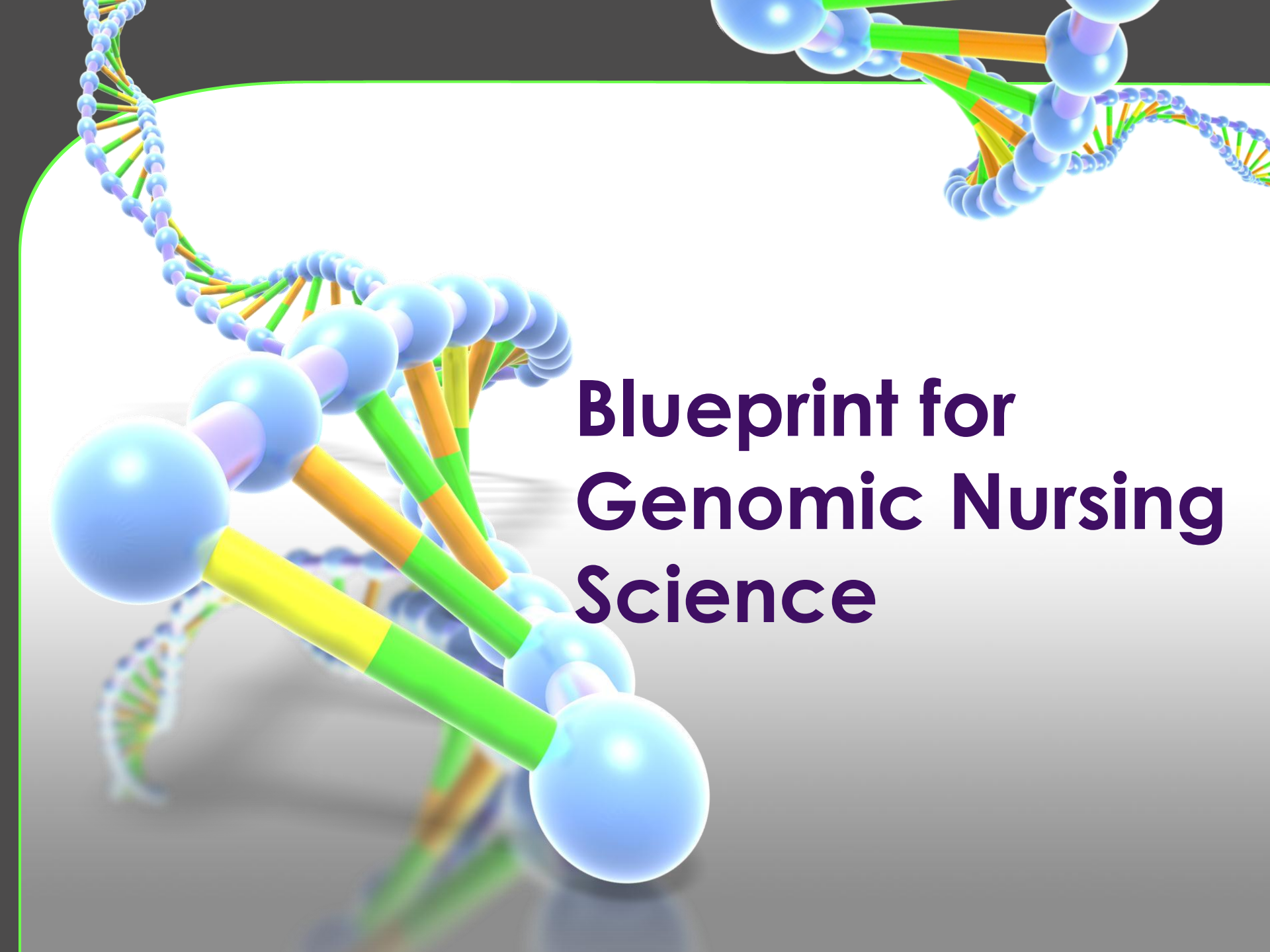


# Blueprint for Genomic Nursing Science

# Speakers

- Jean Jenkins
  Clinical Advisor, NHGRI, NIH

- Kathleen Calzone
  Senior Nurse Specialist, Research,
  NCI, NIH

- Alexis Bakos
  Acting Director,
  Division of Nursing, HRSA

- Ann Cashion
  Acting Scientific Director, NINR
  Intramural Research Program, NIH

