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Increasing nursing capacity in genomics: Overview of existing global genomics resources☆

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Abstract

Background: Global genomic literacy of all health professions, including nurses, remains low despite an inundation of genomic information with established clinical and analytic validity and clinical utility. Genomic literacy and competency deficits contribute to lost opportunities to take advantage of the benefits that genomic information provides to improve health outcomes, reduce healthcare costs, and increase patient quality and safety. Nurses are essential to the integration of genomics into healthcare. The greatest challenges to realizing their potential in successful integration include education and awareness. Identification of resources, their focus, whether they targeted at nursing, and how to access them, form the foundation for a global genomic resource initiative led by the Global Genomics Nursing Alliance.

Objectives: The aim was to identify existing global genomic resources and competencies, identifying the source, type and accessibility.

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Declarations of Interest

Calzone-None; Kirk-None; Tonkin-None; Badzek-None; Benjamin-Salary from Private Healthcare Provider GeneHealth UK; Middleton-None.

Design: Cross sectional online descriptive survey to ascertain existing genomic resources.

Settings: Limited to eighteen countries and seven organizations represented by delegates attending the inaugural meeting in 2017 of the Global Genomics Nursing Alliance.

Participants: A purposive sample of global nursing leaders and representatives of national and international nursing organizations.

Methods: The primary method was by online survey administered following an orientation webinar. Given the small numbers of nurse leaders in genomics within our sample (and indeed within the world), results were analyzed and presented descriptively. Those identifying resources provided further detailed resource information. Additional data were collected during a face-to-face meeting using an electronic audience-response system.

Results: Of the twenty-three global delegates responding, 9 identified existing genomic resources that could be used for academic or continuing genomics education. Three countries have competence frameworks to guide learning and 5 countries have national organizations for genetics nurses.

Conclusions: The genomic resources that already exist are not readily accessible or discoverable to the international nursing community and as such are underutilized.

Keywords

Nursing; Genetics; Genomics; Competency; Education; Genomic resources

1. Introduction

The Global Genomics Nursing Alliance (G2NA) was established in January 2017 to accelerate the integration of genomics into everyday practice. In contrast to other organizations, G2NA is not focused on the genetic specialist, but instead the general nursing community. One of the primary aims of this initiative is to identify existing nursing assets in genomics that could be shared throughout the international nursing community. The overarching intent of this genomic knowledge mobilization is to optimize resource accessibility and reduce duplication of efforts through leadership, collaboration and sharing. In addition to decreasing the burden on any one country, connecting nursing communities globally enables a collaborative conversation to move the profession forward. The ultimate aim is to increase nursing capacity to integrate genomics into practice through supporting improvements in genomic literacy critical to adoption in practice. Cataloging existing resources and determining whether they are leveled for nursing can facilitate the identification of resource gaps that need to be addressed. Any global genomic nursing competency initiative requires an adequate foundation of accessible, nursing-leveled education and practice resources, to be effectively disseminated.

2. Background

The availability of clinically meaningful genomic applications in healthcare continues to accelerate, transforming healthcare delivery in ways that have the potential to increase quality and safety, decrease costs, and improve health outcomes (Williams et al., 2017).

Established clinical applications incorporating genomics span the healthcare continuum from pre-conception to end of life and therefore have clinical implications for all nurses and other healthcare providers (Rehm, 2017). However, integration of genomics into practice is inconsistent globally (Calzone et al., 2018a).

Realizing the benefits provided by these clinical applications is hinged in part at least on a workforce that is competent in genomics. Yet studies globally document limited genomic nursing competency (Calzone et al., 2014; Godino et al., 2013; Skirton et al., 2012; Seven et al., 2015). Perhaps even more alarming is emerging evidence that for nursing faculty, genomic knowledge is limited and is similar to the students they teach (Donnelly et al., 2017; Read and Ward, 2016). These data support the premise that achieving genomic competency in the practicing community is unlikely to be solved in the imminent future without extensive capacity building amongst nursing faculty and through re-training of the entire nursing healthcare workforce.

