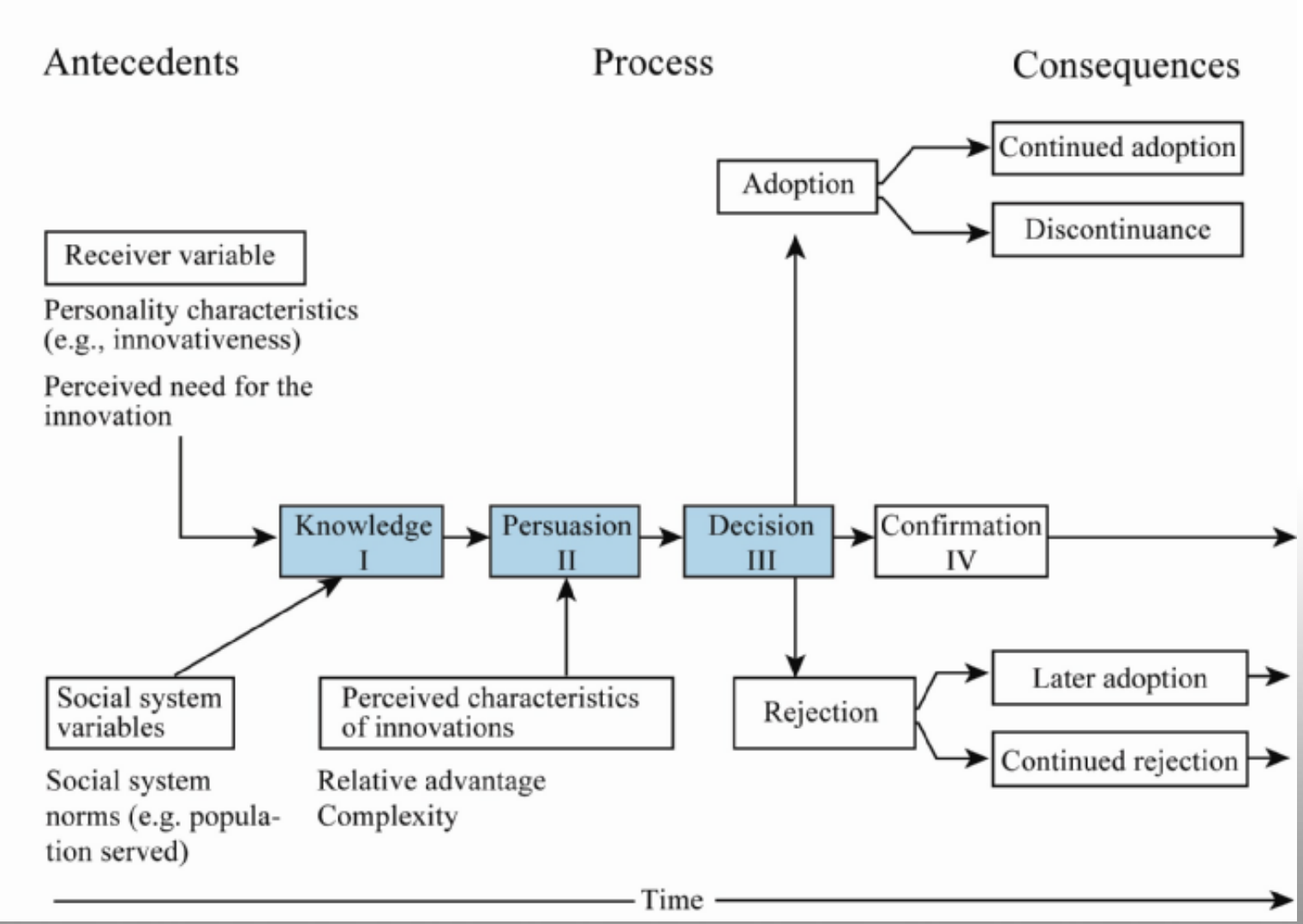
Roger's Diffusion of Innovations

The process which an individual moves through after first hearing about an innovation to final adoption.

- Diffusion
  - Within society or group
    - four stages: invention, diffusion (or communication) through a social system, time and consequences
- Adoption
  - Individual level
    - innovators, early adopters, early majority, late majority, laggards

Rogers, Everett M. (2003). *Diffusion of Innovations, Fifth Edition*. New York, NY: Free Press

Diffusion of Innovations

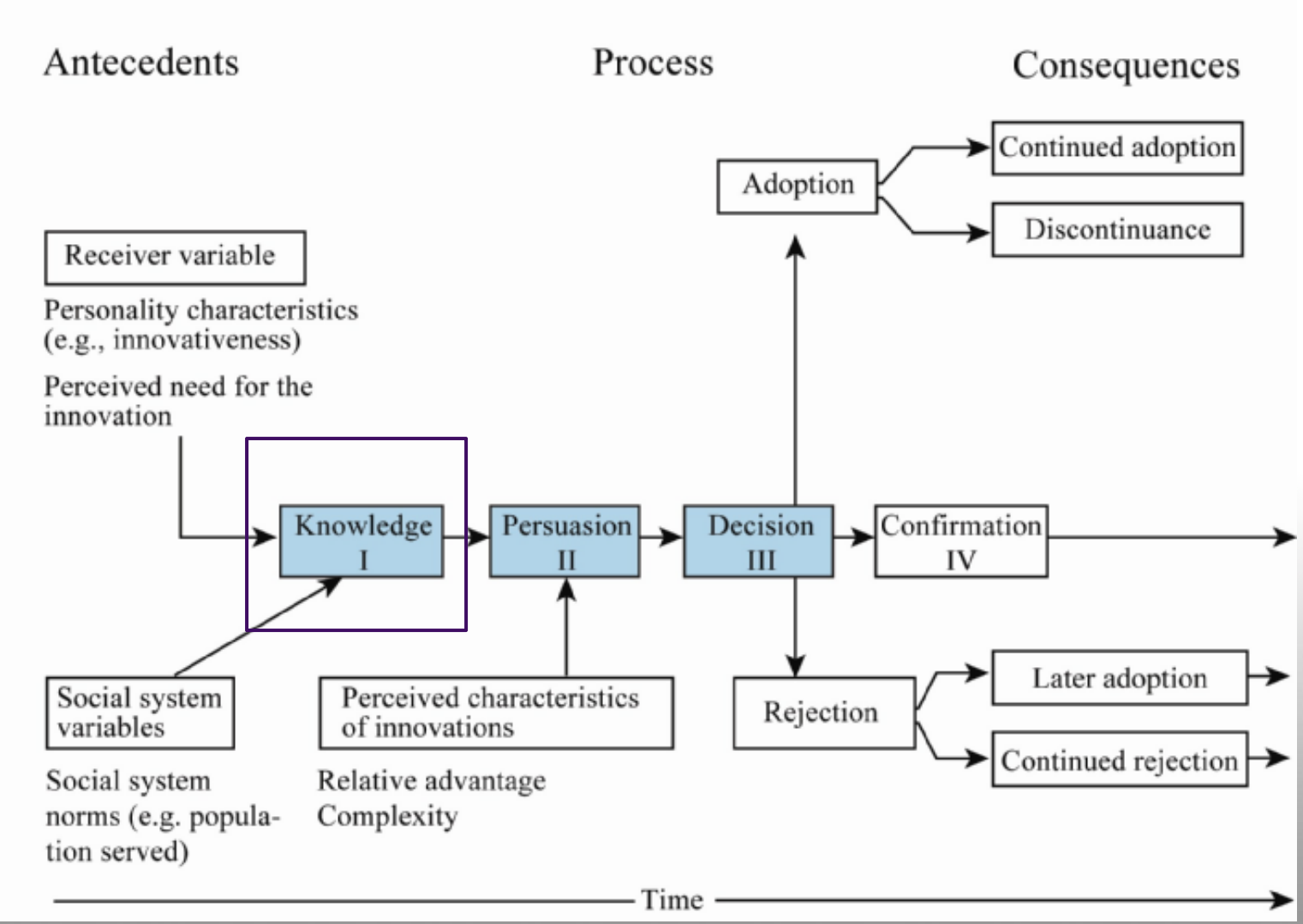


Adopted from: Rogers, Everett M. (2003). *Diffusion of Innovations, Fifth Edition*. New York, NY: Free Press

Genetic/Genomic Nursing Competency Initiative (GGNCI)

- Establish pathways to
  - Influence diffusion of innovation
  - Decrease the time to adoption
  - Decrease the number of rejections
  - Explore elements of the diffusion process to inform intervention development

Diffusion of Innovations



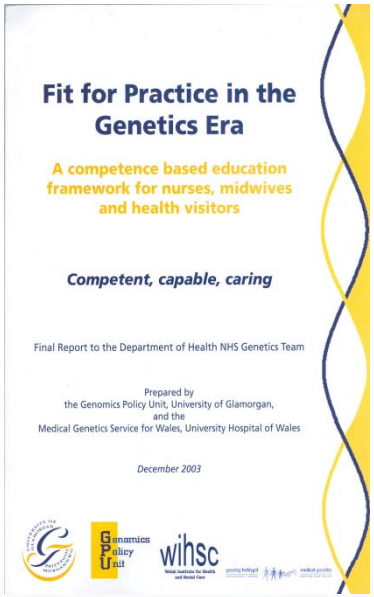
Adopted from: Rogers, Everett M. (2003). *Diffusion of Innovations, Fifth Edition*. New York, NY: Free Press

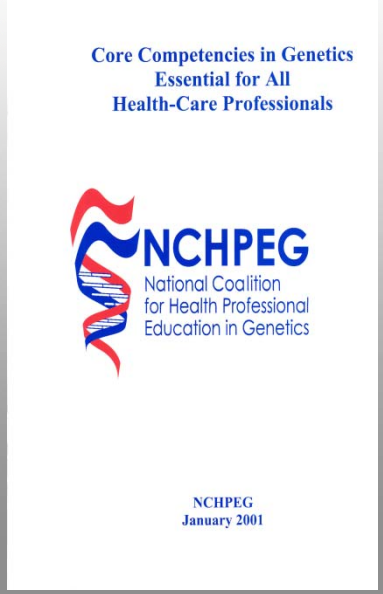
Competency Background

- **Established a Steering Committee**
  - Advise on the methods for competency development and consensus
  - Recommend organizations for partnership expert reviewers
  - Identify key stakeholders
  - Provide connections and insight into key stakeholder organizations (i.e. NLN, AACN)
- **Established Partnership with Key Organizations**
  - Health Resources and Services Administration
  - American Nurses Association
  - Centers for Disease Control
  - National Institute of Nursing Research

Competency Development

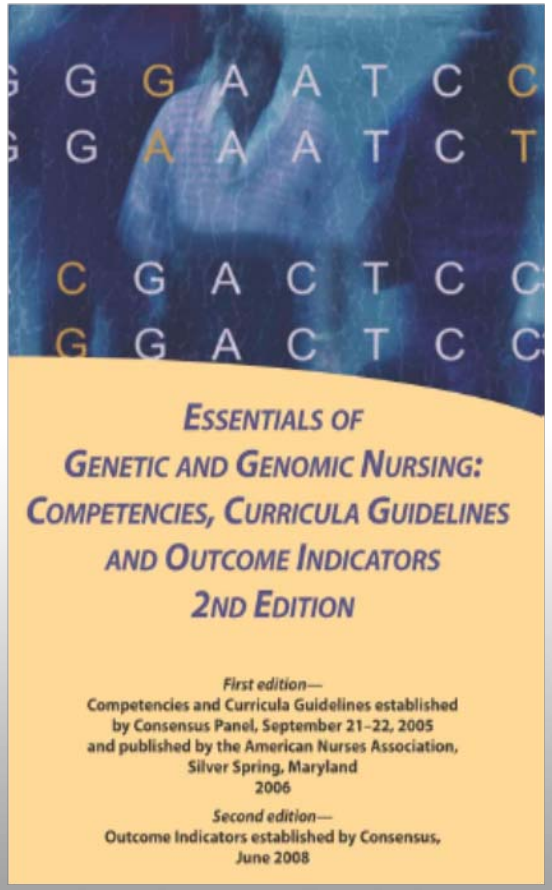
- Identified, analyzed, reviewed and compared available peer reviewed published work reporting practice-based genetic and genomic competencies, guidelines, and recommendations.
- Competencies drafted, reviewed, modified and approved by the Steering Committee.
- Competencies reviewed and modified by nurse representatives to the National Coalition for Health Professional Education in Genetics (NCHPEG) in January, 2005.
- Public comment was solicited with revisions incorporated.
- Consensus Conference September, 2005.