# A Blueprint for Genomic Nursing Science

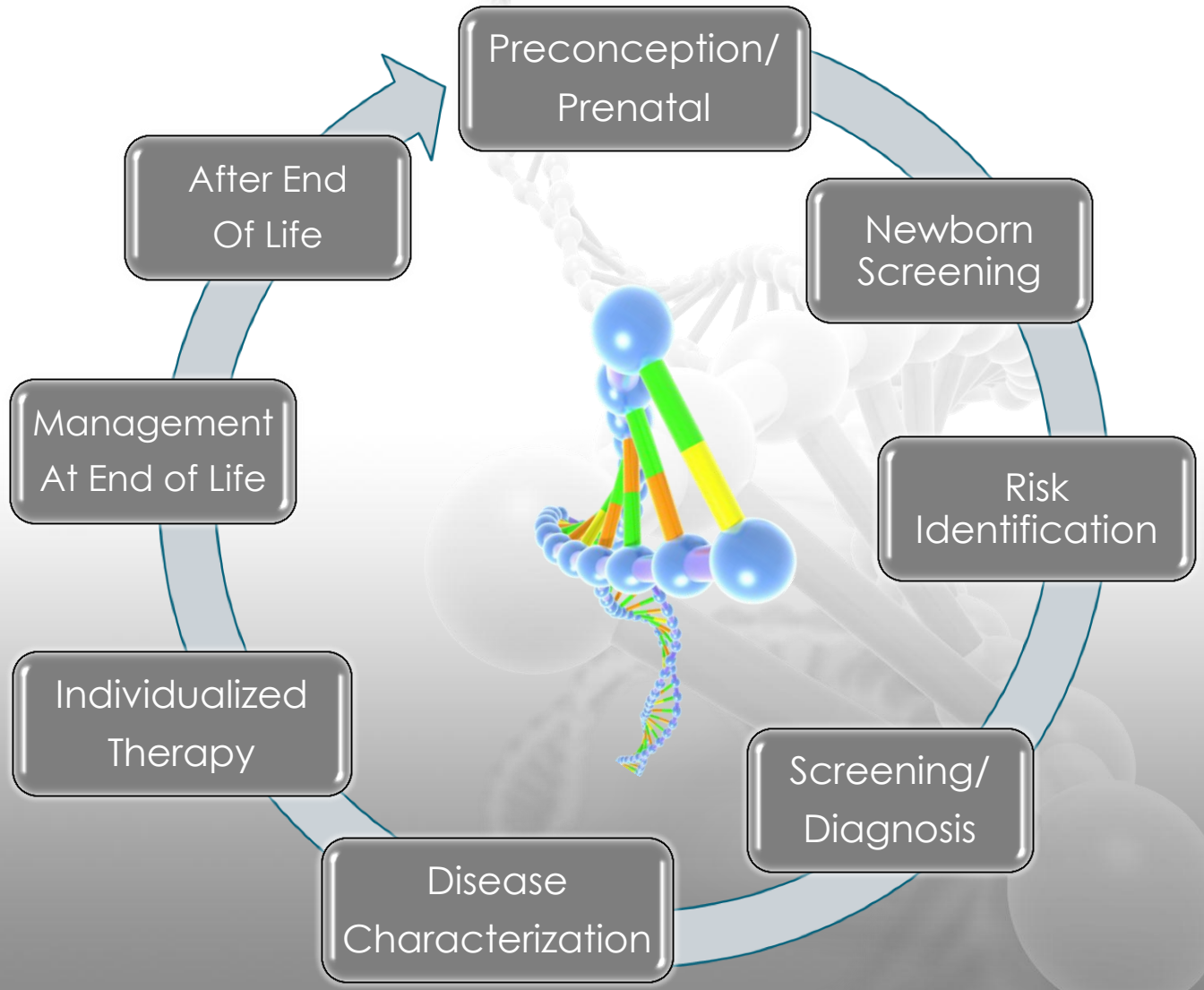
- Todays webinar includes
  - information about the purpose,
  - methods to establish,
  - and focus of the Blueprint,
  - as well as next steps.
- This Blueprint targets research to build the evidence base to inform integration of genomics into nursing practice and regulation.

