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## Establishing the Omics Nursing Science & Education Network

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### Abstract

**Purpose:** To establish a website to advance nursing research and education involving omics technologies and methodologies through facilitating collaborations, use of existing data and samples, mentoring, and access to training opportunities.

**Methods:** The Omics Nursing Science & Education Network (ONSEN) website was established following identification of gaps in omics nursing infrastructure and resources that could be addressed via a concerted, collaborative effort. ONSEN content was created using input from a workgroup of experts in genomics and other omics, education, practice, and nursing research. Alpha testing was conducted with workgroup members, followed by website refinements and enhancements, and subsequent beta testing by potential end users. ONSEN was launched in August 2018.

**Findings:** ONSEN has three main sections. The Education and Training section provides information on mentoring and pre- or postdoctoral opportunities in addition to a knowledge matrix to advance education and skills in genomic nursing science. The Research Collaborations section promotes awareness of ongoing omics nursing research in order to foster collaborations and sharing of samples or data among investigators with programs in omics nursing research or an interest in developing such programs. The Common Data Elements (CDE) section provides information on the benefits of incorporating CDEs into nursing science as well as links to National Institutes of Health resources to facilitate use of CDEs.

**Conclusions:** ONSEN provides opportunities for nurse scientists and trainees to leverage samples and datasets, locate mentors and pre- or postdoctoral positions, further the use of CDEs, and enhance education and skills for integrating omics into nursing science.

**Clinical Relevance:** Advancing omics nursing science via ONSEN resources will accelerate the elucidation of the molecular underpinnings of disease and associated symptoms as well as inform

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the development of rapidly translatable, personalized intervention strategies, grounded in biological mechanisms, for improved health outcomes across populations and the lifespan.

### Keywords

Collaborations; omics; training

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The benefit of incorporating omics into nursing research is well established (Ferranti, Grossmann, Starkweather, & Heitkemper, 2017; Grady & Collins, 2003; McCall et al., 2018). In addition to the ability to study the genome, including DNA sequences, variants, and function (genomics), we now have tools to interrogate the products of the genome, including RNA transcripts (transcriptomics), proteins (proteomics), and metabolic products (metabolomics), as well as tools for examining modifications to the DNA that impact gene expression without altering the DNA sequence (epigenomics), such as attachment of methyl (CH<sub>3</sub>) groups to specific regions of the DNA strand (methylation). Microbiota that inhabit humans have also been shown to influence health and disease, and the ability to use molecular-based methods to study microbial communities and diversity (microbiomics) has added another dimension to the nursing science questions that can be addressed.

In this era of rapid molecular advances combined with high-throughput analytical technologies, it is possible to collect omics information quickly and cost effectively. These data are critical for elucidating the molecular mechanisms underlying the risk, manifestation, and trajectory of disease and associated symptoms, for identifying biological signatures that associate with adverse health outcomes, and for informing the development of intervention strategies (grounded in biological mechanisms) for improved health and quality of life.

As a result of federally supported research and research training programs in addition to capacity-building efforts (e.g., the National Institute of Nursing Research's [NINR's] Summer Genetics Institute), resources and initiatives from national and international professional societies (e.g., Council for the Advancement of Nursing Science, International Society of Nurses in Genetics), and increased integration of omics into nursing curricula, the nurse scientist community is well-positioned to incorporate innovative, omics-based approaches into studies targeting improved outcomes in diverse populations and across the lifespan. This is evidenced by numerous published studies on diverse topics with relevance to nursing science.

Examples of nursing science omics studies include employing genomic, proteomic, metabolomic, and microbiome approaches to enhance the understanding of the molecular underpinnings of symptoms associated with irritable bowel syndrome (Han, Jarrett, Cain, Jun, & Heitkemper, 2019; Heitkemper et al., 2018), identification of genetic variants associated with neurological outcomes in patients experiencing traumatic brain injury (Adams et al., 2018; Osier, Conley, Okonkwo, & Puccio, 2018) and aneurysmal subarachnoid hemorrhage (Donnelly et al., 2015), genetic polymorphisms associated with psychoneurological symptoms in breast cancer survivors (Yang et al., 2019), contributions of microRNAs and microbiota diversity to chronic wound healing (Liang et al., 2016; Loesche et al., 2017), and identification of single nucleotide polymorphisms associated with analgesic failure and high emergency department use in sickle cell disease patients (Jaja et al.,

2015). Globally, the international nursing community is also active in conducting nursing science omics studies. Examples include genomic contributions to suicide attempts (Rao et al., 2018) and exploring genetic risks for depression and functional outcomes following ischemic stroke (Gill et al., 2019). These and other advances will continue to generate the evidence for development of omics-guided, translatable interventions and patient care strategies with the potential to transform nursing practice and policy.

