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Contributors

Genomics Nursing: Scope and Standards of Practice, Third Edition, was produced through extensive revisions to the Genetics/Genomics Nursing Scope and Standards of Practice, Second Edition (2016). In the intervening years, a multitude of changes have occurred in terms of genetic and genomic capacities, national and global socio-political contexts, and the nursing specialty. This document is reflective of those changes as envisioned by a workgroup of genomics nurse specialist clinicians, academicians, researchers, educators, and policy leaders. Our workgroup was guided by a deep commitment to fostering the development of genomics nursing toward a more equitable future for nurses and patients within the context of advancements in precision health.

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About the International Society of Nurses in Genetics

The International Society of Nurses in Genetics (ISONG) is a global nursing specialty organization dedicated to fostering the scientific and professional growth of nurses in human genetics and genomics worldwide.

The vision of ISONG: Caring for people's genetic and genomic health throughout the lifespan and across the continuum of health and disease (ISONG, 2022).

The mission of ISONG is to serve both the nursing profession and the public. ISONG fosters and advocates for the scientific and professional development of its members and the nursing community, in the discovery, interpretation, application, and management of genomic information, for the promotion of the public's health and wellbeing. ISONG advocates for public understanding of genomic health and use of genomic information.

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<ISONG new logo>

About the American Nurses Association

The American Nurses Association (ANA) is the premier professional organization representing the interests of the nation's 4 million registered nurses. ANA advances the nursing profession by fostering high standards of nursing practice, promoting the rights of nurses in the workplace, projecting a positive and realistic view of nursing, and by lobbying the Congress and regulatory agencies on healthcare issues affecting nurses and the public. ANA is at the forefront of improving the quality of health care for all. Founded in 1896, and with members in all 50 states and U.S. territories, ANA is the strongest voice for the profession (ANA, n.d.).

ANA exists to advance the nursing profession by:

- Fostering high standards of nursing practice
- Promoting a safe and ethical work environment
- Bolstering the health and wellness of nurses and
- Advocating on health care issues that affect nurses and the public

Because ANA represents the interests of all registered nurses, we are here to support you to reach your full potential. From career development resources to lobbying Congress on the issues that affect nurses, we are here every step of the way.

Scope of Genomics Nursing

The International Society of Nurses in Genetics (ISONG) represents genomics nurses worldwide and is the official professional organization of nurses in genomics in the United States. ISONG is responsible for defining and establishing the global scope of professional nursing practice in genomics. In keeping with ISONG's responsibility, this document broadly describes genomics nursing practice and then delineates the scope of genomics nursing in the United States.

The ANA Code of Ethics holds that health is a universal human right therefore, the need for nursing is universal. All nurses commit to advancing health, welfare, and safety to achieve and sustain health so persons and communities develop to their fullest potential and live with dignity. ISONG and the ANA recognize that this document is derived from a United States-centric perspective and acknowledge that nurses outside of the United States may have scope and standards of practice that vary from this document. In these cases, the International Council of Nurses' (ICN) documentation on standards of ethical professional nursing practice helps provide clarification for genomic healthcare applications for all nurses at the global level (International Council of Nurses, 2021).

Definition of Genomics Nursing

Genomics nursing integrates nursing with the rapidly expanding field of precision healthcare in all contexts. Defining genomics nursing therefore requires an understanding of nursing, genomics, and precision healthcare:

- Nursing - “Nursing is the diagnosis and treatment of human responses and advocacy in the care of individuals, families, and groups, communities, and populations in the recognition of the connection of all humanity” (ANA, 2021, p. 1).
- Nursing- per ICN, nursing “encompasses autonomous and collaborative care of individuals of all ages, families, groups and communities, sick or well and in all settings. Nursing includes the promotion of health, prevention of illness, and the care of ill, disable and dying people. Advocacy, promotion of a safe environment, research, participation in shaping health policy and in patient and health systems management, and education are also key nursing roles” (ICN, 2022).

- Genomics refers to the ‘study of all the genes in the human genome together, including their interactions with each other, the environment, and the influence of other psychosocial and cultural factors’ (American Nurse Association, 2009).
- Precision health refers to the impact that a person’s unique genetic, genomic, and omic composition have on well-being and health within the context of that person’s lifestyle and social, economic, cultural and environmental context. (Fu et al., 2020).
- Precision healthcare refers to clinical care delivered on the basis of understanding the contribution of an individual’s unique disease risks, including genomic information and social context, and treatment responses for the improvement of health outcomes.

Thus, genomics nursing is nursing within the context of genomic information and in the provision of precision healthcare. Genomics nursing is concerned with the health and interconnectedness of individuals, families, communities, and populations as it relates to hereditary and non-hereditary genomic conditions. Genomic conditions are heritable and non-heritable alterations of human health (including anomalies, behaviors, diseases, issues, or predispositions that may affect a person's health or abilities and may or may not be inherited) that arise in whole or in part due to genetic, genomic, or other omic processes. Thus, genomics nurses are concerned with how single-gene disorders, chromosomal abnormalities, copy number variants, gene-gene interactions, gene-environment interactions, epigenomics, gene expression, and molecular modifications may alter gene expression and/or otherwise affect human health.

The term genomics nursing was chosen with intentionality to address the evolving scientific understanding of the importance of considering the whole genome and its internal and external interactions in the context of precision health. As stated in the previous edition, genetics nursing traditionally involved the care of people with single-gene disorders such as cystic fibrosis or Huntington's disease, and chromosomal disorders such as Down syndrome. However, even single-gene disorders are modified by other genes and the environment. Indeed, the evidence base for genomics continues to rapidly expand, and precision healthcare is advancing both in terms of availability and scope. Thus, the term genomics better reflects the complexity and breadth of the phenomena of concern to genomics nurses. The deliberate selection and use of the term genomics reflects the evolution of the science (Fu et al., 2020; E. Kurnat-Thoma et al., 2021); however, ISONG and ANA acknowledge that:

- Nurses, physicians, and counselors may continue to use “genetic” or “genetics” in their professional titles,
- Certifying boards in this field award credentials that use the term genetic or genetics, and
- Many national and international organizations representing the majority of professionals in this field still use “genetic” or “genetics” in their names as a reflection of either their individual focus on single-gene and chromosomal disorders and/or the professional history of the organization.

While there has been extensive debate around the terminology for recipients of nursing services over the last several decades, inconsistency in the use of such terminology continues. In particular, recent trends toward the use of ‘healthcare consumer’ have been considered by this working group. In consultation with the Board of Directors at ISONG, the terms person or patients were preferred for this revision cycle due to the economic associations of the term ‘consumer’ which may disempower and disenfranchise individuals without the economic means or access to freely participate in healthcare markets. Furthermore, the term consumer may be inappropriate in global healthcare contexts beyond third-party payer systems. This workgroup and ISONG reaffirm the vision of healthcare as a universal human right, in accordance with the ANA Code of Ethics for Nurses, Provision 8 (ANA, 2015). As precision health care models advance, genomics nurses hold an ethical duty to work toward health equity in careful consideration of the differential experiences and opportunities that individuals face based on socioeconomic status and healthcare access within and outside of the United States. Thus, this work group has chosen to focus on the recipients of services as persons rather than as consumers. Recipient(s) of clinical genomics nursing services will be referred to throughout this document as persons or patients. These terms may encompass, for the purposes of this document, individuals, families, communities, and whole populations and includes both those at risk for and with manifested genomic conditions. In particular, when patients are unable to participate in care activities or decision-making (e.g., infants), the word patient may refer to a patient surrogate decision-maker and/or guardian/parent.

Interaction of Genetics and Genomics

The Human Genome Project laid the foundation for enormous advances in the fields of genetics and genomics by completing the first reference sequence of the human genome in 2003. In

response, genomics nursing practice has evolved significantly since the publication of ISONG's *Statement on the Scope and Standards of Genetics Clinical Nursing Practice* in 1998. Research efforts are improving understanding of the functions and interactions of all genes in the human genome as well as interactions with environmental factors. This genetic revolution has resulted in a paradigm shift from genetics to genomics, which is much broader and affects all areas of nursing practice. The ability to understand the role of genetics in human health and detection of diseases is a tremendous step towards better prevention, risk reduction, treatment, and the realization of cures for common diseases and health problems (Green et al., 2020).

Scientific discoveries such as gene editing are enhancing clinical capabilities in diagnosing and delivering advanced treatments for rare, single-gene disorders (Frith, 2020). Likewise, advancements further the ability to predict susceptibility to and prescribe preventive therapies for genetically influenced chronic conditions, such as cancer and obesity (Behravan et al., 2020; Cuevas-Sierra et al., 2019; Rohde et al., 2019). Genomic investigation of infectious diseases, once thought impracticable, has increased the speed of diagnosis, the effectiveness of existing therapies, and the development of new therapies. Particularly during the COVID-19 pandemic, increased reliance on genomic knowledge and technology was brought to the collective forefront of our national awareness. Genomic science and health care were used to 1) sequence viral strain epidemiology patterns and monitor severe public health impacts of variants on global populations and individual disease risks; 2) rapidly create mRNA vaccines and novel therapeutics to save life and reduce suffering at a global scale; and 3) to develop accurate diagnostic tests to guide clinical care and public health protocols. This expanding knowledge will continue to affect how genomics services are defined and delivered. Indeed, such services extend into an increasing variety of settings. Multidisciplinary clinical nursing genomics services may include, among other things:

- Providing and managing comprehensive care, including state-of-the-art and -science of risk assessment, genomic screening, diagnosis, counseling, and therapeutic modalities
- Protection and advocacy of vulnerable and underserved patient populations to ensure equitable healthcare access and patient satisfaction with genomic services that is culturally responsive and appropriate per the patient's needs and wishes

- Administering medications and treatments that are tailored to a patient’s specific genetic information
- Facilitating interdisciplinary referrals for the evaluation and treatment of genomic health conditions
- Interpreting common non-prescribed (Direct-to-Consumer) genetic tests provided by commercial, non-healthcare entities and supporting patient, family, community, and population education
- Evaluating, coordinating, and improving healthcare access to genomic specialty services
- Educating, developing, and maintaining a nursing workforce with appropriate genomics competencies for level of practice and practice setting
- Developing and optimizing routine nursing and clinical workflows to ensure integration of genomics information with the Electronic Health Record (EHR)
- Educating individuals, families, and public and professional populations about genomics
- Assessing, evaluating, and developing recommendations for ethical, legal, and social implications (ELSI) of new and existing genomics services and technologies

Description of Genomics Nursing

The genomics nurse focuses on providing nursing care, education, administration, research, advocacy, and/or policymaking based on an understanding of the underlying genomics of the individuals, families, communities, or populations. Genomics nursing practice encompasses a clear focus on the entirety of the human genome, including interactions between genes and between genes and the environment, and its implications on health and nursing care.

Genomics nursing has and will continue to contribute leadership to the development of genomics and precision healthcare models, for example, through:

- Development of academic frameworks to guide curricula
- Nursing workforce diversification, education, and training
- Competency development within the field of generalist and specialty nursing
- Extensive additions to the evidence-base through the conduct of genomics research

- Expanding genomics use in multiple clinical practice areas, including pharmacogenetics, newborn screening, infectious disease monitoring, oncology, and many others

Comprehensive genomics nursing practice is a dynamic process involving extensive interprofessional collaboration. Genomics nursing may occur in any setting, including but not limited to clinical settings, academia, commercial industry, research laboratories and collaboratives, administrative settings, non-profit organizations, community and/or grassroots settings, and policymaking and legislative forums.

Clinically practicing genomics nurses identify and manage physiological and psychological responses to genomic conditions and provide consultation and education to individuals, families, communities, populations, and the healthcare team. Clinical genomics nursing involves personal and trusting relationships between recipients of care and the nurse. Recipients of genomics nursing care may be individuals, families, communities, or populations including persons at any stage of life, from preconception to postmortem. Individual patients of genomics nurses include people who are symptomatic for a genomic condition, who are at risk for developing a genomic condition, or who may have a child who is at risk. Genomic nurses at varying levels of clinical practice may provide nursing care for patients, for example, by:

- Prescribing and administering pharmacogenetic-based therapies and medications
- Conducting family history assessments to detect the presence of high-risk hereditary and multifactorial genomic conditions
- Making referrals to appropriate colleagues for follow-up testing, treatment, or care coordination for genomic conditions
- Ordering and interpreting chromosomal, genetic, and genomic laboratory tests
- Developing healthcare plans for individuals
- Providing counseling and education to individuals, families, communities, and populations

In addition, genomics nurses may consult with the healthcare team and/or to provide general information to parties interested in genomics or precision healthcare including the public, policymakers, and other stakeholders in public health. Genomics nurses in research generate and

disseminate new knowledge about genomics and its implications for human health and nursing. Genomics nurses in academic or educational roles use current research and standards to support student learning objectives and genomics competencies within the specialty and among generalist nurses. In the healthcare policy area, genomics nurses use the evidence base to establish and guide the future direction of genomics nursing and healthcare policy (E. Kurnat-Thoma et al., 2021).

Of note, provision of basic nursing care in genetics and genomics has been recognized as a fundamental competency of all registered nurses as endorsed by 49 key nursing stakeholder organizations to create a comprehensive document defining the competencies, curricula, and outcomes indicators for genomics in nursing (American Nurse Association, 2009). ISONG agrees with the Consensus Panel that all registered nurses should possess a basic level of understanding of genetics and genomics (American Nurse Association, 2009). However, genomics competencies have been de-emphasized in recent years in the United States due in part to the lack of opportunity for generalist and non-genomic specialty nurses for training and competency deployment (Newcomb et al., 2019). The American Association of Colleges of Nursing (2021) limits the essential competencies of professional nursing related to genetics to a single statement: to “apply individualized information, such as genetic/genomic, pharmacogenetic, and environmental exposure information in the delivery of personalized health care” (p. 30). The specialist genomics nurse possesses competencies and standards of practice that extend well beyond the application of genomics information in the delivery of care in clinical practice settings. Thus, the genomics nurse has a role in educating and supporting nurses in general practice and the practice of other specialties, as well as other members of the healthcare team, toward enhanced care of persons, families, communities, and populations with or at risk for genomic conditions.

