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Nurses Transforming Health Care Using Genetics and Genomics

Kathleen A. Calzone, MSN, RN, APNG, FAAN¹, Ann Cashion, PhD, RN, FAAN², Suzanne Feetham, PhD, RN, FAAN³, Jean Jenkins, PhD, RN, FAAN⁴, Cynthia A. Prows, MSN, CNS, FAAN⁵, Janet K. Williams, PhD, RN, PNP, FAAN⁶, and Shu-Fen Wung, PhD, RN, ACNP, FAHA, FAAN⁷

¹ National Institutes of Health, National Cancer Institute, Center for Cancer Research, Genetics Branch, Bethesda, MD

² Acute and Chronic Care Department, University of Tennessee Health Science Center, Memphis, TN

³ College of Nursing, University of Wisconsin-Milwaukee, Milwaukee WI; Nursing Research Consultant Children's National Medical Center, Washington, DC

⁴ National Institutes of Health, National Human Genome Research Institute, Bethesda, MD

⁵ Divisions of Patient Services and Human Genetics, Children's Hospital Medical Center, Cincinnati, OH

⁶ College of Nursing, The University of Iowa, Iowa City, IA

⁷ College of Nursing, The University of Arizona, Tucson, AZ

Introduction

- Nurses are well positioned to incorporate genetic and genomic information across all aspects of the United States (U.S.) health care system.
- Nurses, the most trusted health professionals [1], make unique contributions to the field of human genetics and genomics and complement the work of other health care providers to improve the health of the public.

Health care benefits greatly from the unprecedented and ongoing work elucidating the genetic/genomic basis of health, illness, disease risk, and treatment response. The progress in genetics and genomics is applicable to the entire spectrum of health care and all health professionals and as such to the entire nursing profession (2.9 million) [2] in the United States regardless of role, clinical specialty, or academic preparation. The majority of disease risk, health conditions and the therapies used to treat those conditions have a genetic and/or genomic element influenced by environmental, lifestyle, and other factors therefore impacting the entire nursing profession [3]. Nurses have intimate knowledge of the patient's, family's, and community's perspectives; an understanding of biologic underpinnings; experience with genetic/genomic technologies and information; skills in communication and building coalitions; and most importantly, the public's trust. Across the lifespan, nursing focuses on health promotion and

Corresponding Author: Kathleen A. Calzone, MSN, APNG, RN, FAAN, National Cancer Institute, Center for Cancer Research, Genetics Branch, 8901 Wisconsin Ave., Building 8, RM 5101, Bethesda, MD 20889-5105, Phone: 301-435-0538, Fax: 301-402-4471, calzonek@mail.nih.gov.

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disease prevention, which is an integral component of genetic/genomic health care practices. Awareness of nurses' strengths and skills, together with the recognition that prevention is the hallmark of genetic/genomic health care, will inform public policymaking groups as they address issues that affect health care practice in the area of genetics/genomics. Policy making process will be informed with new insights will be gained with inclusion of nurses and professional nursing organizations. These policies can facilitate the ability of U.S. health care systems to use genetic/genomic knowledge to promote health and manage disease.

The Potential of Nurses Using Genetic and Genomic Information to Optimize Quality Health Care Outcomes

- The nursing profession is a pivotal provider of quality health care services and is essential to closing the gap between research discoveries that are efficacious to health care and their successful adoption to optimize health.

In order for people to benefit from widespread genetic/genomic discoveries, nurses must be competent to obtain comprehensive family histories, identify family members at risk for developing a genomic influenced condition and for genomic influenced drug reactions, help people make informed decisions about and understand the results of their genetic/genomic tests and therapies, and refer at-risk people to appropriate health care professionals and agencies for specialized care.

The top ten leading causes of mortality in the United States in 2005 (Figure 1) [4] all have a genetic and/or genomic component with heart disease, cancer, cerebrovascular disease, and diabetes representing the vast majority of mortalities. Due to the chronic nature of these conditions and the management needed, nurses are intimately involved in the ongoing treatment and management of these conditions.

Every year, over 106,000 people in the U.S. will die from adverse effects from medications prescribed and administered in correct dosages, and over two million will suffer serious but not life threatening toxicities[5]. Advanced practice nurses prescribe and all nurses regardless of their level of preparation dispense medications as well as provide education, monitor persons using medications, and are often the first line of defense to initiate actions to prevent adverse drug effects.

Among individuals 65 years of age or older, 17.3% of adverse drug event emergency department visits were associated with warfarin (Coumadin), the majority of which were dose-related with 44.2% requiring hospitalization [6]. Individual genetic markers are among the factors that contribute to the determination of warfarin (Coumadin) dose requirements [7]. Translating information about the genetic markers into the clinical arena, where warfarin (Coumadin) dosing and maintenance monitoring have a strong nursing component [8,9], can reduce the incidence of life threatening hemorrhage or sub-therapeutic dosing that can result in thrombosis (clot forming in the body such as lungs and brain) as a consequence of individual responses regulated by genetic makeup.

Despite a burgeoning body of evidence regarding the contribution of genetics and genomics to health or illness, the evidence specific to outcomes of genomically competent nursing practice and the impact on the public's health is extremely limited—if not entirely absent. Yet, individual anecdotes point to the remarkable potential for transforming health care by the genomically competent nurse.

- Nurses knowledgeable about genetics/genomics and skilled at obtaining and assessing risk in a family history have the potential to help people avert adult onset disorders and consequential morbidity and mortality.