## Background

### Creating the Genomic Nursing Science Blueprint

While the breadth and scope of omics nursing science continues to expand, the nurse scientist community nevertheless recognizes that in order to continue or accelerate this expansion there is a need for targeted resources and infrastructure to facilitate identification of gaps in nursing science that can be addressed through omics, to harness advances across scientific disciplines that can shape future omics nursing studies, and to incentivize the next generation of nurse scientists to incorporate omics approaches as they develop their own programs of research. In 2012, the National Institutes of Health (NIH; National Cancer Institute, National Human Genome Research Institute, and the NINR) convened the Genomic Nursing State of the Science Advisory Panel of experts in genomics, education, practice, and nursing research. These experts were tasked with identifying critical genomics problems important to the health of the public that can be addressed through nursing science, and to establish a research blueprint based on gaps in the evidence and expert evaluation of the current state of the science (Genomic Nursing State of the Science Advisory Panel et al., 2013). The final product, the Genomic Nursing Science Blueprint, provides a framework for furthering genomic nursing science to improve health outcomes in addition to delineating research topics for building the evidence of the value of genomic information for advancing nursing science. Training future nurse scientists in genomics was also underscored as a priority.

### Operationalizing the Genomic Nursing Science Blueprint

The Blueprint was followed in 2013 by the Genomic Nursing Science Workshop. The Workshop used a consensus-building, interactive “innovative questions” format that provided a forum for experts from the extramural community to propose research questions relevant to the Genomics Nursing Science Blueprint and aligned with the NINR’s Strategic Plan (Tully & Grady, 2015). The goal was to guide the science over the next 5 to 10 years.

In 2014, the NIH convened a second advisory panel tasked with identifying strategies to operationalize the recommendations outlined in the Genomic Nursing Science Blueprint meeting report (Jenkins, 2014). The Advisory Panel’s overall vision at the outset was a platform, easily accessible and beneficial to trainees through senior investigators and nursing faculty, that could facilitate ongoing omics nursing research, promote collaborations and partnerships, support trainees’ efforts to access information on opportunities and mentorship, and provide a framework to accelerate omics nursing education. To help achieve this vision, the Advisory Panel identified five action items: (a) creation of the Genomic Research Consortium; (b) identification of common data elements (CDEs); (c) development of

strategies to enhance the education, training, and career development of nurse scientists in the area of genomics; (d) identification of core educational elements for genomic nurse scientists; and (e) identification of core elements needed for a web-based platform in support of genomic nurse scientists.

## Methods

### Website Development

To address the Advisory Panel's five action items, three workgroups were assembled consisting of extramural investigators and nursing leaders, each led by an NIH coordinator. These included the Enhancing Research Collaborations Workgroup, the Common Data Elements Workgroup, and the Education and Training Workgroup. The activities of the workgroups served as the foundation for creation of the Omics Nursing Science & Education Network (ONSEN).

### Alpha and Beta Testing

Alpha testing, designed to evaluate ONSEN website content and functionality, was conducted with workgroup members. This was followed by revision and enhancements to the website based on the findings.

Following implementation of the revisions, beta testing was conducted on the "test" website with 83 attendees from the NINR August 2017 Precision Health: From 'Omics' to Data Science Boot Camp. This group included mostly nurses but some non-nurses (16%). Participants held PhD degrees (40%) or master's-level degrees (20%), or were graduate students (40%). All (100%) reported an interest in big data, omics, and precision health. The beta test consisted of an ONSEN website activity in which participants were asked to enter the ONSEN website and review its content and features, set up an account, complete one form of their choosing, search for a mentor or project, find the NIH Common Data Elements Resource Portal, and find the Genomic Knowledge Matrix Systems Physiology section. As they progressed through the website, participants were instructed to record their response to a series of questions on a paper form. This was followed by a talk aloud session with facilitators. Feedback was compiled and classified into priority and second tier revisions. All priority revisions were addressed prior to the launch of the website.