Essential Attributes of Genomics Nursing

The essential features of genomics nursing practice are:

1. Attention to the full range of human experiences and responses pertaining to the continuum of health and illness of patients related to genomic conditions.

2. Application of genomics knowledge (e.g., evidence base) to the processes of nursing practice, education, research, and policy related to:
 - Health education, promotion, maintenance, and restoration
 - Optimization of health and abilities
 - Prevention of illness and injury
 - Alleviation of suffering
 - Support of informed patient decision-making
 - Participation in a complex healthcare system
 - And, when appropriate, a peaceful and dignified death
3. Integration of objective data with knowledge gained from an understanding of the patient's subjective experience with, or risk of, a genomic condition and associated disability or morbidity.
4. Maintenance of principles and practices that promote genomic well-being and healing in consideration of the ethical, legal, and social issues (ELSI) associated with genomic conditions or susceptibility to genomic conditions.
5. The promotion of social justice for people affected by or susceptible to genomic conditions.
6. Establishment of caring relationships with persons and their legally authorized representatives, families, communities, or populations served, including patients, students/trainees, research participants, and policymakers, that facilitate nursing care as appropriate to the situation and setting.
7. Demonstration of leadership through consultation to other members of the healthcare team and/or stakeholders to support a wide variety of persons in policy, governance, and complex health systems.

Nursing is built on a body of knowledge that comprises the dual components of science and art. As a specialty of nursing, genomics nursing is a scientific discipline as well as a professional specialty. At all levels and in all settings, genomics nursing practice is evidence-based, relying on discoveries by nurses and others to continually refine and improve clinical, research, and educational practice outcomes, processes, and value. A number of theories and conceptual frameworks are used for assessing, diagnosing, planning, implementing, and evaluating care that is responsive to the essential attributes of genomics and precision health practice areas (Corwin

et al., 2019; Kurnat-Thoma et al., 2021; Kurnat-Thoma et al., 2022; Reed, 2020). These theories and frameworks—derived from nursing, medicine, social sciences, biology, ethics, and other related fields—provide a foundation for understanding, implementing, and evaluating the practice of genomic nurses.

In particular, ethical and moral dilemmas are common in the context of genomics and precision healthcare, including around questions of fairness to all persons (justice). Thus, sensitivity to diversity and health equity in all settings is an essential component of genomics nursing. *The ICN Code of Ethics for Nurses* (International Council of Nurses, 2021) is the framework for ethical nursing practice worldwide. In the United States, *The Code of Ethics for Nurses with Interpretive Statements, 2nd Ed* (ANA, 2015) provides a framework to guide ethical nursing practice in the United States. In the context of genomic healthcare provision, the ANA (2015) *Code of Ethics, 2nd Edition* requires that genomic nurses have a responsibility to sustain their knowledge and competence in advanced technologies to translate ethical implications of import for clinical practice, nursing education, research and public policy for specialty areas such as genetic testing, national and international guidelines protecting the rights of the human person, and emergent areas of governance and public health. Genomics nurses adhere to the ethical principles that govern all nursing, with special attention and focus to those aspects of genomics healthcare that require advanced ethical consideration.

Genomics nurses in all settings continually update practice and knowledge in line with evolving standards of care in precision health and genomics, as appropriate to their level of practice, training, professional role, and setting. Genomics nurses in all settings work toward the creation and updating of evidence-based policies and practices to support optimal health and learning outcomes of patients, families, communities, populations, and students/trainees. At the local, state, federal, and international levels, genomics nurses advocate for evidence-based healthcare policies that support the health of persons in need of genomic nursing services. In addition, genomics nurses advocate for enhanced development of the nursing and genomics nursing workforce.

Practice Settings for Genomics Nursing

Genomics nurses practice in healthcare settings that include but are not limited to: hospitals and their affiliated clinics, academic medical centers, and universities; institutions of higher education and/or training programs; health and science policy settings; research funding organizations; regional genomic centers; ambulatory and primary healthcare facilities; industrial, community, and school health settings; state and federal agencies, including those that provide services to underserved and vulnerable populations such as Federally Qualified Health Centers; private industry, including clinical and biotechnology laboratories and pharmaceutical companies; managed healthcare organizations; non-profit foundations and organizations; and healthcare recipient and provider insurance organizations. As advances in genomic technology continue to expand into a wider variety of clinical, academic, and research settings so too will genomics nursing practice. Examples of genomics nursing practice across a wide array of settings include:

- Genomics nurses provide information about the relevant inheritance patterns, genomic testing results, and familial implications of test results in acute care settings and specialty clinics that focus on chromosomal and single-gene disorders.
- Genomics nurses contribute expertise and skills to public and community health settings.
- Genomics nurses in oncology assess risks; provide genomic counseling; guide interventions for somatic and hereditary cancers; facilitate screening and diagnostic genomic testing; and educate patients, families, and members of the oncology care team on hereditary cancer syndromes, the impact of the hereditary cancer diagnosis on current care, overall patient and family function, future cancer risk, and familial implications.
- Advanced practice genomics nurses evaluate, diagnose, counsel, and manage patients with or at risk for developing a genomic condition within specific patient populations and in collaboration with interprofessional teams of genomics providers at regional genomics centers in academic-affiliated medical centers.
- Genomics nurses in the non-profit sector provide information, research, patient counseling, leadership, and expertise to foundations and other non-profit organizations dedicated to health and/or populations with specific genomic conditions.

- Genomics nurse managers, leaders, and nursing staff in Magnet certified acute care organizations, or who are on Magnet journeys, facilitate integration of genomics services, genomics nursing leadership, and genomics healthcare outcomes into Magnet accreditation processes and requirements.
- Genomics nurses across a wide range of clinical practice environments ensure adoption of the most recent high quality clinical practice guidelines by participating in evidence-based practice and quality improvement projects and translating the strongest genomics research evidence into routine practice.
- Genomics nurses, advanced practice nurses, nurse leaders and administrators serve on Institutional Review Boards (IRBs) to facilitate regulatory compliance, ensure patient safety and confidentiality, and protect human subjects across the lifespan who choose to participate in genomics research.
- Genomics nurses of all levels of academic preparation contribute their professional expertise, time, and talents to serve on local/state/federal/international leadership and advisory groups (e.g., boards, committees) across a variety of multi-sector organizations to advocate on behalf of patients, populations, the profession of nursing, and the specialty of genomics nursing.
- Leaders in genomic nursing develop, initiate, and sustain a variety of regional, national and international multi-sector collaborations to continuously expand the reach and impact of genomics into healthcare (Kurnat-Thoma et al., 2020).
- Genomics nurse administrators empower their organizations to cultivate and retain highly skilled workforces to develop and participate in new scientific innovations, evidence-based practice, quality improvement, performance improvement and nursing research activities involving genomics services.
- Genomics nurse researchers and scientists perform research and policy analyses to expand genomics knowledge, facilitate creation of updated clinical practice guidelines, and achieve dissemination and implementation of genomics services into everyday clinical practice and community, public health environments.
- Genomics nurses lead the conversation on ethical issues in genomics, within the frameworks provided by national and international codes of ethics, and advocate for

social, health, and nursing policies at the local, state, national, and international level that adhere to the highest standards of ethical practice and quality of care.

The Evolution and History of Genomics Nursing

Previous editions of this document have broken the major events from the history of genomics nursing up by country of origin and may be reviewed for a more modular understanding of the evolution of the specialty within specific nations. Yet, there is a significant degree of overlap in the trajectories of genomics nursing across national borders. Furthermore, the contemporary practice of genomics nursing is built upon decades of work by nurses and others from across the globe. While this document is by necessity a US centric document, the history—and future—of genomics nursing requires an international perspective. Prominent international collaborations that support the specialty include the International Society of Nursing in Genetics (ISONG), the Global Genomics Nursing Alliance (G2NA), and the Asia Pacific Genomic and Genetic Nursing Center (Calzone et al, 2018; Tonkin et al, 2020; Chair et al, 2019). Therefore, the following presents a concise analysis of the history of genomics nursing and the specialty with consideration for the scientific, legislative/regulatory, and philosophical milieus from which the specialty arose.

Early Foundations in Public Health and Maternal-Child Health

Worldwide, public health nurses were among the first healthcare professionals to provide care for and address the needs of patients and families diagnosed with or at risk for genomic conditions. Historically, public health nurses provided genomic services through maternal and child health programs in the US, Canada, and Japan in the latter half of the 20th century. This common trajectory differs slightly in the United Kingdom, where the National Health Service has provisioned nurses to deliver genomics-focused healthcare since shortly after World War II. The United Kingdom's first medical genetics clinics were established in 1946 and were primarily concerned with single gene disorders and chromosomal abnormalities.

By the 1960's, implications of genomics in professional practiced were being discussed by nurses across North America and Europe. Indeed, newborn screening programs for phenylketonuria (PKU), the first societal-scale genomics programs, were rolled out in the US and the United Kingdom during the 1960's and have expanded markedly since (Blair et al.,

2020). Newborn screening programs now identify dozens of genomic conditions and are moving toward a whole genome sequencing approach in many locations. Furthermore, these programs have spread globally and are now in place in all developed countries of the world and in many developing nations as well (Blair et al., 2020). Nurses play a key role in the success of such initiatives, both by ensuring that screening samples are collected and by offering genomic counseling and specialty services to individuals who are screened as at-risk. Yet the early foundations of genomics nursing did not long remain in the domains of reproductive and child health.

Scientific and Regulatory Advances and Initiatives

Over the last half a century, genomics nursing has expanded to include a range of nursing professionals working in conjunction with patients, populations, and collaborative practices across a broad spectrum of genomic conditions, including a strong presence in cancer genomics, neurosciences, adult complex disorders, behavioral sciences, reproductive health care and family planning, risk assessment, communicable disease surveillance and response, and genomic counseling for special and general populations. This expansion has largely been supported by scientific advances in genomics throughout the latter half of the 20th century and to the present. In particular, the successful completion of the international collaborative Human Genome Project (HGP) provided a foundation for numerous scientific advances made possible by the reference sequence of the human genome, followed by the advance of sequencing, computational, bioinformatic, and gene editing technologies.

Concurrent with the scientific advances that enabled expanded practice, landmark state, federal, and international legislation and regulatory efforts helped shape the development of the genomics nursing specialty. Passage of the Genetic Diseases Act in 1976 (United States) and the subsequent funding of state and federal programs to provide prenatal and pediatric genomics services (under the aegis of the Public Health Service) brought the importance of integrating genomics into clinical nursing practice to the attention of nurse clinicians, administrators, researchers, and academicians. The Genetic Information Nondiscrimination Act of 2008 (United States) provided some limited protection for individuals with regard to health care and employment discrimination (but not discrimination in life insurance, education, housing and other cases), thus reducing hesitancy among the public for genetic testing and expanding access

to communities at risk. The Affordable Care Act of 2010 ensured individuals with pre-existing conditions, including genomic conditions, could receive health care insurance (U.S. Department of Health and Human Services (HHS), 2014). More recently, the 21st Century Cures Act (2016; United States) established guidelines for the sharing and responsible use of genomic data. Also in 2016, the Health Information Portability and Accountability Act (HIPAA) was clarified to specify that genomic information in designated record sets for covered entities were also considered protected health information (PHI) for four formats: completed test reports, full gene variant information, underlying data used in the report(s) and any other accompanying information in the designated record set for a covered entity (HHS, 2016). These and other efforts to regulate and protect genomic data have indelibly shaped genomics nursing. A summary of some major scientific and legislative landmarks that influenced the development of genomics nursing as a specialty are provided in Table 1.

Table 1. Significant events in the history of the genomics nursing specialty

Year(s)	Event
1946	• First medical genetics clinic established (United Kingdom)
1960s	• Newborn screening programs rolled out (United States, United Kingdom)
1970	• Sanger’s method of DNA sequencing developed
1976	• US Genetic Disease Act (United States) passed
1980	• Genetic Nurses and Social Workers’ Association formed (United Kingdom, later renamed Association of Genetic Nurses and Counsellors)
1982	• Genetic nurses certified as genetic counselors by American Board of Medical Genetics
1984	• Genetics Nurse Network established
1986	• U.S. Department of Energy and National Institutes of Health co-fund the Human Genome Project (HGP)
1988	• International Society of Nurses in Genetics (ISONG) established
1989	• Medical Research Council (United Kingdom) joined HGP
	• Gene for Cystic Fibrosis is mapped
1990	• HGP officially launched
	• First gene to be officially mapped is BRCA1, a breast cancer gene (Drs. Mary Claire King and Mark Skolnick, National Cancer Institute)
	• The Ethical Legal Social Implications (ELSI) of genetic research advancements are formally recognized as a critical area of research investment and received ~5% of HGP funds.
1992	• First Master’s program in Genetic Counselling in Europe was established (Manchester, United Kingdom)
1993	• First 5-year plan for HGP published
	• Sanger Institute (United Kingdom) joins HGP

- 1994 • HGP's human gene mapping goal achieved
- 1995 • Genetic Privacy and Nondiscrimination Act (United States) introduced
- First bacterial genome sequenced (*Hemophilus influenzae*)
- 1996 • First human gene map published
- Yeast genome sequenced
- Mouse genetic mapping goal of HGP achieved
- 1997 • National Human Genome Research Institute formed as part of the National Institutes of Health (United States)
- Dolly the sheep is the first animal to be successfully cloned and born (University of Edinburgh)
- 1998 • Second 5-year plan for HGP published
- RIKEN Genomic Services Center (Japan) established
- Single nucleotide polymorphism (SNP) sequencing initiated
- Chinese National Human Genome Centres established in Beijing and Shanghai
- ANA and ISONG co-publish *Statement on the Scope and Standards of Genetics Clinical Nursing Practice*
- 1999 • Sequencing of human chromosome 22 completed
- Genetic Nursing Committee (Japan) established
- 2000 • Working draft of human genome completed.
- 2001 • Genetic Counsellor qualifications established (United Kingdom)
- 2002 • Working draft of mouse genome completed (*Mus musculus*)
- Genetic Nursing Credentialing Commission (GNCC) created
- 2003 • Finished human genome sequence completed (92% of base pairs, all genes).
- HGP ended with all goals met
- 2005 • International HapMap Project completed (comprehensive map of common human single nucleotide polymorphisms as a reference dataset)
- 2006 • *Genetic and Genomic Nursing: Competencies and Curricula Guidelines* published by ANA
- Cancer Genome Atlas Project (TCGA) launches to molecularly characterize 33 cancer types
- 2007 • ANA and ISONG co-publish *Genetics/Genomics Nursing: Scope and Standards of Practice*, endorsed by 49 organizations of professional nursing
- Wellcome Trust Case Control Consortium publishes the first large-scale Genome Wide Association Study (GWAS)
- 2008 • Genetic Information Nondiscrimination Act signed into law (United States)
- *Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcomes Indicators, 2nd edition* published by ANA
- 2009 • Consensus panel publishes *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators*
- H3Africa Initiative is established by consensus to develop and launch large-scale sequencing effort to understand disease susceptibility and drug responses in African populations
- 2010 • Affordable Care Act signed into law (United States)
- 2011 • UK Biobank Cohort begins recruitment of 500,000 research participants