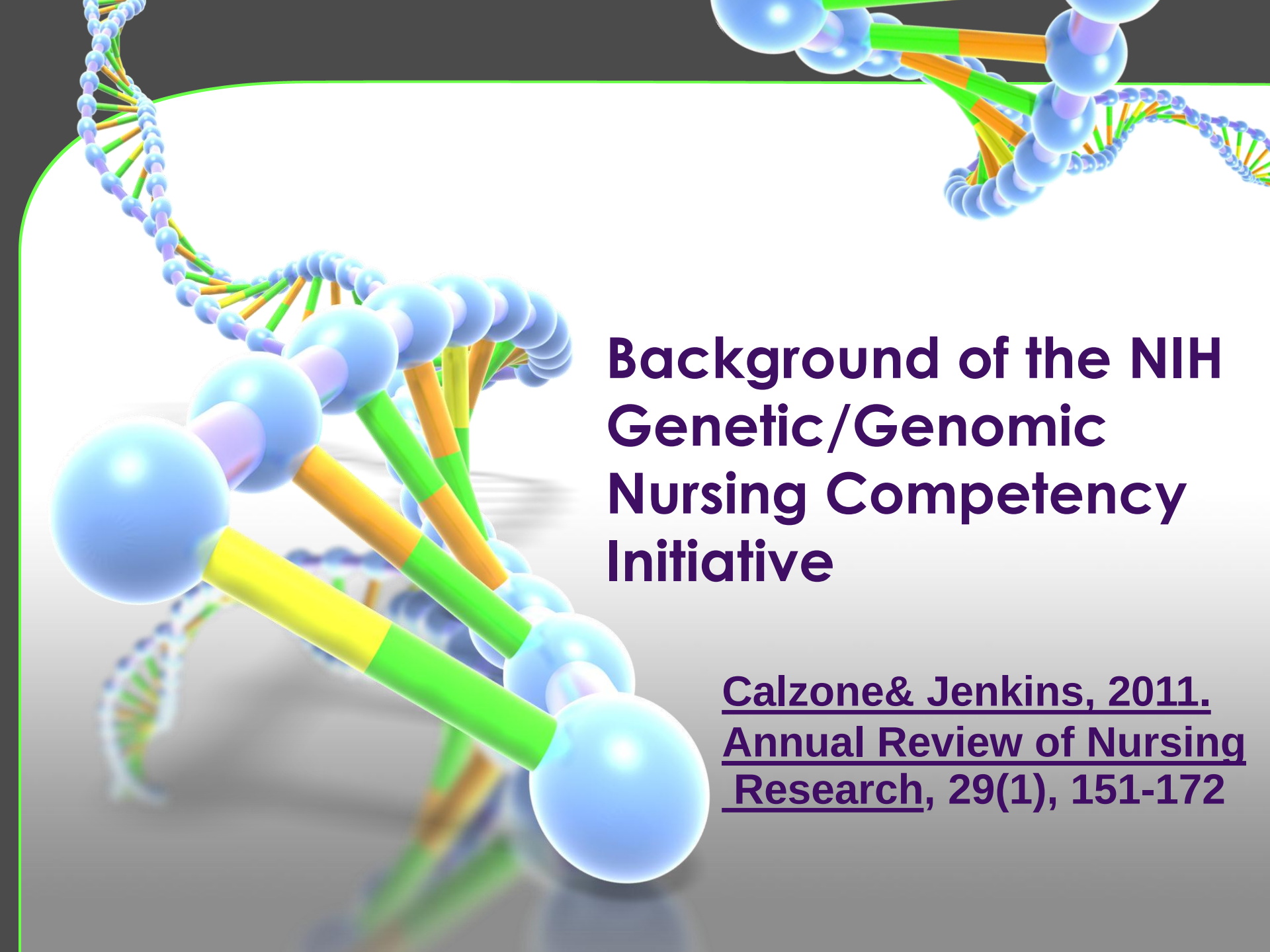
# Funding

- Intramural Program of the National Institutes of Health
  - National Cancer Institute
  - National Human Genome Research Institute
  - National Institute of Nursing Research