## Results

### Omics Nursing Science & Education Network

ONSEN (<https://omicsnursingnetwork.net/>; Figure 1) is an open-access, free, searchable website intended to support nurse scientist trainees, investigators, and educators both nationally and internationally, with the goal of advancing omics nursing science by facilitating collaborations, mentoring, and access to training opportunities. ONSEN has three main sections. The Research Collaborations section promotes awareness of ongoing omics nursing research in order to foster collaborations and sharing of samples or data among investigators with programs in omics nursing research or an interest in developing such programs. The CDE section provides information on the benefits of incorporating CDEs into

nursing science as well as links to NIH resources to facilitate use of CDEs. The Education and Training section provides information on mentoring and pre- or postdoctoral opportunities in addition to a knowledge matrix to advance education and skills in omics nursing science.

### Research Collaborations

There are two main features of the Research Collaborations page (Figure 2). The project data collection form is used by investigators to provide information on the origin and types of data or samples that are available for sharing in addition to descriptions of the research that generated the samples or data, the platforms used for collecting omics data, and demographic and phenotype details. The second feature is a searchable database of project data collection forms, designed to assist other researchers to identify potential partnerships or to leverage existing resources to initiate or advance their own programs of research. It is anticipated that this second feature will be especially useful to trainees and early investigators.

### Common Data Elements

The CDE section (Figure 3) provides opportunities to learn more about the use of CDEs for advancing nursing science, and to access information on CDE resources and efforts. The NIH defines a CDE as “a data element that is common to multiple data sets across different studies” (<http://www.nlm.nih.gov/cde>). Investigators are encouraged to use CDEs in clinical research, patient registries, and other human subject research in order to improve data quality and opportunities for comparison and combination of data from multiple studies and with electronic health records. CDEs continue to be addressed by the nurse scientist community (Redeker et al., 2015), and the resources on ONSSEN’s CDE page will help guide investigators in strengthening their research via incorporation of CDEs.

### Education and Training

The Education and Training section (Figure 4) consists of three main features, the genomic knowledge matrix, mentorship opportunities, and pre- or postdoctoral opportunities. The genomic knowledge matrix outlines the key knowledge and skills needed for nurses to integrate omic science into their research (Regan, Engler, Coleman, Daack-Hirsch, & Calzone, 2019). The mentorship opportunities content provides a mechanism for researchers interested in omics nursing science to find one another. Users can both post their willingness to serve as a mentor or search for mentors based on location or area of omics research. Lastly, the centralized list of pre- or postdoctoral training positions in omics nursing science provides a mechanism for students to find training opportunities.

### Discussion

ONSSEN provides opportunities to leverage existing samples and data from other investigators, as well as to find a research collaborator, mentor, or pre- or postdoctoral position, resources to further the incorporation of CDEs into omics nursing science, and a knowledge matrix to build the knowledge and skills needed to effectively integrate omics into nursing research. ONSSEN was developed following input from an advisory panel that

expressed the need for resources and infrastructure to expand the body of omics nursing research and to help prepare the next generation of nurse scientists to integrate omics as they build their programs of research. The impetus for ONSSEN was in part a recognition that while there is interest across training and career trajectories in embracing an omics approach for addressing nursing science questions, several institutions, especially smaller, less research-intensive institutions as well as the international nursing research community, may lack the infrastructure to support such interests. It is the goal of ONSSEN to provide an open-access, free, easily assessable, interactive, and searchable website to help address this gap. Additionally, a key objective of ONSSEN is to facilitate achieving research priorities identified in the Genomic Nursing Science Blueprint.