- US Veterans Administration begins recruitment of Million Veterans Program to support gene/environment research
- Consensus-based advanced practice nurse and graduate level nursing genetic competencies are endorsed and published
- 2012
 - Biobank Law passed (Finland)
 - Encyclopedia of DNA Elements (ENCODE) is the first and largest international effort of 35 groups around the world to characterize critical “silent” functional regulatory DNA elements previously thought to be “junk” (Valtierra, 2021)
 - Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR) Cas9 gene editing technique is discovered by Drs. Emmanuelle Charpentier and Jennifer Doudna
 - Taiwan Biobank launched to recruit 150,000 individuals with links to Taiwan National Health Insurance database
- 2013
 - Genetic Counsellors and Genetic Nurses (Europe) formed
 - Zebrafish genome is sequenced by high quality shotgun sequencing, providing an ethical animal model comparable to vertebrates for biomedical research
 - American College of Medical Genetics (ACGM; United States) releases its first policy guidance recommendations on the return of secondary findings to patients from whole genome and whole exome sequencing
- 2014
 - Credentialing for genetics/genomics nursing transitioned to American Nurses Credentialing Center (ANCC)
- 2016
 - Genetic Counsellor Registration Board (GCRB; United Kingdom) accredited
 - ANA and ISONG co-publish second edition of *Genetics/Genomics Nursing: Scope and Standards of Practice*
 - The *Genetics and Genomics in Nursing Practice Survey Instrument* is developed and pilot tested in Magnet facilities
 - 21 Century Cures Act passes in U.S. with specific, multi-stage provisions for precision medicine and genomic medicine
 - Cancer Moonshot Initiative (United States) launched
- 2017
 - FinnGen project begun to establish 500,000 participant biobank (Finland)
 - National Health and Medicine Big Data Center launched to support health care of 80 million patients and genomic sequencing for 400,000-500,000 individuals (China)
- 2018
 - Million Genomes Initiative launched to establish research and clinical databank (Europe)
 - National Institutes of Health launches All of Us Research Program to recruit longitudinal cohort of 1 million racially and ethnically diverse participants (United States)
 - Human twin infants are born in China due to the actions of an individual investigator who gravely misused the CRISPR-Cas9 gene editing technique to prevent HIV infection. This resulted in immediate widespread condemnation by the international community, strengthened in-country regulatory enforcement, and a 3-year jail sentence for the lead scientist
- 2019
 - Nurse Portfolio Credentialing Commission, Inc (NPCC) established

2020	<ul style="list-style-type: none">• Whole genome sequencing of 40,000-50,0000 patients initiative launches to improve detection of rare genetic conditions and prevention of cancer (Hong Kong)• COVID-19 pandemic brings unprecedented genomic epidemiological surveillance of viral strains and genomic foundations of vaccine development and diagnostic testing to public attention• A gapless sequence read of the X-chromosome is finalized telomere-to-telomere• Drs. Charpentier and Doudna receive the Nobel prize in Chemistry for their discovery of CRISPR-Cas9• Family of Henrietta Lacks sues a biotech firm for ‘stolen cells’. Lacks was an African American cervical cancer patient from 1951 from whom a physician used her biopsy sample without her consent, and her cellular tissue (HeLa cells) were replicated to become a mainstay of global laboratory experimentation due to their ability to continually grow in vitro.
2021	<ul style="list-style-type: none">• 21st Century Cures Act signed into law• Operation Warp Speed (United States) begins successful delivery of 300 million COVID-19 vaccine doses due to rapid, large-scale investment in and production of medical countermeasures including mRNA-based vaccines. Genome sequencing technology and computational advancements reduced the traditional 10-year vaccine deployment timeline to 10 months.
2022	<ul style="list-style-type: none">• Gapless human genome sequence completed (100% of base pairs)• Cancer Moonshot Initiative (United States) renewed for 25 years and relaunched
2023	<ul style="list-style-type: none">• ANA and ISONG co-publish third edition of <i>Genetics/Genomics Nursing: Scope and Standards of Practice</i>

Evolution of Philosophy for Genomics Nursing

Nursing philosophy comprises a variety of approaches to understanding fundamental truth and creating knowledge in nursing essential for advancing practice and are based on assumptions. For example, empiricist philosophy assumes only physically observable characteristics are true and real, such as a genomic test result or patient’s observable signs of illness (Reed, 2020). A phenomenological philosophy assumes that a patient’s subjective experience is deeply personal and unique to the individual; their contexts and cannot be defined by pre-specified terms, quantitative criteria, or empiric structures. Phenomenology is primarily involved with understanding the nature and meaning of a person’s everyday experiences (Polit & Beck, 2021). Truths can be considered stable (positivist) and concretely defined or plurally relative to a particular situation, time, or cultural context (relativist), (Reed, 2019).

Intermodernism is a form of nursing knowledge development oriented to the post-modern philosophy era. Because nursing often deals with understanding the intangibles of the human experience in health and disease states, neither scientific realism nor relativist constructions adequately provide full understanding of reality. Intermodernism is recognized as a preferred perspective for nursing science knowledge because it rejects both plural relativism and physical truths at the expense of meta-physical abstractions and realities (Reed, 2019). It provides room for including pragmatic qualifiers when evaluating well-established scientific truths in order to better incorporate unexpected variations, alternative observations, and/or unobservable components that are not otherwise readily explainable or are very real to the profession of nursing. As such, intermodernism uses a problem-solving perspective to blend both science and nursing professional practice and provide a practice-based context for application of scientific truths.

There are many theories (epistemology) applied to understanding genomics and genomic nursing healthcare. For example, symptom science relies heavily on a number of nursing care models and theories and omics information to understand and develop personalized approaches to supporting patient care and self-management of symptoms across a variety of chronic illnesses (Kurnat-Thoma et al., 2022). However as genomics knowledge and technology rapidly expands, fundamentally accepted empiric truths radically change, including: physiological measures of human health (e.g., vital sign monitoring efficacy, mHealth) and their correlative environmental factors (e.g., social determinants, lifestyle preferences), omics (e.g., microbiomics, whole genome sequencing, pharmacogenomics, epigenomics), assistive technologies (e.g., geospatial, remote monitoring devices) and patient-centered approaches (e.g., palliative care, self-management of symptoms). Traditional empiric boundaries of nursing science no longer accurately account for all the rapidly changing myriad technologic contexts and patient lived-experience combinations. Relative normative context parameters generated by artificial intelligence and machine learning also sometimes fail to provide the predictive reliability and validity needed for accurate clinical diagnostics, precision therapeutics and patient health decision-making when using genomic, -omic. Intermodernism is thus recognized as an ideal epistemological approach to accommodate multiple disciplinary boundaries permitting examination of personal, social, behavioral contexts in addition to biologic, computational and environmental truths of genomics (Corwin et al., 2019). Thus,

intermodernism philosophy is particularly well suited to generating meaningful precision health and genomic nursing healthcare knowledge (Reed, 2020).

Evolving Professional Landscapes

In 1980, a landmark consensus conference was held to identify current levels of genomics education received by undergraduate and graduate nurses, to describe the genomics knowledge needed by all nurses, and to make recommendations for programs to address the gaps between knowledge and practice (Forsman, 1994). Notable professional societies and networks began The Genetic Nurses Network, a professional organization formed in 1984, brought together for the first-time nurses who identified their practice as genetics nursing.

Shortly thereafter, the International Society of Nurses in Genetics (ISONG) was established in 1988 to foster the scientific, professional, and personal development of genetics nurses worldwide. ISONG's original vision was "Caring for people's genetic health." Today, the vision of ISONG is "Caring for people's genetic and genomic health throughout the lifespan and across the continuum of health and disease" (ISONG, 2022). In 1997, ANA conferred specialty practice status on genetics nursing in the United States. This was followed in 1998 by the initial publication of *Statement on the scope and standards of genetics clinical nursing practice* (ISONG & ANA, 1998). This volume established the scope of genetics nursing and the clinical standards to guide practice in the specialty. The role and specialty standards were updated and expanded in *Genetics/Genomics nursing: Scope and standards of practice* in 2007 and 2016 (ANA & ISONG, 2016; ISONG & ANA, 2007), prior to this, the third edition.

Credentialing in the United States and Abroad

The first nurses certified in genetics received genetic counseling credentials provided by the American Board of Medical Genetics in 1982, a credential limited to those with a master's degree in genetic counseling who passed an examination for certification. Later, ISONG's credentialing committee compiled a list of core competencies and assessment measures for credentialing genomics nurses at the baccalaureate and master's levels (Cook et al., 2003). In 2002, the Genetic Nursing Credentialing Commission (GNCC) was created separately from ISONG to oversee the credentialing of nurses in genomics (Monsen, 2005). In 2014, credentialing for genomics nursing transitioned from GNCC to the American Nurses

Credentialing Center (ANCC). At this time, ANCC's Advanced Genetics Nursing Certification (AGN-BC) is available only for renewal to those already holding the credential, and all new credentialing has transitioned to the Nurse Portfolio Credentialing Commission (NPCC). NPCC, sponsored by ISONG, currently offers two tiers of credentials: Clinical Genetic Nurse (CGN) for nurses with a minimum education preparation of a baccalaureate degree and Advanced Clinical Genetic Nurse (ACGN) for advance practice nurses with a master's degree or above.

Levels of Genomics Nursing Practice

Clinical genomics nursing encompasses a multitude of hereditary and complex diseases and disorders, as well as pharmacogenetics. People with a genomic condition may require health and social services from several professionals, depending on the types of problems caused by the condition. While most of those providing care may focus on a system or a type of problem, the genomics nurse is able to address the impact of the condition as a whole and the issues that arise from the potentially heritable nature of the condition. Furthermore, the genomics nurse offers holistic family care that addresses the needs of the affected individuals, family members at risk for the condition, carriers, and parents of affected children.

The scope of genomics specialty nursing practice comprises two levels: basic and advanced. Both include application of genomics knowledge in risk assessment, outcome identification, intervention, and evaluation. The level of formal education, knowledge, expertise, and skills distinguish the practice level in genomics nursing.

Basic Level

The genomics nurse practicing at the basic level applies fundamental genomics knowledge in the routine provision of care for persons with genomic conditions, including conducting a risk assessment that encompasses environmental and genomics components. The genomics nurse conducts assessments regarding personal and family health history, records the family pedigree, identifies potential risks for an inherited disorder or syndrome, explains potential risks to the patient, and facilitates a referral to a genomics nurse in advanced practice or professional genomics providers as necessary. The genomics nurse at the basic level provides psychosocial support to the patient, evaluates the interventions, and assesses the patient's understanding and ability to implement a plan of surveillance or treatment following the referral.

Education & Credentialing: They are registered nurses educated in nursing at the undergraduate level (BSN preferred) and licensed to practice in the region where their practice takes place. Formal genomics clinical experiences and/or training in the nursing preparatory program and/or on-the-job are expected. Guidance for their practice, continued education, and professional development is provided by one or more professionals trained in genomics, such as graduate nursing or medical faculty with genomics expertise, advanced practice nurses in a genomics healthcare setting, appropriately credentialed genomics professionals, or other clinicians who provide genomics-based clinical services or conduct genomic research within their specialty. The basic-level genomics nurse's knowledge and skills base is maintained through participation in genomics and nursing continuing education. Genomics nurses at the basic level are strongly encouraged to hold specialty certification(s) from one or more nationally or internationally recognized bodies, including but not limited to the Clinical Genomics Nurse (CGN) offered by the Nurse Portfolio Credentialing Commission (NPCC) <https://www.nurseportfolio.org/cgn>.

Advanced Level

Genomics nurses with advanced nursing degrees are using their advanced practice skills to affect the genomic health of individuals, families, communities, and populations through clinical, research, education, policy, administration, and other activities. Technological advances have also expanded clinical nursing practice to include health care provided through telemedicine, computerized patient education, and interactive technology. As a result, contemporary genomics nursing practice is broad and diverse.

In clinical practice, the advanced genomics nurse conducts a more thorough risk assessment and physical assessment, with interpretation of these findings and other risk factors. They provide comprehensive information about the possibility of a known predisposition for a hereditary genomic disorder or disease process. Advanced genomics nurses in clinical settings play a critical role in ensuring that patients are able to engage in the informed consent process fully by 1) discussing the benefit and risks of genomic testing for a hereditary syndrome or for diagnosis clarification with the patient and other stakeholders as appropriate, 2) guiding the patient through test selection, testing, and diagnosis, and 3) ensuring understanding to make an informed

decision about testing and treatment. Thus, the advanced genomics nurse must have a strong knowledge of genetic mutations and heritable diseases to decide the right genomic test for the patient and/or family phenotype, genotype, and differential diagnoses. The genomic nurse determines the need for assistance in communicating test results with patients and families; discusses surveillance and risk reduction options; makes appropriate referrals to providers for relevant care; develops a plan in collaboration with the patient and other health professionals; facilitates communication between the patient, family, and other care providers; evaluates the patient's plan of care; and monitors the outcomes of interventions. While most of those providing care may focus on a system or a type of problem, the genomics nurse is able to address the impact of the condition as a whole and the issues that arise from the potentially inherited nature of the condition. Furthermore, the genomics nurse offers holistic family care that addresses the needs of the affected individuals, family members at risk for the condition, carriers, and parents of affected children.