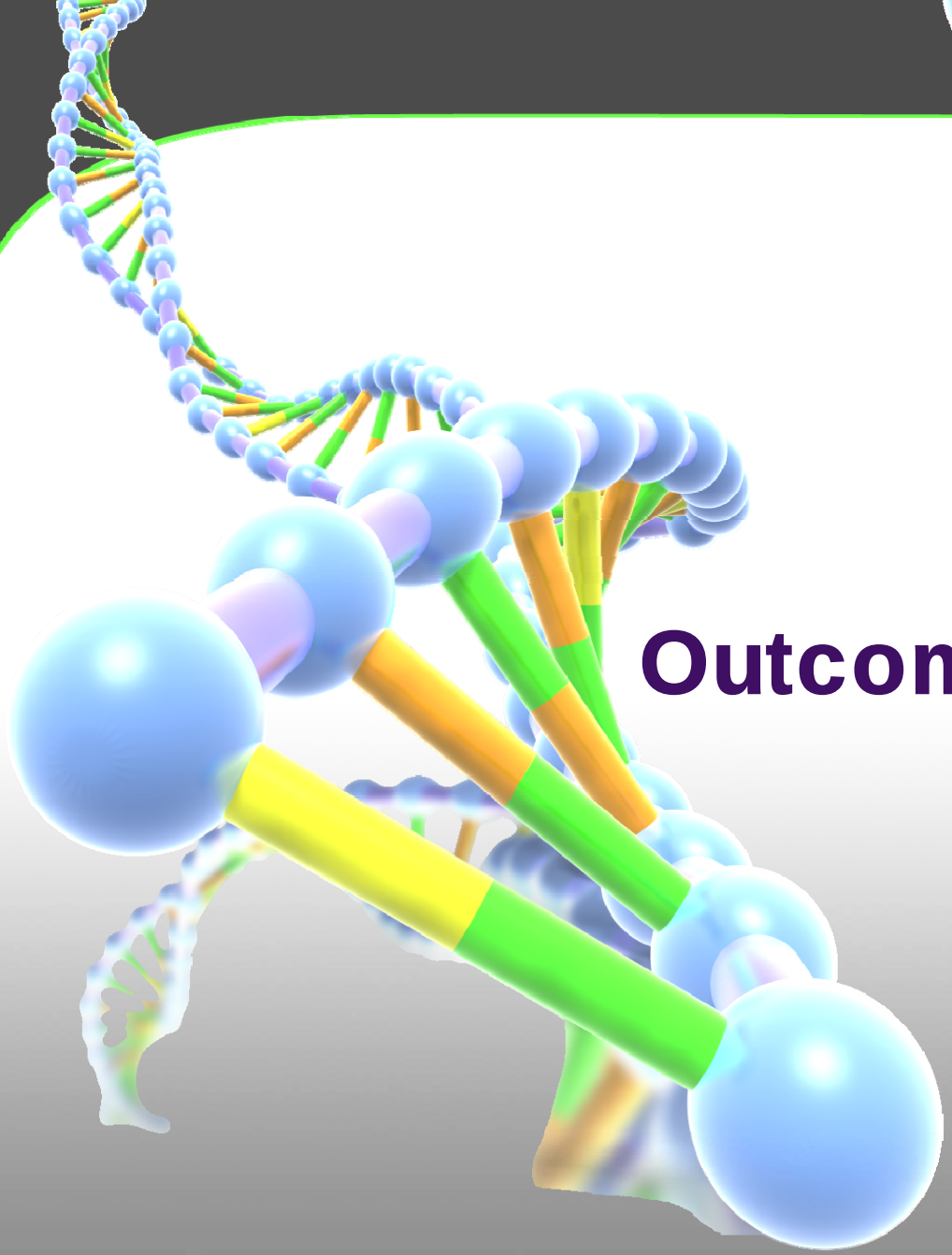


Essentials of Genetic and Genomic Nursing

- Define essential genetic and genomic competencies for **ALL** nurses regardless of level of academic preparation, practice setting or specialty.
- Endorsed by 50 nursing organizations
- October 22-24 2006 Strategic Implementation Meeting
- 2nd Edition incorporated Outcome Indicators
  - Specific Areas of Knowledge
  - Clinical Performance Indicators
- 3rd Edition to be published in 2012 which includes some updates
- Leveling of Competencies for Advanced Practice in press



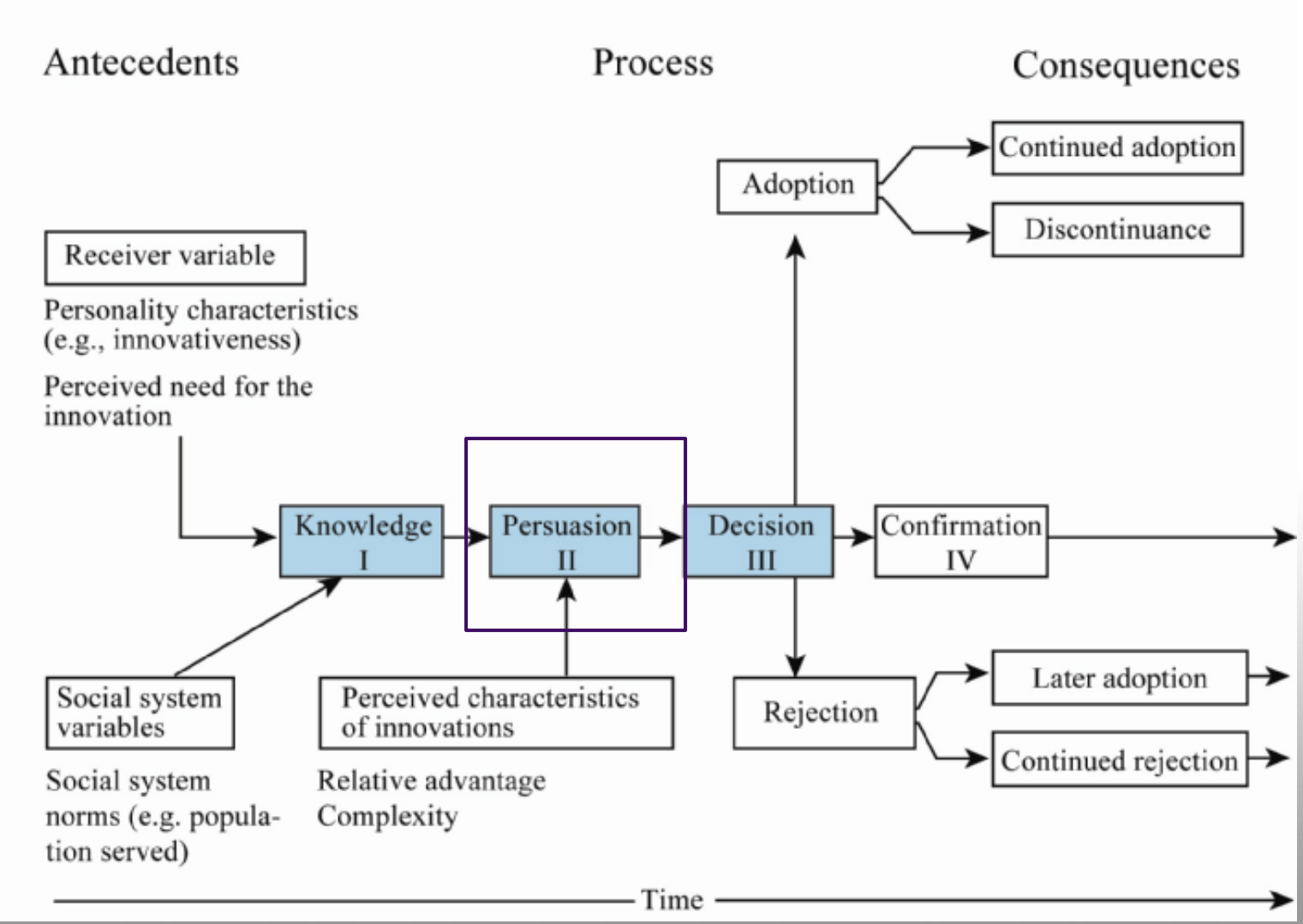
http://www.genome.gov/Pages/Careers/HealthProfessionalEducation/geneticscompetency.pdf



Outcomes of the GGNCI

Academic

Diffusion of Innovations



Adopted from: Rogers, Everett M. (2003). *Diffusion of Innovations, Fifth Edition*. New York, NY: Free Press

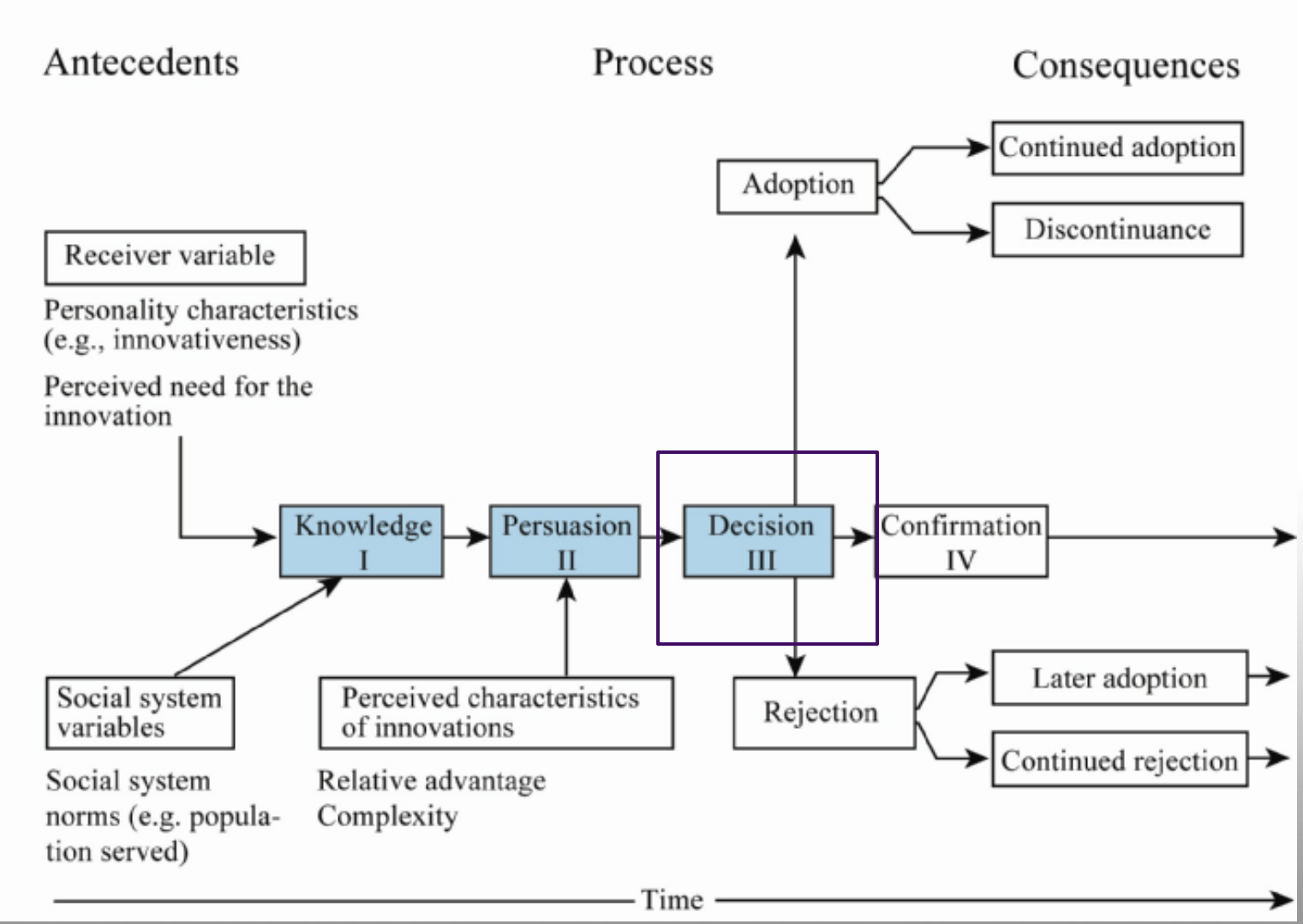
American Association of Colleges of Nursing

The Essentials of Baccalaureate Education for Professional Nursing Practice
October 20, 2008

Executive Summary

"This document emphasizes such concepts as patient-centered care, interprofessional teams, evidence-based practice, quality improvement, patient safety, informatics, clinical reasoning/critical thinking, **genetics and genomics**, cultural sensitivity, professionalism, and practice across the lifespan in an ever-changing and complex healthcare environment."