Given the global nature of this problem, a concerted and strategic effort is needed to increase nursing literacy and competency in genomics. Literacy as defined by the Programme for the International Assessment of Adult Competencies (PIAAC) (Programme for the International Assessment of Adult Competencies (PIAAC) Literacy Expert Group, 2009) is a precursor to competency which is achievement of knowledge, skills, and attitudes (Skirton et al., 2012). One important strategy to achieving this is through evaluating resource availability and utility based on established criteria including goals, content, complexity, methods, presentation, and accessibility (Tonkin et al., 2011). Vetted resources could then be made accessible globally, such as through the G2NA website (www.g2na.org) and email distribution list. Current evidence suggests that multiple countries of varying sizes and types can collaborate to maximize the mobilization of genomic resources (Paneque et al., 2017). G2NA provides the collaborative framework to further enable this, not only through the collection, evaluation and dissemination of identified resources but also potentially in the development of new resources that address identified gaps. As part of a wider scoping exercise for G2NA, the organization started by ascertaining what global assets in genomics already exist. These include learning materials (education resources) and take into consideration other assets such as guidelines and collaborative networks.

2.1. Aims

The aim was to conduct a survey to identify existing global genomic resources, ascertaining the source, type and accessibility. The Faculty of Life Sciences and Education Ethics Committee, University of South Wales reviewed and approved this project.

3. Methods

This was a cross-sectional descriptive study. The primary method was online survey, with additional data collected subsequently using an audience-response system at a face-to-face meeting of participants.

3.1. Recruitment

This project utilized a purposive sampling strategy described in more detail in Calzone et al. (2018a). Survey participation was limited to representatives from different countries (n = 18) and nursing organizations (n = 7) delegates, who were all known to be leading or in-fluential in international nursing initiatives. They were invited to attend an inaugural 3-day meeting of G2NA in Cambridge, United Kingdom (UK) in 2017. Constraints of funding and meeting space dictated the maximum number of places available. Delegates were selected for their leadership and expertise in nursing, healthcare services and policy, and genomics. Those who identified resources in the online survey were then contacted individually by email or telephone to obtain more details about the resources.

3.2. Population

All delegates invited to complete the survey did so. Twenty-five responses were received from 23 individuals, for 18 countries and seven organizations (two individuals completing for their country and an organization).

3.3. Instrument

The bespoke survey instrument was designed to identify country and organizational genomic resources. The instrument was pilot tested by the project leaders, other genomics and nursing experts, examined for face validity and revised iteratively prior to launch. The survey was administered online following an explanatory webinar prior to the inaugural meeting.

To provide a context for the education resources identified, country delegates were asked about: existing standards and/or competencies in genomics for nurses; whether there is a recognized specialist genetics nursing role within their healthcare system, and if so are there agreed standards for specialist genetics nurses; and whether there is a national society for genetics nurses (or nurses with a special interest in genetics) in each country. To assess where academic and clinical genetic/genomic resources were available, using free text boxes, we asked about: the availability and accessibility of up to date and relevant learning resources for nurses; opportunities for education, such as short courses, degree-level programs or modules; and the information technology infrastructure to facilitate learning, networking etc. For delegates responding on behalf of organizations we asked whether there were any learning resources in genomics that their organization produced and whether these specifically targeted nursing.

3.4. Audience Response System Questions

An electronic audience-response system was used to poll 25 delegates attending the Cambridge meeting about the role of G2NA. This included what role G2NA should play in the arena of resources and whether G2NA should collaborate with the interprofessional community or be nursing specific.

3.5. Analysis

Quantitative data were exported into Excel for analysis and results categorized descriptively.

3.6. Follow-up Assessment

Based on the survey findings, individuals identifying resources ($N = 9$) were asked to provide further details about each resource they had identified:

- country and/or organizational origin of the resource;
- official title;
- format;
- description including a brief outline of resource and language(s) used/available;
- topic(s) covered;
- indication for use;
- targetaudience(s);
- cost and specifically for websites, whether resources are down-loadable or registration and/or subscription is required;
- continuing education units available;
- contact/orderinginformationifapplicable; and
- publication date or date last updated.

4. Results

4.1. Education Resources

Less than half of the delegates (9/23) could identify resources in their country or organization (Table 2). The resources listed are for academic and/or clinical environments. The majority of resources identified were websites, although participants from two countries also made reference to books whilst online and offline courses and workshops were identified in four countries (Brazil, Canada, China, UK).

