GENOMIC NURSING SCIENCE BLUEPRINT: NEXT STEPS MEETING
AUGUST 28, 2014

Dr Laura Rodriguez, Director Division of Policy. Communications, and Education, NHGRI, NIH welcomed meeting attendees and provided background information about NHGRI efforts.

Dr Patricia Grady, Director NINR, NIH discussed NINR initiatives, activities, and initiatives related to the Genomic Nursing Science Blueprint.

Dr Kathleen Calzone, NCI, NIH provided an overview of the purpose and process of the meeting. Attendee introductions were made.

Dr Lois Tully, NINR, NIH lead the discussion of the Researcher Wish list as part of moving the Blueprint research forward. TYPES OF RESOURCES NEEDED are identified below:
1. Standardized phenotypes
    a. Establish data collection standards (CIDR http://www.genome.gov/12512879#al-1) and sample processing standards
2. Principles of ethical conduct for this kind of research
    i. Links to White papers (e.g., American Academy of Pediatrics)
    ii. Expert panels at AAN (e.g., tools, policies)
3. IOM's White Papers, Policies and best practices
4. IRB template for studies that have a genomic component
5. Existing data repositories
    i. Steps needed to access them
    ii. Training to learn how to access
6. Links to clinical standards and guidelines (e.g., ACS; Heart Association)
7. Families/Individuals-Language for lay population; consumer information
8. Education
9. Blogs-where to find them and how to use them to translate genomics as part of normal science.
    a. New Nursing Science Blog that is moderated.
10. Show NINR genomics in context of priorities and all other genomics research
11. Improve researcher capacity through education
    i. Ideas
    ii. IRB template
    iii. Places to store DNA
    iv. Partnerships
    v. Training on how to lead a research team, how and who to include on your research team
12. Tools
    i. Generic framework (e.g., FAQ of how to make it happen)
    ii. Repository of ongoing studies (e.g., clinicaltrials.gov) template like Wikipedia
    iii. Information about informed consent for sample collection-consistent language
    iv. Craig's list of samples-allow search capacity; create
    v. FDA regulations
    vi. Mechanism to endorse (e.g., AAHRPP certification http://www.aahrpp.org/)
    vii. Establish consultation mechanisms such as through regional nursing research networks
        a. Identify navigators/coaches/mentors for genomic nursing science
13. Partnership with Research Groups Regionally-connections, partners
    a. Mechanism to pull in younger, new nursing scientists.
14. Training grant-could also access them to gather information
15. Social and Behavioral Research (SBR) education program (http://www.nchpeg.org/bssr/index.php)
16. Facebook approach to questions/gaps/resource dissemination

GAPS:
1. Translator of information already out there. Depth of knowledge that's elsewhere or part of mainstream nursing science.
2. New researchers-make it international
3. Identification of skill set of genomic nursing researchers and/or leading a team of researchers
4. Researcher has to think about how does genomics impact the person. Have to think about what doing and how to integrate genomic questions/variables.

5. Partnerships-framework. Consider how to impact and standardize science by both new and seasoned researchers.
6. Laboratory resources-Center for inherited disease research (http://www.cidr.jhmi.edu/)
7. Are there resources that can be invested into repositories to support research and where can send samples?
8. Core for nurse scientists for laboratory resources (e.g., Program officer)
    a. Mechanisms for how investigators can apply.
9. Bioinformatics-how to manage, store, use, data produced
10. Get people to share resources they discovered (e.g., data sharing). For example: Facebook approach of education and resources. Post questions that highlight the gaps in knowledge.

RECOMMENDATIONS:
1. Regional network to help all of us drill down and make it happen.
2. Navigator model-genomics life coach.
3. SGI graduates-survey (n=300) to determine what are the barriers they have encountered when developing and implementing genomics nursing research.
4. Could also survey NINR trainees.
    a. What are barriers, what are issues that challenge them, what did they need that would have helped them, what worked well, what has contributed to their success.