# Genetic and Genomic Influences Across the Healthcare Continuum

Interdisciplinary Collaboration to Improve Patient Outcomes

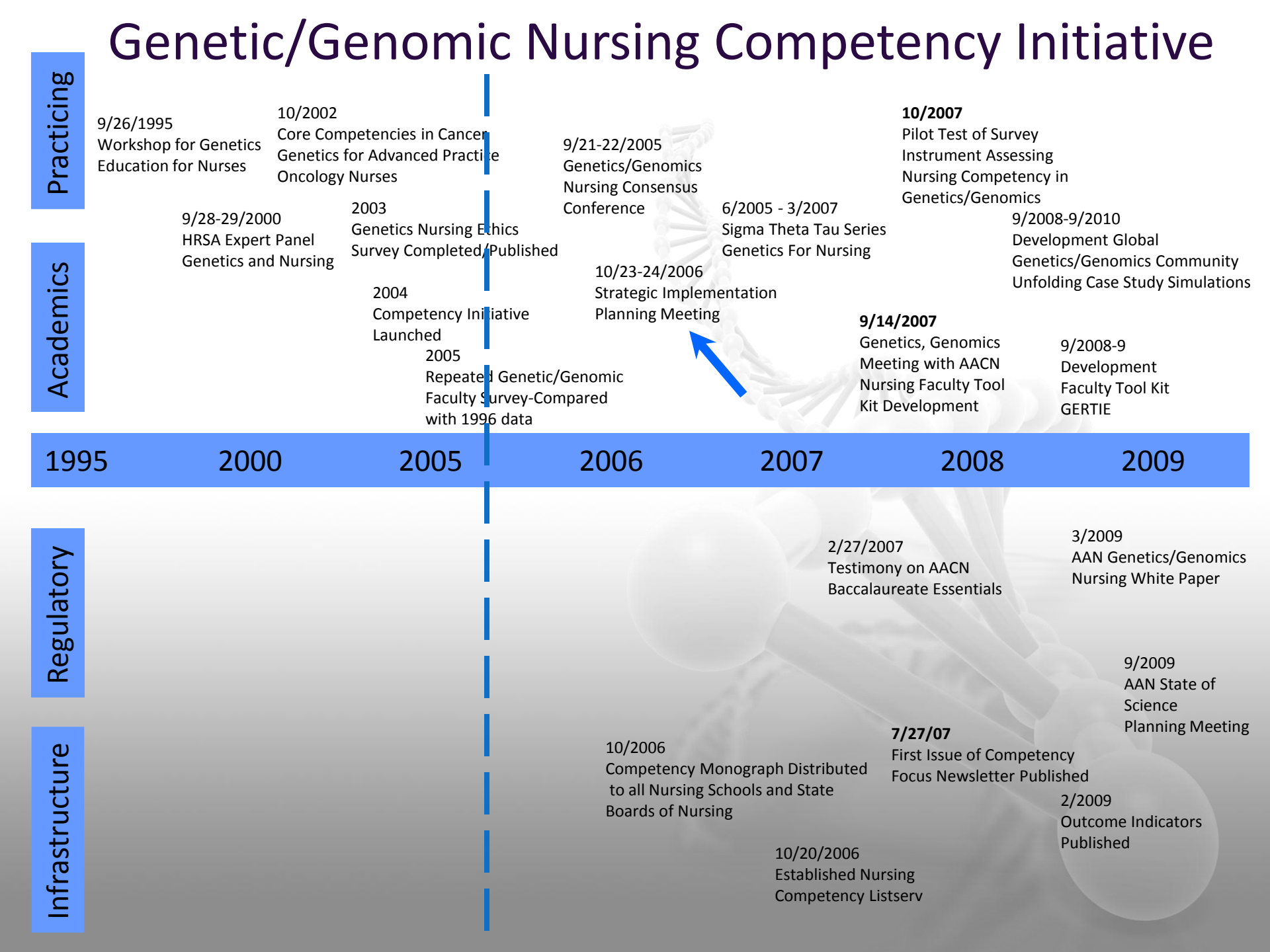




# Background of the NIH Genetic/Genomic Nursing Competency Initiative

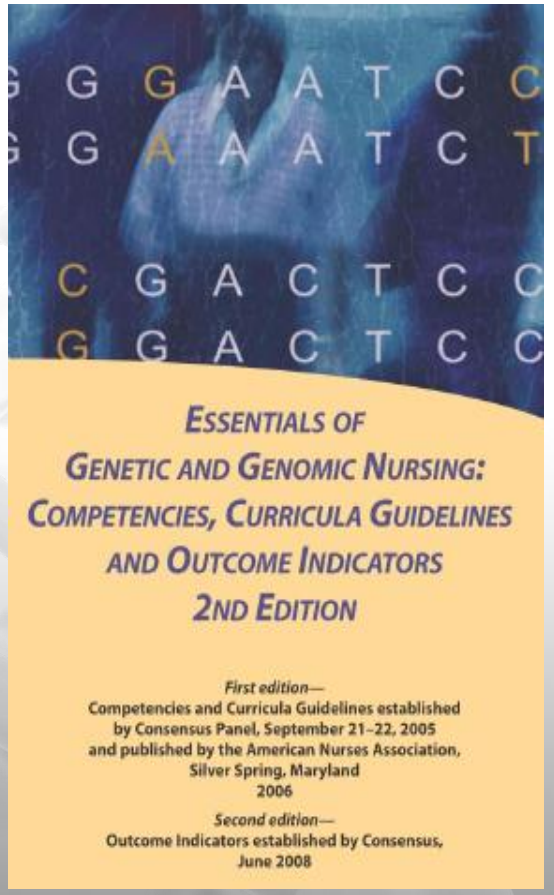
Calzone& Jenkins, 2011. Annual Review of Nursing Research, 29(1), 151-172