4.2. Role of G2NA

Most delegates (14/22) voted that the role G2NA should play in resources should be to both develop resources and serve as a repository. All delegates either agreed (6/23) or strongly agreed (17/23) that G2NA should collaborate with the interprofessional genomics community.

4.3. Competencies

Three countries and one region (Table 1) indicated that they had existing genomic competencies for nurses. The 1st edition of the UK competencies (Kirk et al., 2003) were foundational for development of the European nursing competencies. However, of the existing genomic competency resources, only the European competencies addressed professions beyond nursing for primary, secondary, and tertiary (defined as genetic specialist) care throughout Europe (Skirton et al., 2010). The professions covered by these competencies include: general practitioner; general nurse/midwife; medical specialist in fields other than genetics; specialist nurse, specialist midwife and specialist allied health

professional; specialist dentist; clinical geneticist; genetic specialist nurse or genetic counsellor; molecular geneticist; cytogeneticist; and biochemist/biomedical scientist.

4.4. Organizations and Genetics Certification

Five countries have a national society for genetic nurses, Japan http://idenkango.com/, UK (genetic counselors and nurses) http://www.agnc.org.uk/, Netherlands http://www.nvgc.info, Brazil https://m.facebook.com/Sociedade-Brasileira-de-Enfermagem-em-Gen%C3%A9tica-e-Gen%C3%B4mica-SBEGG-373296846131673/, and Taiwan http://www.taiwangc.org.tw/. Certification in genetic nursing is offered by Japan and the United States (US). Additionally, Taiwan and UK certify or register nurses as genetic counselors. In the UK, nurses and other (non-nursing) graduates wishing to train as genetic counselors must meet the requirements set out by the UK and Eire Genetic Counsellor Registration Board http://www.gcrb.org.uk/media/9339/applicant-guidelines-v3-july-2017.pdf.

The International Society of Nurses in Genetics (ISONG; https://www.isong.org/) is a global nursing specialty organization dedicated to genomic health care, education, research, and scholarship. Although ISONG's key focus is on nurses working within the genomics specialty, one of its goals is to promote the integration of genetics and genomics more widely across nursing education, research and care at all levels of professional practice.

5. Discussion

This survey identified assets that can be used to facilitate genomics education. Competence frameworks or curriculum guidelines for all nurses are available in three countries and the European region. Five countries have national organizations for genetics nurses, and learning materials were identified in nine countries. That educators and clinicians looking to integrate rapidly changing cutting-edge knowledge and skills into professional practice should have access to current, accurate resources is axiomatic. However, it is important to note that resources are not limited to just learning material. In considering factors essential for major education reform, Spillane and Thompson (1997) describe the resources necessary to build capacity in education in terms of capital (Spillane and Thompson, 1997). Human capital refers to the expertise of leaders, social capital includes the availability of social links and open communication, and financial capital includes resources that might be allocated to staffing, time and materials. They argue that the development and uptake of social capital is critical to the development of human capital. The value of financial resources in capacity building 'is heavily conditioned by the levels of human and social capital' in the region (Spillane and Thompson, 1997). There are parallels with their framework and the challenges to build genomics capacity within nursing which this survey throws light upon (Jenkins and Calzone, 2014; Calzone et al., 2018b). Gilbert et al. (2017) add a further perspective, in their consideration of human and social capital theories in relation to nursing leadership and organizational change (Gilbert et al., 2017). They also include 'organizational capital' (which they describe as a phenomenon of policies, procedures and technology) and propose a conceptual model to capture the influence of nurse leaders on the human and social capital of their teams and thus on organizational outcomes.

In the wider survey (Calzone et al., 2018a) only six delegates reported visible nursing leadership driving the integration of genomics in nursing within their countries, which was considered to be a significant issue. However, the existence of competency frameworks, an international genomics nursing organization (ISONG) and four national specialty organizations reported in this survey is an indication that both human capital (expertise) and social capital are available, albeit limited. G2NA plans to build on these collaborative networks to enhance social capital and promote access to human capital through the expertise and experience of members in education, practice, research and policy. The conceptual framework set out by Gilbert et al. (2017) may provide useful guidance in informing strategy for such development.