Diffusion of Innovations



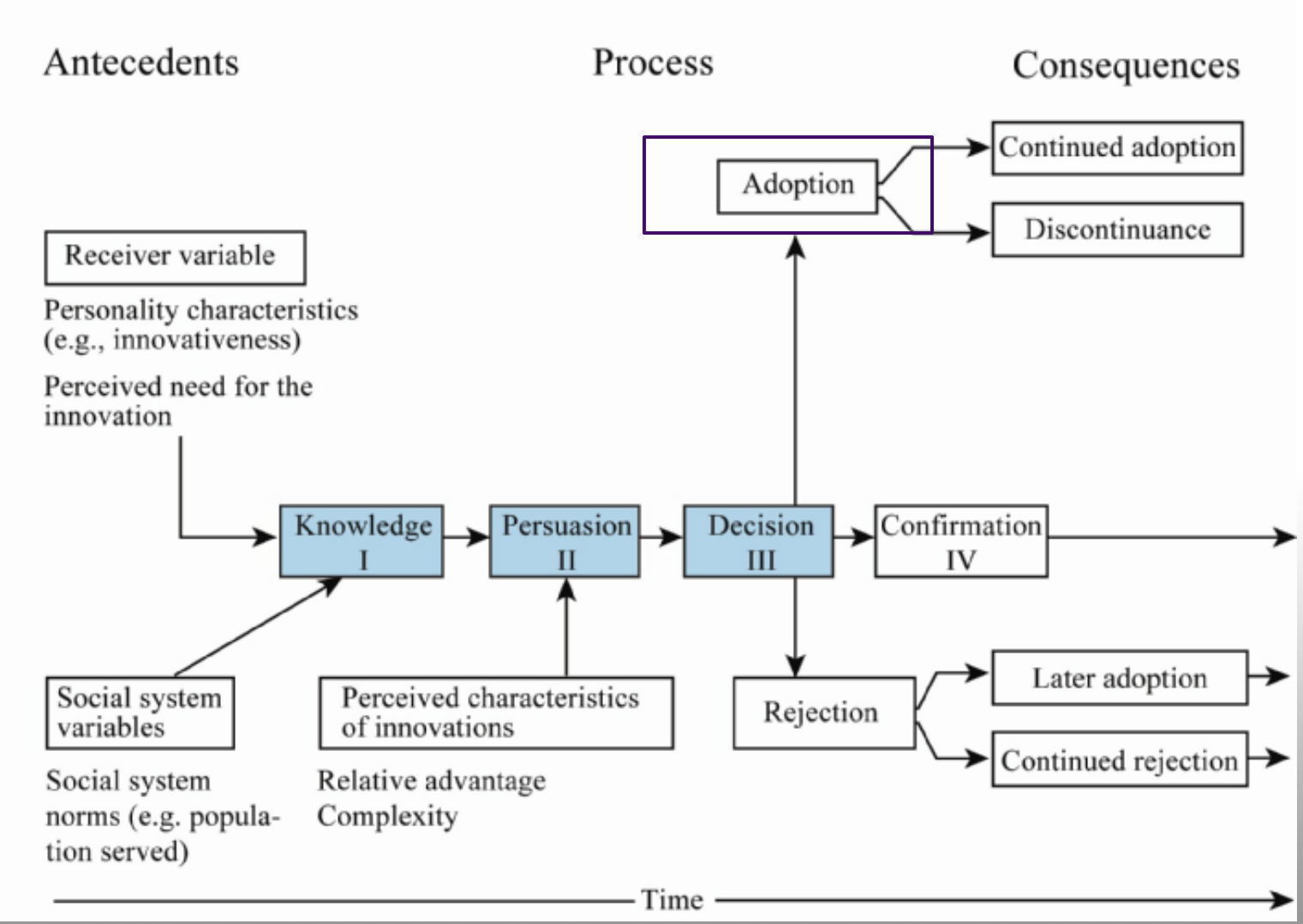
Adopted from: Rogers, Everett M. (2003). *Diffusion of Innovations, Fifth Edition*. New York, NY: Free Press

Baccalaureate Faculty Survey

- 74% rated their own person knowledge of genetics and genomics as low or very low
- 83% either agreed or strongly agreed that preparing nurses to use genetic and genomic information was an important role for nurse educators
- 93% agreed or strongly agreed that **now was the time** to start teaching genetics and genomics
- 31% had already made curriculum changes
- 66% intended to make changes within 6 months

Jenkins, J., Calzone, K. (2012). Are nursing faculty ready to integrate genomic content into curricula? Nurse Educator, 37, 25-29.

Diffusion of Innovations



Adopted from: Rogers, Everett M. (2003). *Diffusion of Innovations, Fifth Edition*. New York, NY: Free Press

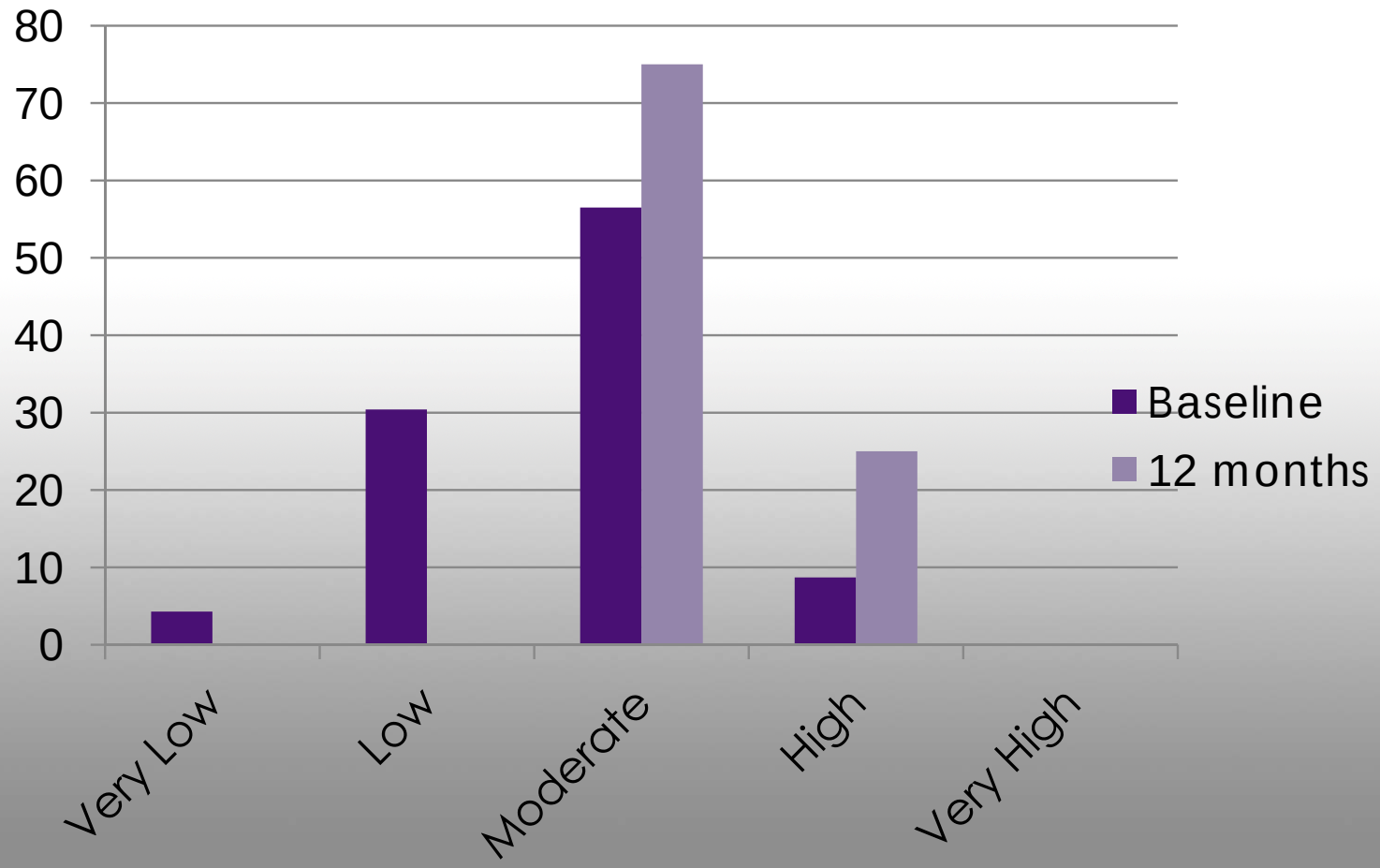
Faculty Champion Initiative

- AIM: Utilize self selected opinion leaders in a year long genetic/genomic curriculum integration education and support intervention to increase content integration
  - Expand teaching capacity
  - Provide resources, support and access to experts
- One year commitment
  - Kick Off meeting
    - Included a webinar for national viewing
  - Year long school specific Action Plan
  - Quarterly reports
  - Monthly Conference Calls
  - Online networking with faculty exemplars using Community of Genetic Educators
  - Attendance at the Faculty Champion Realization meeting 9/2010
    - Faculty present outcomes

Topic	IDENTIFIED IN ACTION PLAN BY NUMBER OF FC (%)	COMPLETED ACTIVITY BY NUMBER OF FC (%)
Faculty Knowledge Survey	17 (90%)	13 (76%)
Curriculum Surveys	12 (63%)	10 (83%)
Faculty Meeting Discussion	11 (58%)	9 (82%)
On-line CE Course	10 (53%)	6 (60%)
Attend Genetics Meetings	6 (32%)	5 (83%)
Curriculum Mapping	6 (32%)	5 (83%)
Review FC Resources Provided	6 (32%)	5 (83%)
Provide Genetics Workshop	6 (32%)	4 (67%)
Develop CE Program Materials	6 (32%)	3 (50%)
Faculty Interviews	5 (26%)	5 (100%)
Syllabus reviews	5 (26%)	5 (100%)
Worked with Curriculum Ctt	5 (26%)	4 (80%)
Literature Reviews	5 (26%)	3 (60%)
Created Advisory Group	5 (26%)	3 (60%)