# Genetic/Genomic Nursing Competency Initiative



# Essentials of Genetic and Genomic Nursing

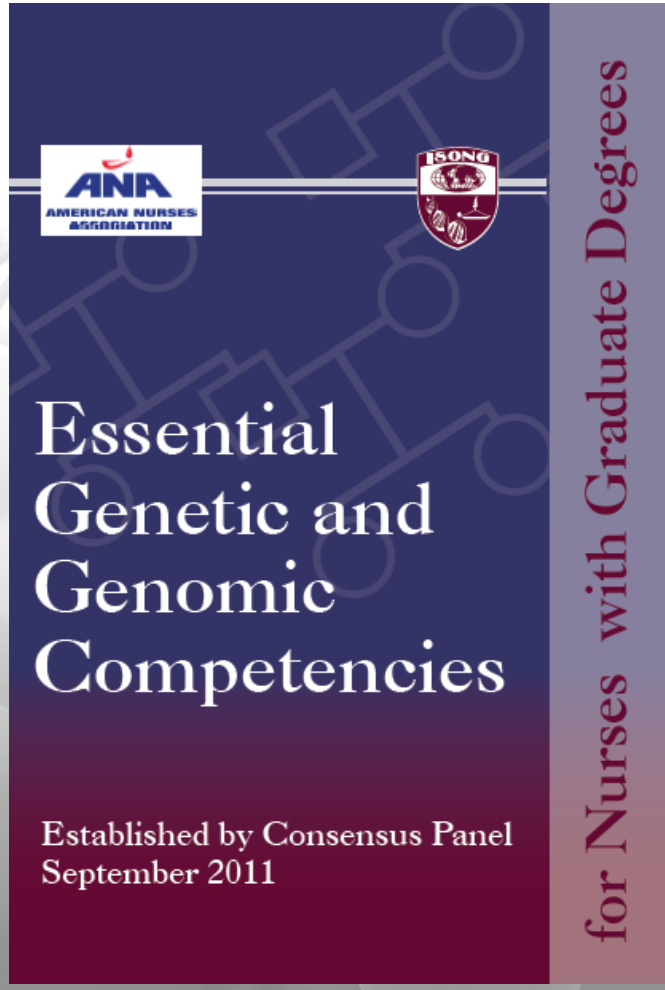
- Define essential genetic and genomic competencies for **ALL** nurses regardless of level of academic preparation, practice setting or specialty
- Endorsed by 50 nursing organizations
- October 22-24 2006 Strategic Implementation Meeting
- 2nd Edition incorporated Outcome Indicators
  - Specific Areas of Knowledge
  - Clinical Performance Indicators
- 3rd Edition may be published in 2013 which includes some updates




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

# Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees

- Define essential genetic and genomic competencies for **ALL** graduate nurses regardless of level of academic preparation, practice setting or specialty.
- Established by a process of consensus




http://nursingworld.org/MainMenuCategories/EthicsStandards/Genetics-1/Essential-Genetic-and-Genomic-Competencies-for-Nurses-With-Graduate-Degrees.pdf

# Significance

- Evidence specific to outcomes of genomically competent nursing practice and the impact on the public's health is extremely limited if not entirely absent.
- The paucity of outcome data is hindering efforts to incorporate genomics into curricula, licensure, academic and healthcare organization accreditation.
- No one health care discipline is at the forefront in the assessment of the evidence.
- Nurses are one of the primary health professions on the leading edge in the integration of genomics.
- The outcomes of this initiative can be used as a model to advance similar efforts to establish a research outcome agenda across other healthcare disciplines.

# Background of the Genomic Nursing State of the Science Initiative

# Aims of this Initiative

- Establish a blueprint for genomic nursing science that can be used to focus research efforts to fill identified evidence gaps
- Establish the blueprint through
  - Analysis of the evidence
  - Expert evaluation of the current state of the science
  - Public comment

# Methods To Achieve These Aims

# Methods

- State of the Science Advisory Panel Convened
- Evidence Reviews
- Meetings
  - Interactive Webinars (2)
  - In-person meetings (2)
- Public Comment

# Advisory Panel

- 16 members (2 coordinators, 14 invited members)
- Members were selected based on:
  - Expertise In Genomics
  - Nursing Research
  - Nursing Workforce Issues
  - System Change
  - Health Services Measurement
  - Evidence Based Synthesis
- Represented
  - Practice Environments
  - Academics
  - Under-represented Populations
  - Interdisciplinary Groups
  - Federal Agencies
    - HRSA, Bureau of Health Professions, Division of Nursing
    - National Institute of Nursing Research

# Advisory Panel Members

**Co-Chairs:**

| | |
|---|---|
| Kathleen Calzone, PhD, RN, APNG, FAAN | National Cancer Institute |
| Jean Jenkins, PhD, RN, FAAN | National Human Genome Research Institute |

**Members:**

| | |
|---|---|
| Alexis Bakos, PhD, MPH, RN | Health Resources and Service Administration |
| Ann Cashion, PhD, RN, FAAN | National Institute of Nursing Research |
| Nancy Donaldson, PhD, RN, FAAN | University of California, San Francisco |
| W. Gregory Feero, MD, PhD | National Human Genome Research Institute |
| Suzanne Feetham, PhD, RN, FAAN | University of Wisconsin-Milwaukee |
| Patricia Grady, PhD, RN, FAAN | National Institute of Nursing Research |
| Ada Sue Hinshaw, PhD, RN, FAAN | Uniformed University of the Health Sciences |
| Ann Knebel, PhD, RN, FAAN | National Institute of Nursing Research |
| Nellie Robinson, MS, RN, FAAN | Children's National Medical Center |
| Mary Ropka, PhD, RN, FAAN | University of Virginia |
| Diane Seibert, PhD, CRNP, FAANP | Uniformed University of the Health Sciences |
| Kathleen Stevens, EdD, RN,ANEF, FAAN | University of Texas Health Science Center |
| Lois Tully, PhD | National Institute of Nursing Research |
| JoAnn Webb, MHA, RN | American Organization of Nurse Executives |

# Genomic Nursing State of the Science Advisory Panel

# Evidence Reviews

- Two approaches
  - Systematic evidence review
  - Research Portfolio Online Reporting Tools (RePORT) for NINR and other nursing specific research