Educational Preparation, Continuing Education, and Credentialing: Advanced level genomics nurses are registered nurses educated at the graduate level, typically with a master's degree, doctoral degree, or graduate certification in nursing, genomics, or a related field. They may hold advanced practice registered nurse (APRN) credentials with or without prescriptive authority. Educational expectations for advanced genomics nurses include human, molecular, biological, and population genomics; technological applications related to genomics; therapeutic modalities; and ethical, legal, and social implications of genomics information and technology. In addition, advanced genomics nurses are expected to have completed clinical experiences or on-the-job training in the specialty area for their practice, supervised by a professional trained in genomics.

Specialty educational programming is becoming more common and is offered by a variety of universities in various forms at the master's and doctoral levels. For example, at the time of this revision, the University of Pittsburgh offers a certificate in Public Health Genetics (<https://www.publichealth.pitt.edu/certificates#genetics>), and Vanderbilt School of Nursing offers a Doctor of Nursing Practice Program Genetics Fellowship for Family Nurse Practitioners (<https://nursing.vanderbilt.edu>). The genomics nurse in advanced practice is expected to maintain their knowledge and skill base through ongoing participation in genomics and nursing continuing

education. This knowledge can be acquired through completion of didactic and clinical courses in a formal program of study leading to a master's or doctoral degree in nursing with a concentration in advanced practice in genomics nursing. Didactic or clinical courses can also be obtained through postgraduate degree certification programs and continuing education offerings. Nurses may elect to achieve a PhD in Nursing or a related discipline, or a practice doctorate that includes academic courses focused on specific clinical or research genomics content. A graduate degree nurse who practices in genomics at the advanced level is strongly encouraged to hold specialty certification(s) from nationally or internationally recognized bodies including but not limited to the Advanced Clinical Genomics Nurse (ACGN) offered by NPCC <https://www.nurseportfolio.org/acgn>. Advanced genomics nurses may alternately hold one of the following credentials:

- Advanced Genetics Nursing Certification (AGN-BC) historically offered by the American Nurse Credentialing Center (ANCC) but now only available for renewal
- The CGRA certification through the National Consortium of Breast Centers (as described above)
- Certification awarded upon completion of The City of Hope Intensive Course in Genomic Cancer Risk Assessment (CGRA), an accredited program through the Continuing Medical Education (ACCME) <https://cgracertification.org>.

Ethics in Genomics Nursing Practice

The *Code of Ethics for Nurses with Interpretive Statements* (Code of Ethics; ANA, 2015) and other national and international codes of ethics for nurses, combined with genomic scientific advances in healthcare, create a moral obligation for the entire nursing profession to stay current in genomic knowledge and capacities (Tluczek et al, 2018). For all nurses engaged in care of persons with genomic conditions, respecting individual autonomy with the knowledge that hereditary disorders can impact biological relatives' health is central to maintaining ethical care standards, and special attention must be given to the ethical implications of incidental or secondary findings. Additionally, national and international guidelines must be regularly examined to ensure ethical conduct in healthcare adequately protects the rights of all individuals and populations (Tluczek et al., 2019).

This is particularly true in light of the rapid evolution of genomics knowledge and healthcare. Genomics nurses often provide care and support patients and families through emotionally and politically charged situations, such as genomic testing and decision-support provided by the genomics nurse for pregnant or dying patients or genome editing technologies. Genomics nurses further provide support for decision-making for policymakers, patients and other stakeholders during times of political and historical crisis (e.g., COVID-19). At all levels, genomics nurses strive to provide ethically sound care in accordance with the current best practices and the utmost professionalism. The following section provides a basis for interpreting each Provision of the *Code of Ethics* through a genomic nursing lens (ANA, 2015). These statements should be taken in addition to the general ethical obligations of professional nursing presented in the *Code of Ethics* and in international ethics guidelines for nursing.

Provision 1

The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person.

Genomics nurses recognize healthcare as a human right which transcends all individual differences. They consider all relevant individual and community factors in the provision of genomic healthcare (e.g., culture, language, sexual orientation, gender identity or expression, and religious or spiritual beliefs of patients or populations) and act to minimize or remove the effects of implicit and explicit biases and health disparities. In particular, genomics nurses must carefully navigate individual and community factors in light of genomic variations in risk and prevalence based on genomic ancestry and other considerations to ensure equitable care even in the context of differential patient risk and resources; cultural, religious, and personal values and beliefs; and individual identities. Further, genomics nurses have an ethical duty to be good stewards of patient and community resources, ensuring that 1) patients are protected from unwanted, unwarranted, or unnecessary treatments, tests, and procedures; and 2) that patients are connected with appropriate resources based in the best available scientific evidence to enable equitable access to prevent injury or illness, restore health, alleviate suffering, and/or receive palliative and/or end-of-life care as needed.

In genomic healthcare, the prevention of unnecessary suffering from excessive, unwarranted, unwanted, or unnecessary medical testing, treatments, and procedures is of particular importance. Nurses have a responsibility to provide information to patients on available testing and treatment options in accordance with informed consent while considering the necessity, utility, and meaningfulness of recommended tests and procedures to each person based on the person's individual values and without regard to socioeconomic status, illness, functional status, age, or proximity to death. The basic ethical tenets of autonomy and informed consent are essential in providing individualized education, care, and resources related to decisions about genomic testing, results, management, and outcomes. Genomics nurses present known benefits, risks, and harms of each option (including no treatment) in language that is easily understandable, complete, accurate, and without deceit, coercion, or undue influence. Genomics nurses fully support the self-determination of patients, families, and communities. Information about genomics and genomic conditions is understood to have a different impact on each individual; thus, care and support are guided by an understanding of each individual's needs and patient interactions with family, communities, and environment are carefully considered in the provision of genetic counseling services.

Professional interactions and relationships with colleagues and other members of the care team enhance the ability to achieve the shared goals of providing compassionate, transparent, and effective health services to the individual and family, community, and population. Such interactions also help to promote conditions of fair treatment and integrity, resolve conflicts, advance compromise, and preserve caring relationships. The genomic nurse seeks to limit and address (as appropriate) harmful behaviors such as bullying, incivility, harassment, intimidation, threats, and other forms of workplace violence across interdisciplinary and nursing contexts.

Provision 2

The nurse's primary commitment is to the patient, whether an individual, family, group, community, or population.

Genomics nurses may be exposed to a wide range of conflicting loyalties, interests, priorities, and expectations between stakeholders through the genomic healthcare continuum, including balancing the interests of patients, families, community leaders, physicians, genetics counselors,

healthcare organizations, health plans, commercial entities, and regulatory requirements, among others. Yet, genomics nurses must maintain a professional focus on the patient. As conversations about family history and impact on family health proceed, the genomics nurse provides guidance based on best interest of the patient in consideration for the interests of the family and community. The genomics nurse demonstrates respect for resources, both financial, personal, and medical, regardless of input from industry or personal bias. For example, the genomics nurse educates the patient and recommends genomic testing as appropriate with the patient's biological relatives in mind, but if the patient decides not to have the recommended test or not to share relevant results, the genomics nurse supports the patient's decision. Genomics nurses provide safe, high quality, patient-centered genomic healthcare while preserving the profession's full scope of practice regardless of the level of involvement in direct patient care activities (e.g., educators, administrators, policymakers, consultants, researchers/scientists).

Additional findings (sometimes called secondary or incidental findings), or findings of genetic variants or information unrelated to the test indication are of particular ethical concern related to beneficence, autonomy, and justice (Miller et al., 2022). Additional findings may include information about potential health issues that have no known treatment, that have low penetrance, or that have social implications for patients as in the case of unsuspected discoveries about paternity or ancestry. Currently, there is debate in the genomics provider community as to the best approach to take when inadvertent information is gained from genomic testing. For example, the use of multigene tests offers opportunity for efficiency and cost-effectiveness but may result in an increase in equivocal or unexpected results that are inconsistent with the patient's clinical presentation and family history. In order to provide ethically sound care, genomics nurses must thoughtfully address the potential harms and unintended consequences that can arise from genomic research and testing. The genomic nurse always seeks a therapeutic professional relationship with each patient that is respectful of personal boundaries and patient autonomy in the receipt of additional findings. Nurse administrators ensure monetary resources appropriately benefit as many patients, families, and communities as possible, especially those who are most vulnerable and marginalized.

Provision 3

The nurse promotes, advocates for, and protects the rights, health, and safety of the patient.

Privacy is the right to control and disclose (or not disclose) information pertaining to oneself and one's circumstances as well as the timing of and extent to which disclosure occurs. The need for genomic healthcare does not substantiate unnecessary intrusion into a client's life. Genomics nurses seek to safeguard the right to privacy at all levels (patient, family, community, and population). This may entail providing a private setting for conversations of a personal or revelatory nature, safeguarding patient data, and communicating by reliable and private means (e.g., secured networks and software) when in-person consultation is not available. The genomics nurse is aware of and practices in accordance with relevant federal and state regulations and legislation to protect privacy and confidentiality, including but not limited to:

- The Health Insurance Portability and Accountability Act (HIPAA) of 1996 and its 2014 update and 2016 genomic information inclusion clarification
- Genetic Information Nondiscrimination Act (GINA) of 2008
- HITECH Act of 2009 and its 2021 amendment
- The 21st Century Cures Act of 2016
- State laws governing patient privacy and genomic data

Education about and interpretation of genomic test results, guidance in clinical management, and discussion with other family members and healthcare professionals must be individualized and provided in sufficient privacy and confidentiality so as to avoid negative consequences of genetic discrimination including altered relationships, stigma, loss of employment, and loss of insurance benefits.

Patients have a right to participate in clinical research as human subjects for treatment of their genomic condition. Participants and legal guardians or surrogates must receive adequate information to make informed choices. This includes the right to withdrawal from research at any time without reprisals or consequences beyond that inherent to stopping treatment/participation. Genomic nurses help patients to understand the benefits and risks of participating in clinical research, particularly in the presence of cutting-edge scientific advances that may prove difficult for individuals without genomics training to understand, such as CRIPSR-Cas9. Genomics nurses have an ethical duty to report to appropriate oversight bodies including Internal Review Boards if patient rights are compromised.

In order to protect the safety of patients with genomic conditions, genomics nurses seek to ensure that all nurses have sufficient skills, knowledge, and training in genomics to care for patients with a genomic condition as appropriate to the level and specialty of the nurse. Genomic nurses help to support a culture of safety and accountability by establishing, supporting, and utilizing processes that protect patients impacted by harmful contributory system failures, including appropriate reporting of errors or near misses, particularly related to genomic testing and treatment.

Provision 4

The nurse has authority, accountability, and responsibility for nursing practice; makes decisions; and takes action consistent with the obligation to promote health and to provide optimal care.

Like all nurses, genomics nurses are accountable for their own practice when providing independent services to patients. The Standards of Practice and Standards of Professional Performance in this document are the guiding document for genomics nurses, in conjunction with all relevant regulatory and professional ethics standards. Nurses not in clinical practice or direct patient care maintain accountability to patients by sharing responsibility for practice in accordance with the *Code of Ethics*. Nurses in management and nurse administrators have a unique responsibility to provide safe environments for genomic applications, to appropriate assignments and delegation of responsibilities. This includes licensure, certification, adequate staffing burdens and loads, competency evaluation and adequacy documentation, and protective policies that ensure nurses and advanced practice nurses are not placed in inappropriate assignments with insufficient resources to safely perform their role(s). Nurse managers and administrators should ensure open communications can occur so that a professional nurse can express their safety concerns without fear of reprisal or job loss for refusing an inappropriate assignment for which they cannot safely perform without specific training or sufficient material support. Genomic nurse educators and preceptors must have sufficient knowledge and skill to oversee their students. Nursing students providing genomic healthcare must have sufficient knowledge to support their assigned patients and also receive appropriate level of supervision by their preceptors and educators. At all levels of practice, the genomics nurse is responsible for

maintaining competence in practice and to comply with state and federal regulations governing ordering, prescriptive authority, release of test results, credentialing, and scope of practice.

Genomics nurses must use reasonable judgment in using their vested authority to delegate tasks or care activities to others. Given the complexity of many genomics healthcare tasks, genomics nurses must ensure that delegated tasks are within the scope of practice and degree of competence and training of the person to whom they are delegated, in consideration with state practice acts, organizational policy, and professional nursing standards. In addition, clinical practice technologies such as clinical decision support tools and artificial intelligence algorithms are frequently employed in genomic healthcare. Since nurses are held accountable for system and or technology failures, genomics nurses must discern when it is and is not appropriate to replace nursing personnel or judgment with automated assistive clinical practice technologies.

Provision 5

The nurse owes the same duties to self as to others, including the responsibility to promote health and safety, preserve wholeness of character and integrity, maintain competence, and continue personal and professional growth.

A genomics nurse's moral respect for human dignity extends to all persons, including themselves. This means the genomic nurse views their own moral worth with utmost respect and dignity, no matter what their cultural background, personal attributes, or life situation may be. The affirmation and understanding nurses extend to patients must also be extended to themselves in full consideration of the moral duties owed to each. Genomic nursing involves assessing, intervening, evaluating, protecting, promoting, advocating, educating, and performing research in order to ensure the health, safety, and well-being of others and society. Genomics nurses should model and practice the same level of health maintenance and health promotion activities they teach, research, and/or recommend to others including obtaining timely and necessary healthcare. Genomics nurses are at especially high risk of fatigue, moral distress, emotional exhaustion, burnout, and compassion fatigue, particularly those who work with patient populations who have limited lifespans or who face significant adverse outcomes. Successfully navigating and mitigating these harms requires adequate self-care in balance with satisfying work, as described in both the *Code of Ethics for Nurses with Interpretive Statements*. Genomics

nurses also need access to satisfying work that allows them to practice at the full scope of their education, credentials, and training. A key nursing executive/administrative responsibility in any organization is to help each of their staff maintain an appropriate balance between satisfying work and protection of personal health, safety, and well-being.