It is also important to note that progress in omics nursing research remains limited to a few countries. As such, there remains a need to advance the omics research agenda with broader global and more diverse populations. Establishment of the Global Genomics Nursing Alliance coupled with the International Society of Nurses in Genetics provides the collaborative infrastructure to begin to fill this evidence gap (Calzone et al., 2018). But to achieve this aim requires mechanisms that can be accessible to the global nursing research community such as a web-based platform like ONSSEN.

ONSSEN's resources are also not limited to nurse scientists that are primarily engaged in bench science. Specifically, the genomic knowledge matrix can benefit educators in developing nursing PhD curricula. CDEs are not bench science specific and have applications across scientific topics and disciplines. Importantly, ONSSEN can provide opportunities to advance behavioral and other research without the need to acquire bench skills or have access to an operational laboratory. As an example, omics data have the potential to shed light on the observed interindividual differences in response to behavioral interventions among persons with seemingly similar disease or symptoms. As such, the Research Collaborations page of ONSSEN can be used to post information on a behavioral intervention study and seek a bench scientist collaborator to analyze archived or newly collected biological samples to determine the contribution, if any, of omic variants to the intervention response, especially for those studies in which the intervention did not demonstrate efficacy or that found wide variation in intervention response. The authors encourage the nurse scientist community to seek innovative ways to advance nursing science via ONSSEN.

While the initial feedback on ONSSEN from the nurse scientist community has been positive, the authors acknowledge that the benefit and sustainability of ONSSEN hinges upon its utilization by nurse scientists who post information to the website in addition to the enthusiasm of trainees and others in the nurse scientist community to pursue ONSSEN's resources. It is also recognized that ONSSEN cannot remain static and must evolve to reflect scientific advances as they emerge. For example, until fairly recently, omics nursing focused primarily on genomics; this has now expanded to include multiple omics, presenting novel and exciting challenges and opportunities to increase the breadth of nursing science questions that can be addressed. There is no doubt that this trend will continue going forward.

## Conclusions

It is evident that omics will continue to play a prominent role in nursing research, and that this role will expand with the emergence of new omics discoveries and high-throughput innovations that rapidly and cost-effectively generate omics data. Going forward, as we continue our efforts to implement a precision health approach to nursing research, it will be increasingly essential for nurse scientists to acquire the omics-based skills and tools needed to generate scientific advances and translate such advances into patient care strategies. ONSEN provides an open access, free platform to help achieve this goal by fostering opportunities to leverage resources, build collaborations nationally and internationally, and optimize education and training strategies aimed at achieving the Genomic Nursing Science Blueprint research recommendations effectively and collaboratively.