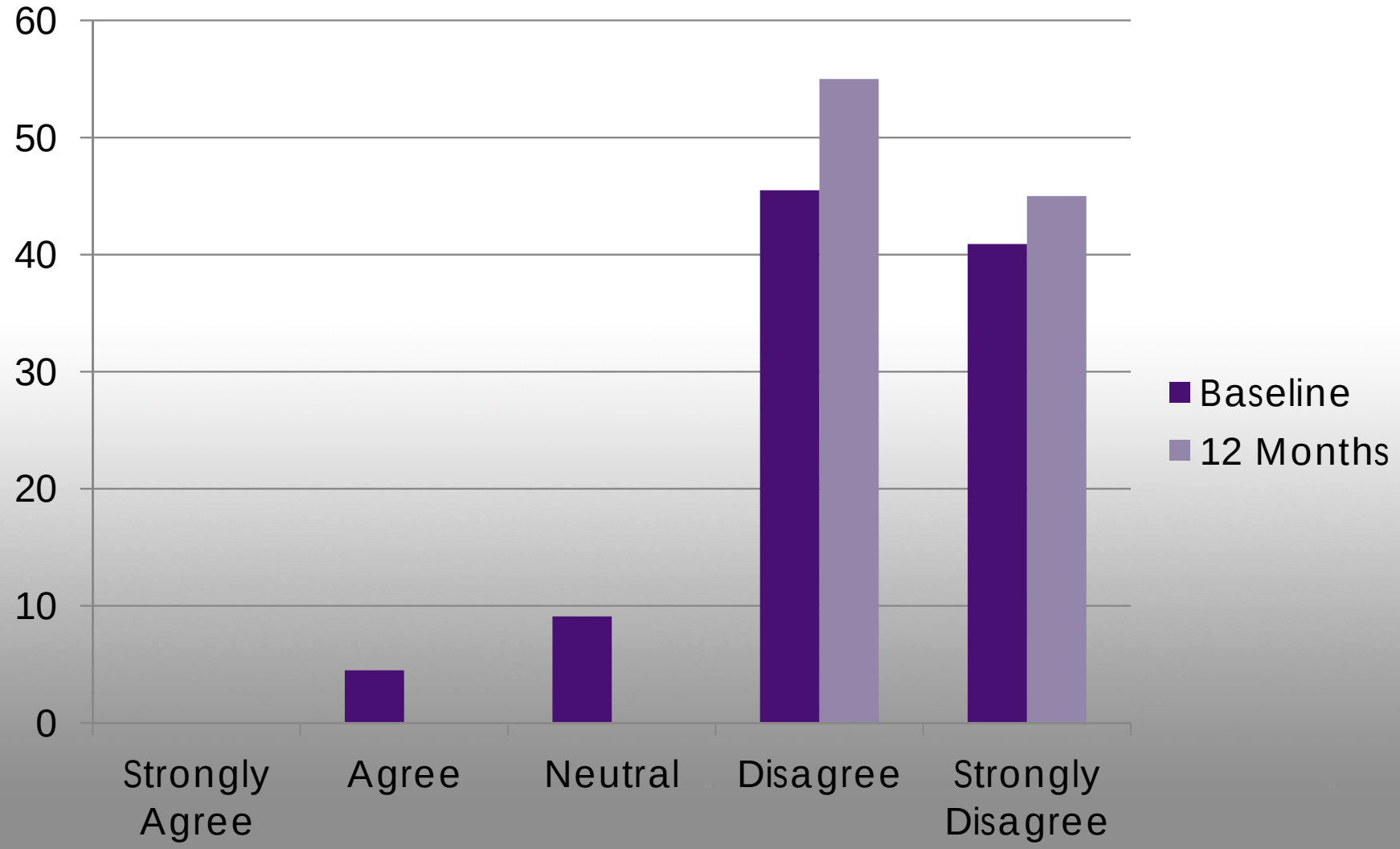
Knowledge Outcomes

Self reported genetic/genomic knowledge



Attitudes

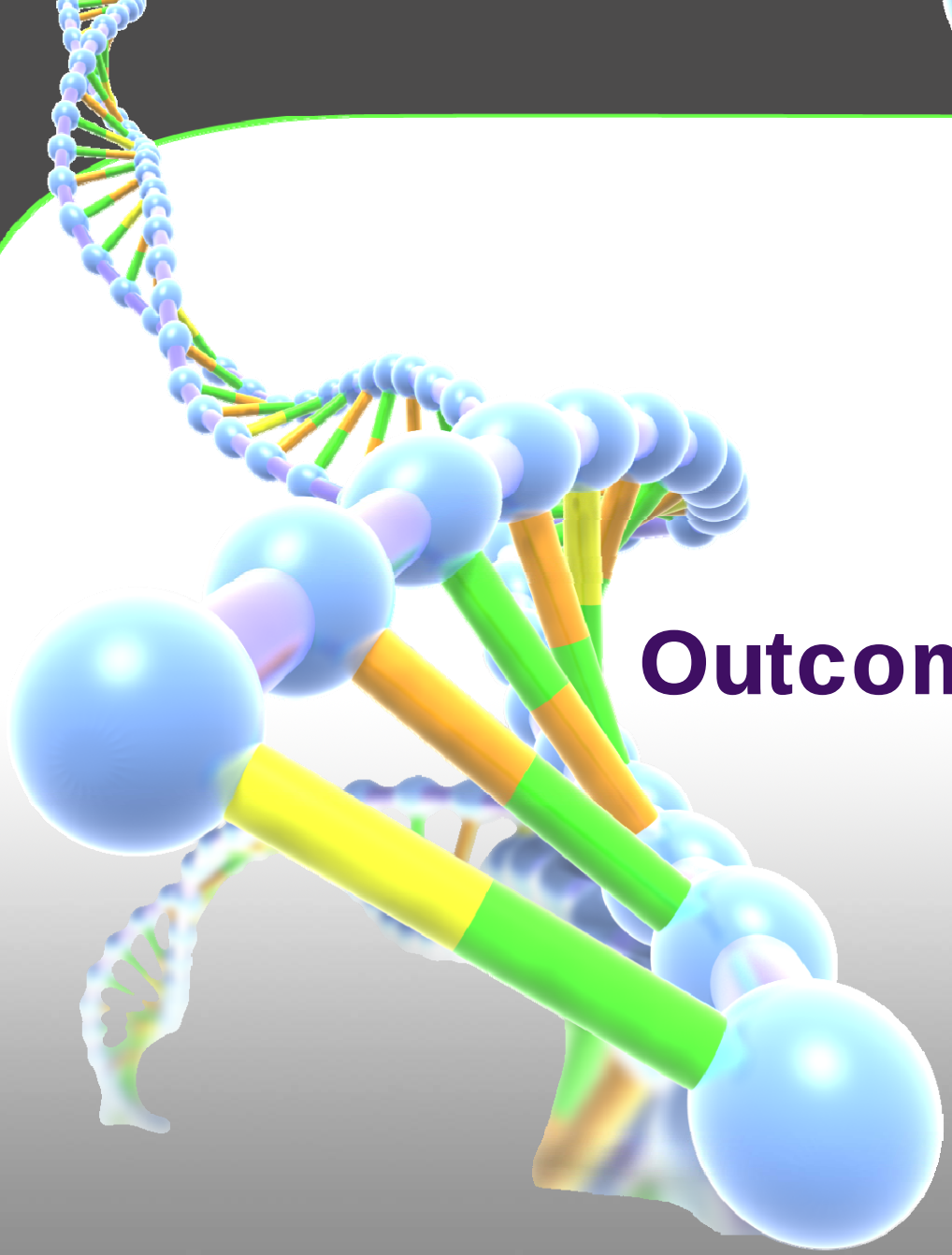
The promise of genetics/genomics for healthcare has been exaggerated



Faculty Champion Realization Meeting
Bethesda, MD
September 27, 2010

Next Steps

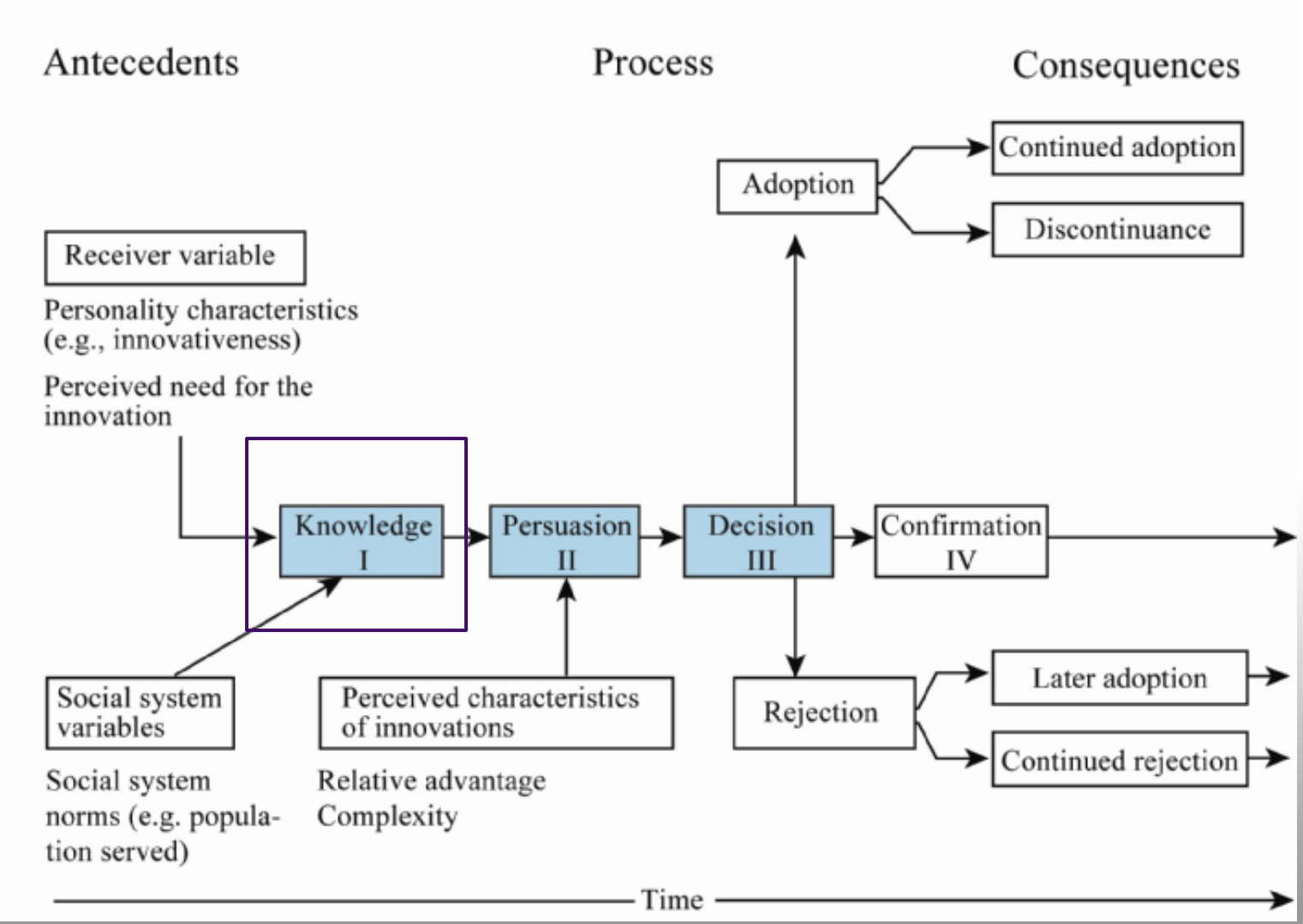
- Have received funding from NHGRI to host 10 faculty for August 6-10, 2012 Summer Short Course
  - Emphasis on Faculty from Minority Serving Institutions
  - Competitive Application Open until April 2, 2012