Because nurses operate as moral agents, they have a particular responsibility to provide their viewpoints, in full consideration of the potential implications for patients, families, communities, and populations they serve. Genomic nurses are expected to distinguish between personal opinions and professional counsel. The provision of fully formed personal opinions to clients may be an element of ethical professional nursing conduct as long as appropriate professional boundaries are maintained and the client's free will is fully respected. This often occurs in genomic healthcare interactions when there are indeterminate test results with an uncertain final outcome that cannot be easily predicted by risk calculation metrics. Nurses must be aware of the potential of their words and actions to have undue influence and do everything possible to avoid coercion, manipulation, and unintended influence—such as cultivating professional boundaries to preserve therapeutic relationships. Genomics nurses must practice with empathy, respect, competence, and compassion for all patients, particularly those whose personal characteristics, lifestyles, situations, or genomic conditions are stigmatized.

Genomic conditions may provoke extensive ethical debate and moral distress in all realms. Genomics nurses, in accordance with the duties of all professional nurses, have an explicit duty to maintain ethical practice at all times and to encourage open moral discourse when faced with morally challenging issues. If decisions are morally objectionable and poses direct harms to clients, families, communities, and/or populations, genomics nurses may refuse participation; however, they are expected to bring their conscientious objections to the appropriate authority in a transparent and timely manner, and to ensure that alternative provisions are made to provide patients with care. As it true for all nurses, conscientious objection may not be based on personal prejudice, bias, convenience, or arbitrariness.

Genomics nurses seek to maintain competence and continue their professional growth through demonstrating excellence in their practice, whatever their role, setting, or situational context. Genomics nurses demonstrate their life-time commitment to learning across a wide range of

concepts and demonstrate competence to engage in ethical controversies through a variety of activities that enhance professional and personal growth. Genomic nurses should seek to engage in activities that broaden their understanding of the world and their patients. Nurses must maintain a posture of cultural humility and seek to further their knowledge and understanding of diverse populations by engaging with communities to enhance and extend cultural competency as well as enhancing their understanding and service to self. Relevant activities include reading, reflecting, and studying broadly, developing skills to better manage personal finances and health, and engaging in civic and policy advocacy, recreation, and leisure.

Provision 6

The nurse, through individual and collective effort, establishes, maintains, and improves the ethical environment of the work setting and conditions of employment that are conducive to safe, quality health care.

Genomics nursing occurs in a wide range of environments, including clinical settings, academic centers, and research facilities. In order to promote an ethical environment, the genomics nurse must recognize that there can be conflicting values and perverse financial incentives in the work environment that may influence patient care or research findings. For example, a clinic's income may be dependent in part on genomics nurses advocating for testing that is burdensome and futile in the absence of effective treatment or preventive strategies. Competing companies offering genomic tests may offer gifts and meals to providers in order to exert influence over patient care decisions and treatments. Similarly, a research team's continued funding may depend on statistically significant findings such that there is incentive for individuals or groups to falsify or manipulate data or images. Genomics nurses in such situations must maintain the highest standards of ethical action and are obligated to report to appropriate authorities if unethical actions are being taken due to financial incentives or other types of secondary gain. If not in a position of authority over working conditions, the genomics nurse should actively seek involvement from those with authority over the work environment to ameliorate subversive and harmful employment conditions that may be unsafe or otherwise detrimental to patients, colleagues, employees, students/trainees, oneself, and/or institutional credibility.

Provision 7

The nurse, in all roles and settings, advances the profession through research and scholarly inquiry, professional standards development, and the generation of both nursing and health policy.

Genomics research is the necessary foundation to propel the utilization of genomics knowledge into clinical practice, standards development, and policy creation. Historically, there have been cases in which knowledge gained from genomics research has violated ethical principles, but not necessarily the rules in place at the time of the research. For a case study on historical research abuses, please see Appendix B: Henrietta Lacks and the HeLa Cell Line.

Genomic nurses engaging in research have an ethical duty to consider potential impacts of unintended or secondary findings, including but not limited to unexpected findings related paternity and parentage and genomic conditions for which there are no currently available treatment options or cures. Patients and research participants have a right to their data and a right to refuse knowledge they believe to be undesirable or potentially harmful. Whenever feasible, decisions regarding the disclosure of unintended findings should be made in concert with research participants to ensure that burdensome findings are not inappropriately disclosed in situations where they may do more harm (whether psychological or relational) than good. Furthermore, genomic nurses must consider the potential impact of findings on persons beyond the research participant when counseling participants about disclosing genomic information to others such as potential carriers or affected family members. The provision of genetic counseling should be considered in the event where findings from research are likely to cause distress and/or result in known heritable risks to human health. These ethical principles are particularly relevant in the context of research conducted in stigmatized or marginalized populations. For example, Arizona State University was forced to return DNA samples and pay a Native American tribe \$700,000 plus funds for a clinic and school after the tribe sued them for failing to obtain consent and misusing their DNA for unauthorized research (Drabiak-Syed, 2010). Communities, particularly those existing in small biological enclaves or consanguineous populations, should be considered and consulted in all genomic research activities involving their members, whenever possible.

Similarly, genomics nurses are expected to maintain strict adherence to professional standards of conduct and professional ethics when seeking to contribute to policy creation and development at all levels. Policymaking decisions and advocacy must be founded in the ethical guidelines of the nursing profession, including respect for persons and justice, with an explicit focus on health equity.

Provision 8

The nurse collaborates with other health professionals and the public to protect human rights, promote health diplomacy, and reduce health disparities.

Genomics is opening new frontiers in science and health care operations. Genomics nurses must be prepared to handle the ethical challenges and potential unintended consequences that may come from using genomic data to develop healthcare knowledge. Inappropriate interpretations of genetic risk have a meaningful risk of causing unintended harms to populations who are stigmatized and/or those who believe they are not at risk. For example, BRCA mutations have been largely ascribed to the Ashkenazi Jewish population, leaving many individuals who possess these mutations unaware that these variations occur in other populations, if at a lesser frequency.

While all humans have the same genes, genomic variances are known to cluster in ethnic groups. Privacy violations and stigmatization can result from genomic findings. Harm has already occurred as a result of failure to recognize genomic vulnerability. Individuals, families, and communities retain their rights to privacy even in the context of societal benefits.

Genomics nurses are important team members in the development and implementation of projects using genomic data and may take leadership positions, including as primary investigators in genomics research. As such, genomics nurses have an ethical duty to safeguard the public and individual patients/participants. As genomic data from many people are increasingly used to predict disease risk and provide care to individual patients, families, and communities, this ethical duty expands rather than recedes. Artificial intelligence algorithms for clinical decision support are frequently trained on large volumes of data, yet the integrity and representativeness of the data sets are critical to ensuring that outputs are equitable and accurate. Genomic nurses have a duty to understand potential biases and weaknesses within clinical decision support systems that they employ.

Provision 9

The profession of nursing, collectively through its professional organizations, must articulate nursing values, maintain the integrity of the profession, and integrate principles of social justice into nursing and health policy.

Weighing the risks and benefits of genomic information is challenging. Genomic information holds much promise, but many of the clinical tests currently available are not covered by third-party payers and/or lack adequate insurance reimbursement. Few outcome measures have been endorsed and adapted for routine genomics clinical operations in the form of standardized performance measures. Genomics technology tends to precede knowledge of its clinical utility. Thus, genomics nurses, both individually and collectively, must question the value of new genomic technologies to patients and society as they emerge. Genomics nurses must continue to advocate for the well-being of patients and society even in contexts where financial or research incentives compete with the interests of the patient, family, or community. However, there are a number of well proven interventions that are strongly recommended for routine implementation from which substantial portions of the population can benefit. These include Centers for Disease Control and Prevention Tier I conditions (e.g., Lynch Syndrome), neonatal screening, and precision oncology diagnostics and therapeutics for a wide range of pediatric and adult contexts.

Genomics nurses must question how and whether new genomic technology and findings affect nursing advice and care. For example, the identification of a genomic predisposition to skin cancer through genomic testing in fair-skinned individuals currently does not change the advice for skin cancer prevention. Similarly, genomic testing may predict fully penetrant, terminal conditions for which there are no treatments available (e.g., Huntington's Disease), though these tests may still be of value in the context of preconceptual counseling, family planning, and cascade screening. Genomics nurses acknowledge that the risks and benefits of learning genomic information for an individual patient are often not the same as for their family members.

As genomics nursing evolves and genomics is increasingly incorporated into the standard of care, recognition must be given that the perception and definition of "healthy" may be threatened by genomic information. Genomics nurses must urgently and continually question whether genomic findings are helpful or harmful in the specific context of their practice. Genomic

findings help when successful treatment of disease results, or disease is prevented in high-risk individuals. Harm from genomic findings can be physical, psychological, emotional, or financial. Particularly for people who are disease-free, genomic findings may effectively turn a healthy person into a sick person. Indeterminate and/or uncertain results, false-positive, and false-negative genetic test results can cause clear harm to patients and families. Increased screening tests can be beneficial, but also cause increased risks, costs, and psychological harm.

Unanticipated findings, or findings that are not sought when testing is ordered, also have the potential to harm families. For example, cases abound wherein genomic testing for clinical or personal knowledge purposes have revealed alternate paternity or other situations wherein family dynamics are compromised by changes in the pedigree and/or where individuals misapply genomics knowledge to stigmatize individuals based on carrier status.

Genomics nurses are critical to the promotion of access to appropriate care related to genomic findings, yet must also be mindful of the impact genomic findings can have on self-concept and society's perception of health and disease. There are a number of ethics groups, research institutes, and scholarship programs around the world that support the valuable area of ethical considerations of properly applying advanced genomic technologies to human health such as the U.S. National Academy of Medicine, National Academy of Sciences *International Commission on the Clinical Use of Human Germline Genome Editing* (WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing, 2021).

The Future of Genomics Nursing

For the genetics/genomics specialist nurse, the future holds much promise. Genetic/genomic testing is increasingly becoming the standard of care in many clinical areas. For example, knowledge of how the genome reacts to epigenetic influence is growing and is already relevant in oncology care. Next generation exome testing is challenging the traditional paradigm of how testing decisions are made by the clinician. The possibility of mining big data in order to gain genomic information from whole patient populations to improve the care of individuals within and beyond that populations becoming less far-fetched as technology continues to advance. Clinical decision support tools and databases will continue to be deployed to enhance the knowledge, scope, and quality of genomics nurses and genomic nursing care. Yet the rapid

advancement of genomics within the healthcare field also poses challenges to generalists and specialists alike. Two of these challenges have come to the forefront and will doubtlessly require focus from the genomics nursing specialty going forward: enhancing the genomics education and training of both specialist and generalist nurses and achieving health equity across vulnerable populations.

Genomics Knowledge and Education

With the advance of precision healthcare priorities at the national level through legislation and research funding priorities, genomic information will be increasingly important to the care of individual patients with conditions not historically considered to be genomic, including complex disorders with combination multigene and environmental or behavioral etiologies such as diabetes and cardiovascular disease and communicable diseases such as COVID-19. All licensed registered nurses, not just those specializing in genomics, have a role in the delivery of genomics services and the management of genomic information. Fulfillment of this role requires genomics knowledge to identify, refer, support, and care for persons affected by, or at risk for genomic conditions.

As the public becomes more aware of the role genomics play in health and disease, nurses in all areas of practice are being asked to address basic genomics-related questions that can identify disease risk, diagnosis, ideal treatments, and therapeutic response to treatment. Widespread use of genomics requires that the nursing workforce be adequately educated to implement technological advances that are capable of improving the health of patients, families, communities, and populations (Calzone, Jenkins, et al., 2018; Jenkins et al., 2015; E. Kurnat-Thoma, 2020). Clinically applicable technologies and information, such as emerging vaccine development, disease identification, and pharmacogenomics, are rapidly expanding and changing healthcare delivery across settings and practice levels. Application of genomics technology, population risk mitigation strategies, and early identification of disease variants during the COVID-19 pandemic have exposed how genomics is a critical interdisciplinary area of research and healthcare intervention. Nurses in all clinical settings will be increasingly relied on to recognize and apply proven genomics-led technology and interventions and to appropriately refer clients who can benefit from genomics services. The use of genomic technology and requires a baseline genomics knowledge embedded within the discipline of professional nursing

education in the United States (American Association of Colleges of Nursing, 2021; International Council of Nurses, 2021). As such, the continuing evolution of genomics and other advances in healthcare will require that future registered nurses be prepared, at the minimum, at the baccalaureate level.

Looking to the future, nurses, both within the specialty and beyond it, should continue to strongly advocate for inclusion of scientific content relevant to their practice into nursing programs at all levels and into nurse regulation activities such as registration and licensure (Calzone et al., 2018; Tonkin et al., 2020). All nurses should receive genomics education in both their nursing program and up-to-date clinical practice behaviors. Practicing nurses should be strongly encouraged to participate in continuing education and workforce development programs that feature genomics concepts, technological applications, and therapeutic modalities relevant to their specific clinical setting(s). Nurse administrators and managers in clinical practice settings should develop the scientific capacity and competency of their workforces by ensuring their staff have protected time and available resources to perform nursing scholarly inquiry activities that improve patient outcomes, including evidence-based practice, quality improvement, and nursing research. Advanced genomics nurses are called upon to support growth of the genomics field and the application of genomics into nursing practice by 1) providing continuing education opportunities for colleagues and generalists, 2) advocating for the inclusion of genomics education and training at all levels, 3) interfacing genomic technology with healthcare systems to bring forth utility and value that support population health, and 4) demand industry support for expertise at all levels of practice, including reimbursement/compensation for that expertise and recognition of the genomics nurse as a specialist.

Vulnerable Populations & Health Equity

The widening use of clinical genomics has created enormous growth in screening, diagnosing, treatment, and management of both rare and common diseases, but these improvements in care have not been equitably allocated to all populations (Hays et al., 2021). Identification of significant, population-level disparities in health, healthcare quality, and access to services have been increasingly recognized in recent years as a major contributor to poor health in the United States (Centers for Disease Control and Prevention, 2020). Vulnerable populations are generally defined as those groups of people who are at risk for disparate health outcomes or healthcare

access based on one or more economic, cultural, ethnic/racial, or health characteristic (Waisel, 2013). The description of vulnerable populations in the context of genomics healthcare requires an expansive interpretation, to include economic status, geographic location, health status, age, developmental or functional status, communication barriers, race, gender, and ethnicity (Hays et al., 2021).