# Webinars

- Webinar #1
  - Introduction of Panel Members
  - Introductions to the Genomic Nursing State of the Science Advisory Panel Initiative
  - Purpose and Significance of the Genomic Nursing State of the Science Initiative
  - Methods to Achieve These Aims
  - Overview of Completed Work
- Webinar #2
  - Stakeholder perspectives
    - Nursing leadership, consumers, medicine
  - Systematic Evidence Review presentation
  - Requests from Panel for additional preparatory materials

# In Person Meetings

- Meeting 1-June 8, 2012
  - Models for establishing the research agenda
  - Overview of the evidence gaps
  - Scope of research
  - Key priorities
  - Specific research directions
  - Funding considerations

**<<<PUBLIC COMMENT PERIOD>>>**

- Meeting 2-September 20, 2012
  - Key note: Patricia Grady, NINR Director
    Setting the Context of Genomic Research at NINR
  - Review of Public Comments
  - Revision of blueprint based on Public Comments
  - Manuscript
  - Discussion of next steps

# Public Comment Period
# July 16-August 16, 2012

- Chris Kasper (August 16, 2012, 02:01)

  Would like to suggest the inclusion of research initiatives in the emerging areas of genotoxicity of metals and epigenetic effects of battlefield toxicants. Both of these areas of research are rapidly expanding due to the introduction of new technology as well as international conflicts.

- Allison Vorderstrasse (August 15, 2012, 20:55)

  Thank you for addressing this great need.
  I had a few comments/additions:
  Under the area of Common Chronic Conditions, I would highlight the need to explore clinical and personal utility of risk factors/counseling including genomic risk testing. This is also an area where environmental factors are highly influential as you have acknowledged, so possibly areas such as nutrigenomics and epigenetics would be included in that area as well.
  Under the area of client self-management, it seems that effective interventions to support self-management would also be highly relevant. Along those lines I would add to the interdisciplinary collaborators in terms of health coaches, nutritionists, and others in behavioral medicine/integrative medicine who are so active in this area of research and practice.

- Elizabeth Ness (August 10, 2012, 14:36)

  I would like to echo other reviewers? comments about the hard work that the group has put in to developing this draft research agenda. One thing that seems to be missing and not sure if it falls under capacity building, but there is nothing about the knowledge or assessing the knowledge that research nurse coordinators need to have related to genetics/genomics that is beyond what the "average" nurse needs to have. This is particularly important given that many clinical research studies have some type of genomic component to them as either a primary or secondary objectives and many of these studies have nurses functioning as study coordinators whose role is to reinforce the informed consent process as well as obtain samples and ultimately provide patient education. Thank you for the opportunity to comment.

- Lisa Aiello-Laws (August 8, 2012, 18:26)

  Thank you for your hard work. This is an important document to structure the future.

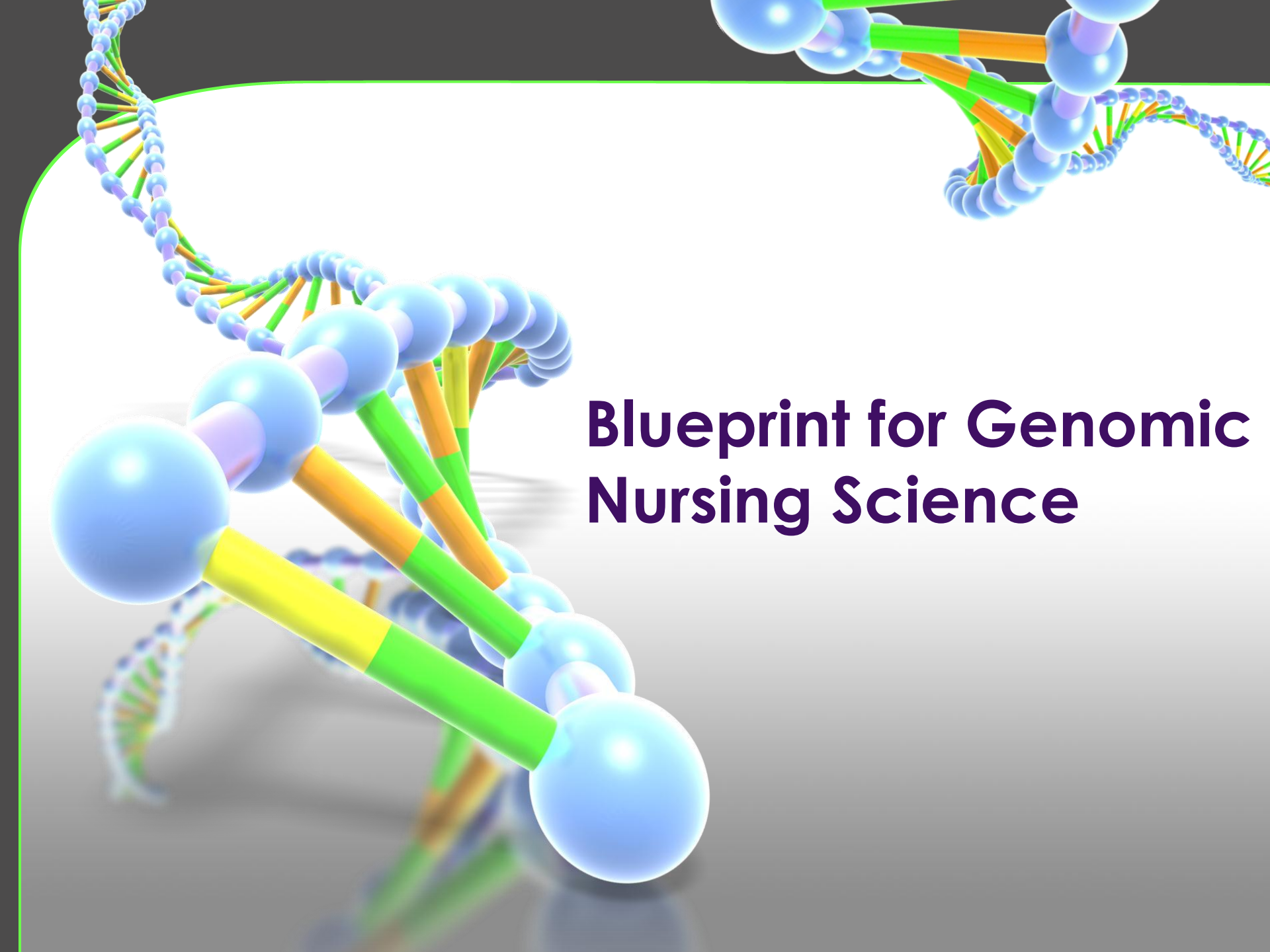
  I have a few comments. These issues may be more specific within the categories than you want to add, but I think they are important.

