



Precision health: Advancing symptom and self-management science

Kathleen T. Hickey, EdD, RN, FNP-BC, ANP-BC, FAHA, FAAN^a,
Suzanne Bakken, PhD, RN, FAAN, FACMI^{b,*},
Mary W. Byrne, PhD, DNP, MPH, FAAN^{c,d}, Donald (Chip) E. Bailey, PhD, RN, FAAN^e,
George Demiris, PhD, FACMI^f, Sharron L. Docherty, PhD, PNP-BC, FAAN^e,
Susan G. Dorsey, PhD, RN, FAAN^{g,h}, Barbara J. Guthrie, PhD, RN, FAANⁱ,
Margaret M. Heitkemper, PhD, RN, FAAN^j,
Cynthia S. Jacelon, PhD, RN-BC, CRRN, FGSA, FAAN^k,
Teresa J. Kelechi, PhD, RN, FAAN^l, Shirley M. Moore, PhD, RN, FAHA, FAAN^m,
Nancy S. Redeker, PhD, RN, FAHA, FAANⁿ, Cynthia L. Renn, PhD, RN^o,
Barbara Resnick, PhD, RN, CRNP, FAAN, FAANP^p,
Angela Starkweather, PhD, RN, ACNP-BC, CNRN, FAAN^q,
Hilaire Thompson, PhD, RN, ARNP, CNRN, AGACNP-BC, FAAN^r,
Teresa M. Ward, PhD, RN^r, Donna Jo McCloskey, PhD, RN, FAAN^s,
Joan K. Austin, PhD, RN, FAAN^{s,t}, Patricia A. Grady, PhD, RN, FAAN^s

^aCardiac Electrophysiology, Columbia University School of Nursing, Columbia University Medical Center, New York, NY

^bSchool of Nursing and Department of Biomedical Informatics, Columbia University, New York, NY

^cDepartment of Anesthesiology, Columbia University School of Nursing, Columbia University College of Physicians and Surgeons, New York, NY

^dCenter for Children and Families, Columbia University School of Nursing, Columbia University College of Physicians and Surgeons, New York, NY

^eDuke University School of Nursing, Durham, NC

^fUniversity of Pennsylvania, School of Nursing, Philadelphia, PA

^gDepartment of Pain and Translational Symptom Science, School of Medicine, University of Maryland Baltimore, Baltimore, MD

^hDepartment of Anesthesiology, School of Medicine, University of Maryland Baltimore, Baltimore, MD

ⁱBouve College of Health Sciences, Northeastern University School of Nursing, Boston, MA

^jDepartment of Biobehavioral Nursing and Health Informatics, University of Washington School of Nursing, Seattle, WA

^kUniversity of Massachusetts Amherst College of Nursing, Amherst, MA

^lMedical University of South Carolina, College of Nursing, Charleston, SC

^mFrances Payne Bolton School of Nursing, Case Western Reserve University, Cleveland, OH

ⁿSection of Pulmonary, Critical Care and Sleep Medicine, Yale University, New Haven, CT

^oDepartment of Pain and Translational Symptom Science, University of Maryland Baltimore, Baltimore, MD

^pOrganizational Systems and Adult Health Nursing Department, University of Maryland Baltimore, Baltimore, MD

* Corresponding author: Suzanne Bakken, Columbia University, 560 West 168 Street, New York, NY 10032.

E-mail address: sbh22@cumc.columbia.edu (S. Bakken).

0029-6554/\$ -see front matter © 2019 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license. (<http://creativecommons.org/licenses/by-nc-nd/4.0/>)

<https://doi.org/10.1016/j.outlook.2019.01.003>

[¶]University of Connecticut School of Nursing, Storrs, CT
[†]University of Washington School of Nursing, Seattle, WA
[§]National Institute of Nursing Research, Bethesda, MD
[‡]Indiana University School of Nursing, Bloomington, IN

ARTICLE INFO

Article history:

Received 3 May 2018
 Received in revised form
 9 January 2019
 Accepted 15 January 2019
 Available online January 18,
 2019.

Keywords:

Precision health
 symptom science
 Air self-management
 Major nursing
 informatics
 data science

ABSTRACT

Background: Precision health considers individual lifestyle, genetics, behaviors, and environment context and facilitates interventions aimed at helping individuals achieve well-being and optimal health.

Purpose: To present the Nursing Science Precision Health (NSPH) Model and describe the integration of precision health concepts within the domains of symptom and self-management science as reflected in the National Institute of Nursing Research P30 Centers of Excellence and P20 Exploratory Centers.

Methods: Center members developed the NSPH Model and the manuscript based on presentations and discussions at the annual NINR Center Directors Meeting and in follow-up telephone meetings.

Discussion: The NSPH Model comprises four precision components (measurement; characterization of phenotype including lifestyle and environment; characterization of genotype and other biomarkers; and intervention target discovery, design, and delivery) that are underpinned by an information and data science infrastructure.

Conclusion: Nurse scientist leadership is necessary to realize the vision of precision health as reflected in the NSPH Model.

Cite this article: Hickey, K.T., Bakken, S., Byrne, M.W., Bailey, D.(E.), Demir, G., Docherty, S.L., Dorsey, S.G., Guthrie, B.J., Heitkemper, M.M., Jacelon, C.S., Kelechi, T.J., Moore, S.M., Redeker, N.S., Renn, C.L., Resnick, B., Starkweather, A., Thompson, H., Ward, T.M., McCloskey, D.J., Austin, J.K., & Grady, P.A. (2019, July/August). Precision health: Advancing symptom and self-management science. *Nurs Outlook*, 67(4), 462–475. <https://doi.org/10.1016/j.outlook.2019.01.003>.

Introduction

Precision health is most often described in relationship to precision medicine with authors identifying both commonalities and distinctions. Precision medicine is defined as “the emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person” (NIH, 2018c). The purpose of tailoring the unique characteristics of an individual to medical treatment and preventive measures is to achieve optimal health outcome for each patient/person. Through analysis of large data, precision medicine’s goal is to enhance understanding and use of genetics, environment, and lifestyle factors essential for understanding spectrum of care from prevention through treatment (Kellogg, Dunn, & Snyder, 2018). The aim is to discover factors that have the potential to contribute to or prevent illness. Such discoveries are used to provide the right treatment, for the right individual, at the right time. Inherent in this approach is the importance of individuals taking an active part in their health care and health promoted related decisions. This can potentially lead to cost savings for the individual and society (House, 2015).

Minor was one of the first to differentiate and extrapolate the prevention aspect of precision medicine (Minor, 2016). He suggested that there is a critical need

to not only focus on curing and treatment but also to focus more intensely on the prevention aspect of precision medicine. This can be done by operationalizing precision health which considers individual lifestyle, genetics, behaviors, and environment context and is used to facilitate interventions aimed at helping individuals achieve well-being and optimal health. Multiple authors further suggested that there are three domains of precision health: (a) successfully developing and implementing lifestyle interventions within diverse settings; (b) effectively and efficiently identifying who will maximally benefit from the intervention within those settings; and (c) effectively engaging and retaining the diversity of individuals’ experiences while being cognizant of the variation, quality, and availability of resources, expertise, and policies that have the potential to influence the individual’s experiences, health behaviors, and lifestyles (Khoury & Evans, 2015; Khoury & Galea, 2016). Precision health interventions are adjusted or tailored to the variations in individuals’ biology, genetics, behaviors, lifestyle, and environment at base line and over time (Khoury & Evans, 2015; Khoury & Galea, 2016; Khoury, Gwinn, Glasgow, & Kramer, 2012). Khoury and Evans further stated that like precision medicine, precision health involves the use of aggregation and analysis of large volumes of data to produce generalizable knowledge.