Vulnerable populations may or may not also be underserved populations. Underserved populations in genomic health care are those which have reduced or no access to genomic services for a host of reasons which may or may not create a population-level vulnerability. Genomics nurses must consider that even in the context of adequate access to care, vulnerable populations may have disproportionately reduced access to genomic technologies and/or be under- or inadequately represented in research related to and extending from factors that identify them as vulnerable, including structural racism, medical mistrust, and historical practices that create current-day disparities in access, such as red-lining (De Wolfe et al., 2021; Plascak et al., 2022).

Today and increasingly in the future, genomics nurses play a major role in efforts to enhance the equitable provision of genomics care through efforts in recognizing vulnerable populations within genomics practice and advocacy for optimal outcomes for those populations. Genomics nurses must demonstrate enhanced ethical decision-making and practice standards related to vulnerable populations and the reduction or elimination of health disparities. Equitable access to appropriate genetic testing technologies, information, and counseling according to each person's culture, religion, omics, knowledge level, literacy and health literacy, comprehension abilities, and preferred language is a requisite of genomic nursing practice and research (National Human Genome Institute, 2021; Tangcharoensathien et al., 2016; Tluczek et al., 2019). The future of genomics nursing requires focus on protecting the well-being of vulnerable populations and ongoing effort to address the exiting gaps in consumer health access and reimbursement pathways for genomic testing and services.

Similarly, health equity is achieved when every person has the opportunity to attain full health potential and no person is disadvantaged because of a socially determined circumstance (Centers for Disease Control and Prevention, 2022). Fair and equitable access to genomic services are not

available to all populations and persons, a problem that is compounded by the unequal access of some populations to participation in genomic research (Jooma et al., 2019). Even within populations affected by genomic conditions, inequity exists due to underrepresentation of minority groups within genomic research. For example, minority populations affected by cystic fibrosis, including African Americans and individuals of Hispanic ethnicity, have worse health outcomes despite comparable access to and use of care resources (DiMango et al., 2021). African American and Hispanic individuals with cystic fibrosis are severely underrepresented in research, particularly on genome-specific therapeutics (McGarry et al., 2022).

In addition to questions of health care access and access to genomic services, a focus on health equity requires genomics nurses to attend to the conditions and contexts in which people live, work, play, and learn. For example, during the COVID-19 pandemic, lack of access to running water impaired the ability of Native Americans living in rural reservation communities to follow recommendations regarding hand hygiene (Running Bear et al., 2021), thus perpetuating the spread of the virus. Vulnerable populations with enhanced risk factors due to genomic conditions such as cystic fibrosis may be particularly at risk of the detrimental effects of physical and social conditions that contribute to poor outcomes.

All registered nurses, advanced professional nurses, and advanced practice nurses working within genomics have an obligation to understand the barriers to genomic technology experienced by diverse populations and individuals. Diverse and underserved populations must be included in genomic research, and research must extend beyond traditional pools of participants, often solely based near academic medical centers. Genomic nurses have an ethical duty to encourage the building of the genomic evidence base towards health equity. Increasing genomic provider knowledge or confidence in interpreting genomic data and reducing implicit bias in underserved populations can result in more precise application towards genomic equity (Jooma et al., 2019). Policy development is required in the future to enable genomic translation towards health equity.

Summary

The expansion of genomics knowledge offers nurses across the globe the opportunity to better understand how the human body functions and to apply new genomics technologies and

computational scientific advances to direct patient care. Previously limited to rare disorders, knowledge of genomics is now necessary for routine care across a spectrum of common and even communicable disease states, as demonstrated by the ongoing COVID-19 pandemic. An understanding of the influence of genomics on health and of available testing is essential in the diagnosis and treatment of many diseases and offers new opportunities for disease prevention, early detection, health promotion, and ELSI considerations. Nurses in all settings are expected to utilize knowledge of genomics in their practice, yet the specialist in genomics nursing has a scope and ethical/moral obligations extending beyond the basic genomics knowledge and skills than those required of all nurses. Additional competencies for genomics nurses and an expanded scope of practice are rooted in the understanding that genomics nurses receive specialty education and training and that these nurses practice in an array of settings across diverse populations.

Standards of Practice

Standard 1. Assessment

The genomics nurse collects comprehensive data pertinent to the patient's health and/or the situation.

Competencies

The genomics nurse:

- Performs assessments that include collection, interpretation, and evaluation of comprehensive data while honoring patient uniqueness. Physical, functional, psychosocial, emotional, cognitive, sexual, cultural, age-related, environmental, spiritual, and economic assessments are performed in a systematic and ongoing process.
- Gathers historical data including the patient's health history, family health history, familial relationships, and relevant hereditary and non-hereditary risk factors.
- Bases data collection and assessment on knowledge of human genomic principles, genomics services and resources, current genomic and nursing research, and relevant professional guidelines and recommendations.
- Documents physical findings associated with genomic conditions as well as pertinent test information, medications, and medication reactions.
- Identifies barriers (e.g., psychosocial, literacy, financial, cultural) to care and services, including barriers to effective communication.
- Makes appropriate adaptations to address barriers.
- Locates appropriate resources for patient referral.
- Honors the patient's personal and cultural values and beliefs and wishes.
- Assesses family dynamics and impact on patient health and wellness.
- Recognizes that genomic information may have great impact for patient and relatives.
- Maintains professional guidelines and recommendations as appropriate to the patient and practice setting.

- Maintains currency of knowledge base of genomics topics relevant to the specialty population or setting in which practice occurs.
- Prioritizes patient information and the immediate needs of patient care.
- Uses appropriate evidence-based assessment techniques, instruments, and tools.
- Synthesizes available data, information, and knowledge relevant to the situation to identify patterns and variances.
- Applies ethical, legal, and privacy guidelines and policies to the collection, maintenance, use, and dissemination of data and information.
- Assesses for response to medications or therapies for genomic conditions, including side effects and adverse events.
- Communicates findings, recommendations, and referrals as appropriate with the interdisciplinary clinical team.

Additional competencies for the advanced genomics nurse:

- Creates and documents the pedigree from relevant family history.
- Uses pedigree, family history, and risk assessment data in the conduct and interpretation of physical assessment.
- Analyzes the effect of interactions among individuals, families, communities, and social systems on genomic conditions.
- Synthesizes the results, assessment findings, history, and other relevant data, leading to clinical understanding.
- Identifies actual or potential risks to the patient's health and safety or barriers to health and safety.
- Uses family history and pedigree information to plan and conduct a targeted physical assessment.
- Initiates diagnostic tests and procedures relevant to the patient's current status, including but not limited to genomic tests and diagnostic procedures.
- Assesses the utility of specific genomic testing for patients and populations based on actionability of results and principles of health equity at the individual and global level.

- Interprets screening and diagnostic tests and procedures relevant to the patient's current status.
- Assesses, as appropriate, reproductive risk for genomic conditions and procreation concerns.
- Assesses pharmacogenomics in the course of prescribing therapies and medications, particularly in light of the potential for adverse reactions.
- Educates patients and families/caregivers regarding rationale for assessments and testing as well as genomics concepts, disease process, risk, and prevention/treatment as relevant to the individual needs of that patient and family.

Standard 2. Diagnosis

The genomics nurse analyzes the assessment data to determine actual or potential diagnoses, problems, or issues.

Competencies

The genomics nurse:

- Derives the potential and actual nursing diagnoses from assessment data, symptomology, personal history, family history, and test results.
- Validates the diagnoses or issues with the patient, family, community, group, other healthcare providers, and medical/state records when possible and appropriate.
- Uses standardized classification systems and available clinical decision support tools with an understanding of the strengths and limitations of these tools.
- Documents diagnoses or issues in a manner that facilitates the determination of the expected outcomes and plan.

Additional competencies for the advanced genomics nurse:

In addition to the registered nurse competencies, the graduate prepared genomics nurse:

- Uses information and communication technologies to analyze diagnostic practice patterns of nurses and other members of the professional healthcare team

- Employs aggregate data to describe and convey diagnoses, problems, and issues of patients and organizational systems
- Educates patients, treatment staff, and the community of genomic diagnoses and diseases as appropriate while maintaining confidentiality of individual patients.
- Assists staff in developing and maintaining competence in the diagnostic or problem identification process.
- Systematically compares and contrasts clinical findings with normal and abnormal variations and developmental events in formulating a differential diagnosis.
- Formulates a differential diagnosis and/or risk assessment based on patient history, pedigree, other family history, test results, and clinical data.
- Prioritizes diagnoses, problems, and issues based on mutually established goals to meet the needs of the patient.
- Incorporates standardized terminologies and coding methodologies to ensure correct documentation of diagnoses, problems, and issues.

Standard 3. Outcomes Identification

The genomics nurse identifies expected outcomes for a plan individualized to the patient or the situation.

Competencies

The genomics nurse:

- Engages with the patient, and where feasible the family, to identify expected outcomes.
- Collaborates with members of the healthcare team to identify expected outcomes.
- Integrates assessment data, diagnoses, evidence, and best practices to identify expected outcomes.
- Facilitates continuity of care in the development of expected outcomes.
- Documents expected outcomes as measurable goals.
- Modifies expected outcomes according to changes in the status of the patient or evaluation of the situation.

Additional competencies for the advanced genomics nurse:

- Defines expected outcomes that incorporate cost and clinical utility and that are aligned with the benchmarks identified by members of the interprofessional team.
- Takes an active role in educating others regarding the identification of expected outcomes.
- Identifies quality outcome measures in relation to the expected outcomes, safety, and quality standards of the practice setting.
- Identifies expected outcomes that incorporate scientific evidence and are achievable through implementation of evidence-based practices.
- Advocates for improvements in methodology, treatments, and resources to enhance outcomes.
- Contributes to research to enhance outcomes, process, and value through improvements in assessment, diagnosis, and treatment of genomic conditions and related human responses.
- Identifies expected outcomes that incorporate and/or encourage cost and clinical effectiveness, patient satisfaction, and continuity and consistency among providers.
- Differentiates outcomes that require care process interventions from those that require system-level interventions.
- Identifies the benefits, limitations, and risks of genomic information and/or therapies for the patient and family.
- Identifies genomic healthcare methods and outcomes that can be influenced by nursing.

Standard 4. Planning

The genomics nurse develops a plan that prescribes strategies and alternatives to attain expected outcomes.

Competencies

The genomics nurse:

- Develops an individualized plan in partnership with the patient, family, and other health care team members.
- Develops culturally appropriate, timely, cost-effective, and evidence-based plan of care in full consideration of the patient's culture, values, beliefs, individual strengths (e.g., support system and capacity), and priorities.
- Establishes the plan priorities with the patient, family, and others, as appropriate, based on the patient/family's chief concern(s), especially related to genomic diagnosis and/or risk.
- Conducts all planning in the context of patient-based values and culture, including the right to reject unwanted and/or burdensome testing and treatment.
- Adheres to all clinical, national, and international guidelines and/or research protocols as appropriate to the situation.
- Considers patient's health status, capabilities, and capacities as integral components of the plan of care with a particular focus on assuring informed consent and respecting patient autonomy.
- Includes strategies in the plan that address each of the identified diagnoses, problems, or issues, including physical, emotional, and psychosocial concerns. These strategies may include but are not limited to strategies for:
 - Promotion and restoration of health and maximum wellbeing across the lifespan
 - Risk reduction
 - Prevention of illness, injury, and disease
 - Alleviation of suffering
 - Supporting caregivers
 - Promotion of health equity through continual assessment for disparities in care planning and provisioning
 - Provision of supportive and palliative care when appropriate
- Integrates current scientific evidence, trends, and research.
- Modifies the plan according to the ongoing assessment of the patient's response and other outcome indicators.

- Documents the plan in a manner that uses standardized language or recognized terminology.

Additional competencies for the advanced genomics nurse:

- Considers the economic impact of the plan on the patient, family, caregivers, or other affected parties and identifies strategies to support individuals and families of limited means to achieve equitable care for all patients.
- Identifies diagnostic strategies and therapeutic interventions that reflect current contextual information, research literature and expert clinical knowledge.
- Selects or designs strategies to meet the multifaceted needs of complex patients.
- Leads the design and development of interprofessional processes to address the identified diagnosis or issue.
- Actively participates in the development and continuous improvement of systems that support the planning process, including health policy development and improvement to health systems at the local, state, national, and international levels.

Standard 5. Implementation

The genomics nurse implements the identified plan.

Competencies

The genomics nurse:

- Assumes responsibility for the safe and efficient implementation of the plan
- Partners with the patient, family, significant others, and caregivers, as appropriate, to implement the plan in a safe, feasible, and timely manner.
- Demonstrates caring behaviors toward patients, significant others, and groups of people receiving care.
- Utilizes technology to measure, record, and retrieve patient data; implement the nursing process; and enhance nursing practice in accordance with current standards and laws governing patient data.

- Utilizes evidence-based interventions and treatments specific to the diagnosis or problem.
- Provides holistic care that addresses the needs of diverse populations across the lifespan.
- Advocates for health care that is sensitive to the needs of the patient with particular emphasis on the needs of diverse populations.
- Applies appropriate knowledge of major health problems and cultural diversity in implementing the plan of care.
- Utilizes community resources and systems to implement the plan.
- Collaborates with healthcare providers from diverse disciplines and backgrounds to implement and integrate the plan.
- Accommodates for different styles of communication used by patients, families, and healthcare providers.
- Integrates traditional and complementary healthcare practices as appropriate to patient's cultural and personal values.
- Implements the plan in a timely manner in accordance with patient safety goals.
- Promotes the patient's capacity for the optimal level of participation, self-determination, and problem-solving.
- Documents implementation and any modifications to the identified plan

Additional competencies for the advanced genomics nurse:

- Facilitates utilization of systems, organizations, and community resources to implement the plan.
- Initiates and engages in collaboration with appropriate colleagues to implement the plan.
- Incorporates new knowledge and strategies to initiate change in nursing care practices if desired outcomes are not achieved, and as standards of care evolve.
- Appreciates that advancement of technology commonly precedes knowledge of clinical application in genomics and beyond.
- Selects from the available genomic interventions and tests using knowledge of validity, clinical utility, and the quality of potential new information or impact on outcomes.