WISH LIST BY GROUPS
Yellow
1. Longer K23s to allow researcher the time they need to develop R01s (3-5 vs 3)
2. Access to genomic coordinating centers to enhance collaboration across disciplines with funding requirements that demand inclusion of nurses. Communication to Deans/Leaders about this change of policy.
3. Central online portals to link resources and organizations
4. Education for nurses - basic, genomics focused on the translational piece that captures the complexity of how genomics influences outcomes from the environmental triggers that shape population health and individual outcomes
5. Make this global
6. Need more complexity in research(multilevel=population and individual, link genomic with clinical data
7. Nurses are at the intersection between social science and basic science. Gene environment intersection. Recognize that nurses can do this kind of research.
8. Using a CTSA model
9. Helping nurse researchers partner and network across institutions
Blue
1. Make all studies interdisciplinary and then emphasize developing resources to help with building this. Opportunities to break down barriers between research and clinical silos: breaking down silos to allow collaboration across the universities, medical centers and community.
2. Medical centers, community, prevention, diversity
3. Focus on populations and phenotypes where nurses have a lot of impact
4. Centralized center for biodata and samples
5. Come up with common data elements so that we can apply the same approaches - coordinating central resources to emphasize similarity in terms of analysis – e.g., gold standard tools for phenotyping symptoms etc.
6. Facilitate resources for nurses to access education and training even if they are in a center that does not have opportunities for doing genomics research (for new or established scientists)
7. Mentoring, access to training/help/collaboration
8. Requiring funding researchers to mentor new nurse scientist of scientist who are new to the field
Green
1. Regional consortium in terms of methodological, genomic etc. expertise and resources where nurse researchers can collaborate
    1. Include academic, tertiary, practice and family/consumer groups
2. Biorepositories in which standardization of data and samples is applied
3. IPE approaches to leverage resources across the system
4. Translators and motivators to encourage the use of genomics and banking samples
    1. What resources are available
    2. Educational opportunities
    3. Overcoming boundaries with other disciplines
    4. Merge clinician and basic researchers
5. Phenotyping - leverage nursing expertise in this field

6. What do we need to know in order to partner effectively
7. Common data elements/tools and measures
8. Establish motivators such as the clinical ladders
    1. Integrate questions on practice into nursing research
9. Educational opportunities:
    - Identification of genomic nursing scientist core knowledge and skill set
    - translational piece - common language
    - Educating other nurses to be consumers of nursing research
        o Requires faculty preparation

Dr Ann Cashion, NINR, NIH lead the discussion of the
RESOURCE GAPS IDENTIFICATION, ASSESSING, DETERMINING

What types of resources are needed by researchers that would provide support for genomic nursing research?
1. Phenotyping that have patient report measures:
2. IRB/ethical research tools
3. Link to direct sites and resources
4. IOM and other health policy sites
5. Existing data repositories and what steps you need to take to access them.
6. Links to standards and guidelines for genomics and genetics
7. Patient resources: G2C2 links out to sites: instruments that provide language that can be used to help build things like consent documents or scripts to approach groups for inclusion in studies
8. Moderated blogs: topic specific -
9. Translator - gap in nursing science that we don't know how to break down information or translate it so that it's relevant for nursing science and demonstrates the integration of genetics into nursing science and practice.
10. Mentoring opportunities.
11. Cold Spring Harbor type classes such as - basic genomics

Dr Jean Jenkins, NHGRI, NIH facilitated visioning for platform realization. What do we need? This reflects the best estimate of priority topics based on feedback at the meeting:

1. Common data elements/tools/measures
2. Identification of genomic nurse scientists core knowledge/competencies/skill set
3. Regional Research Consortium
4. Standardized phenotypes for nursing science
5. Education opportunities
6. Practice to research translation
7. Networking opportunities
8. Interprofessional partnerships
9. Expert consultation/navigation/mentor/coach
10. Bioinformatics storage data analysis
11. Regulatory guidance/policy
12. Social media research communication
13. Family/community/lay communication
14. Laboratory procedures 5

CORE ELEMENTS FOR NURSE SCIENTISTS WHO WANTS TO HAVE A GENOMIC COMPONENT TO THEIR RESEARCH.
1. Basic genetics class
2. Biostats-computational. Need to understand what they mean based on research question.
3. Clinical genetics which includes ELSI, complex and single gene disorders, pharmacogenomics
4. Introduction to the laboratory
5. Directory of Nursing conducting genomic based research and focus of research
6. Pre-doc: suggest have to do their own analysis

EDUCATION, TRAINING, AND CAREER DEVELOPMENT
1. Interdisciplinary, transdisciplinary
2. Individualized mentoring team and plan
    - Apprenticeship model

- Early career and mid-career
3. Be able to speak the language and sit at the table with research team as PI
4. Competencies in general (not level specific)
5. Infrastructure K, F, T awards mentors=collaborators
6. P awards- have an education and training mission. GSR slot to train an individual.
7. SGI, Bootcamps, Links to educational resources and lecture materials
8. Web-based platform that's dynamic for potential trainees to tap into for matching
9. Links to practicing community (NP, DNP)
10. Professional leadership mentoring-facilitate nurse leader development
11. Regional Consortiums-have an education and training mission
12. Diversity increased by using this platform. Present the platform presented in a way to bring attention to attracting diverse population of trainees
13. Measurable objectives/evaluation process for platform that can change in response
14. Visiting scholar

COMMON DATA ELEMENTS
1. Web-based data entry tool-backend files that start with common data elements (e.g., demographics, like cancer cooperative groups).
2. Categories-demographic, meds, symptoms, PROMIS, physiologic measures, family history (e.g., 2 or 3 generations), environment, GIS, socioeconomic.
          Establish minimum core dataset
3. Decide how to use, share, and analyze the information (e.g., bioinformatics) to put together classes of data.
4. How data will be used by patients, families, and will the data be identified or anonymous? Issues that need to be determined with data sharing discussions.
5. ELSI
6. How to code interventions.
7. 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.