The focus on prevention, management, and alleviation of symptoms is perhaps nursing science's greatest contribution to precision health, characterized by symptom prevention and reduction, as well as quality of life improvement while maintaining a disease agnostic lens (Cashion, Gill, Hawes, Henderson, & Saligan, 2016). Underpinned by the National Institute of Nursing Research's (NINR) Symptom Science Model (Cashion & Grady, 2015), NINR-funded P20/P30 Centers are poised to align symptom science within the varying contexts of precision health including "omics" approaches (e.g., epigenetics/genomics and microbiome), behavioral science including self-management, and sociocultural as well as physical environment.

Incorporating the concept of precision health into ongoing research is of particular and growing importance to nursing scientists who focus on symptom and self-management science. The concept also is significant for the development, testing, and targeting of nursing interventions across the health care continuum (Cashion & Grady, 2018). The NINR also emphasizes the development of symptom science and self-management of chronic conditions and the application of precision health methods to address these major health concerns (NIH; NINR, 2016). This requires careful conceptualization of precision health's role and the integration of multiple data sources (e.g., phenotype including lifestyle and environmental factors, genotype, and other biomarkers) supported by an information and data science infrastructure (Page et al., 2018; Starkweather et al., 2018).

The purpose of this paper is to describe the application of a precision health approach to symptom and self-management research. We introduce the Nursing Science Precision Health (NSPH) Model; describe the application of

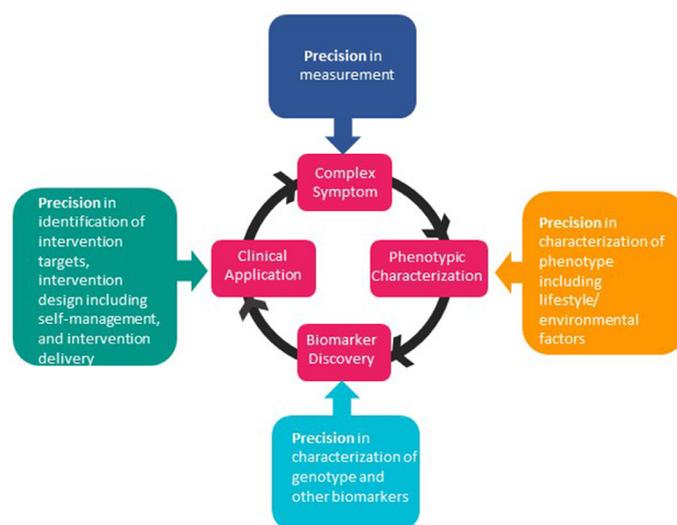
precision health approaches for advancing the science of symptom and self-management using examples from the NINR Symptom and Self-Management P20/P30 Centers; consider the role of precision health across the translational continuum from bench to population; and discuss the needs for information and data science infrastructure, research partnerships, and ethical considerations.

This paper is one of a series of publications on symptom and self-management science (Moore et al., 2016; Page et al., 2018; Redeker et al., 2015). These papers emerged from the collected work of the Center Directors held annually at the National Institutes of Health (NIH). The current paper reports on the evolution of the work begun with presentations and discussions at the 2017 meeting focused on precision health approaches for symptom and self-management research.

Precision Health Approaches for Advancing the Science of Symptom and Self-Management

The Nursing Science Precision Health Model

The NSPH Model includes four precision concepts (i.e., components) that reflect the nursing perspective but may also be of relevance to other scientists: (a) measurement, (b) characterization of phenotype including lifestyle and environmental factors, (c) characterization of genotype and other biomarkers, and (d) intervention target discovery, design, and delivery. This is reflected by the arrows in the model (Figure 1). Environment is used to broadly represent context in the model. The



Information and Data Science Infrastructure for Precision Health
 Data sources: reliable valid standardized survey/measure, health service data, electronic health records, personal health records, image, physiological monitors, behavior sensing devices
 Data integration strategies: common data elements (CDEs), common data models
 Data science components: people (data contributors, generators, users), data, technologies (e.g., accessible research repositories, cloud services, software, data commons), policy frameworks

Figure 1 – The Nursing Science Precision Health Model (NSPH) Applied to Stages of NIH Symptom Science Model. The four precision components in the boxes with arrows and the information and data science infrastructure comprise the NSPH. These components can be applied to different phenomena as illustrated by the example of the stages of the NIH Symptom Science Model.

application of precision approaches is enabled by an information and data science infrastructure, considered the fifth component of the NSPH Model. The five model components can be applied to different phenomena. This is illustrated in [Figure 1](#) through the example of symptom science in which the stages of the NIH Symptom Science Model ([Cashion et al., 2016](#)) are used as targets for precision health. Given the focus of the P20/P30 Centers, the application of precision health to symptom science and self-management research is further described in the following sections.

Precision Health and Symptom Science

From a precision health perspective, symptom science focuses on developing personalized (or precision) strategies to diagnose, treat, and prevent the adverse symptoms of illness across diverse populations and settings. Precision measures may help explain why individuals with the same clinical diagnosis have dissimilar symptoms with different severity, triggers or degree of life interference and diverse responses to pharmacologic and nonpharmacologic therapies. For example, specific biomarkers may reflect tissue damage produced by inflammation that results in pain, nausea, or fatigue ([Page et al., 2018](#); [Starkweather, Lyon, & Schubert, 2013](#)). Omics approaches provide information on potential physiological mechanisms at play (i.e., proteomics and inflammation) and serve as outcome measures (i.e., diet changes and microbiome). Nurse scientists focus on understanding the biological underpinnings of symptoms that are inherently self-reported subjective phenomena and the extent to which they reflect or predict biological risk or vulnerability to changes in health. Several nurse scientists are conducting research that integrates precision health to better understand symptom burden, to predict or prevent disease, and to optimize individual treatment and quality of life improvement ([Cashion & Grady, 2015](#); [Cashion et al., 2016](#); [Lyon et al., 2016](#); [Tantoy et al., 2017](#); [Young et al., 2017](#)). For example, an intramural program of research at NINR is examining the underpinnings of symptom distress mechanisms in digestive disorders, specifically the biobehavioral relationships between inflammation and symptoms ([Henderson, 2013](#)). In particular, Henderson's research is focused on the discovery of the mechanisms involved in symptom distress related to digestive disorders, specifically the biobehavioral relationships between brain-gut microbiota axis and patient symptoms. Through her research, Henderson has demonstrated that chronic gastrointestinal symptoms have an underlying subclinical inflammatory mechanism.

Scientists will use the information emerging from these studies to more precisely target symptom interventions to phenotypes reflecting behavioral, lifestyle, environmental, and biological characteristics. This will assist in providing the right intervention to the right individual at the right time. These approaches will also enable the study of the effects of symptom

science interventions on symptom phenotypes and their biological and/or behavioral underpinnings.

Precision Health and Self-Management

Self- and family management is an ongoing process comprising strategies to help individuals with chronic conditions, and their families and caregivers, to better understand and manage their illness and enhance health behavior in the context of one's environment ([Grey, Knafel, & McCorkle, 2006](#); [Lorig & Holman, 2003](#); [Ryan & Sawin, 2009](#); [Schulman-Green et al., 2012](#)). It includes focusing on self-identified needs or problems that require continual monitoring and taking appropriate actions. Precision health approaches support the identification of relevant self-management intervention targets based on well-characterized phenotypes (e.g., behavioral, environmental, and physiological) as well as design and delivery of the self-management intervention. The Center for Excellence for Self-Management Advancement through Research and Translation (SMART) has shown one way in which precision health can improve self-management. Researchers at SMART are using functional magnetic resonance imaging (fMRI) to evaluate how quickly and efficiently an individual's brain can switch between the neural networks that handle emotional and analytic information, which is associated with the ability to change behavior in response to emotional or analytical information. The goal of this research is to use fMRI results to determine if a particular individual will respond to emotional vs. analytical information and change his or her behavior to better self-manage their symptoms ([Laidman, 2015](#)).