- Uses advanced communication skills to promote relationships between patients and the healthcare team, to provide a context for safe and open discussions of the patients' and/or familial experiences, and to improve outcomes.
- Actively participates in the development and continuous improvement of systems that support the implementation of the plan.

Standard 5A. Coordination of Care

The genomics nurse coordinates care delivery.

Competencies

The genomics nurse:

- Manages the patient's care and transitions of care in order to maximize independence, quality of life, and health outcomes.
- Assists patient with decision-making regarding options and alternatives, including facilitation of communication between patient, family, and other members of the healthcare team as needed.
- Communicates with the patient, family, and system during transitions in care.
- Advocates for the delivery of dignified and humane care by the interprofessional team.
- Documents the coordination of care.

Additional competencies for the advanced genomics nurse:

- Provides leadership in the coordination of interprofessional health care for integrated delivery of patient care services.
- Synthesizes data and information to prescribe necessary system- and community-support measures, including modifications of surroundings.
- Initiates appropriate referrals to facilitate coordination of care.

Standard 5B. Health Teaching and Health Promotion

The genomics nurse employs strategies to promote health and a safe environment.

Competencies

The genomics nurse:

- Provides health teaching that addresses genomics impact on such topics as healthy lifestyles, risk-reducing behaviors, developmental needs, activities of daily living, preventive self-care, and symptom self-management.
- Provides teaching related to hereditary and environmental risks to genomic health.
- Provides individualized risk assessment specific to the patient's and/or familial concerns and risk factors.
- Uses health promotion and health teaching methods appropriate to the situation and to the patient's individual characteristics, including but not limited to values, culture, family, developmental and functional capacities, learning needs, language, general and health literacy, and resources.
- Uses information technologies to communicate health promotion and disease prevention information to the patient in a variety of settings.
- Provides patient with information about intended effects and potential adverse effects of proposed therapies and/or interventions.
- Documents health teaching and health promotion activities.

Additional competencies for the advanced genomics nurse:

- Synthesizes empirical evidence on risk behaviors, learning theories, behavioral change theories, motivational theories, epidemiology, and other related theories and frameworks when designing health education information and programs.
- Conducts personalized health teaching and counseling considering comparative effectiveness research recommendations.
- Provides genomic counseling as appropriate.
- Designs health information and patient education appropriate to the patient's developmental level, learning needs, readiness to learn, and cultural values and beliefs.

- Evaluates health information resources (such as those available on the internet) in the area of practice for accuracy, readability, and comprehensibility to help patients access quality health information.
- Engages consumer alliances and advocacy groups, as appropriate, in health teaching and health promotion activities.

Standard 5C. Consultation

The graduate-level prepared genomics nurse provides consultation to influence the identified plan, enhance the abilities of others, and effect change.

Competencies for the advanced genomics nurse:

- Synthesizes empirical evidence, clinical data, and practice frameworks when providing consultation.
- Facilitates the effectiveness of a consultation by involving the patients and stakeholders in decision-making and negotiating role responsibilities.
- Communicates consultation recommendations to patient and members of the healthcare team.
- Facilitates patient to communicate health information relevant to family members.
- Documents consulting activities and communication with patient and health care team members.

Standard 5D. Prescriptive Authority and Treatment

The graduate-level prepared nurse with prescriptive authority prescribes procedures, referrals, treatments, and therapies in accordance with state and federal laws and regulations.

Competencies for the advanced genomics nurse:

- Identifies therapies that are aimed at prevention of potential or expected needs related to genomic health or conditions.

- Prescribes evidence-based treatments, therapies, and procedures in consideration of the patient's comprehensive healthcare needs and in accordance with treatment and prevention plans.
- Prescribes specific pharmacological agents or treatments according to a current knowledge of pharmacology, physiology, and pharmacogenomics based on clinical indicators, the patient's status and needs, and the results of diagnostic and laboratory tests.
- Evaluates therapeutic and potential adverse effects of pharmacological and non-pharmacological treatments.
- Provides patient with information about intended effects and potential adverse effects of proposed prescriptive therapies.
- Provides information about costs and alternative treatments and procedures, as appropriate.
- Evaluates and incorporates complementary and alternative therapy into education and practice as appropriate based on patient personal preferences and cultural indications and/or evidence-based guidelines.

Standard 6. Evaluation

The genomics nurse evaluates progress toward attainment of outcomes.

Competencies

The genomics nurse:

- Conducts an ongoing systematic, criterion-based evaluation of the outcomes in relation to the structures and processes prescribed by the plan of care and the indicated timeline.
- Collaborates with the patient and others involved in the care or situation in the evaluation process.
- Uses ongoing assessment data to revise the diagnoses, outcomes, plan, and implementation as needed.
- Disseminates the results to the patient, family, and others involved, in accordance with state, federal, and international regulations/guidelines and patient preferences.

- Participates in assessing and assuring the responsible and appropriate use of interventions in order to minimize unwarranted or unwanted treatment and patient suffering.
- Seeks opportunities for feedback and evaluation of the effectiveness of the strategies used.
- Documents the results of the evaluation.

Additional competencies for the graduate-level prepared genomics nurse

The graduate-level prepared genomics nurse:

- Evaluates the accuracy of the diagnosis and the effectiveness of the interventions and other variables in relation to the patient's attainment of expected outcomes.
- Synthesizes the results of the evaluation to determine the effect of the plan on patient, families, groups, communities, institutions, and populations.
- Adapts the plan of care and/or outcomes according to evaluation of response using ongoing assessment data and evaluation of scientific evidence.
- Uses the results of the evaluation to make or recommend changes to processes, policies, regulations, or protocols that affect patient outcomes and/or care, as appropriate.

Standards of Professional Performance

Standard 7. Ethics

The genomics nurse practices ethically.

Competencies

The genomics nurse:

- Uses the *Code of Ethics for Nurses with Interpretive Statements*, 2nd edition (ANA, 2015) to guide practice.
- Uses the *Guide to Nursing's Social Policy Statement* (ANA, 2015) to guide understanding of nursing's relationship with society and society's relationship with nursing.

- Delivers care in a manner that preserves and protects patient autonomy, dignity, rights, values, and beliefs
- Delivers care that respects individual and community diversity in race, color, religion or creed, national origin or ancestry, sex (including gender, gender expression or identity, pregnancy, and sexual orientation), age, physical or mental disability, genetic information, veteran status, and citizenship.
- Recognizes the centrality of the patient and family as core members of any healthcare team.
- Upholds patient confidentiality within legal and regulatory parameters.
- Assists patients in self-determination and informed decision-making.
- Maintains a therapeutic and professional patient–nurse relationship within appropriate professional role boundaries.
- Contributes to resolving genomics-related ethical, legal, and social issues involving patients, colleagues, community groups, systems, nations, and other stakeholders.
- Takes appropriate action regarding instances of illegal, unethical, or inappropriate behavior that can endanger or jeopardize the best interests of the patient or situation involving the use of genomics services and information.
- Speaks up when appropriate to question genomics healthcare practice(s) when necessary for safety and quality improvement.
- Seeks continual improvements in knowledge, skills, and competencies for genomics nursing through participating in and/or leading continuing education for self, peers, and interdisciplinary colleagues.
- Maintains sufficient expertise in ethical, legal, and social implications of scientific advances in genomics, including medication and treatment safety, quality, and genomic test interpretation
- Advocates for equitable patient care and removal of health disparities.

Additional competencies for the advanced genomics nurse:

- Participates in interprofessional teams to address ethical, legal, and social risks, benefits, and outcomes.

- Provides information on the risks, benefits, and outcomes of healthcare regimens such as genomic testing to allow informed decision-making by the patient, including informed consent and informed refusal.
- Participates in and/or leads clinical or research teams that promote equitable access to genomic healthcare for improved lived experience and outcomes of patients with acute and chronic conditions.
- Engages in system, national, and international level policy advocacy for the protection of patients, families, communities, populations, and nations for the access and provision of responsible, appropriate genomic healthcare (e.g., lifesaving vaccines, diagnostics, therapeutics).

Standard 8. Advocacy

The genomics nurse demonstrates advocacy in all roles and settings.

Competencies

The genomics nurse:

- Champions the voice of the patients, families, communities, and populations with genomic conditions and/or in need of genomics healthcare.
- Recommends appropriate levels of care, coordinates timely and appropriate care transitions, and ensures allocation of resources to optimize patient- and family-centered genomic healthcare outcomes
- Promotes patient safety through the prevention of avoidable events (in-hospital complications, procedures, adverse events, errors, near misses, etc.), safe work environments, and adequate resources for safe practice.
- Advocates for patients in healthcare initiatives within all practice settings.
- Demonstrates a willingness to address persistent, pervasive systemic inequity in genomic healthcare such as: inclusion and protection of underserved and/or vulnerable populations, provision of adequate informed consent, and facilitating shared decision making.

- Informs legislative and political stakeholders about the essential role of genomics nurses and the vital components needed by nurses to provide optimal genomic healthcare delivery.
- Develops policies that improve care delivery and access for underserved and/or vulnerable populations while recognizing the reality of a broad definition of vulnerability in relation to genomic healthcare (refer to Vulnerable Populations & Health Equity, p. 43).
- Promotes policies, regulations, and legislation at the local, state, regional, national, and global levels to improve genomic healthcare access and delivery.
- Considers societal, political, economic, and cultural factors to address social determinants of health.
- Role models healthy advocacy behavior including but not limited to respect for persons, beneficence, justice, patient and family confidentiality and privacy, non-discriminatory judgement, recognition of impaired practice, safeguarding those with decreased autonomy through reporting of identified abuses, whistleblowing, nurturance of sound moral dispositions of mind and character, and facilitation of restoration or health and independence.
- Addresses the urgent need for prioritizing a diverse and inclusive workforce as a strategy to improve outcomes related to the social determinants of health and healthcare system and social inequities.
- Advances policies, programs, and practices within the healthcare environment that maintain, sustain, and restore the physical environment and natural world around them.
- Contributes to nursing and interdisciplinary professional organizations.

Additional competencies for the advanced genomics nurse:

- Analyzes the impact of geographic, societal, political, economic, and cultural factors on healthcare disparities.
- Develops alliances with various groups to promote advocacy goals.
- Pursues resources to improve the delivery of care services and outcomes.

- Influences leaders, legislators, governmental agencies, organizations, and international bodies to address social determinants of health.
- Promotes universal application of full practice authority in all settings and roles in meeting healthcare needs for diverse populations.
- Advocates for a direct reporting structure to the appropriate leadership level that endorses and supports the advance practice genomics nurse's full scope of practice capacity in accordance with their education, training, and licensure level.
- Endorses the profession's *Consensus Model for APRN Regulation: Licensure, Accreditation, Certification, & Education* of the U.S. APRN Consensus Work Group and National Council of State Boards of Nursing APRN Advisory Committee (2008).

Standard 9. Respectful and Equitable Practice

The genomics nurse practices with cultural humility and inclusiveness.

Competencies

The genomics nurse:

- Demonstrates respect, equity, and empathy in actions and interactions with all patients, families, communities, and populations.
- Respects patient, family, and stakeholder decisions without bias.
- Participates in life-long learning to understand cultural preferences, worldviews, choices, and decision-making processes of diverse patients, communities, organizations, and populations.
- Routinely reflects upon personal and cultural values, beliefs, biases, and heritage.
- Applies knowledge of differences in health beliefs, practices, and communication patterns without assigning value to the differences.
- Readily recognizes the effects and impact of systematic and individual discrimination and oppression on practice within and among diverse groups and takes direct action to address harmful behaviors (i.e., verbalization, avoidance, reporting, etc.).
- Uses appropriate skills, communications, tools and interventions for the culture, literacy, and language of the individuals and populations served.

- Communicates with appropriate language and behaviors, including the use of qualified healthcare interpreters and translators in accordance with patient and family needs and preferences.
- Serves as a role model and educator for cultural humility and the recognition and appreciation of diversity and inclusivity.
- Identifies the culture-specific meaning of interactions, terms, policies, stakeholders, content, and situational contexts.
- Advocates for policies that promote and restore health and prevent harm among diverse patients and groups.
- Promotes equity in all aspects of health and healthcare.
- Advances organizational policies, programs, services, and practices that reflect respect, equity, and values for diversity and inclusion.

Additional competencies for the advanced genomics nurse:

- Engages patients, key stakeholders, and others in designing and establishing internal and external cross-cultural partnerships.
- Conducts research, evidence-based practice, and quality improvement initiatives to improve healthcare and outcomes for culturally diverse patients, families, communities, populations, and stakeholders.
- Develops recruitment and retention strategies to achieve a multicultural workforce.
- Engages in shared decision-making when planning and evaluating processes when the patient's, family's or community's cultural preferences and norms create incompatibility with evidence-based practice.

Standard 10. Communication

The genomics nurse communicates effectively in a variety of formats in all areas of practice.

Competencies

The genomics nurse:

- Assesses communication format for preferences of patients, families, colleagues, stakeholders, and policymakers.
- Assesses their own communication skills in encounters with others.
- Seeks continuous improvement of their own communication and conflict resolution skills.
- Conveys genomic and other information to patients, families, the interprofessional team, and others in communication formats that promote accuracy and relevancy.
- Questions the rationale supporting care processes and decisions when they do not appear to be in the best interest of the patient.
- Discloses observations or concerns related to hazards to self, peers, patients, research participants, students, and others in all practice settings to appropriate individuals and/or systems with oversight authority.
- Discloses observations or concerns related to errors in care or all practice settings to the appropriate individuals and/or systems with oversight authority.
- Persists in disclosure via escalating
- Works closely with or as part of an interdisciplinary team to maintain communication with other providers to minimize risks associated with transfers and transitions in care delivery (care coordination).
- Contributes their nursing perspective in discussions with the interprofessional team, administrators, and policymakers.

Standard 11. Collaboration

The genomics nurse collaborates with patient, family, and others in the conduct of nursing practice.

Competencies

The genomics nurse:

- Partners with others to affect change and produce positive outcomes through the sharing of knowledge of the patient and/or the patient's situation.
- Communicates with the patient, the family, and the healthcare providers regarding patient care and the nurse's role in the provision of that care.