Outcomes of the GGNCI

Practicing

Diffusion of Innovations



Adopted from: Rogers, Everett M. (2003). *Diffusion of Innovations, Fifth Edition*. New York, NY: Free Press

2010 National Nursing Workforce Study

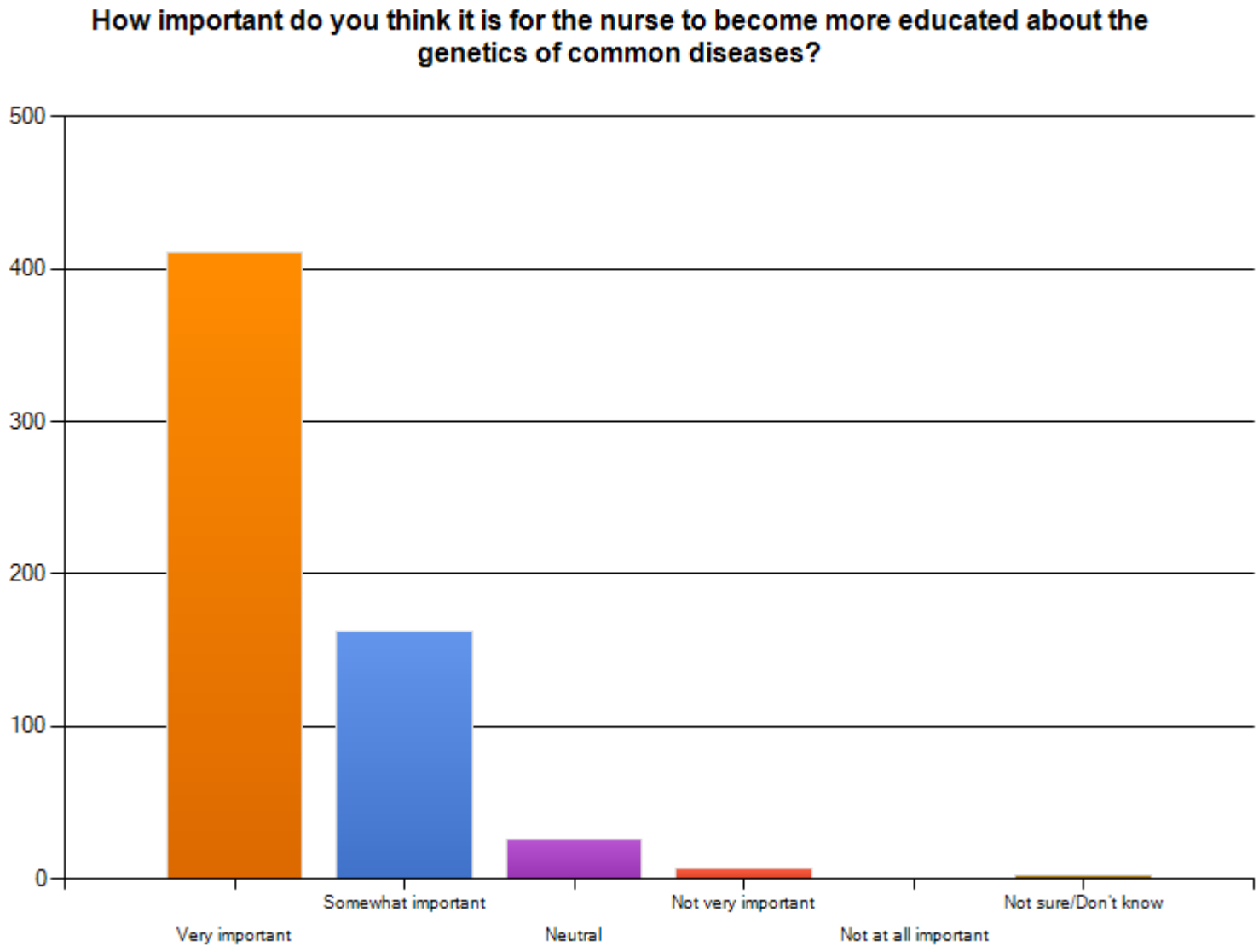
Response N=620

- 619 registered nurses, 1 LPN
  - LPN excluded from analysis

Population

- 60% were members of ANA
- 96% female; Age range 21-76, mean 51; 92% Caucasian
- Average years in practice range .5-50, mean 19.5
- Highest Level of Nursing Education
  - 16% Diploma/Associate Degree
  - 39% BSN
  - 34% MSN
  - 11% PhD or DNP

Attitudes


How important do you think it is for the nurse to become more educated about the genetics of common diseases?
500
400
300
200
100
0
Very important
Somewhat important
Neutral
Not very important
Not at all important
Not sure/Don't know

Use of Family History in Practice

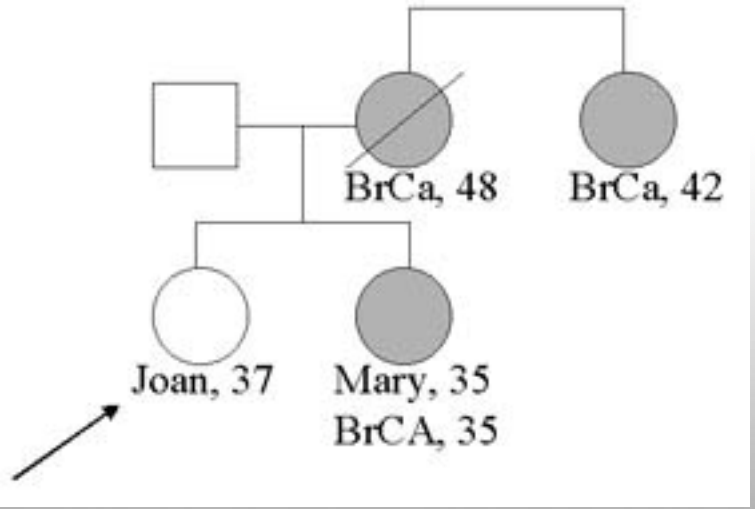
In the past 3 months, collected a family history that included:

-Three generations;

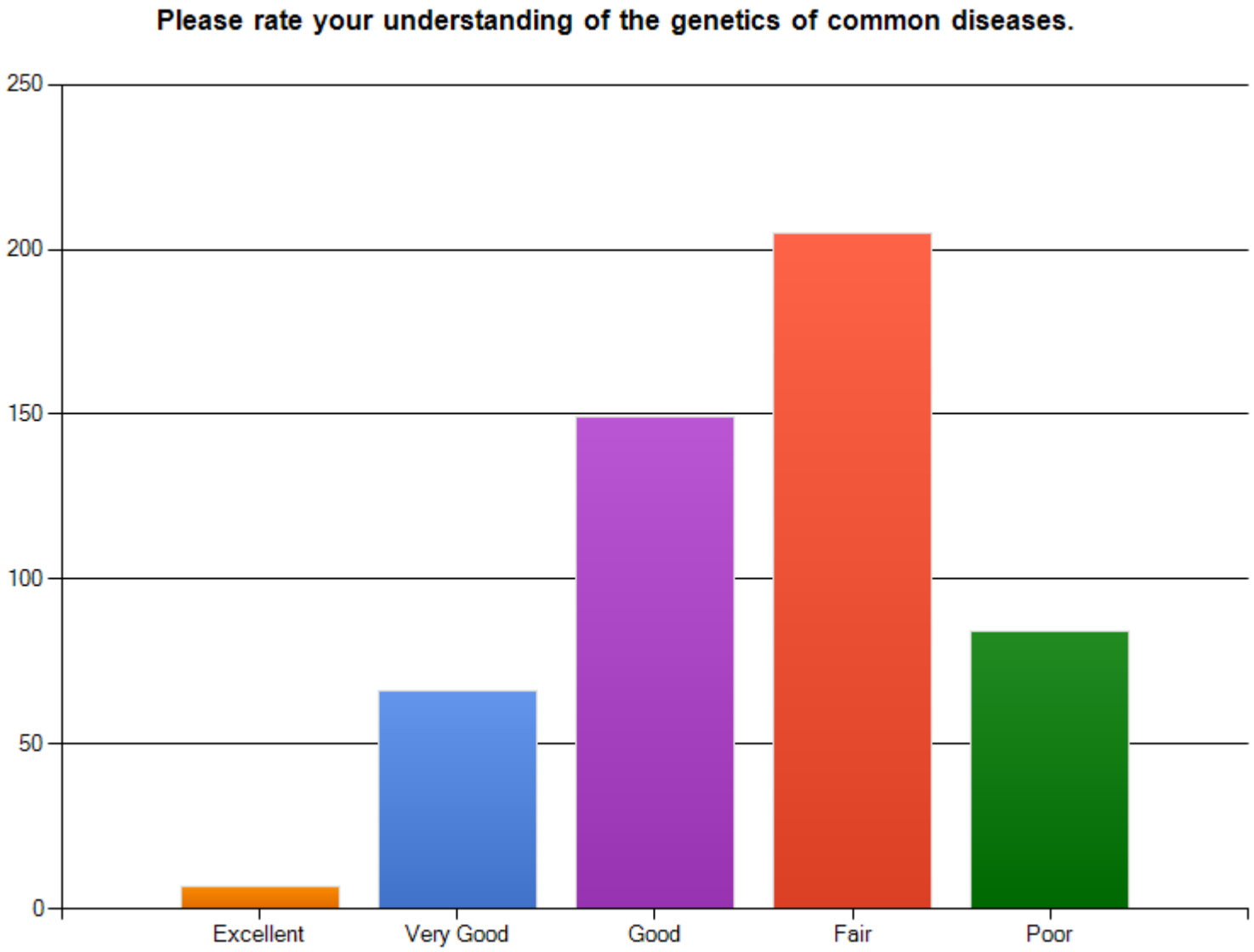
-Age of diagnosis;

-Age at death

- 5% Always
- 10.5% Often
- 18.5% Occasionally
- **66.0% Rarely or never**



Knowledge


Please rate your understanding of the genetics of common diseases.
250
200
150
100
50
0
Excellent
Very Good
Good
Fair
Poor

Knowledge

- A total knowledge score was calculated from 12 knowledge questions
  - Mean 8.99/12, Median 9.00/12, Range 1-12, SD 1.69
- 99% correctly answering a question about whether genomic risk (as indicated by family history) has clinical relevance for coronary heart disease.
  - 60% incorrectly stated that diabetes and heart disease are caused by a single gene variant.
  - There was a statistically significant relationship between higher levels of education and correct response to this question

    $p<0.001$
    - 22.7% Diploma/Associate Degree
    - 28.5% BSN
    - 54.7% MSN
    - 67.3% PhD or DNP

Genetics Education

Essential Competencies

- 33% Have heard or read about the Essential Competencies

Genetics Education

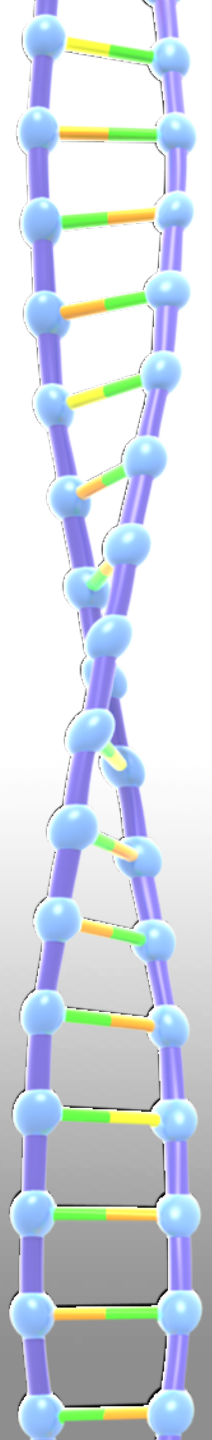
- 60% reported that their nursing curriculum DID NOT include genetics content
- 64% have **NOT** attended a course since licensure that included genetics as a major component
- 73% would be willing to attend a course on their own time