Precision Health Activities of Individual Centers

The P20 and P30 Centers offer unique contributions to precision health by gathering experts around a specific topic (i.e., symptom foci and self-management), integrating various tools or strategies in nursing science such as omics measures, novel technologies and analytic strategies, and garnering resources to mentor and support nurse investigators in leading interdisciplinary teams. While there are similarities and differences across the NINR centers whose main foci are symptom and self-management science, all share the common potential to contribute to precision health in nursing. Exemplars of these center initiatives are included in [Table 1](#) in [Appendix A](#).

Precision Across Translational Research Stages: From the Bench to Population Health

The NIH Roadmap discusses two basic steps of translation. First, basic science research must be translated to humans (*T1 translation*), and then secondarily translated into clinical practice (*T2 translation*) (

nihroadmap.nih.gov/). Further work has demonstrated that this second phase of translation includes two separate steps, first knowledge from T1 translational studies must be translated to patients (T2), and then translated into actual clinical practice (T3 translation) (Westfall, Mold, & Fagnan, 2007). Finally, moving scientific knowledge into population health and thereby changing everyday lives of individuals represents the focus of (T4) (Kon, 2008). These stages of translational research are shown in Figure 2.

Some components of the NSPH model (Figure 1) are more relevant to particular stages of the translational research cycle; for example, the component of “precision in design and delivery of interventions” is most relevant beyond the basic science stage. However, “precision in measurement” is a fundamental principle underpinning the scientific method and as such spans across research stages and an essential component of research reports because each stage provides evidence to support the hypothesis and assumptions of the following stage.

Clinical research using omics-based measures provides an example of the “precision in measurement” component of the NSPH model that is necessary at the basic science stage and beyond. Relevant issues that need to be considered and reported include:

- When and how the specimen was collected, processed, and stored (provenance).
- The duration of time the specimen will be stored and for what future use.

- The minimum amount of specimen required and criteria for screening out inadequate or poor-quality specimens.
- Technical protocols used for assay analysis including instrumentation, reagents, calibrators, analytical standards, and controls.
- Acceptability criteria for the quality of assay batches and assessment of technical artifacts.
- Sufficient detail on how data were cleaned, algorithms used for calculations/normalization, software and version used, and quality measures used to check and secure data workflow.

Additional validation of assay performance is conducted by establishing analytical metrics, including accuracy, precision, coefficient of variation, sensitivity, specificity, linear range, limits of detection, and limits of quantification. Assay performance for prognosis or assessment of risk, as well as for determining treatment, is dependent on the inclusion and exclusion criteria of the sample. Thus, sample selection should be carefully considered when evaluating the application in clinical practice and diverse populations. In addition, tests used to determine treatment in a clinical trial or in clinical practice must be performed in a Clinical Laboratory Improvement Amendments-certified laboratory. Although Clinical Laboratory Improvement Amendments-certified laboratories have these procedures in place, the technical protocols and quality control measures used can be different across laboratories (McShane et al., 2013).

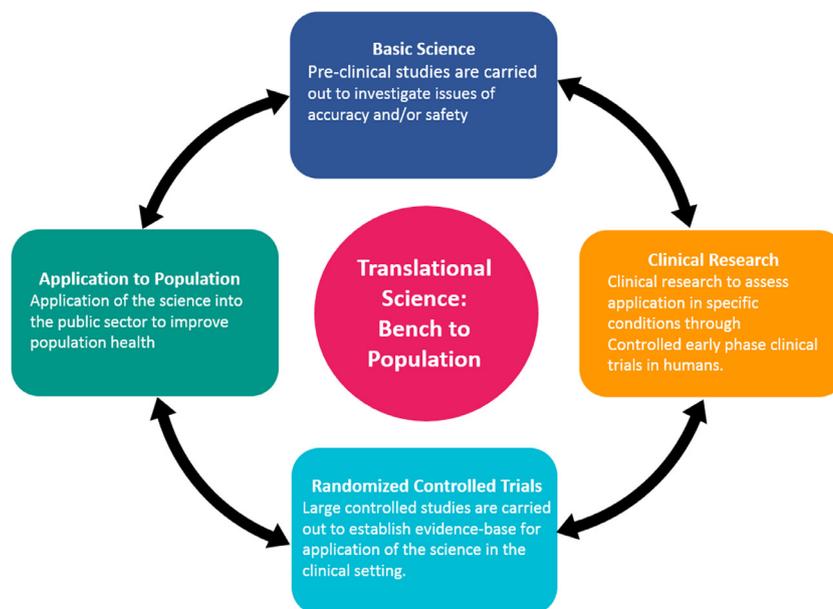


Figure 2 – Translational Science: Bench to Population. Stages of translation (T1–T4) are represented in each of the boxes from the bench (T1) to population health (T4). The accuracy of identifying the mechanisms of a symptom or behavior has implications for the study of self-management in later stages of translation. Boxes in the figure reflect that each stage (T1–T4) of the translational process may inform the need for greater mechanistic understanding of the symptom or behavior, or increased methodological accuracy across research settings. Adapted from Kon, A.A. (1988). *The clinical and translational science award (CTSA) (consortium and the translational research model. American Journal of Bioethics, 8(3), 58-W3.*

Healthcare providers can also use precision approaches to identify the influence of lifestyle and the environment on the onset of pathology even prior to the onset of symptoms, and to reveal the underlying mechanisms of symptoms once they occur. However, in order to reach that level of application and translation, diverse populations need to be involved as the biological phenotypes can vary as a result of the complex interplay between host genes, ancestry of certain phenotypes, lifestyle, culture, environment, diet and gut microbes (Ferranti, Grossmann, Starkweather, & Heitkemper, 2017; Nicholson et al., 2012; Taylor & Barcelona de Mendoza, 2018). For example, obesity is impacted by a variety of lifestyle factors ranging from activity level and diet to career and social activities. Likewise an individual's environment can have a significant impact on feasibility of particular treatment plans, as patients in low income areas may not have access to healthy food options (Go et al., 2013; Healthy-People, 2014). Maintaining precision when evaluating these variables is necessary to translate precision health to the population health level.

Information and Data Science Infrastructure for Precision Health

New Data Sources Support Precision Health Approaches

Improved information and data science infrastructure are needed at the institutional and national levels to fulfill the promise of precision health. Data sources, including traditional methods such as standardized surveys, health services data, electronic health records, personal health records, omic reports, imaging techniques (e.g., fMRI), and physiological monitoring are increasingly complemented by mobile health (mHealth) devices, wearable technology (e.g., actigraphy), and passive monitoring systems that measure biological, behavioral, and environmental characteristics (Bakken & Reame, 2016; Brennan & Bakken, 2015; Colijn, Jones, Johnston, Yaliraki, & Barahona, 2017). Existing online collections of patient-generated data, including symptoms, represent another emerging data source. For example, the *PatientsLikeMe* online community allows patients to share their data in ways that can be used by scientists to conduct observational studies to gain insight into complex symptom experiences or treatment effectiveness (Lejtkowicz, Caspi, & Miller, 2012; Townsend et al., 2015). Passive monitoring technologies can be embedded in the infrastructure of the home, creating the concept of the Smart Home in which various sensors such as motion sensors, bed sensors, temperature, stove sensors, water pressure fluctuations, and door and window sensors contribute to understanding an individual's behavior. Moreover, such technologies overcome research challenges including data collection burden and recall bias (e.g.,

the use of bed and other sensors instead of a sleep diary) and have the potential to increase the efficiency of data capture (Williams, Feero, Leonard, & Coleman, 2017). One example, is in the area of diabetes where integration of these heterogeneous data sources facilitates characterization of the phenotype including lifestyle and environmental factors as well as genotype and other biomarkers, and may be used to target individuals most likely to benefit from symptom or self-management interventions (Arnett & Claas, 2016; Fitipaldi, McCarthy, Florez, & Franks, 2018).