- Recognizes and communicates the impact patient's genomic care may have on family member's health risks and care needs.
- Promotes conflict management, engagement, reconciliation, and resolution.
- Participates in consensus building or conflict resolution in the context of patient- and family-centered care.
- Applies group process and negotiation techniques with patient and colleagues.
- Adheres to standards and applicable codes of ethical conduct that govern behavior among peers and colleagues to create a work environment that promotes mutual cooperation, respect, and trust.
- Cooperates in creating a documented plan focused on outcomes and decisions related to healthcare and delivery of genomic services that indicate communication with patients, families, and others.
- Participates in research opportunities.
- Engages in teamwork and team-building processes.

Additional competencies for the advanced genomics nurse:

- Partners with other disciplines to enhance patient outcomes through interprofessional activities, such as education, consultation, management, technological development, dissemination, policymaking, and/or research opportunities.
- Invites and honors the contribution of the healthcare patient, family, team members and additional stakeholders in order to define and achieve optimal outcomes.
- Leads in establishing, improving, and sustaining collaborative relationships to achieve safe, high-quality patient care.
- Documents plan-of-care communications, rationales for plan-of-care changes, and collaborative discussions to improve patient, family, community, and population outcomes.

Standard 12. Leadership

The genomics nurse demonstrates leadership in the professional practice setting and the profession.

Competencies

The genomics nurse:

- Oversees the nursing care given by others while retaining accountability for the quality of care given to the patient.
- Demonstrates a commitment to continuous, lifelong learning and education for self and others.
- Mentors students, trainees, and colleagues for the advancement of nursing practice, the profession, and quality health care.
- Treats colleagues with respect, trust, and dignity.
- Develops communication and conflict resolution skills.
- Participates in general and specialized professional nursing organizations including but not limited to the International Society of Nurses in Genetics.
- Participates in general and specialized organizations beyond nursing to advance the voice of nursing into interdisciplinary spaces relevant to genomics.
- Seeks ways to advance nursing autonomy, integrity, and accountability.
- Participates in efforts to advocate for social justice in healthcare and health-affecting social policies that promote patient, family, community, population, and societal well-being and which contributes positively to the nursing profession.
- Participates in policymaking related to genomic healthcare at the organizational, local, state, national, and/or international levels with the goal of advancing the health of patients, families, communities, and society and enhancing the nursing profession and/or workforce.

Additional competencies for the advanced genomics nurse:

- Engages with and serves within decision-making bodies to improve the professional practice environment and patient outcomes and provide equitable genomics healthcare.
- Provides direction to enhance the effectiveness of the interprofessional team.
- Promotes advanced practice nursing and role development in the context of genomics health care by interpreting its role for patients, families, and others.

- Models expert practice of genomic healthcare to interprofessional team members and patients.
- Mentors students, trainees, registered nurses in basic practice, interdisciplinary professionals, and peers in the acquisition of clinical genomics knowledge, skills, abilities, advocacy, and judgment.

Standard 13. Education

The genomics nurse attains knowledge and competence that reflect current nursing practice.

Competencies

The genomics nurse:

- Participates in educational activities related to appropriate knowledge bases and professional issues.
- Demonstrates a commitment to lifelong learning through self-reflection and inquiry to address learning and personal growth needs.
- Seeks experiences that reflect current practice to maintain genomic knowledge, skills, abilities, and judgment in clinical practice or role performance.
- Acquires knowledge and skills appropriate to the genomics specialty, population, setting, role, or situation.
- Seeks formal and independent learning experiences to develop and maintain clinical and professional skills, and knowledge of genomics.
- Identifies learning needs based on nursing knowledge, the various roles the genomics nurse may assume, the changing needs of the population, and the sociopolitical contexts for genomic healthcare.
- Attains core competencies in genomics for nurses recommended in the professional guidelines, *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators, 2nd Edition* (Consensus Panel, 2008).
- Participates in formal or informal consultations to address genomics issues in nursing practice as an application of education and knowledge base.

- Shares educational findings, reflections, experiences, and ideas with peers in a mutually respectful manner.
- Contributes to a work environment that is conducive to the education of healthcare professionals.
- Maintains professional records that provide evidence of genomics competence and lifelong learning.

Additional competencies for the advanced genomics nurse:

- Attains core competencies in genomics for nurses recommended in the professional guidelines, *Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees* (Greco, Tinley, & Seibert, 2012).
- Uses the fundamental genomic knowledge content required for nurse scientists as recommended in the Genomic Knowledge Matrix for Nursing Science (Regan et al, 2019).
- Participates in continuing education on the evolving practice landscape for APRNs on the state, federal, and international levels.
- Recognizes the need for additional professional competencies to accomplish the objective of fully integrating genomics into specialty content areas including nursing informatics and doctoral standards of scientific nursing scholarship (McCormick & Calzone, 2017; Regan et al, 2019).

Standard 14. Scholarly Inquiry

The genomics nurse integrates scholarship, evidence, and research findings into practice.

Competencies

The genomics nurse:

- Identifies clinical questions involving genomics in the healthcare or practice setting that can be answered through scholarly inquiry.
- Uses current evidence-based knowledge, including research findings and scientific theory, to guide practice in all settings.

- Incorporates validated scientific and scholarly evidence when initiating changes in nursing practice.
- Evaluates evidence for currency, relevancy to the problem and population, and scientific validity prior to and during use, with particular attention to retractions, letters of concern, and other indications that evidence may be suspect in its methodology or conclusions.
- Integrates current healthcare genomics research findings and other evidence to expand clinical knowledge, skills, abilities, and judgment; to enhance role performance; and to increase knowledge of professional issues.
- Participates, as appropriate to education level and position, in the formulation of evidence-based practice, quality improvement, and nursing research through unit, department, and organizational committees, journal clubs and projects.
- Shares peer-reviewed, evidence-based findings research findings with colleagues.
- Seeks feedback from peer evaluations of performance and patient satisfaction data as appropriate to practice setting.
- Promotes ethical principles of research in all settings.

Additional competencies for the advanced genomics nurse:

- Critically appraises data and scientific contributions to generate meaningful evidence for genomics nursing practice using appropriate models, frameworks, tools, and appraisal systems.
- Contributes to nursing knowledge by conducting or synthesizing genomic research and other evidence that discovers, examines, and evaluates current practice, knowledge, theories, criteria, policies, and innovative approaches to improve healthcare outcomes.
- Promotes a climate that is supportive and respectful of research and conducive to nursing scholarly inquiry.
- Disseminates genomics research findings through activities such as presentations, peer-reviewed publications, consultations, media, public health education, and journal clubs or through involvement in community and/or professional organizations.

- Mentors other nurses to develop scholarly inquiry skills related to genomic evidence, data gathering and interpretation, research, evaluation of evidence, and dissemination of nursing scholarship.

Standard 15. Quality of Practice

The genomics nurse contributes to quality genomics nursing practice.

Competencies

The genomics nurse:

- Demonstrates quality by documenting the application of the nursing process in a responsible, accountable, and ethical manner in compliance with relevant regulations.
- Maintains appropriate certifications and credentials to demonstrate quality of practice.
- Uses creativity and innovation to enhance nursing care.
- Participates in quality improvement. Activities may include:
 - Identifying aspects of practice important for quality monitoring.
 - Using outcome indicators to monitor quality, safety, and effectiveness of nursing practice.
 - Collecting data to monitor quality and effectiveness of nursing practice.
 - Analyzing quality data to identify opportunities for improving nursing practice.
 - Formulating recommendations to improve nursing practice and/or standardize outcomes.
 - Implementing activities to enhance the quality of nursing practice.
 - Developing, implementing, and/or evaluating policies, procedures, and guidelines to improve the quality of practice.
 - Participating on and/or leading interprofessional teams to evaluate clinical care or genomic or general health services.
 - Participating in and/or leading efforts to minimize costs and unnecessary duplication.
 - Identifies and corrects process inefficiencies in day-to-day work routines.
 - Analyzing factors related to quality, safety, and effectiveness.

- Analyzing organizational systems for barriers to quality patient outcomes.
- Implementing processes to remove or weaken barriers within organizational systems.

Additional competencies for the advanced genomics nurse:

- Provides leadership in the design and implementation of quality improvements and performance improvements.
- Designs innovations to effect change in practice and improve outcomes.
- Evaluates the practice environment, safety, effectiveness, and quality of nursing care in relation to existing genomics evidence and internal and external outcomes indicators.
- Selects an appropriate methodology, framework, and/or tools to aid in performance of rapid-cycle innovations and change implementation, including but not limited to Plan-Do-Study-Act, Lean, Six Sigma, Cause and Effect diagrams, etc..
- Identifies opportunities for the generation and use of genomics research and evidence.
- Maintains professional certification as an Advanced Practice Nurse in Genetics [AGN-BC, formally Advanced Practice Nurse in Genetics (APNG)].
- Uses the results of quality improvement to initiate changes in nursing practice and the healthcare delivery system.

Standard 16. Professional Practice Evaluation

The genomics nurse evaluates their own nursing practice in relation to professional practice standards and guidelines, relevant statutes, rules, and regulations.

Competencies

The genomics nurse:

- Provides care appropriate to the age, developmental level, culture, gender identity, and sexual orientation of patients in a culturally and ethnically competent manner.
- Engages in self-evaluation of genomics nursing practice on a regular basis, identifying areas of strength as well as areas in which professional growth would be beneficial.

- Obtains formal and informal feedback regarding their own practice from patients, peers, professional colleagues, and others.
- Takes action to achieve goals identified during the evaluation process
- Provides the evidence for practice decisions and actions as part of the informal and formal evaluation processes.
- Interacts with peers and colleagues to enhance their own professional nursing practice or role performance in genomics nursing.
- Provides peers with formal or informal constructive feedback regarding their practice or role performance in genomics nursing.

Additional competencies for the advanced genomics nurse:

- Engages in a formal process seeking feedback regarding their own genomics nursing practice from patients, peers, professional colleagues, and others.
- Submits/presents scientific research and clinical scholarly findings to peer-reviewed journals, professional conferences, and other appropriate forums (e.g., expert panel presentations, moderation of panels, testimony before legislative bodies) for professional dissemination of scholarship that advances the nursing profession and the genomics specialty.

Standard 17. Resource Stewardship

The genomics nurse utilizes appropriate resources to plan and provide nursing services that are safe, effective, and financially responsible.

Competencies

The genomics nurse:

- Assesses individual patient care needs, especially related to genomics, and resources available to achieve desired outcomes.
- Identifies patient care needs, potential for harm, complexity of the task, and desired outcome when considering resource allocation, especially related to genomics.

- Delegates elements of genomics care to appropriate healthcare workers in accordance with any applicable legal or policy parameters or principles.
- Identifies the evidence when evaluating resources and weighs known or suspected benefits against risks, including financial and opportunity costs (e.g., potential lost benefits from alternative treatment or testing opportunities).
- Advocates for resources, including genomics technology, that enhance nursing practice.
- Assists the patient and family in identifying and securing appropriate services to address identified needs.
- Assists the patient and family in factoring costs, risks, and benefits in decisions about treatment and care related to their health.

Additional competencies for the advanced genomics nurse:

- Utilizes organizational and community resources to formulate interprofessional plans of care.
- Formulates innovative solutions for patient care problems that utilize resources effectively to maintain high levels of health care quality.
- Develops evaluation strategies to demonstrate cost-effectiveness, cost–benefit, and efficiency factors associated with genomics nursing practice.
- Recommends genomic tests that are associated with improved patient outcomes.
- Educates patients about the relative costs, benefits, and risks of testing and treatment options
- Advocates for social justice with regard to access and affordability of services and treatments.
- Advocates for representation of all persons in genomics research and quality improvement with a goal toward improving health equity.

Standard 18. Environmental Health

The genomics nurse practices in an environmentally safe and healthy manner.

Competencies

The genomics nurse:

- Attains knowledge of environmental and epigenetic health concepts, such as implementation of environmental health strategies that address gene–environment influences on health.
- Promotes a practice environment that reduces environmental health risks for workers and patients, families, and communities in all settings.
- Assesses the practice environment for presence of risk factors such as hazardous medical byproducts/waste, sound, odor, noise, polluted air/water, and light that threatens health.
- Advocates for the judicious and appropriate use of products in health care, including genomic tests.
- Communicates environmental health risks including risks associated with gene–environment interactions and toxic substance exposure reduction strategies to patients, families, colleagues, communities, organizations, and populations.
- Utilizes scientific evidence to determine if a product or treatment is an environmental threat.
- Participates in strategies such as population-based genomic screening to promote healthy communities, including infectious disease strain monitoring and other genomics-based public health activities.
- Fully supports local, state, federal, and international public health epidemic and pandemic surveillance efforts and public health recommendations during infectious disease outbreaks.
- Fully considers impacts of environmental justice on health disparities involving marginalized and vulnerable individuals, families, communities, and populations living in or near areas that are at disproportionately high risk of climate emergencies, unhealthy land uses, environmental hazards, and traumas. This includes but is not limited to health disparities impacting racial/ethnic, low-income/poor, rural, immigrant/refugee and indigenous populations.

- Anticipates risks to vulnerable and underserved communities in the event of a natural disaster, epidemics, pandemics and can contribute to emergency planning policies that ensure critical healthcare needs of genomics patients, patients, families, are met (e.g., supplies of specialty medications and/or clinic visits for treatment administration).

Additional competencies for the advanced genomics nurse:

- Creates partnerships and alliances to promote sustainable environmental health policies and conditions that incorporate current knowledge of epigenomics and environmental factors that influence genomic health.
- Analyzes the impact of social, political, and economic influences on the environment and genomic susceptibilities associated with human health exposures, infectious disease outbreaks, and natural disasters.
- Critically evaluates the manner in which environmental and genomic health issues are presented by the popular and social media and takes all feasible steps to responsibly refute misinformation in their local organizations and communities.
- Advocates for implementation of environmental principles and ethical stewardship of natural resources for delivery of nursing practice in all settings.
- Advocates for climate resilience.
- Advocates for equitable environmental related to health within the provision of genomics healthcare to preserve sustainability and reduce the carbon footprint of genomic healthcare (e.g., net-zero emissions).
- Supports nurses in advocating for and implementing principles in nursing practice that promote environmental safety at local, state, federal and international levels.

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