That less than half of the delegates could identify country or organization specific genomic resources supports the conclusion that many countries could benefit from access to resources developed elsewhere. The finding that the majority of resources are web-based is of potential value for global access. Web features such as Google Translate could add value in interpretation, although we recognize the limitations of this approach. Utilizing and/or repurposing established resources would decrease the burden and expense of new resource development and decreases duplication of effort. Gupta et al. (2017) note the rapid increase in demand for e-learning resources, particularly in low- and middle-income countries where resources are likely to be limited. They highlight the role that high-income countries should play in recognizing the needs of low- and middle-income countries, supporting them to develop education systems that meet local needs. This echoes the points raised by Bannier (2016). She promotes the potential for transnational education programs to assist developing nations in building intellectual infrastructure and highlights the need for culturally sensitive resources.

Existing assets identified in the survey include genomic competencies at basic and advanced levels in more than one country. These could serve as the basis for development of a global minimal nursing competency framework for general and advanced practice nurses who are not genetic specialists.

Many of the resources identified do not specifically target nurses. This is important when looking to utilize resources developed for the interprofessional community. Nurses typically have low genomic competence and confidence given they have no underpinning in the topic (Calzone et al., 2018b). An essential element of implementation science is literacy in the language associated with a given innovation, in this case genomics (Williams et al., 2017). Published strategies focused on genomic implementation initiatives that include nurses have started with awareness campaigns to facilitate nurses recognizing that genomics is relevant to their practice (Bennett et al., 2010; Jenkins et al., 2015). This is supported by Rogers' Diffusion of Innovation theory, which emphasized that individuals presented with an innovation, benefit from a recognized need for the innovation to facilitate uptake of learning opportunities on the pathway to adoption of the innovation (Rogers, 2003) and is consistent with Knowles' Adult Learning Theory (Knowles et al., 2015). Barriers to adoption include both system complexity as well as technical and knowledge complexity (Rogers, 2003). Therefore, having resources that are relevant, easy to reach, understand and use is critical to overcoming complexity.

The G2NA leaders and representatives of the funders met to discuss what infrastructure was needed to support a resource repository, whether G2NA should be a primary repository or point to existing resources, and whether an existing resource repository could be leveraged to include the global community. The existing resource is the Genetics/Genomics Competency Center (G2C2) (Calzone et al., 2011) where all resources undergo peer review assessing accuracy and currency of the material and which is reassessed periodically. A global resource repository was felt to be a catalyst for interprofessional collaboration with groups such as the Global Genomic Medicine Collaborative. G2C2 is already an interprofessional repository including nurses, physician assistants, pharmacists, genetic counselors, and physician resources.

G2NA leaders have discussed with G2C2 the website capacity to expand the number of resources and the international infrastructure to support functions such as language translation for widest global utility. The G2C2 leadership was open to global growth, pending funding. G2NA is also currently considering the optimal mechanisms to facilitate dissemination, including via its own website.

5.1. Limitations

We recognize that the information provided by this survey is limited only to those delegates participating in the G2NA initiative and our sample is understandably small because there are limited nurse leaders worldwide with a particular interest in genomics. The resources summarized in this report may not represent all resources within each country and do not represent a full compilation of the existing resources globally. Several countries were not represented due to funding constraints and space limitations for the G2NA retreat. Additional resource landscape analysis will be required.

5.2. Next Steps

Further work is planned to identify existing genomics education resources leveled for nursing, targeting countries and organizations not involved in the initial G2NA survey. In tandem, the G2NA intends to work towards development of both minimum and optimum genomics competency frameworks for nurses which can be of global relevance but also recognize real world constraints. Once the expanded resource assessment and competency framework are complete, resources will be mapped to the nursing competencies. Any gaps identified will guide new resource development and repurposing of existing resources for nursing, to be shared globally. Education resources alone are not suf-ficient without the practical guide of how and when to use a resource and who is the most applicable audience, underpinned by sound pedagogy, and drawing on the expertise of leaders within genomics, nursing, and education. A strategic implementation approach undertaken by the G2NA members is planned which will raise awareness about the resource(s) within their constituency and the accompanying detail of how these resources can be optimally used to achieve genomic competency. Search Engine Optimization is also needed to ensure that once developed, the resources can easily be found.