Common Data Elements and Common Data Models Address Challenges in Data Integration

The increase in the types and quantity of data needed for precision health is a challenge to integration that may occur at data capture through use of common data elements (CDEs), by mapping data to a common data model (CDM) prior to analysis, or at the analysis stage. CDEs, standardized definitions of variables with specified responses that facilitate comparison of data across studies (Sheehan et al., 2016), are developed through a formalized process across NIH (Busse, Morgan, Taggart, & Togias, 2012; Grinnon et al., 2012; Moore et al., 2016). CDEs address the challenge of the wide array of measures and approaches used to measure common symptoms including poor sleep, pain, breathlessness, depression, and fatigue, and self-management concepts such as engagement, motivation, activation, and self-efficacy (Lorig & Holman, 2003; Lyon et al., 2014; Moore et al., 2016; Saad et al., 2014). In collaboration with NINR, Center Directors continue to lead initiatives related to the selection and use of CDEs for specific symptoms and self-management components including behavioral measures (Moore et al., 2016; Redeker et al., 2015) and biomarkers (Page et al., 2018). The use of CDMs, such as the Observational Health Data Sciences and Informatics Observational Medical Outcomes Partnership CDM, in which data from heterogeneous sources are mapped to the CDM prior to analysis, facilitate the exchange of data from multiple sources, encourage the reuse of data, and facilitate the collection of observational clinical data (Garza, Del Fiol, Tenenbaum, Walden, & Zozus, 2016). In integration at the data analysis stage, analyses are conducted separately (e.g., in different organizations) and then the results are combined for interpretation.

Data Science Methods Enable Precision Health

Data science methods need to be incorporated in the infrastructure to support precision health throughout the research process as shown in the NSPH Model (Figure 1). Data science is most often considered in relationship to Big Data, which has the characteristics of high volume, velocity (e.g., data in motion), variety, and veracity (i.e., biases, "missingness," nonnormal distributions). At the NINR 2017 meeting, Brennan stated, "Data science is not just statistics on steroids" (Brennan, 2017). Data science proceeds on the

perspective that the precision, control, and integrity of the data are introduced at the point of the analytics, not at the point of data capture. Discovery through large volumes of data with an unpredictable velocity and unknown level of veracity requires analytics that differ from inferential statistics. Data science analytics are not held to the same constraints as traditional inferential statistics in part because the focus is often the population rather than a sample. Rather, data science, informed by domain expertise and imagination, is a new pathway to discovery (Brennan & Bakken, 2015). New study designs and analytic methods are needed that support the integration of different types of data, including biological, behavioral, environmental, social, and self-report. Expertise in large data, longitudinal, and cohort analyses is imperative in order to manage issues associated with large data sets and longitudinal studies, including nonlinearity, heterogeneity, and missing data. Examples of applicable analytic approaches include systems modeling and other predictive models, network analysis, visualization methods (i.e., forest plots and vector analysis), growth mixture modeling, latent curve analysis, propensity scores, survival analysis, classification and regression trees, and machine learning, including deep learning, via neural networks.

NIH Investments in Information and Data Science Infrastructure to Support Precision Health

NIH has made a significant investment in an information and data science infrastructure. The four main interconnected component categories supporting progress in precision health at NIH are People, Data, Technologies, and Policies (“All of Us,” 2018; “Data Science,” 2017; “National Information Center on Health Services Research and Health Care Technology (NICHSR),” 2001).

People

People include the data contributors such as individual participants, businesses and markets, and government; the data generators including all those in the care delivery systems and researchers; and the data users such as clinicians, researchers, policy makers, and the public. There is a substantial need for researchers with data science competencies. The National Library of Medicine is investing in data science competency development for informaticians through its institutional training programs, and NINR has held a series of week-long boot camps aimed at advancing data science and precision health competencies (NIH, 2003, 2018a). In addition, the National Human Genome Research Institute at the NIH released the Method for Introducing a New Competency: Genomics toolkit to assist healthcare providers to integrate genomics and new scientific discoveries into patient care. (NIH, 2017) To further aid nursing

researchers interested in including omics in their research programs, the NIH developed the Omics Nursing Science and Education Network. The Omics Nursing Science and Education Network website provides general education on omics, information on CDEs, and opportunities for collaboration and mentorship. (NIH, 2018b) Through its investments in the P20/P30 Centers program, NINR supports education in data-driven precision health for nurse scientists and nurse scientists in training.

Data

The basic goal of useful data in any repository is that it meets the Findable, Accessible, Interoperable, and Reusable (FAIR) criteria. Meeting the FAIR goals is significantly supported by use of CDEs that are structured to allow both human and machine access and discovery (Wilkinson & Dumontier, 2016). As a starting place to advance nursing science, NINR’s Centers program is contributing to both the development and storage of CDEs relevant to symptom science. However, there is a need to harmonize similar CDEs, propose new CDEs, and promote efficient processes for accessing and searching CDE repositories.

Technology

The expansion of data collection in general, the granularity of the omics data, and the increasingly graphic/image-based nature of clinical data is pushing storage capacity. Other technology needs include accessible research repositories and cloud services, data and user communications within the repositories, software for discovery/analytics/visualization, and the establishment of a “Data Commons” that will ensure usability and fine-grain data access. The size of our emerging datasets already often require bringing analytics to the data, as opposed to transporting the data. A Data Commons would support this approach.

Policy Frameworks

Policy frameworks support data-driven precision health goals including safe and trustable ways to manage genomic, clinical, and patient-generated data, and refined concepts of confidentiality and privacy to fit the models of data-driven discovery, data-informed care, as well as expanded requirements for data sharing. Moreover, beyond policy frameworks at the NIH level, policy frameworks are needed to inform prompt access at the institutional level to important NIH resources such as Clinical Genome Resource—“an authoritative central resource that defines the clinical relevance of genes and variants for use in precision medicine and research” (clinicalgenome.org). These evolving policies will require public engagement in balancing open science with research participant privacy and confidentiality in the context of precision health.