  1.In order to increase compliance with assessing family history, would we want to develop, or decide on, a specific tool as the recommended tool that can be used in EMRs and other computer systems? To ease and expedite the providers' usage.

  2. I think psychosocial should be its own category. With the lack of parity in mental health care, this area is often ignored. This can include client issues, community issues, as well as nursing attitudes and beliefs.

  3. Within research and curriculum, I agree that we need to follow up/research if genetics/genomics is being integrated, and its' effectiveness.

http://www.genome.gov/27549386#al-1



# Blueprint for Genomic Nursing Science

# Advisory Panel Conclusions

- Focus on research producing clinically evidence along the translation science continuum
  - Use multifacted methodologies and measurements
  - Build on existing work
- Framework is NINR Strategic Plan Areas
- Clients definition consistent with Genomic Nursing Competencies
  - Persons, families, communities, and/or populations
- Two major research areas
  - Focus on the Client
  - Focus on the context in which health care is delivered
- Cross cutting themes

# Focus on the Context versus Client

## Context

- Capacity building of the profession
  - Nurse scientists
  - Nursing faculty
  - Students
  - Practicing nurses at all levels of academic preparation, role, clinical specialty
- Environmental influences
  - Health disparities
  - Cost
  - Policy implications
  - Public education

## Client

- Evidence needed to guide practice

# Innovation

| Specific Nursing Research Category | Topic Areas |
|---|---|
| Technology development | Incorporation of new technologies (e.g. whole genome sequencing) |
| | Ethics |
| | Policy and guidelines to support applications |
| | Applications (e.g. clinical and analytic validity, and clinical utility) |
| | Genomic bioinformatics |
| | Translation, dissemination, implementation<br>i. Use of technology in information delivery<br>ii. Performance improvement by provider (e.g. point of care support)<br>iii. Resources that support genomic research (e.g. registries of tools, best practices, nursing outcomes) |

# Innovation

| Specific Nursing Research Category | Topic Areas |
|---|---|
| Informatics Support Systems | Data storage and use to facilitate research process and outcomes |
| | Facilitate cross-generational sharing of genomic data (e.g. family history, laboratory analysis |
| | Managing, analyzing, and interpreting genomic information (e.g. sequencing data) |
| | Point of care decision support for client and healthcare provider |
| | Common terminology and taxonomy |
| | Common formats for data storage/exchange and queries |
| Environmental Influences | Evidence based guidelines |
| | Healthcare reform |
| | Economics (e.g. cost effectiveness) |
| | Regulatory gaps and/or variability |

# Training

| Specific Nursing Research Category | Topic Areas |
|---|---|
| Capacity Building | Training future nursing scientists in genomics |
| | Preparing nursing faculty in genomics |
| | Education of current and future workforce in genomics (e.g. research nurse coordinators, advanced practice nurses, other healthcare professionals) |
| | Preparation of clinical and administrative leaders to advance appropriate genomics/genetics integration into practice |
| | Innovative use of biorepositories (e.g. informed consent, result interpretation) |
| | Bioethics |
| Education | Optimal methods to:<br>-train the existing nursing workforce in genomics |
| | -train the nursing leadership in genomics to support genomic translation, research, and practice |
| | -integrate nursing genomic competencies in basic prelicensure and postlicensure in academic programs |

