**Genomic Nursing Science Blueprint: Next Steps**

**Meeting Summary**

The National Human Genome Research Institute, National Cancer Institute, and National Institute of Nursing Research convened an Advisory Panel which met via webinar on July 31, 2014 (Appendix A) and in person on August 28, 2014 (Appendix B). The Advisory Panel consisted of nursing experts in key areas of genomics, education, practice and nursing research (Appendix C). The purpose of this meeting was for these experts to consider opportunities to facilitate genomic nursing research, identify researcher resources and gaps, explore exemplar models to be used as a framework that supports research, and envision a platform for promotion of genomic nursing research and collaboration.

The Advisory Panel identified resource needs and gaps and made key recommendations (Appendix D). Five action items were identified for further discussion: 1) creation of a Genomic Research Consortium, 2) identification of common data elements, 3) development of ways to enhance the education, training, and career development of nurse scientists in the area of genomics, 4) identification of core educational elements for genomic nurse scientists, and 5) the identification of core elements needed for a web-based platform in support of genomic nurse scientists. The Advisory Panel recommended the priority activity be focused on establishing the consortium from which the web-based platform could be created and incorporated. The Advisory Panel recommendations will be used to develop strategies to promote genomic nursing science aimed at achieving the Genomic Nursing Science Blueprint [1] research recommendations more quickly, efficiently, effectively, and collaboratively.

**Next Step Action Plan**

Advisory panel members agreed to facilitate the development and organization of the consortium through topic specific work-groups. Meetings will occur monthly via conference calls organized by the meeting planning group who will continue to direct the next step action plan.
Appendix A. Webinar Agenda

Genomic Nursing Science Blueprint: Next Steps
Webinar Agenda

July 31, 2014 1:00-2:00PM
NIH, Natcher Bldg 45, Room F1/F2

1:00-1:10  Introduction-Purpose of the webinar and plans for August 28 meeting
Jean Jenkins, PhD, RN, FAAN
National Human Genome Research Institute

1:10-1:15  Blueprint publication-brief overview
Jean Jenkins, PhD, RN, FAAN
National Human Genome Research Institute

1:15-1:45  Model Reviews
Kathleen Calzone, PhD, RN, APNG, FAAN
National Cancer Institute, NIH
i. eMERGE: http://www.genome.gov/27540473
ii. PhenX: http://www.genome.gov/27541903
iii. Improvement Science Research Network:
     https://improvementscienresearch.net/about/experts/stevens.asp
iv. AHRQ Innovations Exchange:
v. PROMIS: http://www.nihpromis.org/#2

1:45-1:50  Discussion about Pre-meeting assignment
Lois Tully, PhD
National Institute of Nursing Research
   What would be most useful to you as a researcher to move
   genomics research forward (e.g., standing conference calls,
   networking opportunities, somewhere to access standardized tools
   and resources, etc)?

1:50-2:00  Questions
Appendix B: Meeting Agenda

Genomic Nursing Science Blueprint: Next Steps
Meeting Agenda

August 28, 2014
NIH, Natcher Bldg 45, Room F1/F2

8:00-8:30 Arrival

8:30-8:45 Welcome
Laura Lyman Rodriguez, Ph.D.
Director, Division of Policy, Communications, and Education
National Human Genome Research Institute, NIH

8:45-9:00 NINR Blueprint Initiatives
Patricia A. Grady, PhD, RN, FAAN
Director, National Institute of Nursing Research, NIH

9:00-9:30 Purpose and Process of Meeting: Overview
Kathleen Calzone, PhD, RN, APNG, FAAN
National Cancer Institute, NIH

9:30-10:15 Moving the Blueprint Research Forward: Researcher Wishlist
Facilitator: Lois Tully, PhD National Institute of Nursing Research, NIH

10:15-10:30 Break

10:30-11:15 Framework for Supporting Genomic Nursing Research: Exemplar Model Discussion
Kathleen Calzone, PhD, RN, APNG, FAAN
National Cancer Institute, NIH

11:15-12:00 Researcher Resources: Identifying, Assessing, Determining Gaps
Facilitator: Ann Cashion, PhD, RN, FAAN
National Institute of Nursing Research, NIH

12:00-1:00 Working Lunch
Facilitator: Jean Jenkins, PhD, RN, FAAN
National Human Genome Research Institute, NIH

1:00-2:15 Visioning for Platform Realization: What do we need?
Facilitator: Jean Jenkins, PhD, RN, FAAN
National Human Genome Research Institute, NIH

2:15-2:30 Break
2:30-4:00  Recommended Platform Components: How do we get there?
Facilitator: Kathleen Calzone, PhD, RN, APNG, FAAN
National Cancer Institute, NIH

4:00-4:30  Actualizing a Plan that Promotes Genomic Nursing Science: Next Steps
Jean Jenkins, PhD, RN, FAAN
National Human Genome Research Institute, NIH

4:30  Meeting Adjourns
Appendix C: Meeting Attendees
Genomic Nursing Science Blueprint: Next Steps Meeting
Advisory Panel

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Appendix D: Resource Needs and Gaps/ Key Recommendations and Action Items