Ethical Considerations for Precision Health

Researchers and healthcare providers must consider a variety of ethical issues when designing and implementing precision health studies, and when applying precision health approaches to a specific patient or population. Using the Belmont Report principles of respect for persons, beneficence, and justice that undergird the Federal Policy for the Protection of Human Subjects also known as the Common Rule, nurse scientists have delineated important considerations for precision health from the perspective of omics (Williams & Anderson, 2018) and big data for symptom science (Bakken & Reame, 2016). Respect for persons is primarily enabled through informed consent. Omics considerations include understandable informed consent process with key point summary and details regarding potential domains of personal utility and broad consent for possible future use (Williams & Anderson, 2018). Respect for persons can be threatened by the increasing availability of data science approaches that support data extraction and integration and may reveal information that individuals have chosen to not to disclose (Cato, Bockting, & Larson, 2016) as well as use of data in unanticipated ways including for financial profit (Bakken & Reame, 2016). Methodological transparency in reporting is a key requirement for beneficence across types of precision health studies to ensure reproducibility as well as provide the foundation to generate hypotheses for the next stages of research. Additional beneficence considerations of relevance to omics research include privacy of research participants, confidentiality of data, and weighing benefits and risks if findings are return to research participants (Williams & Anderson, 2018). There is currently no requirement to report additional genetic mutations that are found when looking for a particular mutation of known or unknown significance. However guidelines proposed by the Clinical Sequencing Exploratory Research Consortium and the Electronic Medical Records and Genomics Network informing participants of mutations when the results are actionable and the research participant has consented to receive them (Jarvik et al., 2014). A recent report from the National Academy of Sciences on return of individual biomarker research results including omics and recommends a set of communication practices that include attending to health literacy (Committee on Return of Individual-Specific Research Results Generated in Research Laboratories, 2018). Justice is enabled by trustful relationships that influence willingness to participate in research including provision of omics specimens by individuals traditional under-represented in research, equity in opportunity to benefit from both participation in the research but also the provision in care as a result of research findings, and consideration of key societal factors (Williams & Anderson, 2018). Moreover, to support the principle of

justice and advancement of health equity, nurse scientists selecting data sources for precision health research must carefully consider which populations are present in the data source. For example, Latinos and Blacks are under-represented in omics data sources, but in surveys of Internet users, more likely than non-Latino whites to use Twitter (Greenwood, Perrin, & Duggan, 2016)—a social microblogging platform whose content is extractable for research. The principles from the Belmont Report remain relevant in the era of precision health, but new technologies, data sources, and methods require continued assessment to ensure the protection of research participants.

Precision Health Partnerships

New and enhanced research partnerships are crucial to advance the precision health agenda. These partnerships are necessary to not only access, generate, and store the data that can be obtained from clinical trials, care delivery systems, patient-worn devices, government data bases, research repositories, and industry, but also to create scientific and socially-relevant conceptualizations and hypotheses for study. Obtaining data from electronic health records and personal health records requires research collaborations with healthcare delivery systems and the establishment of institutional research policies. Consequently, it is imperative for Centers to take advantage of existing infrastructure including expertise in their institution, and then addressing the unique gaps. The Precision in Symptom Self-Management (PriSSM) Center (P30 NR016587) at Columbia University is used as a case report to illustrate this point (see Appendix B). Cross-Center partnerships are also essential. Many of the P20/P30 Centers use omics tools to understand the mechanisms that underlie symptom variations, identify individuals who are vulnerable to specific symptoms, or evaluate self-management interventions. Other Centers are focused on studying personal informatics and use of bioinformatics to deliver personal health and omics data to the individual and/or family as strategies to improve health and well-being. By leveraging the collective expertise across Centers, nurse scientists will have greater access to experts in their areas of interest, teams can enhance programs of research by coordinating workflows, and methods can be strengthened by dissemination of research protocols.

Involving patients as research partners and team members will become more common as real-time and longitudinal patient-generated data from patient-worn devices and sensors become an increasingly used aspect of research. Collaborations with public health, government, and health insurance agencies will provide efficiencies in research by making use of currently available data sets (Murdoch & Detsky, 2013;

Schneeweiss, 2014). Partnerships with industry have potential to speed the research, pipeline advancing knowledge from basic to applied research and spur entrepreneurship to make research products that support precision health publicly available faster. Partnerships across nursing organizations that advance nursing science and policy is also important. For example, the American Academy of Nursing published a blueprint of nursing science priorities to inform a shared vision for future collaborations, areas of scientific inquiry, and resource allocation (Eckardt et al., 2017). This blueprint aligns with many of the priorities of our Centers and the NINR strategic plan, which includes precision science, big data and data analytics. It highlights the need for alignment and future strategic planning that combines resources across multiple mechanisms and nursing organizations to ensure the vision of precision health across the life span is achieved. Lastly, to apply precision health approaches for symptom and self-management science, a cadre of nurse scientists is needed to collaboratively engage with disciplines that have not traditionally been part of nursing research teams, including data scientists, mathematicians, bench scientists, engineers, and policy researchers.

Conclusion

The spectrum of precision health spans one's genetic code to their zip code and offers the opportunity for nurse scientists to lead the way in advancing symptom and self-management science. Precision health can stimulate discovery in many areas across the lifespan but the impact of precision health is only beginning to be realized. In order to reach the goal of precision health, approaches must be applied throughout the stages of research translation from basic science to clinical research and ultimately at the population level to improve health and prevent disease. Moreover, nurse scientists need to become increasingly more knowledgeable and facile in integrating precision health approaches as they develop symptom and self-management interventions.

Acknowledgments

We thank Dr. Patricia Flatley Brennan, Director, National Library of Medicine, National Institutes of Health, for her presentation at the 2017 Center Director meeting which informed the information and data science infrastructure component of this paper. The preparation of the manuscript was supported by: Center for Pain Genomics (P30NR014129), Center for Adaptive Leadership in Symptom Science (P30NR014139), SMART Center II: Brain Behavior Connections in Self-Management Science (P30NR015326), Center to Advance Chronic Pain Research

(P30NR016579), Center for Innovation in Sleep Self-Management (P30NR016585), Precision in Symptom Self-Management (PriSSM) Center (P30NR016587), Yale Center for Sleep Disturbance in Acute and Chronic Conditions (P20NR014126), UManage Center: UMass Center for Building the Science of Symptom Self-Management (P20NR016599), Center for Accelerating Precision Pain Self-Management (P20NR016605), and The Symptoms Self-Management Center (P20NR016575) and Northeastern Center for Technology in Support of Self-Management and Health (P20NR015320).

Appendix A: Specific Implementation Examples from each Center

Table 1

Appendix B: Case Study of P30 Use of Institutional Information and Data Science Infrastructure and Associated Data Science and Precision Health Competencies

The Precision in Symptom Self-Management (PriSSM) Center utilizes institutional information and data science infrastructure including the Data Science Institute and the GENIE Virtual Biobank (Columbia's National Genomics Research Institute [NGRI]-funded Electronic Medical Records and Genomics [eMERGE] Network project). For example, PriSSM investigators collaborated with the Data Science Institute Health Analytics Center to design a Data Sharing Hub for accessing data that does not include protected health information. Enabled by an Administrative Supplement through the Office of Women's Health Research, PriSSM takes advantage of the GENIE Virtual Biobank to support its objective of expanding its existing sociotechnical infrastructure by analyzing and integrating existing samples and data sets. This is done to create an integrated data set to enable symptom self-management feasibility research that considers sex/gender. GENIE provides information about existing biospecimens from Columbia researchers and facilitates collaboration and use of samples or data across projects. Ultimately the PriSSM integrated data set will comprise genomic data, survey data including NINR CDEs, environmental data based upon geocodes, and clinical data. In addition, Center investigators contribute their unique expertise related to information visualization, and data science infrastructure to Columbia's precision health initiatives. For example, PriSSM has made its information visualization designs, methods, and software (Electronic Tailored Infographics for Community Engagement, Education, and Empowerment³) available to the research community at Columbia and beyond (Arcia et al., 2013; Arcia et al., 2016; Arcia, Velez, & Bakken, 2015; Unertl et al., 2016) to support return of individual research results.