ANA House of Delegates

- NIH Pilot Survey
  - Do you think your senior staff members see genetics as an important part of **your** role?
    - 35% Yes
    - 43% No
    - 22% Don't Know
- Greater proportion of nursing leaders
- Paper survey using the same instrument
- Status, 249 responses
  - Data analysis ongoing
    - [Preliminary] 71% describe their genetic/genomic knowledge base as poor or fair (63% NNWFS)

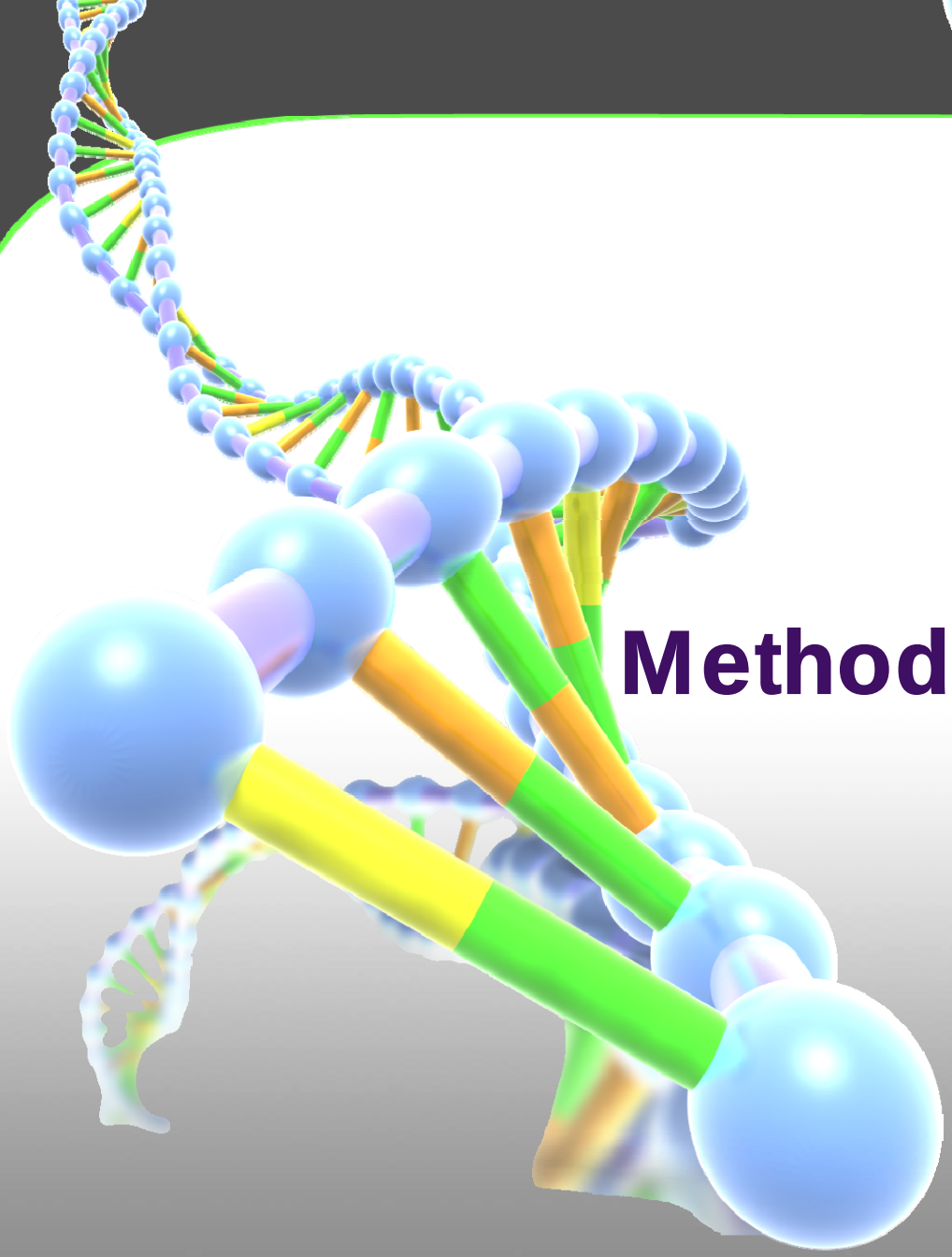
National Council State Boards of Nursing Funded Project

- Develop, implement and evaluate a year-long genomic education program in which we will train, support, and supervise institution administrator and educator dyads to increase nursing capacity to integrate genetics and genomics through assessments of program satisfaction, and institutional achieved outcomes
  - Secondary aim is to establish a network of genomic nursing practice educators, and leaders willing to serve as consultants to other institutions integrating genomics
  - Establish model that can be used to prepare the nursing workforce for integration of any new innovation



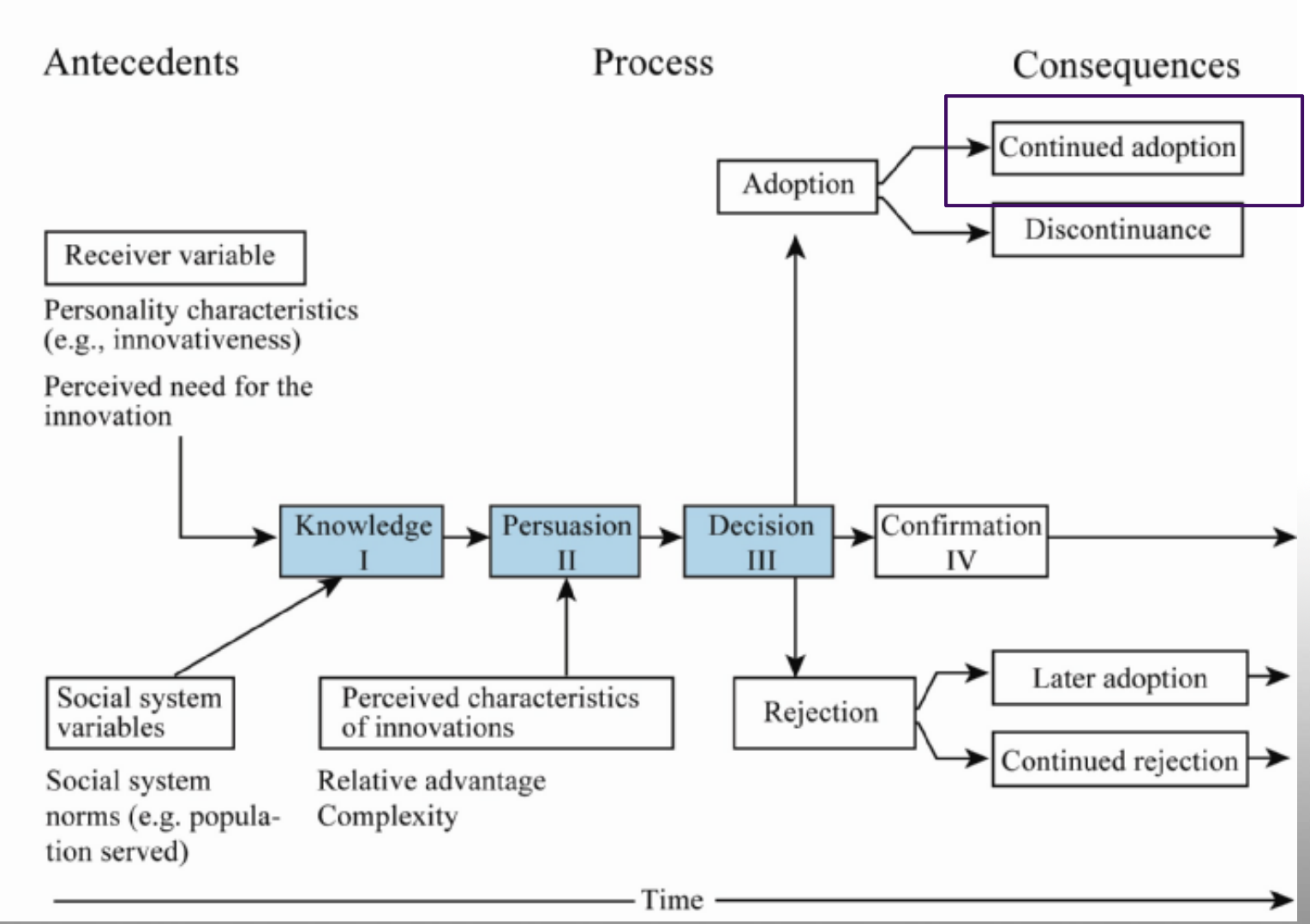
National Coalition of Ethnic Minority Nurse Associations (NCEMNA)

- NCEMNA Associations
  - Asian American/Pacific Islander Nurses Association, Inc.
  - National Alaska Native American Indian Nurses Association, Inc.
  - National Association of Hispanic Nurses, Inc.
  - National Black Nurses Association, Inc.
  - Philippine Nurses Association of America, Inc.
- Survey of Minority Nurses Beliefs, Practices and Competencies of Genetic / Genomics
  - Survey development and pilot testing completed March 2009
  - Survey closed December 2011
- Compare findings to NNWFS
- Utilize findings to develop genetic/genomic education intervention



Methods for Sustainability

Diffusion of Innovations



Adopted from: Rogers, Everett M. (2003). *Diffusion of Innovations, Fifth Edition*. New York, NY: Free Press

Genetics/Genomics Competency Center for Education (G2C2)

- Provide healthcare professionals with a learning management system
  - Mapping matrix based on core competencies and outcome indicators (mapping matrix)
  - Peer review genetic/genomic educational materials
    - Content is accessible, accurate and up-to-date
    - Complexity, organization, usability
  - Interdisciplinary
    - Nurses, PA's, Genetic Counselors

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

G2C2 Definitions

G2C2 Terms	Definition
Competencies	A high level educational goal for learners.
Core Knowledge	Specific areas of knowledge learners need to achieve a competency.
Performance Indicator	A measurable knowledge, skill or ability of a professional that demonstrates competency.
Learning Activity and Resources	Content designed to develop professional ability.
Assessments	Exercises designed to measure the outcome of a Learning Activity.

Beta Test
Functional Assessment Outcomes

Population: Nursing Educators (N=56)

- 94.7% agreed or strongly agreed that they were able to find a relevant competency
  - 85.4% found the related performance indicator
  - 76.3% found the associated learning activity or resource
- 24% undecided as to whether the information provided was sufficient to understand the copyright restrictions and education value of the resource
- 91% agreed or strongly agreed the competency based matrix improved their understanding of what content needed to be included in the curriculum
- 87.5% felt that the mapping matrix made conceptual sense

Calzone, K et al. (2011). Establishment of the Genetic/Genomic Competency Center for Education. Journal of Nursing Scholarship. 43, 351-358.

G2C2

GENETICS/GENOMICS COMPETENCY CENTER FOR EDUCATION

Competencies & Guidelines

Search Educator Resources:

Genetic Counselor

Search

Nurse

Search

Physician Assistant

Search

Share Your Resources

What you can do on this site:

1. **Search for genetics/genomics resources to use in your classroom**
   Find websites, download PDFs, locate courses–enhance your class content with genetic/genomic resources for Nurses, Physician Assistants, and Genetic Counselors.
2. **Review the Competency Guidelines and Curriculum Map**
   Need to match your classroom genomics teaching to competencies? View the guidelines and the curriculum map to find the right resources to download.
3. **Share resources, activities, and assessments to be included on this site**
   Do you have activities, resources or assessments you would like to share? Submit websites, PDFs or any other resources to include in the curricular materials.

The **Genetics/Genomics Competency Center for Education** provides links to curricular materials and resources for educators of Genetic Counselors, Nurses, and Physician Assistants.