The Advisory Panel identified the following **Resource Needs and Gaps:**

- **Standardized phenotypes**
  - Data collection standards (e.g., CIDR [http://www.genome.gov/12512879#al-1](http://www.genome.gov/12512879#al-1))
  - Sample processing standards
- **Links for information dissemination**
  - White papers (e.g., American Academy of Pediatrics)
  - Clinical standards and guidelines (e.g., ACS; Heart Association)
  - Ongoing studies (e.g., clinicaltrials.gov) template
  - Craig’s list of samples-allow search capacity; create
- **Regulatory requirements**
  - Principles of ethical conduct for this kind of research
  - FDA regulations
  - IRB templates for studies that have a genomic component
  - Standardized language for informed consent for sample collection-consistent language
- **Existing data repositories**
  - Steps needed to access them
  - Training to learn how to access
  - Data sharing
- **Biorepositories**
  - Place to store DNA
- **Education and Training**
  - Identification of skill set of genomic nursing researchers and/or leading a team of researchers
  - Bioinformatics
    - How to manage, store, use, data produced
  - Training on how to lead a research team
    - How to compile
    - Who to include on your research team
  - Social and behavioral research
- **Social media platform for information exchange**
  - Blogs
    - Where to find them
    - How to use them to translate genomics as part of normal science
  - New Nursing Science Blog that is moderated.
  - Facebook approach to questions/gaps/resource dissemination
- **Families/Individuals-Language for lay population; consumer information**
- **Consultation mechanisms**
  - Navigator model
    - Genomics life coach
  - Resource Core
    - Nurse scientists to consult on laboratory resources
  - Regional nursing research networks
  - Identify navigators/coaches/mentors for genomic nursing science
Mechanism to pull in younger, new nursing scientists

- Incentives for genomic nursing science
  - Mechanism to endorse (e.g., AAHRPP certification [http://www.aahrpp.org/])

Key Recommendations/Action Items: The Advisory Panel prioritized the following 5 action items for further discussion and refinement of the recommendations:

1-Genomic Research Consortium

- Scope
  - Regional versus international

- Goals
  - Information exchange
  - Networking
  - Standardized procedures
  - Facilitate new collaborations

- Structure
  - Cores
    - Biostatistical core
    - Clinical core
    - Laboratory core
  - Collaborative network infrastructure
  - Consortium agreement/rules of engagement

- Membership
  - Interdisciplinary
  - Individuals interested in this area
  - Nurses in genomic science network

- Focus
  - Populations
  - Ethical, legal, social implications (ELSI)
  - Quality metrics

- Organizations for partnerships
  - Southern, Eastern, Mid-western, and Western Research Groups
  - International Society of Nurses in Genetics

- Next Steps
  - Assemble an Advisory Group for visioning-begin with the meeting attendees
  - Investigate Academic/NIH partnership

2-Common Data Elements

- Web-based data entry tool
  - Back-end files that start with common data elements (e.g., demographics, modeled after cancer cooperative groups)

- Categories-demographic, meds, symptoms, PROMIS, physiologic measures, family history (e.g., 2 or 3 generations), environment, GIS, socioeconomic
  - Establish minimum core dataset

- Bioinformatics
  - How to use, share, and analyze the information
Classes of data.
- Data access and use by patients, families
- Data identifiability
- Data sharing

- Interventions
  - How to code

- Financial discussions-multiple investigators.

- All are excited about this work. Partnerships to create and support this and be on the website together. Have data use agreements. Make it a federal/academic partnership. Think creatively. Start conversation about nursing focused consortium.

3-Education, Training, and Career Development Mechanisms
- Interdisciplinary, transdisciplinary learning
- Guided by Genomic Nursing Science Competencies
- Funding infrastructure
  - K, F, T awards mentors=collaborators
  - P awards- have an education and training mission
  - GSR slot to train an individual
  - Summer Genetics Institute (SGI)
  - Bootcamps
- Consortium
  - Education and training mission
    - Links to practicing community (NP, DNP)
    - Visiting scholar
    - Links to educational resources and lecture materials
  - Professional leadership mentoring-facilitate nurse leader development
    - Apprenticeship model
    - Web-based platform for trainee matching
- Measurable objectives/evaluation process for platform that can change in response

4-Core Elements for Genomic Nurse Scientists
- Basic genetics class
- Introduction to the laboratory
- Bioinformatics
- Clinical genetics
  - Basic and clinical genetics
  - ELSI
  - Complex and single gene disorders
  - Pharmacogenomics
- Directory of Nurses conducting genomic based research and focus of research
- Pre-doctoral opportunities

5-Recommended Platform Components
- Phenotypes
  - Common data elements and descriptors
  - Web-based data entry tools
- Collaborations
- Incentives
  - Data sharing, types of data
  - Publication authorship plans
  - Consultation services

- Research priorities
  - Replication studies

- Information Exchange
  - Best practices
  - Listserv
  - Funding opportunities

- Education
  - Workshops
  - Interprofessional education
  - Team science

- Biobanking

- Infrastructure
  - Advisory Group
  - Stakeholder representation
References