

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://improvementscienceresearch.net/about/experts/stevens.asp>
iv. AHRQ Innovations Exchange:
<http://www.innovations.ahrq.gov/index.aspx>
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

Bernice Coleman, PhD, ACNP-BC, FAHA, FAAN

Research Scientist II, Nursing Research and Development
Nurse Practitioner, Heart Transplant / Mechanical Assist Device Programs
Cedars Sinai Medical Center Los Angeles California
8700 Beverly Blvd.
Los Angeles, CA 90048
Telephone: (310) 423-6178
Email: bernice.coleman@cshs.org

Yvette Conley, PhD

Professor of Nursing and Human Genetics
University of Pittsburgh
440 Victoria Building
3500 Victoria St
Pittsburgh, PA 15261
Telephone: (412) 383-7641
Email: yconley@pitt.edu

Sandra Daack-Hirsch, PhD, RN

Associate Professor
101 College of Nursing Building
364 CNB
50 Newton Road
Iowa City, IA 52242-1121
Telephone: (319) 335-7061
Email: sandra-daack-hirsch@uiowa.edu

Patricia Dennehy RN, DNP, FNPC, FAAN

Consultant
51 Bay Way
San Rafael CA 94901
Telephone: (415) 453-6840, Cell: (415) 272-0876
Email: pdennehy@glide.org, patdennehy1@gmail.com

Susan G. Dorsey, PhD, RN, FAAN

Associate Professor of Nursing
Associate Dean for Research
Co-Director, UM Center to Advance Chronic Pain Research
University of Maryland Baltimore
655 W Lombard Street
Baltimore MD 21201
Telephone: (410) 706-7250
Email: sdorsey@son.umaryland.edu

Mary Engler, PhD, RN, MS
Senior Clinician and Training Director
National Institutes of Health, NINR
Division of Intramural Research
1 Cloister Ct
Rm 253, MSC 4733
Bethesda, MD 20892-4733
Telephone: (301) 594-0081
Email: mary.engler@nih.gov

Patricia A. Grady, PhD, RN, FAAN
Director
National Institute of Nursing Research
National Institutes of Health
MSC 2178
31 Center Drive
Bethesda, MD 20892
Telephone: (301) 496-8230
Email: gradyp@mail.nih.gov

Kathleen Hickey, EdD, FNP, ANP, FAHA, FAAN
Assistant Professor of Nursing
Nurse Practitioner Cardiac Electrophysiology
Columbia University Medical Center, School of Nursing Room 356
617 West 168th Street
New York, NY 10032
Telephone: (212) 305-4944
Email: kth6@columbia.edu

Pamela S. Hinds, RN, PhD, FAAN
William and Joanne Conway Chair in Nursing Research
Associate Director, Center for Translational Science
Director, Department of Nursing Research and Quality Outcomes
Children's National Health System
Washington, DC 20010
Telephone: (202) 476-6967/4432
Email: pshinds@childrensnational.org

Ada Sue Hinshaw, PhD, RN, FAAN
Dean and Professor
Graduate School of Nursing
Uniformed Services University
4301 Jones Bridge Road
Bethesda, MD 20814
Telephone: (301) 295-9004
E-mail: adasue.hinshaw@usuhs.mil

Ann R. Knebel, PhD, RN
Deputy Director
National Institute of Nursing Research
National Institutes of Health
MSC 2178
31 Center Drive
RM 5B05C
Bethesda, MD 20892
Telephone: (301) 496-8230
Email: ann.knebel@nih.gov

Debra E. Lyon, RN, PhD, FAAN
Kirbo Endowed Chair
Professor and Executive Associate Dean
College of Nursing, University of Florida
1225 Center Drive,
Gainesville, FL 32610
Telephone: (352) 273-6398
E-mail: delyon@ufl.edu

Mary Regan, PhD, RN
Associate Professor
Organizational Systems & Adult Health
University of Maryland's School of Nursing
655 W Lombard Street
Baltimore, MD 21201
Telephone: (410) 706-1175
Email: regan@son.umaryland.edu

Lynn Rew, EdD, RN, AHN-BC, FAAN
Denton & Louise Cooley and Family Centennial Professor in Nursing
The University of Texas at Austin, School of Nursing
1700 Red River Street Office-NUR 4.139 | NUR 3.434
Austin, TX 78701
Telephone: (512) 471-7941 | (512) 475-7039
Email: ellerew@mail.utexas.edu

Jacquelyn Taylor, PhD, RN, PNP-BC, FAAN
Associate Professor
Robert Wood Johnson Foundation, Nurse Faculty Scholar Alumna
Associate Resident Fellow
Yale School of Nursing - Rm 22005
Yale University West Campus
P.O. Box 27399
West Haven, CT 06516
Telephone: (203) 737-2364
Email: Jacquelyn.taylor@yale.edu

Shanita D. Williams, PhD, MPH, APRN
Chief, Nursing Education and Practice Branch (NEPB)
Division of Nursing and Public Health
Bureau of Health Workforce
Health Resources and Services Administration
5600 Fishers Lane, Parklawn Building, Room 9-89
Rockville, MD 20857
Telephone: (301) 443-1253
Email: swilliams3@hrsa.gov

MEETING PLANNERS

Kathleen Calzone, PhD, RN, APNG, FAAN
National Cancer Institute
Center for Cancer Research/Genetics Branch
37 Convent Drive
Bldg 37 Rm 3039, MSC 4256
Bethesda, MD 20892
Telephone: (301) 435-0538
E-mail: calzonek@mail.nih.gov

Ann Cashion, PhD, RN, FAAN
Scientific Director
National Institutes of Health, National Institute of Nursing Research
3 Center Drive, Building 3/5E28
Bethesda, MD 20892
Telephone: (301) 496-0294
E-mail: ann.cashion@nih.gov

Jean Jenkins PhD, RN, FAAN
Clinical Advisor, Genomic Healthcare Branch
Division of Policy, Communications, and Education
National Human Genome Research Institute, NIH
Bldg. 31 Rm 4B09
Bethesda, MD 20892
Telephone: (301) 547-1897
Email: jean.jenkins@nih.gov

Lois Tully PhD
Program Director
Office of Extramural Programs
National Institute of Nursing Research (NINR)
National Institutes of Health
6701 Democracy Boulevard, Room 710
Bethesda, MD 20892
Telephone: (301) 594-5968
Email: tullyla@mail.nih.gov

INVITED SPEAKER

Laura Lyman Rodriguez, Ph.D.

Director, Division of Policy, Communications, and Education

National Human Genome Research Institute

National Institutes of Health

31 Center Drive; Room 4B09

Bethesda, MD 20892-2152

Telephone: (301) 594-7185

Email: rodrigla@mail.nih.gov

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>)
 - 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
 - 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

1. Genomic Nursing State of the Science Advisory Panel, C., K.A., Jenkins, J., Bakos, A.D., Cashion, A.K., Donaldson, N., Feero, W.G., Feetham, S., Grady, P.A., Hinshaw, A.S., Knebel, A.R., Robinson, N., Ropka, M.E., Seibert, D., Stevens, K.R., Tully, L.A., Webb, J.A., *A Blueprint for Genomic Nursing Science*. *Journal of Nursing Scholarship*, 2013. **45**(1): p. 96-104.