Table 1 – Precision Health Activities of P20/P30 Centers

NINR P30 Centers of Excellence						
Grant number	Principal Investigator	Center Name	Institution	Symptom foci	Exemplars of Self-management	Contribution and Future Directions to Precision Health
P30NR014129	Dorsey, Susan G.	Center for Pain Genomics	University of Maryland, Baltimore	Pain		Genomics Transcriptomics Epigenetics
P30NR014131	Page, Gayle (Contact) and Smith Michael T	Center for Sleep-Related Symptom Science	Johns Hopkins University	Sleep disturbance		Measurement of sleep outcomes within a biobehavioral context
P30NR014134	Waldrop-Valverde, Drenna	Center for Neurocognitive Studies	Emory University	Cognition (concentration, memory, and planning) and emotional distress		Improve knowledge of biological and behavioral mechanisms associated with cognitive and affective symptoms in chronic illness
P30NR014139	Docherty, Sharron (Contact) and Bailey, Chip	Center for Adaptive Leadership in Symptom Science	Duke University	Cognitive/Affective	Comanagement of chronic conditions with patients and providers	Precision health interventions that target self-management phenotypes
P30NR015326	Moore, Shirley	SMART Center II Brain Behavior Connections in Self-Management Science	Case Western Reserve University		Chronic illness intervention development and testing	Understanding neuroprocessing phenotypes associated with self-management behaviors
P30NR015339	Kim, Miyong	Center for Transdisciplinary Collaborative Research in Self-Management Science	University of Texas, Austin		Develop, test, and disseminate innovative self-management solutions to improve the health outcomes of people with chronic conditions	Application of advanced new technologies and methods, including hardware, software, and biological and analytical approaches
P30NR016579	Dorsey, Susan (Contact), Renn, Cynthia and Resnick, Barbara	Center to Advance Chronic Pain Research	University of Maryland, Baltimore	Pain		Genomics Transcriptomics Epigenetics
P30NR016585	Ward, Teresa (Contact) and Heitkemper, Margaret	Center for Innovation in Sleep Self-Management	University of Washington	Sleep deficiency in pediatric and adult chronic conditions	Beta testing of interventions to promote sleep self-management	Validation of sleep self-management interventions
P30NR016587	Bakken, Suzanne (Contact) and Hickey, Kathleen	Precision in Symptom Self-Management (PriSSM) Center	Columbia University	Multiple symptoms in Latinos	Characterization of fatigue in elderly Latino home care patients, Targeted fatigue self-management intervention for Latino PLWH	Multiple data streams for precise characterization of genotype, phenotype, and environment, “omics”, precision in intervention target discovery, design, and delivery

(continued on next page)

Table 1 – (Continued)

NINR P30 Centers of Excellence						
Grant number	Principal Investigator	Center Name	Institution	Symptom foci	Exemplars of Self-management	Contribution and Future Directions to Precision Health
P20NR014126	Redeker, Nancy (Contact) and Yaggi, Henry (Klar)	Yale Center for Sleep Disturbance in Acute and Chronic Conditions	Yale University	Sleep disturbance Fatigue	Self-management of Sleep disturbance	Predicting who will need an intervention for sleep and who responds to an intervention
P20NR015331	Barton, Debra (Contact) Dinov, Ivo	Center for Complexity and Self-Management of Chronic Disease (CSCD)	University of Michigan	Cardiovascular Dementia and Alzheimer's Parkinson's ALS Development and Aging Substance Use, cognition and fatigue related to cancer	Self-monitoring Self-health-awareness Normative comparison Diabetes, Oral adherence to chemotherapy;	Data science methods Predictive analytic protocols Population-wide vs. personalized forecasting of clinical outcomes and disease progression
P20NR015320	Guthrie, Barbara	Northeastern Center for Technology in Support of Self-Management and Health	Northeastern University		Self-management for older adults at risk for poor health outcomes	State-of-the-art monitoring and communication technologies, development of novel self-management interventions
P20NR015339	Schiffman, Rachel	Self-Management Science Center at UWM	University of Wisconsin, Milwaukee		Self-management for individuals and families with or at high risk for chronic conditions across the lifespan	Defining the specific nature, dose, and potential impact of interventions on self-management behaviors
P20NR016599	Jacelon, Cynthia	UManage Center: UMass Center for Building the Science of Symptom Self-Management	University of Massachusetts Amherst	Fatigue, Sleep disturbances	Using Wearable and hand held technologies	Development and testing of wearable and hand held technologies to use for precision health
P20NR016605	Starkweather, Angela	Center for Accelerating Precision Pain Self-Management	University of Connecticut	Pain Anxiety Depression Fatigue	Intervention development and testing	Evaluating omic-based personalized pain self-management interventions
P20NR016575	Kelechi, Teresa	The Symptoms Self-Management Center	Medical U. South Carolina	Pain Fatigue	Technology enhanced and community engaged application development	Using personal informatics to enhance pain and fatigue symptom self-management

Use of the information and data science infrastructure requires data science and precision health competencies. To advance the data science and precision health competencies among those associated with the PriSSM Center, investigators, pilot investigators, and trainees self-rate their competencies on a 4 point scale from novice to expert in four aspects of data science (explore data to find and construct a narrative, represent and transform data, build mathematical models using data, and visually present and communicate insights/findings from data); in characterization of phenotype, genotype, and environment; and in using precision health approaches to identify self-management intervention targets, and design and deliver symptom self-management interventions. The annual assessments inform the educational activities of the Center including an Information Visualization course focused on research synthesis, the PriSSM Visualization Design Studio, cosponsored activities with the Data Science Institute, and a 16-hour workshop series focused on Genomics for Nurse Scientists without Genomics Training. The last is aimed at establishing foundational knowledge to collaborate with genomics specialists and to integrate genomics into symptom self-management grants.