Conclusion

Many studies have documented how limited healthcare provider genomic competency diminishes the ability to integrate genomics appropriately into practice, impacting the quality and safety of patient care (Calzone and Jenkins, 2012; Calzone et al., 2013a; Korf et al., 2014; Harvey et al., 2007; Rare Disease, U., 2016). Unfortunately, little has changed with regard to healthcare provider and educator genomic competency over the past several years yet the generation of evidence based clinically relevant genomic applications continues at an astonishing pace (Read and Ward, 2016; Rare Disease, U., 2016). Nursing, as the largest health profession globally, can benefit from sharing information, resources, and strategies to increase genomic literacy and competency across the profession.

Most nurses indicate that to learn more about genomics, they prefer both a mix of print and electronic learning resources (Kirk et al., 2007; Calzone et al., 2013b). There are some excellent resources in genomics available globally and most are accessible online, further extending their potential reach. However, many are not known outside the country in which they were developed. Additionally, most do not make explicit their relevance to nursing practice. There is considerable merit in curating and sharing existing and new resources through an international repository, further informed by a more extensive survey of existing resources. Awareness of genomic resources accessible globally is necessary prior to launching any global effort aimed at addressing nursing genomic literacy and competency deficits. G2NA aims to act as a catalyst for such global effort, contributing and developing human and social capital, harnessing expertise in collaborative efforts to build and disseminate learning materials. In doing so, we also support the spirit of the Cape Town Open Education Declaration in making educational resources open for all and promoting a collaborative, participatory approach that includes the ‘open sharing of teaching practices that empower educators to benefit from the best ideas of their colleagues’ (Cape Town Open Education Declaration, Read the declaration, 2008).

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Table 1

Country/region specific genetic/genomic competencies.

Country/region	Title	Nursing target	Location
Europe	Core Competences for Generalists and Those Specializing in a Field Other Than Genetics (Williams et al., 2017)	Nurses and other healthcare providers	https://www.eshg.org/fileadmin/www.eshg.org/documents/CoreCompetence03GeneralistsAndNonGeneticSpecialists.pdf
Japan	*Competencies of Genetic Nursing* Practise Required For General and *Genetic Nurses* (Rehm, 2017)	All nurses	http://onlinelibrary.wiley.com/doi/10.1111/j.1742-7924.2007.00075.x/epdf
UK	Fit for Practice in the Genetics/Genomics Era (Calzone et al., 2018a)	All nurses	http://genomics.research.southwales.ac.uk/media/files/documents/2013-09-05/ffpgge-nursing-learning-outcomes.pdf
USA	Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators, 2nd Edition (Calzone et al., 2014)	All nurses	https://www.genome.gov/pages/careers/healthprofessionaleducation/geneticscompetency.pdf
	Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees (Godino et al., 2013)	Nurses with graduate degrees	http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Resources/Genetics-1/Essential-Genetic-and-Genomic-Competencies-for-Nurses-With-Graduate-Degrees.pdf

Table 2

Web genomic education resources for nurses and health providers.

Title	Description/topics	Target audience(s) All providers = All; Nurse = RN; Doctor = MD; Other = O	Downloading information
Australia			
Centre for Genetics Education programs	Provides fact sheets, resources and a national database of genetics services and support groups.	All	http://www.genetics.edu.au/
Genetics in Family Medicine: The Australian Handbook for General Practitioners	National educational resource on genetic medicine. Includes downloadable patient/family fact sheets.	All	https://www.nhmrc.gov.au/guidelines-publications/g11
Brazil			
Brazilian Society of Genetics	In Portuguese Genetics (plants, animals and humans) society, provides e-books and the journal Genetics and Molecular Biology.	MD, RN, O	https://www.sbg.org.br/
Brazilian Society of Medical Genetics	In Portuguese Society of medical geneticists. Annual congress.	MD, RN, O	http://www.sbgm.org.br/
Roberto Giuliani Institute - Genetics for All Institute	In Portuguese Conduct courses, training and support projects aimed at the dissemination, education, diagnosis and management of genetic diseases.	MD, RN, O	http://www.igpt.org.br
Canada			
Genetics Education Canada Hosted Workshops	Education in genetics and genomics. Workshops delivered by genetic leaders. Includes various genes, new technologies, research, ethical and psychosocial issues, assessment and interventions, case application.	All, public All, O	www.geneticseducation.ca https://www.desouzainstitute.com/