# Cross Cutting Themes

| Specific Nursing Research Category | Topic Areas |
|---|---|
| Health Disparities | Racial, ethnic, socioeconomic, and cultural influences on disease occurrence and response to disease and treatment |
| | Genomic health equity (e.g. access) |
| | Diseases that disproportionately affect specific groups (e.g. minorities |
| | Targeted therapeutics |
| | Overcoming misinformation and genomic "myths" |
| Cost | Cost effectiveness |
| | Comparative effectiveness |
| | Value |
| Policy | Policy as a context of science |
| | Research to inform policy |
| Public Education | Health literacy |
| | Genomic literacy |

# Health Promotion and Disease Prevention

| Specific Nursing Research Category | Topic Areas |
|---|---|
| Risk Assessment | Biologic plausibility (e.g. pathways, mechanisms, biomarkers, genotoxicity) |
| | Comprehensive screening opportunities |
| | Components of risk assessment (e.g. biomarkers, family history) |
| | Risk-specific healthcare decision-making |
| Communication | Risk communication |
| | Informed consent |
| | DTC marketing and testing (e.g. uptake, utilization, dissemination) |
| Decision Support | Informed consent |
| | Match of values/preferences with decisions |
| | Risk perception/risk accuracy |
| | Effect of decision support on decision quality (e.g. knowledge, personal utility) |

# Advancing the Quality of Life

| Specific Nursing Research Category | Topic Areas |
|---|---|
| Family | Family context(e.g. family functioning, and structure, family relationships, and communication) |
| | Ethical issues |
| | Healthcare provider communication with families |
| Symptom Management | Biologic plausibility (e.g. pathways, mechanisms, biomarkers, epigenetics) |
| | Clinical utility |
| | Personal utility |
| | Pharmacogenomics (e.g. therapy selection, medication titration) |
| | Decision making |
| | Evidence based effectiveness of approaches |

# Advancing the Quality of Life

| Specific Nursing Research Category | Topic Areas |
|---|---|
| Disease States (encompassing acute, common complex, and chronic) | Genomic based interventions that reduce morbidity and mortality |
| | Gene/environment interactions (e.g. epigenetics, genotoxicity) |
| | Pharmacogenomics |
| | Evidence based effectiveness of treatments/support |
| Client Self Management | Collecting and conveying information that informs self management (e.g. family history) |
| | Lifestyle behaviors |
| | Environmental exposure and protection (e.g. occupational) |
| | Synergy of client and provider expectations (e.g. client/family centered care) |
| | Personal utility |

# Next Steps

- Further refinement of the Blueprint
  - NINR funded initiative
- Infrastructure
  - Designing, implementing, and evaluating clinical and educational infrastructure to support genomic capacity and competency
- Measurement
  - Existing measures adapted for genomic use
  - Build capacity to measure the impact of genomically focused nursing practice on patient care quality, costs, and outcomes
  - Database infrastructure
- Funding
  - Agencies and other funding streams (e.g. foundations) should explore avenues for funding blueprint nursing science

# Conclusions

- Genomics underlies all healthcare and is fundamental to nursing practice
- Nursing research in genomics will help establish evidence base needed to facilitate translation of genomics into practice to improve health outcomes
- The Blueprint for Genomic Nursing Science provides the platform to accelerate research addressing critical gaps

# Blueprint for Genomic Nursing Science

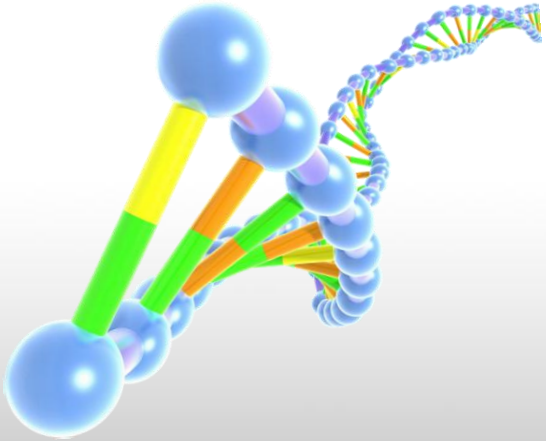
- **Journal of Nursing Scholarship March 2013 Genomic Special Issue (all articles open access)**

  http://www.genome.gov/27552093

  Or

  http://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/jnu_12007_Rev_EV.pdf

# Questions/Discussion




# Journal of Nursing Scholarship Genomic Nursing Webinar Series

- **Revisit the webinars presented by** nursing and medical expert authors of manuscripts published in the *Journal of Nursing Scholarship* 2013 Genomics Special Issue.
- Archived video and slides from each webinar available at:

  http://www.genome.gov/27552312