REFERENCES

- All of Us. (2018). Retrieved from <https://allofus.nih.gov/>.
- Arcia, A., Bales, M. E., Brown, W., Co, M. C., Gilmore, M., Lee, Y. J., & Bakken, S. (2013). Method for the development of data visualizations for community members with varying levels of health literacy. *AMIA Annual Symposium Proceedings*, 2013, 51–60.
- Arcia, A., Suero-Tejeda, N., Bales, M. E., Merrill, J. A., Yoon, S., Woollen, J., & Bakken, S. (2016). Sometimes more is more: Iterative participatory design of infographics for engagement of community members with varying levels of health literacy. *Journal of the American Medical Informatics Association*, 23(1), 174–183, doi:10.1093/jamia/ocv079.
- Arcia, A., Velez, M., & Bakken, S. (2015). Style guide: An interdisciplinary communication tool to support the process of generating tailored infographics from electronic health data using EnTICE3. *EGEMS (Wash DC)*, 3(1), 1120, doi:10.13063/2327-9214.1120.
- Arnett, D. K., & Claas, S. A. (2016). Precision medicine, genomics, and public health. *Diabetes Care*, 39(11), 1870–1873, doi:10.2337/dc16-1763.
- Bakken, S., & Reame, N. (2016). The promise and potential perils of big data for advancing symptom management research in populations at risk for health disparities. *Annual Review of Nursing Research*, 34(1), 247–260, doi:10.1891/0739-6686.34.247.
- Brennan, P. F. (2017). The precision health continuum: Public health National Infrastructure Perspective. *NIH. Presentation at the 2017 Center Directors Network Meeting*.
- Brennan, P. F., & Bakken, S. (2015). Nursing needs big data and big data needs nursing. *Journal of Nursing Scholarship*, 47(5), 477–484, doi:10.1111/jnu.12159.
- Busse, W. W., Morgan, W. J., Taggart, V., & Togias, A. (2012). Asthma outcomes workshop: Overview. *Journal of Allergy and Clinical Immunology*, 129(3 Suppl), S1–S8, doi:10.1016/j.jaci.2011.12.985.
- Cashion, A. K., Gill, J., Hawes, R., Henderson, W. A., & Saligan, L. (2016). National Institutes of Health Symptom Science Model sheds light on patient symptoms. *Nursing Outlook*, 64(5), 499–506. <http://dx.doi.org/10.1016/j.outlook.2016.05.008>.
- Cashion, A. K., & Grady, P. A. (2015). The National Institutes of Health/National Institute of Nursing Research intramural research program and the development of the National Institutes of Health Symptom Science Model. *Nursing Outlook*, 63(4), 484–487, doi:10.1016/j.outlook.2015.03.001.
- Cashion, A. K., & Grady, P. A. (2018). Response to the Commentary: Precision Health: Using omics to optimize self-management of chronic pain in aging: From the perspective of the NINR Intramural Research Program. *Research in Gerontology Nursing*, 11(1), 14–15, doi:10.3928/19404921-20171220-02.
- Cato, K. D., Bockting, W., & Larson, E. (2016). Did i tell you that? Ethical issues related to using computational methods to discover non-disclosed patient characteristics. *Journal of Empirical Research on Human Research Ethics*, 11(3), 214–219, doi:10.1177/1556264616661611. clinicalgenome.org. ClinGen Clinical Genome Research.
- Colijn, C., Jones, N., Johnston, I. G., Yaliraki, S., & Barahona, M. (2017). Toward precision healthcare: Context and mathematical challenges. *Frontiers in Physiology*, 8, 136, doi:10.3389/fphys.2017.00136.
- Committee on Return of Individual-Specific Research Results Generated in Research Laboratories. (2018). *Returning individual research results to participants: Guidance for a new research paradigm*. Washington, DC: National Academies Press.
- Data Science. (2017). Retrieved from <https://datascience.nih.gov/>.
- Eckardt, P., Culley, J. M., Corwin, E., Richmond, T., Dougherty, C., Pickler, R. H., & DeVon, H. A. (2017). National nursing science priorities: Creating a shared vision. *Nursing Outlook*, 65(6), 726–736, doi:10.1016/j.outlook.2017.06.002.
- Ferranti, E. P., Grossmann, R., Starkweather, A., & Heitkemper, M. (2017). Biological determinants of health: Genes, microbes, and metabolism exemplars of nursing science. *Nursing Outlook*, 65(5), 506–514, doi:10.1016/j.outlook.2017.03.013.
- Fitipaldi, H., McCarthy, M. I., Florez, J. C., & Franks, P. W. (2018). A global overview of precision medicine in Type 2 Diabetes. *Diabetes*, 67(10), 1911–1922, doi:10.2337/dbi17-0045.
- Garza, M., Del Fiol, G., Tenenbaum, J., Walden, A., & Zozus, M. N. (2016). Evaluating common data models for use with a longitudinal community registry. *Journal of Biomedical Informatics*, 64, 333–341, doi:10.1016/j.jbi.2016.10.016.
- Go, A., Mozaffarian, D., Roger, V., Benjamin, E., Berry, J., Borden, W., & AHA Statistics Committee & Stroke Statistics Subcommittee. (2013). Heart disease and stroke statistics—2013 update: A report from the American Heart Association. *Circulation*, 127(1), e6–e245, doi:10.1161/CIR.0b013e31828124ad.
- Greenwood, S., Perrin, A., & Duggan, M. (2016). Social Media Update. 2016; <http://www.pewinternet.org/2016/11/11/social-media-update-2016/>. Accessed April 25, 2017.
- Grey, M., Knafl, K., & McCorkle, R. (2006). A framework for the study of self- and family management of chronic

- conditions. *Nursing Outlook*, 54(5), 278–286, doi:10.1016/j.outlook.2006.06.004.
- Grinnon, S. T., Miller, K., Marler, J. R., LU, Y., Stout, A., Odenkirchen, J., & Kunitz, S. (2012). NINDS common data element project—Approach and methods. *Clinical Trials*, 9(3), 322–329.
- HealthyPeople. (2014). Disparities.
- Henderson, W. (2013). *Symptom distress mechanisms in digestive disorders*. National Institute of Nursing Research 1ZIANR000018-05.
- House, T. W. (2015). *Fact sheet: President Obama's precision medicine initiative*. Retrieved from <https://www.whitehouse.gov/the-press-office/2015/01/30/fact-sheet-president-obama-s-precision-medicine-initiative>.
- Jarvik, G. P., Amendola, L. M., Berg, J. S., Brothers, K., Clayton, E. W., Chung, W., & Burke, W. (2014). Return of genomic results to research participants: The floor, the ceiling, and the choices in between. *American Journal of Human Genetics*, 94(6), 818–826, doi:10.1016/j.ajhg.2014.04.009.
- Kellogg, R. A., Dunn, J., & Snyder, M. P. (2018). Personal omics for precision health. *Circulation Research*, 122(9), 1169–1171, doi:10.1161/CIRCRESAHA.117.310909.
- Khoury, M. J., & Evans, J. P. (2015). A public health perspective on a National Precision Medicine Cohort Balancing Long-term Knowledge Generation with early health benefit. *JAMA-Journal of the American Medical Association*, 313(21), 2117–2118, doi:10.1001/jama.2015.3382.
- Khoury, M. J., & Galea, S. (2016). Will precision medicine improve population health. *JAMA-Journal of the American Medical Association*, 316(13), 1357–1358, doi:10.1001/jama.2016.12260.
- Khoury, M. J., Gwinn, M. L., Glasgow, R. E., & Kramer, B. S. (2012). A population approach to precision medicine. *American Journal of Preventive Medicine*, 42(6), 639–645, doi:10.1016/j.amepre.2012.02.012.
- Kon, A. A. (2008). The Clinical and Translational Science Award (CTSA) Consortium and the translational research model. *American Journal of Bioethics*, 8(3), 58–60, doi:10.1080/15265160802109389 discussion W51-53.
- Laidman, J. (2015). Changing habits. *Think*. Retrieved from <http://case.edu/think/fall2015/altering-behavior.html#.W7NuvFRdph>.
- Lejbkiewicz, I., Caspi, O., & Miller, A. (2012). Participatory medicine and patient empowerment towards personalized healthcare in multiple sclerosis. *Expert Reviews in Neurotherapy*, 12(3), 343–352, doi:10.1586/ern.11.161.
- Lorig, K. R., & Holman, H. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, 26(1), 1–7.
- Lyon, D. E., Cohen, R., Chen, H., Kelly, D. L., Starkweather, A., Ahn, H. C., & Jackson-Cook, C. K. (2016). The relationship of cognitive performance to concurrent symptoms, cancer- and cancer-treatment-related variables in women with early-stage breast cancer: A 2-year longitudinal study. *Journal of Cancer Research and Clinical Oncology*, 142(7), 1461–1474, doi:10.1007/s00432-016-2163-y.
- Lyon, D., McCain, N., Elswick, R. K., Sturgill, J., Ameringer, S., Jallo, N., & Grap, M. J. (2014). Biobehavioral examination of fatigue across populations: Report from a P30 Center of Excellence. *Nursing Outlook*, 62(5), 322–331, doi:10.1016/j.outlook.2014.06.008.
- McShane, L. M., Cavenagh, M. M., Lively, T. G., Eberhard, D. A., Bigbee, W. L., Williams, P. M., & Conley, B. A. (2013). Criteria for the use of omics-based predictors in clinical trials: Explanation and elaboration. *BMC Medicine*, 11, 220, doi:10.1186/1741-7015-11-220.
- Minor, L. (2016). We don't just need precision medicine, we need precision health. Retrieved from <http://www.forbes.com/sites/valleyvoices/2016/01/06/we-dont-just-need-precision-medicine-we-need-precision-health/#470d3550415e>.
- Moore, S. M., Schiffman, R., Waldrop-Valverde, D., Redeker, N. S., McCloskey, D. J., Kim, M. T., & Grady, P. (2016). Recommendations of common data elements to advance the science of self-management of chronic conditions. *Journal of Nursing Scholarship*, 48(5), 437–447, doi:10.1111/jnu.12233.
- Murdoch, T. B., & Detsky, A. S. (2013). The inevitable application of big data to health care. *JAMA-Journal of the American Medical Association*, 309(13), 1351–1352, doi:10.1001/jama.2013.393.
- National Information Center on Health Services Research and Health Care Technology (NICHSR). (2001). Retrieved from <https://www.nlm.nih.gov/nichsr/>.
- Nicholson, J. K., Holmes, E., Kinross, J., Burcelin, R., Gibson, G., Jia, W., & Pettersson, S. (2012). Host-gut microbiota metabolic interactions. *Science*, 336(6086), 1262–1267, doi:10.1126/science.1223813.
- NIH. Symptom science: promoting personalized health strategies. Retrieved from <https://www.ninr.nih.gov/newsandinformation/iq/symptom-science-workshop>
- NIH. (2003). Grants and funding: Extramural Programs (EP). <https://www.nlm.nih.gov/ep/GrantTrainInstitute.html>.
- NIH. (2017). Method for Introducing a New Competency: Genomics (MINC). Retrieved from <http://genomicsintegration.net/index.php>.
- NIH. (2018a). NINR “Precision Health: Smart Technologies, Smart Health” Boot Camp. Retrieved from <https://www.ninr.nih.gov/training/trainingopportunitiesintramural/bootcamp>.
- NIH. (2018b). ONSEN Omics Nursing Science & Education Network. Retrieved from <https://omicsnursingnetwork.net>.
- NIH. (2018c). What is Precision Medicine?
- NINR. (2016). The NINR Strategic Plan: Advancing Science, Improving Lives. Retrieved from https://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/NINR_StratPlan2016_reduced.pdf.
- Page, G. G., Corwin, E. J., Dorsey, S. G., Reddeker, N. S., McCloskey, D. J., Austin, J. K., & Grady, P. (2018). Biomarkers as common data elements for symptom and self-management science. *Journal of Nursing Scholarship*, 50(3), 276–286.
- Redeker, N. S., Anderson, R., Bakken, S., Corwin, E., Docherty, S., Dorsey, S. G., & Grady, P. (2015). Advancing symptom science through use of common data elements. *Journal of Nursing Scholarship*, 47(5), 379–388, doi:10.1111/jnu.12155.
- Ryan, P., & Sawin, K. J. (2009). The individual and family self-management theory: Background and perspectives on context, process, and outcomes. *Nursing Outlook*, 57(4), 217–225, doi:10.1016/j.outlook.2008.10.004 e216.
- Saad, S., Dunn, L. B., Koetters, T., Dhruva, A., Langford, D. J., Merriman, J. D., & Miaszkowski, C. (2014). Cytokine gene variations associated with subsyndromal depressive symptoms in patients with breast cancer. *European Journal of Oncology Nursing*, 18(4), 397–404, doi:10.1016/j.ejon.2014.03.009.
- Schneeweiss, S. (2014). Learning from big health care data. *New England Journal of Medicine*, 370(23), 2161–2163, doi:10.1056/NEJMp1401111.
- Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., & Whittmore, R. (2012). Processes of self-management in chronic illness. *Journal of*