Home My Resources Help About the Project Survey

G2C2

GENETICS/GENOMICS COMPETENCY CENTER FOR EDUCATION

Competencies & Guidelines

Search Educator Resources: Genetic Counselor Nurse Physician Assistant

Share Your Resources

Search Resources for Nurse

TO PERFORM A SEARCH, YOU MUST:

1. Choose a curricular area
2. Enter a search term OR choose a topic

1. Choose a Curricular Area

- **Learning Activities & Resources**
  Exercises designed to develop professional ability and resources that facilitate
- **Competencies & Core Knowledge**
  A high level educational goal for learners. Specific areas of knowledge learners
- **Performance Indicators**
  A measurable knowledge, skill or ability of a professional that demonstrates c
- **Assessments**
  Exercises designed to measure the outcome of a Learning Activity.

2. Search G2C2

Enter Search Term(s)

Search

Or, Choose a Topic:

Search Topic

G2C2

GENETICS/GENOMICS COMPETENCY CENTER FOR EDUCATION

Search Educator Resources: Genetic Counselor Nurse

Search Page » Results

Learning Activities & Resources for Nurse

Search Results for:

"family history"

- View » American Medical Association Family History Tools
- View » U.S. Surgeon General's Family History Initiative
- View » Applying Genomics in Nursing Practice
- View » Family History - National Human Genome Research Institute
- View » Genetics Training for Physician Assistants family history module
- View » Applying Genomics - Genetics Education Program for Nurses
- View » National Society of Genetic Counselors

Learning Activities & Resources

U.S. Surgeon General's Family History Initiative

Read Reviews Write a Review

Save this Resource

Resource(s):
Resource 1
Resource 2

Author:

Office of the Surgeon General
301-443-4000
5600 Fishers Lane Room 18-66
Rockville, Maryland 20857

Description:
Website from the Surgeon General in cooperation with other agencies with the U.S. Department of Health and Human Services has launched a national public health campaign, called the Surgeon General's Family History Initiative, to encourage all American families to learn more about their family health history.
This new, revised version of the tool, called "My Family Health Portrait" is a web-enabled program that runs on any computer that's connected to the web and running an up-to-date version of any major Internet browser.

Goals & Learning Objectives:
1.To educate learners on the importance of family history and to encourage all American families to learn more about their family health history.
2.To aid the user in organizing famil information in order to create and pr representation of his or her familys the health disorders that may be pa generation to the next.

Resource Evaluation:
This work has been evaluated by th competency task force of the NHG nursing education.

Suggested Audience:
Consumers

Format:
Website

Cost:

Save this Resource

Associated Competencies & Core Knowledge:

U.S. Department of Health & Human Services
HHS.gov
Improving the health, safety, and well-being of America

HHS Home | HHS News | About HHS Font Size − +

- SG Family Health History
- Before You Start
- My Family Health Portrait Tool
- Other Resources

Surgeon General's Family Health History Initiative

Health care professionals have known for a long time that common diseases - heart disease, cancer, and diabetes - and rare diseases - like hemophilia, cystic fibrosis, and sickle cell anemia - can run in families. If one generation of a family has high blood pressure, it is not unusual for the next generation to have similarly high blood pressure. Tracing the illnesses suffered by your parents, grandparents, and other blood relatives can help your doctor predict the disorders to which you may be at risk and take action to keep you and your family healthy.

To help focus attention on the importance of family history, the Surgeon General, in cooperation with other agencies with the U.S. Department of Health and Human Services, has launched a national public health campaign, called the Surgeon General's Family History Initiative, to encourage all American families to learn more about their family health history.

My Family Health Portrait Tool

Americans know that family history is important to health. A recent survey found that 96 percent of Americans believe that knowing their family history is important. Yet, the same survey found that only one-third of Americans have ever tried to gather and write down their family's health history.

Home My Resources Help About the Project Survey

You Have 1 Resource Saved

X

Saved Learning Activities:

- U.S. Surgeon General's Family History Initiative Go To Page
- National Office of Public Health Genomics Go To Page

» Show Details

Email these resources to yourself: Enter your email address Send

Contribute New Materials

Global Genetics and Genomics Community (G3C)

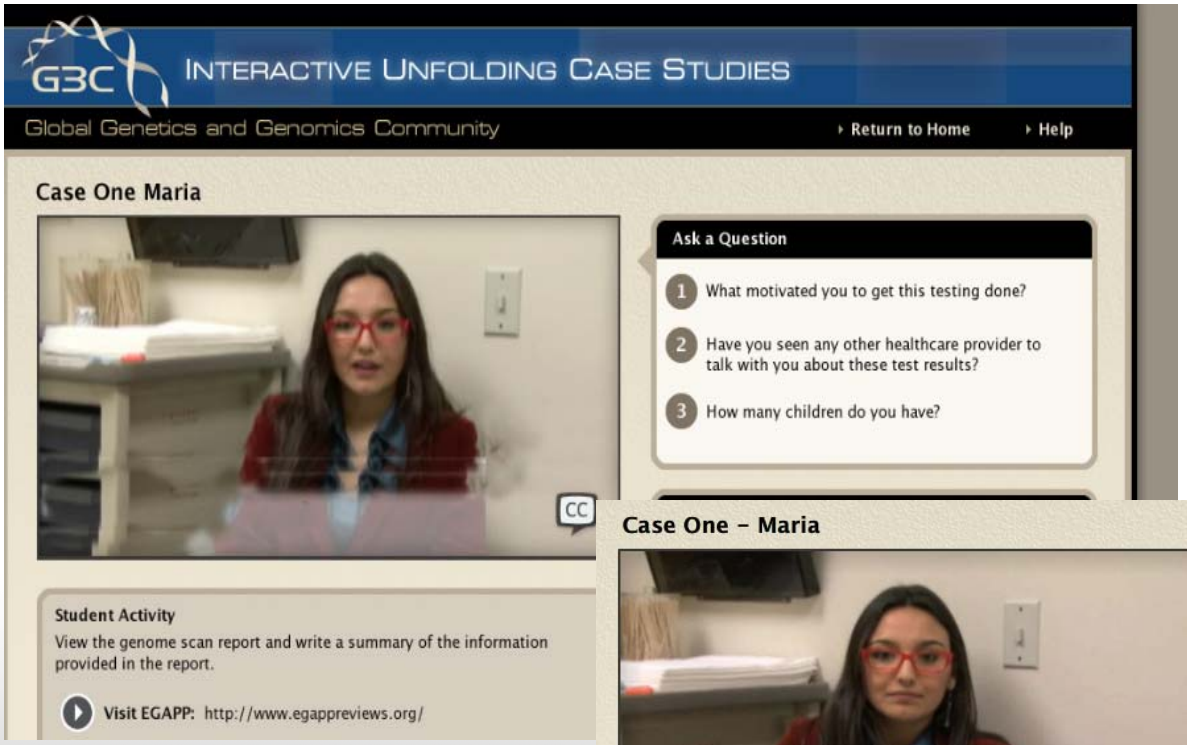
- Selected based on a gap analysis performed following the Genetics/Genomics Toolkit for Faculty June 2008 meeting which identified and vetted currently available education resources for G2C2

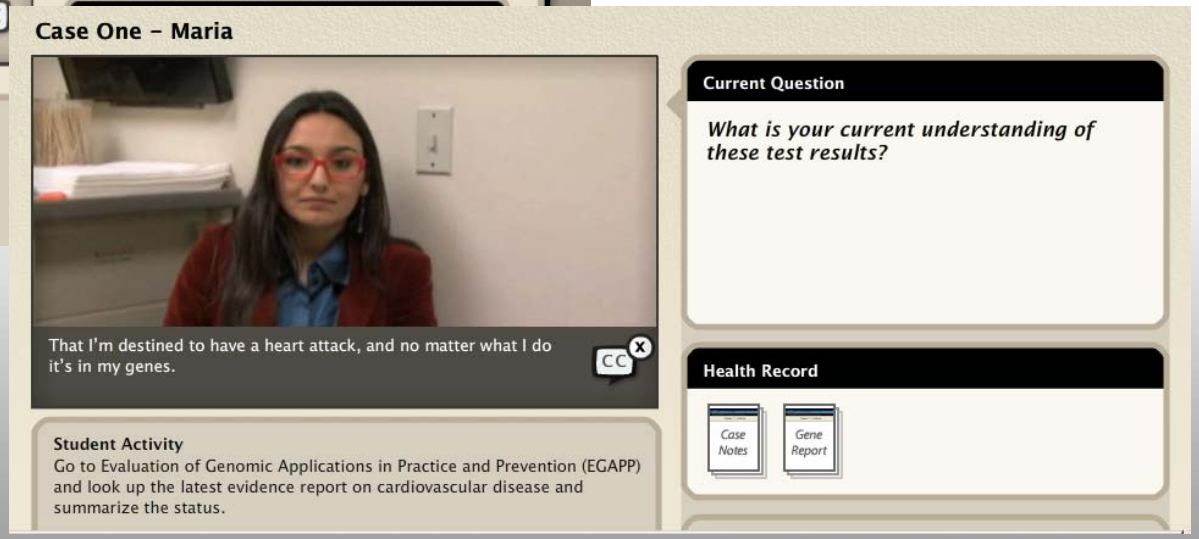
http://www.g-3-c.org

G3C

- High Fidelity Simulated Online Unfolding Case Studies
  - Ethnically diverse
  - Focus on common public health issues
- Portable, web-based, open access
- Bilingual (English/Spanish)
- Interactive, self-paced, self-directed, unfolding case studies
- Utilizing professional actors as simulated patients
- Incorporates student/learner education activities and resources
- Faculty support includes suggestions on how to use cases in the curriculum

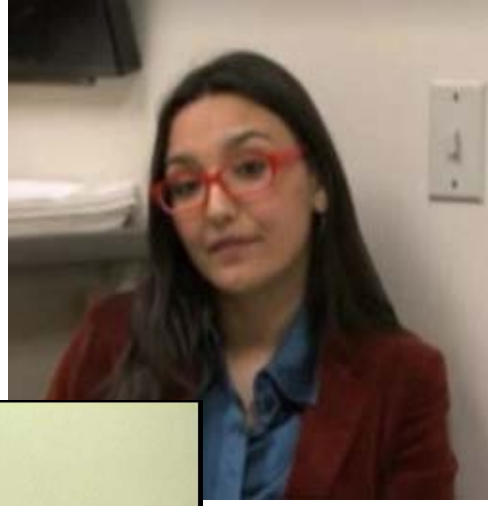
G3C Use


G3C
INTERACTIVE UNFOLDING CASE STUDIES
Global Genetics and Genomics Community
Return to Home
Help
Case One Maria
Ask a Question
1 What motivated you to get this testing done?
2 Have you seen any other healthcare provider to talk with you about these test results?
3 How many children do you have?
CC
Student Activity
View the genome scan report and write a summary of the information provided in the report.
Visit EGAPP: http://www.egappreviews.org/


Case One – Maria
That I'm destined to have a heart attack, and no matter what I do it's in my genes.
CC
Student Activity
Go to Evaluation of Genomic Applications in Practice and Prevention (EGAPP) and look up the latest evidence report on cardiovascular disease and summarize the status.
Current Question
What is your current understanding of these test results?
Health Record
Case Notes
Gene Report

Cases

- Ethnically diverse
- In and Outpatient
- Address
  - Family history assessment
  - Direct to consumer marketing/testing
  - Family issues
  - Personal values assessment
  - Genetics/genomics of common diseases (diabetes, cardiovascular disease, pharmacogenomics, prenatal testing)



Beta Testing

Continuing Education Population

- NIH Nurse Educators
  - Complete one G3C case and review other G3C content
  - Online outcome survey
  - Qualitative Educator interview