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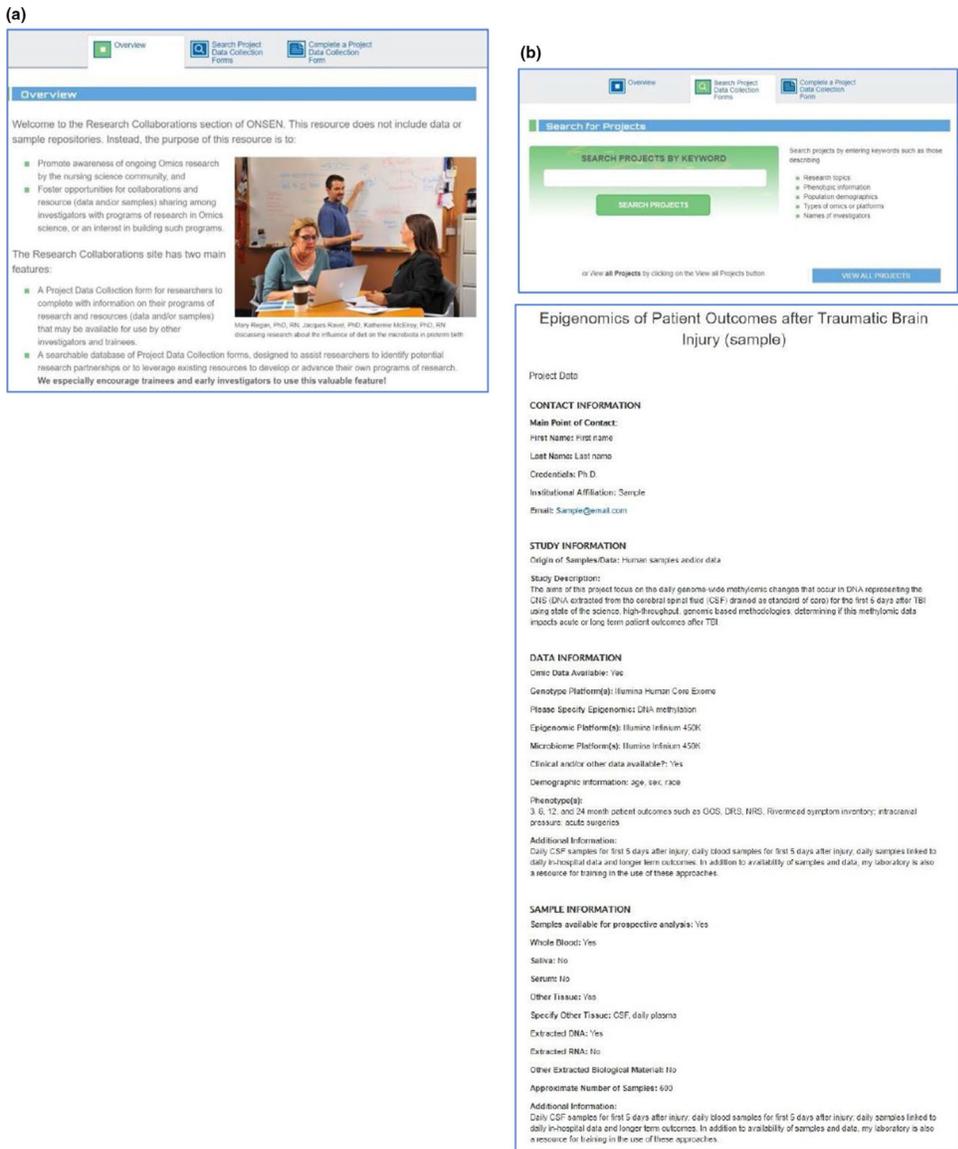
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### Clinical Resources

- Global Genomics Nursing Alliance. <https://g2na.org/>
- International Society of Nurses in Genetics. <https://www.isong.org/>
- National Institute of Nursing Research. <https://www.ninr.nih.gov/>
- Omics Nursing Science & Education Network. <https://omicsnursingnetwork.net/>



**Figure 1.** Omics Nursing Science & Education Network (ONSEN) home page.



**Figure 2.** Omics Nursing Science & Education Network (ONSEN) Research Collaborations section. (a) Research Collaborations overview. (b) Collaborations and data/sample sharing opportunities.

(a)

*Common Data Elements*

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**Overview**

The goal of the Common Data Elements section of ONSEN is to inform existing nurse scientists and academic faculty training nurse scientists seeking to expand their scholarship into Omics, and to develop strategies to promote Omics nursing science. These efforts are all aimed at achieving the Genomic Nursing Science Blueprint research recommendations more quickly, efficiently, effectively, and collaboratively.



Jacquelyn Y. Taylor, PhD, RN is having DNA samples from her blood pressure study analyzed.

(b)