REGIONAL GENOMIC RESEARCH CONSORTIUM
1. Regional
2. Biostatistical core
3. Clinical core
4. Laboratory core
5. Population focus-clinics in different areas
6. Goal-standardize procedures, information available for the masses
7. Members: people interested in that area; nurses in genetics network;
8. The primary purposes of the Consortium:
- Work together
- Create new scientist linkages to work on projects and publish together
- Create a collaborative network infrastructure
- Make it valuable for more than just nurses
9. Assemble an Advisory Group for visioning-begin with the meeting attendees
10. Consider connections with Southern, Eastern, Mid-western, and Western Research Groups (they meet once a year and are active in training). There was an assumption that members currently embrace genomics.
11. ISONG is global and may be worth connecting with for genetics expertise.
12. Include an ELSI focus.
13. Quality-tie genomics with clinical indicators. Partnering-standards for technology; quality control metrics and milestones. NOTE: Dr Dennehy noted that HRSA division of health services has 16 measures to assess in primary care. Unsure if they are the best indicators. Magnet sensitive measures are moving. Few social determinant measures included.

RECOMMENDED PLATFORM COMPONENTS
1.   Phenotype descriptions
2.   Platform for doing collaborative research
- Web-based data entry tools
- Incentives for collaborative activities in nursing science
- Consortium agreement/rules of engagement
- Data sharing, types of data
- Publication authorship plans

- Best practices
- Common data descriptors
- Peer review
- Advisory process
- Key stakeholders on advisory committee
- Stakeholder agreement for all the above
- Need buy-in from the nursing scientific community of the focal area and baseline research priorities
- Infrastructure building

3. Consider need for replication of studies. Coordinate dissemination to build the evidence. This was considered a good idea but concern about how to support. Biobanking role?

4. Are there existing networks from which we could create a partnership. J. Taylor said yes-we could modify based on our need. For example PCORI patient centered networks.

5. Provide consultation (e.g., phone conference every so often)

- Presentations, cite issues, network
- Share funding opportunities, communication
- Nursing issues within genomics-circumscribe it
- Listserv

6. Educational mission: workshops, IP, team science

7. How to make others feel it is important to come to the table (e.g., beyond the bench)? Pull in clinical partners to make it translational. Foster collaboration between nurse scientists and clinicians (e.g., staff nurses)

DREAMS: Biorepository based on symptom science; National research consortium; anchor local expertise and then go international.

AROUND THE ROOM COMMENTS:

1. International consortium; academic collaboration

2. Responsible for health needs of the population; workforce competency; communication of needs; team based care. Partnerships-nurses to lead teams; health innovation, not leave vulnerable populations behind. Clear criteria and definitions of roles. Value based care.

3. Consider having ISONG as a partner

4. Can also bring together multidisciplinary nurse teams with varied expertise. Improves diversity in nurse scientists studying vulnerable populations.

5. Symptom science biorepository with data attached

6. Board of National Centers Consortium could be a very good partner with those concerned with health disparity issues. When think about looking across areas, consider them as a partner. They do have data sets. EHR data and could create early discussions. They also do a lot of teaching.

7. If it improves the lives of the individual and family and we can show that, genomics will become commonplace.

8. Ways to leverage common data elements/tools and ways to link both efforts with phenotypes would be powerful

9. Need for other nurse scientists to understand why genomics is important to include in studies. Given charge to collect and biobank samples.

10. Noted the need for validation studies.

11. Need a language to capture what is needed, such as upcoming ICD codes (e.g., common nomenclature that can be captured in the EHR

12. Next generation. With the depth of talent on the room we have a real opportunity to launch nursing science as a career. Unique opportunity to bring along this flexible next generation.

13. Consortium available for disease specific and age specific. Nothing across all ages, health, and diseases. Note child and family voice. They offer a new analytic challenge. Interesting way to move genomics forward. Family Literacy-include as part of this plan.

14. Community Health Centers have consumers on their Boards. Need an Awareness Campaign.

NEXT STEPS:

1. Messaging-ambassadors to talk to the researchers

2. Get a group together to organize the consortium

- Look at innovative models
- Get buy-in
- Begin fact finding

3. Planning work group: HRSA does support consortiums doing synergistic work (grants are for one year ahead).

4. Divide and conquer

5. Create meeting report and determine who will be responsible for what

6. Need to identify common data elements

7. Have a follow-up meeting to launch work efforts (e.g., webinar or CANS, Academy, ISONG)

8. Education-creation of content
9. Have standing monthly calls
10. Patient/family thread (e.g., Genetic Alliance; Patients like me)
11. Publication describing the outcomes from this meeting.