- Nursing Scholarship, 44(2), 136-144, doi:[10.1111/j.1547-5069.2012.01444.x](https://doi.org/10.1111/j.1547-5069.2012.01444.x).
- Sheehan, J., Hirschfeld, S., Foster, E., Ghitza, U., Goetz, K., Karpinski, J., & Huerta, M. (2016). Improving the value of clinical research through the use of common data elements. *Clinical Trials*, 13(6), 671-676, doi:[10.1177/1740774516653238](https://doi.org/10.1177/1740774516653238).
- Starkweather, A. R., Coleman, B., Barcelona de Mendoza, V., Hickey, K. T., Menzies, V., Fu, M. R. . . , & Harper, E. (2018). Policy brief: Strengthen federal and local policies to advance precision health implementation and nurses' impact on healthcare quality and safety. *Nursing Outlook*, 66(4), 401-406.
- Starkweather, A. R., Lyon, D. E., & Schubert, C. M. (2013). Pain and inflammation in women with early-stage breast cancer prior to induction of chemotherapy. *Biological Research in Nursing*, 15(2), 234-241, doi:[10.1177/1099800411425857](https://doi.org/10.1177/1099800411425857).
- Tantoy, I. Y., Cooper, B. A., Dhruva, A., Cataldo, J., Paul, S. M., Conley, Y. P., & Miaskowski, C. (2017). Changes in the occurrence, severity, and distress of symptoms in patients with gastrointestinal cancers receiving chemotherapy. *Journal of Pain and Symptom Management*, 55(3), 808-834, doi:[10.1016/j.jpainsymman.2017.10.004](https://doi.org/10.1016/j.jpainsymman.2017.10.004).
- Taylor, J. Y., & Barcelona de Mendoza, V. (2018). Improving-omics-based research and precision health in minority populations: Recommendations for nurse scientists. *Journal of Nursing Scholarship*, 50(1), 11-19, doi:[10.1111/jnu.12358](https://doi.org/10.1111/jnu.12358).
- Townsend, C. K., Dillard, A., Hosoda, K. K., Maskarinec, G. G., Maunakea, A. K., Yoshimura, S. R., & Kaholokula, J. K. (2015). Community-based participatory research integrates behavioral and biological research to achieve health equity for Native Hawaiians. *International Journal of Environmental Research and Public Health*, 13(1), doi:[10.3390/ijerph13010004](https://doi.org/10.3390/ijerph13010004) ijerph13010004.
- Unertl, K. M., Schaeffbauer, C. L., Campbell, T. R., Senteio, C., Siek, K. A., Bakken, S., & Veinot, T. C. (2016). Integrating community-based participatory research and informatics approaches to improve the engagement and health of underserved populations. *Journal of the American Medical Informatics Association*, 23(1), 60-73, doi:[10.1093/jamia/ocv094](https://doi.org/10.1093/jamia/ocv094).
- Westfall, J. M., Mold, J., & Fagnan, L. (2007). Practice-based research—"Blue Highways" on the NIH roadmap. *JAMA-Journal of the American Medical Association*, 297(4), 403-406, doi:[10.1001/jama.297.4.403](https://doi.org/10.1001/jama.297.4.403).
- Wilkinson, M. D., & Dumontier, M. (2016). The FAIR Guiding Principles for scientific data management and stewardship. 3, 160018. doi:[10.1038/sdata.2016.18](https://doi.org/10.1038/sdata.2016.18)
- Williams, J. K., & Anderson, C. M. (2018). Omics research ethics considerations. *Nursing Outlook*, 66(4), 386-393, doi:[10.1016/j.outlook.2018.05.003](https://doi.org/10.1016/j.outlook.2018.05.003).
- Williams, J. K., Feero, W. G., Leonard, D. G., & Coleman, B. (2017). Implementation science, genomic precision medicine, and improved health: A new path forward. *Nursing Outlook*, 65(1), 36-40, doi:[10.1016/j.outlook.2016.07.014](https://doi.org/10.1016/j.outlook.2016.07.014).
- Young, E. E., Kelly, D. L., Shim, I., Baumbauer, K. M., Starkweather, A., & Lyon, D. E. (2017). Variations in COMT and NTRK2 influence symptom burden in women undergoing breast cancer treatment. *Biological Research in Nursing*, 19(3), 318-328, doi:[10.1177/1099800417692877](https://doi.org/10.1177/1099800417692877).