**Quick Links**

Links for More Information about CDEs

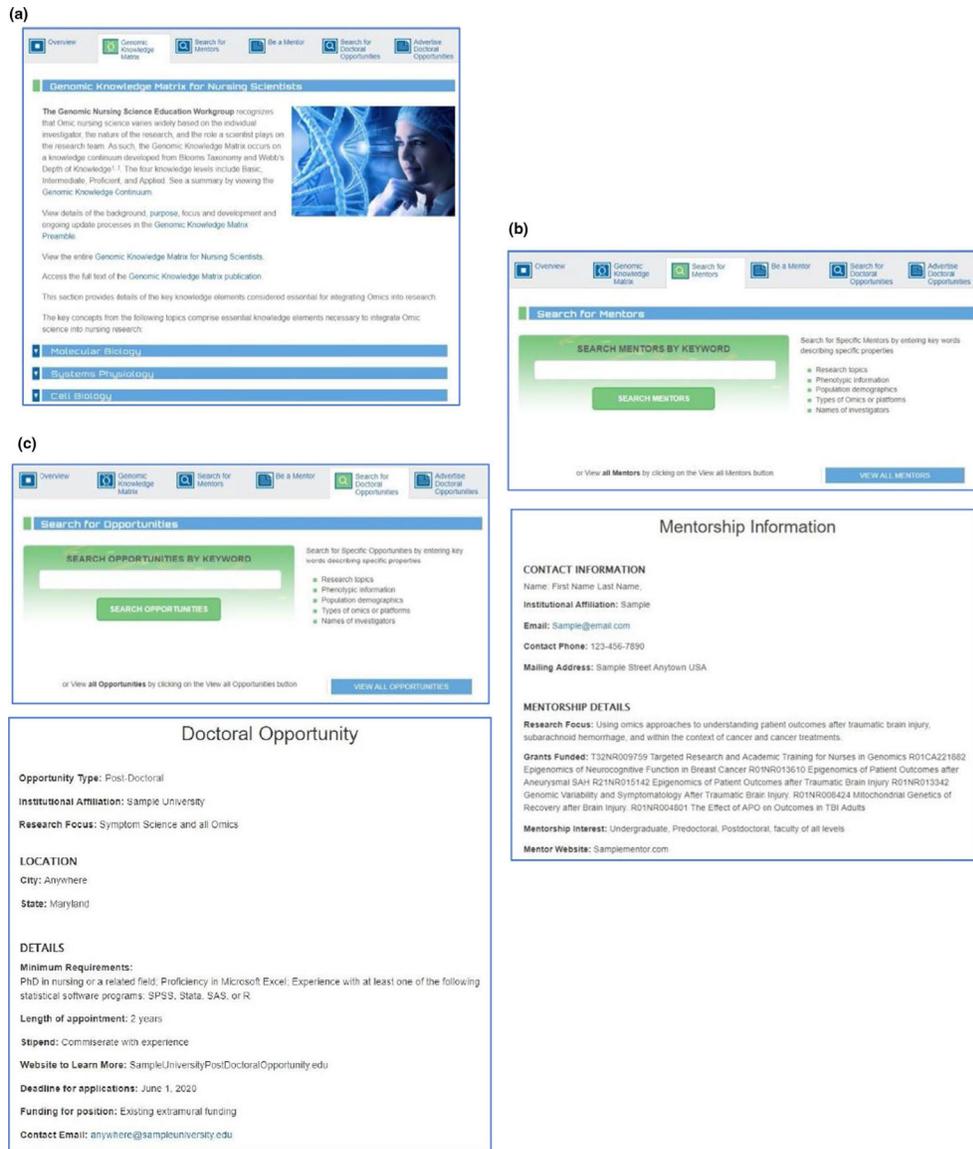
**National Institutes of Health (NIH)**

- Main CDE resource portals for NIH: Browse these websites to links to all NIH CDE collections, subject areas for CDEs, and a summary table of NIH CDE tools
  - <http://www.nlm.nih.gov/cde/>
  - <https://cde.nlm.nih.gov/cde/search>
- NIH CDE resource summary by initiatives and tools: Find information on various databases where CDE definitions and databases are found including PROMIS and PhenX, tools for CDE collection such as REDCAP, and data standards such as SNOMED
  - <http://www.nlm.nih.gov/cde/summaries.html#cLBP>
- NIH data sharing repositories by Institute: Search data sharing repositories across the NIH
  - [https://www.nlm.nih.gov/NIHbmic/nih\\_data\\_sharing\\_repositories.html](https://www.nlm.nih.gov/NIHbmic/nih_data_sharing_repositories.html)

**National Institute of Nursing Research (NINR)**

- Overview of NINR's efforts at defining CDEs
  - <https://www.ninr.nih.gov/researchandfunding/cdes-moreinfo#VwPg9xv2aUn>

**Figure 3.** Omics Nursing Science & Education Network (ONSEN) Common Data Elements (CDE) section. (a) CDE overview. (b) CDE resources (partial).



**Figure 4.** Omics Nursing Science & Education Network (ONSEN) Education and Training section. (a) Genomic knowledge matrix. (b) Mentorship opportunities. (c) Doctoral opportunities.