Academic Population

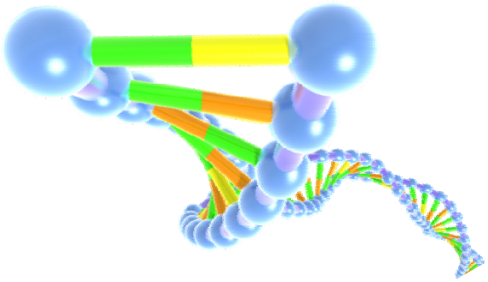
- Samuel Merritt University School of Nursing
  - 2011 Fall semester faculty use of G3C with their students as they see fit
  - Online outcome survey
  - Qualitative Faculty interview

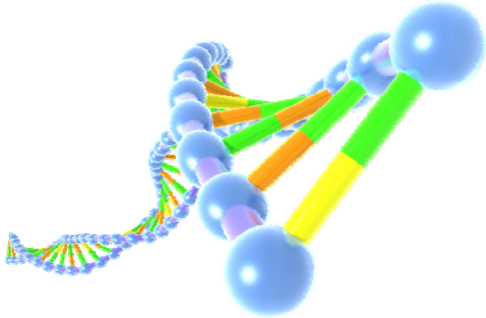
G3C Platform

- Cases
  - Two alpha and beta test cases
  - Four cancer cases developed in 2011
  - Three cases filmed in early 2012
  - Four interdisciplinary cases to be established
- Funded Improvements
  - Expand the number of question options
  - Numeric weighting of questions based on optimal critical decision-making
  - Real time feedback
  - Online pedigree drawing
  - Awarding CEU's and CME's

Competency focus
UPDATING THE NURSING COMMUNITY ON THE IMPLEMENTATION OF THE ESSENTIAL NURSING COMPETENCIES AND CURRICULA GUIDELINES IN GENETICS AND GENOMICS.
Essential Genetic and Genomic Competencies for Nurses With Graduate Degrees
Competency focus
NURSING COMMUNITY ON THE IMPLEMENTATION OF NURSING COMPETENCIES AND CURRICULA
dicators Published with Second Edition
Domain: Professional Responsibilities
Specific Areas of Knowledge
Clinical Performance Indicators
Competency focus
Implementation Are We Now?

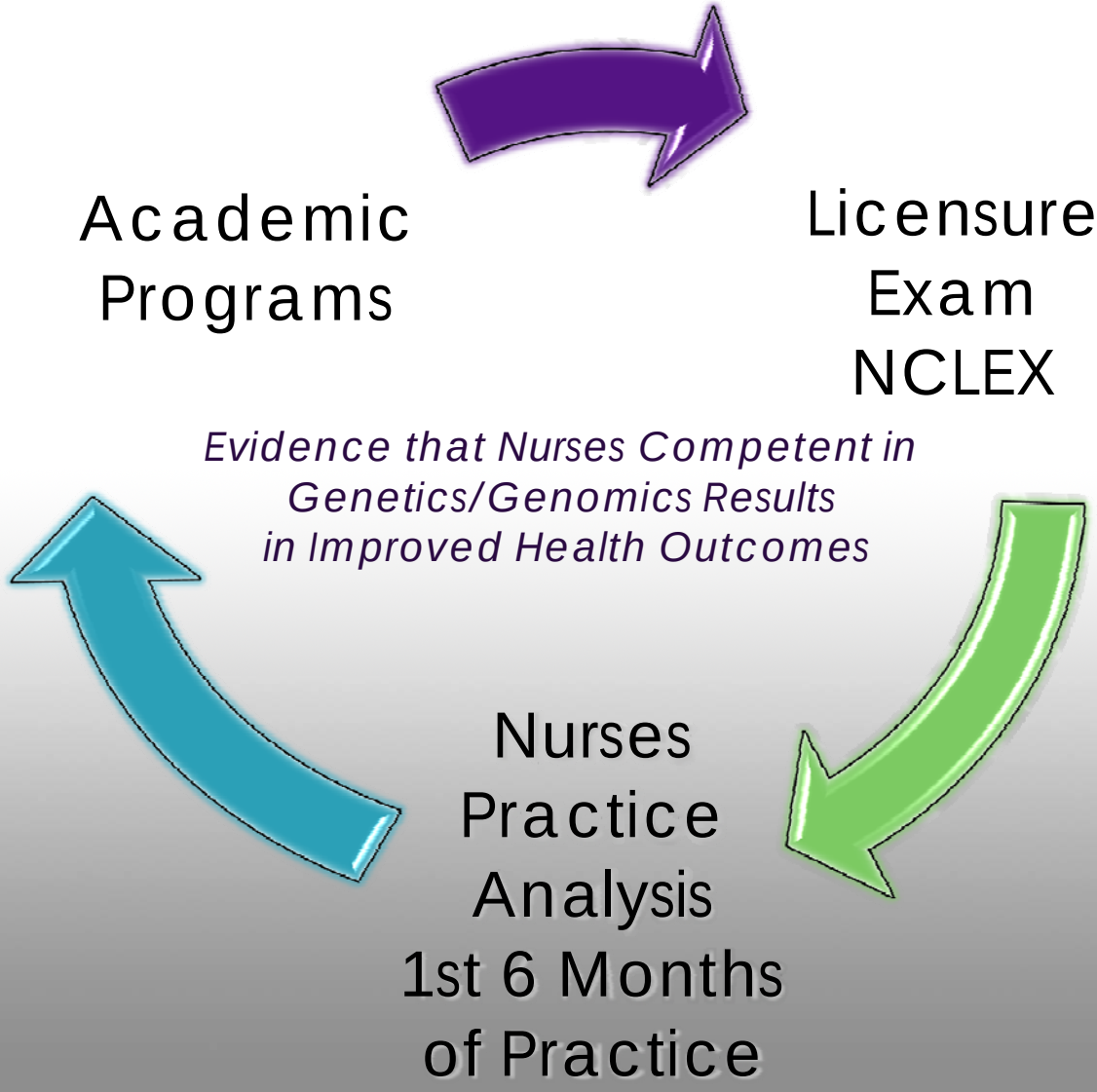
Publications



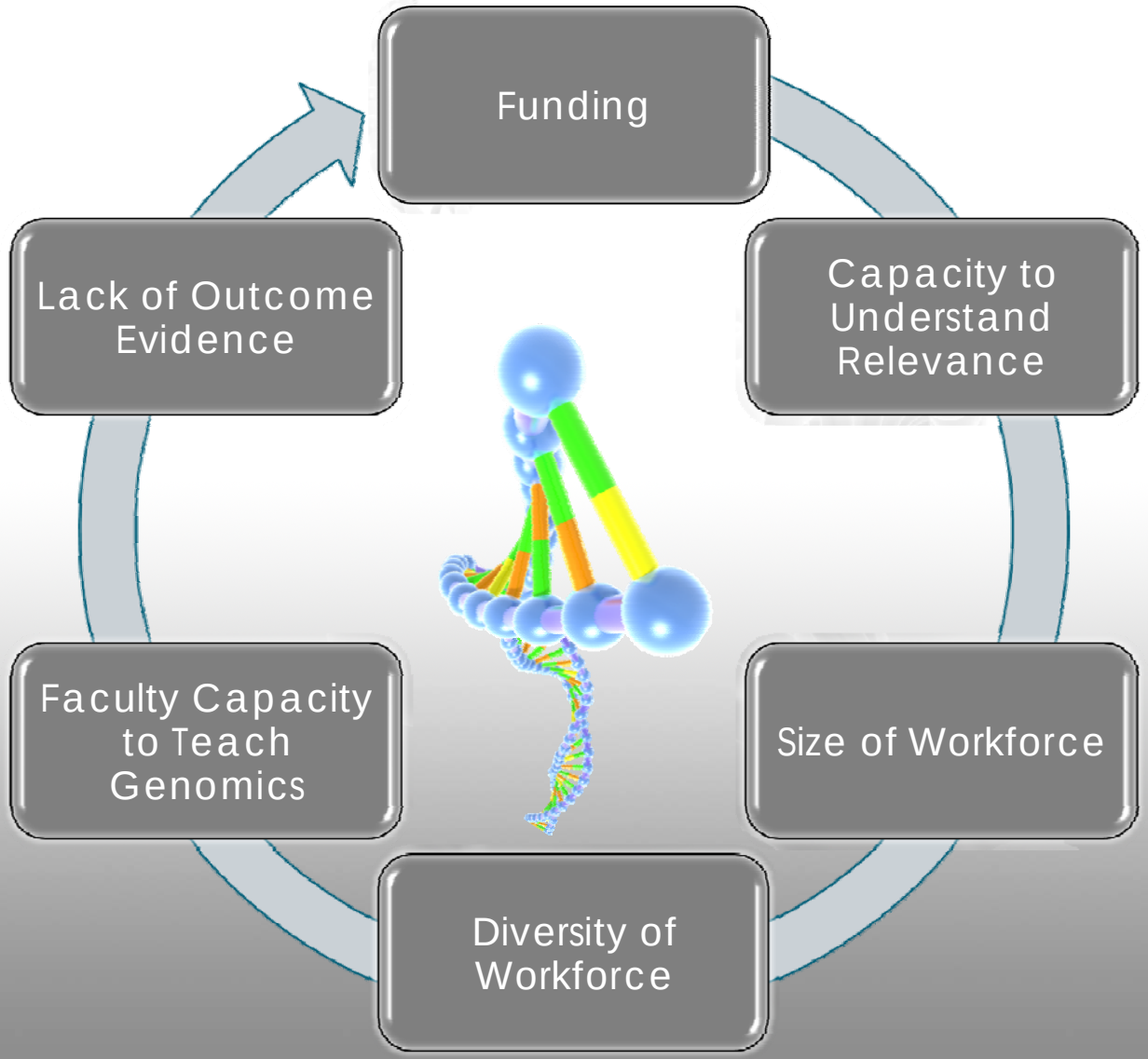


- 2013 Journal of Nursing Scholarship Special Issue: Genomic Nursing
- 2011 Journal of Nursing Scholarship Series: Genetics/Genomics and Nursing Education
- Calzone, K.A., Cashion, A., Feetham, S., Jenkins, J., Prows, C.A., Williams, J.K., Wung, S.F. (2010). Nurses Transforming Health Care Using Genetics and Genomics. Nursing Outlook, 58, 26-35.
- 2005-2007 Journal of Nursing Scholarship Series: Genetics and Genomics in Nursing

State of the Science in Genetic/Genomic Nursing



Challenges and Opportunities

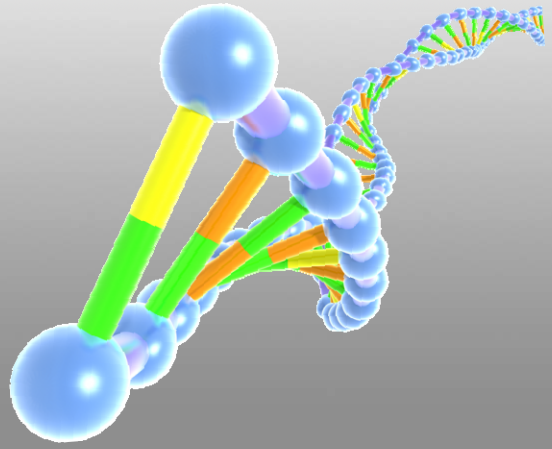


Funding

- National Institutes of Health
  - National Human Genome Research Institute
  - National Cancer Institute
  - National Institute of Nursing Research
  - Office of Rare Disease
- Other Agencies and Organizations
  - Health Resources Services Administration
  - Department of Defense
- Organizations/Groups
  - American Nurses Association
  - National Council of State Boards of Nursing
  - National Capital Area Simulation Center

Co-Chair, Genetics/Genomics Nursing Competency Initiative

Jean Jenkins, PhD, RN, FAAN
National Human Genome Research Institute

Questions/Discussion

calzonek@mail.nih.gov
301-435-0538