Title	Description/topics	Target audience(s) All providers = All; Nurse = RN; Doctor = MD; Other = O	Downloading information
Zane Cohen Centre for Digestive Diseases	Colorectal and related disease information including genetics.	All, public	http://www.zanecohencentre.com
British Columbia Cancer Agency	Cancer information including cancer genetic testing and resources (e.g. videos, websites).	All, public	http://www.bccancer.bc.ca/screening/health-professionals/hereditary
Canadian Cancer Society Hereditary Breast & Ovarian Cancer	Hereditary breast and ovarian cancer information.	All, public	http://support.cbcf.org/get-information/hereditary-breast-ovarian-cancer-hboc
China (Hong Kong)			
Collaboration: Faculty of Medicine of CUHK and Baylor College of Medicine	Every 2 months joint genetic counseling. Educational seminars.	All	http://www.obg.cuhk.edu.hk/bcm-cuhk-sym/
Beijing Genomics Institute	Genomics courses and workshops on cancer genetics, prenatal diagnosis, and general genetics. Free online lectures, some in English and Japanese.	All, O	http://events.genomics.cn/training/show_training?id=189
Japan			
Genetic Database	In Japanese Provides clinical and basic information for gene diagnosis and genetic testing.	All	http://www.congre.co.jp/gene/DB.html
Orphan Net Japan: ONJ	In Japanese Genetic clinical practice for rare diseases and genetic testing.	All, public	http://onj.jp/
GENE Reviews Jan	In Japanese Commentaries provided by experts on symptoms and diagnosis of hereditary diseases, genetic testing, genetic counseling, and information on clinical genetic medicine.	All, public	http://grj.umin.jp/
IDEN Net (Clinical Genetic Medicine Information Network)	In Japanese Network of clinical genetic departments providing	All	http://idennet.jp

Title	Description/topics	Target audience(s) All providers = All; Nurse = RN; Doctor = MD; Other = O	Downloading information
	information on genetic tests.		
Netherlands			
Cardiogenetics	In Dutch Information on cardiac genetics.	All	https://www.cardiogenetica.nl
Oncoline	In Dutch National guidelines in oncology and palliative care.	All	http://www.oncoline.nl/
Huisarts en Genetica	In Dutch Hereditary genetics clinical and education resources.	All	http://www.huisartsengenetica.nl/
Kanker	In Dutch Dutch Cancer Society information and peer support initiative.	All, public	https://www.kanker.nl/
ELFF	In Dutch Li-Fraumeni Syndrome resources.	All, public	http://li-fraumeni.nl/
United Kingdom			
Health Education England-Genomics Education Programme	Education and resource website on genomics and precision medicine. Provides links to image and video resources and to online and taught courses in genomics.	All	https://www.genomicseducation.hee.nhs.uk/
Telling Stories, Understanding Real Life Genetics	Story based video clip teaching and learning resource. Includes clinical genetics, ethical, legal and social implications, family history, genetic conditions, genetic counseling, genetic/genomic testing, risk assessment.	All	http://www.tellingstories.nhs.uk/
GenEquip - Genetics Education for Primary Care	Online case-based learning modules, educational webinars and practical tools for practice.	All	https://www.primarycaregenetics.org/?page_id=109&lang=en
phgFoundation (Public Health Genomics Foundation)	Independent think tank undertaking commissioned work and other	All, public, O	http://www.phgfoundation.org/

Title	Description/topics	Target audience(s) All providers = All; Nurse = RN; Doctor = MD; Other = O	Downloading information
	projects. Policy documents and reports.		
Your Genome	Information about basic biology, genomes and implications for health and society.	All, O	http://www.yourgenome.org/
United States			
Genetics and Genomics Competency Center (G2C2)	Peer reviewed genomic resource repository.	All	http://genomicseducation.net/
Global Genetics and Genomics Community	Online, unfolding, interactive case studies with simulated patients.	All	http://genomicscases.net/en
Method for Introducing a New Competency (MINC)	Toolkit is to assist those interested in integrating genomics into practice.	All	http://genomicsintegration.net/
Omics Nursing Science and Education Network (ONSEN)	Facilitate investigator driven Omic research through a collaborative research network infrastructure providing information, resources, and networking opportunities.	All	http://omicsnursingnetwork.net