More than 180,000 new cases of breast cancer are diagnosed annually of which approximately 5–10% will have an inherited susceptibility to the disease [10]. As part of new patient multidisciplinary consultation, a nurse case manager took a brief family pedigree of a woman to identify any information consistent with an inherited susceptibility to cancer. The nurse identified a paternal family history of early onset breast cancer and her ethnic heritage, Ashkenazi Jewish, both of which influenced her risk of having a mutation (change in a gene) in a breast cancer susceptibility gene. The nurse referred this woman to a cancer genetic specialist. The woman called the nurse case manager to tell her that she was tested for mutations in *BRCA1* and *BRCA2* and was found to have one of the common Ashkenazi Jewish founder mutations. She proceeded to have her ovaries removed to reduce her risk of ovarian cancer and learned that the pathology showed pre-cancerous cells. Did this genetically competent nurse save this woman from a future diagnosis of ovarian cancer? Almost certainly, the answer is yes. The evidence points to not only a reduction in morbidity and potential mortality by substantially reducing her risk of ovarian cancer, but also to a health care savings of hundreds of dollars per life year [11] as a consequence of the nurse's actions.

Annually, approximately 180,000 to 250,000 individuals in the United States will suffer a sudden cardiac death [12]. Nurses knowledgeable in genetics/genomics can help people avert sudden cardiac death. A cardiovascular advanced practice nurse (APN) performed a cardiac echocardiogram on a patient who told the story about several family members who had died suddenly from a heart attack. Intrigued, the APN obtained a family history and shared it with one of the cardiologists. Over several years, the APN collected an extensive multiple generation family history that included members located in many states and several countries and found that many had died in their teens and early adult years. The family participated in a research study and eventually the gene and disease specific mutation were identified [13]. A woman from the family described the benefits of undergoing genetic testing as a guest speaker at a genetic nursing conference. When the woman discovered that she did have the family gene mutation associated with sudden cardiac death she scheduled her first appointment with a cardiologist. Over an 8 year period, she had an implantable cardioverter defibrillator (ICD) placed which cardioverted her on two separate occasions and then she had two ablation surgeries for atrial fibrillation (irregular heart beats which can be life-threatening). At the conference, she was pregnant with her first child. She explained that her pregnancy was possible because of the APN's genetic knowledge and close monitoring, education of other health care professionals involved in the woman's prenatal care, and her guidance and support throughout the pregnancy. In this family, the APN had averted the premature death of many at risk family members by listening to and further investigating a family history over ten years.

- In preconception and prenatal settings, nurses have an opportunity to help families prepare for a child with a genetic condition.

Congenital malformations are the leading cause of infant death in the United States [14]. Recently, a 48 year old woman recalled her experiences with the birth and eventual death of her two children with different chromosome disorders. She contrasted her tumultuous experience with her first baby to her dramatically better experience 10 years later with her second baby. When the woman was 30 years old she received a call at work from the obstetrician's office that her genetic screen was abnormal. A follow up amniocentesis revealed that her developing baby had trisomy 18 (Edwards syndrome). Suffering from years of emotional guilt after terminating a pregnancy when she was young, the woman elected to continue her pregnancy. When her daughter was born, the mother felt very little support from the nurses and physicians. She described them as task oriented and very clinical. When she was discharged home with her baby the mother felt abandoned by the health care system; her only contact with health care professionals being her baby's pediatrician, who had never cared for a child with trisomy 18 during his 20 years of practice. Ten years later, the woman became pregnant with her "miracle child." Because of her age and history of having a previous child

with a chromosome disorder, the woman elected to have an amniocentesis for reassurance. Unfortunately, the results revealed she was pregnant with a male fetus who had trisomy 13 (Patau syndrome). In contrast to her previous experience, she was referred to a pediatric hospice service. The woman was reassured by the nurses' and physicians' knowledge about trisomy 13 and the expected clinical course. The nurse made sure all labor and delivery and postnatal staff were knowledgeable about trisomy 13 and aware of the expected birth as well as the plan for comfort care. The nurse maintained contact with the woman during the pregnancy and provided hospice care during the woman's son's 12 week lifespan.

Context and Solutions

Research

- The goal of nursing research in clinical genetics and genomics is to improve the quality of health care for patients and families.

Context—Nursing research can provide a foundation of content for maintaining wellness through prevention and health promotion. The paucity of outcome data is hindering efforts to incorporate genetics/genomics into curricula, licensure, certification, and academic and health care organization accreditation. Nursing research that investigates the behavioral, social, and physiological benefits and risks for individuals and families is needed to verify the value of this new science to patient and family care. There is an urgent need for nursing research that provides evidence for genetic/genomic practice guidelines and to document outcomes of genetic/genomic based nursing care. For example, there is a lack of nursing research to provide important insights about how nurse' knowledge in genetics/genomics can optimize patient outcomes. There is also an urgent need to connect the patients and families who need these research discoveries with the potential benefits of increasingly available options for care. For example, more research is needed to explore how family members access, use, and cope with genetic/genomic information that can influence the achievement of present and future health goals.

Solutions—Nursing research examines questions from a biobehavioral perspective that links clinical and basic science, as well as genetic and genomic research [15]. Increased funding is needed for nurse researchers to conduct basic, clinical and translational genetic/genomic research. In addition, continued support is needed for pre and postdoctoral fellowships, the National Institute of Nursing Research Summer Genetics Institute, and other innovative programs. Public and private funds to support these key components for preparation of tomorrow's nurse genetic/genomic researchers are required to achieve genetic/genomically literate researchers who will conduct innovative genetic and genomic research and obtain valuable scientific data.

Education

- Education is required for nurses and all health professionals to assure that the revolutionary advances in genetics and genomics reach the patients and families for whom they were developed
- Nurses, other health care professionals and their employers will ultimately face significant liability for failing to incorporate genetic/genomic discoveries into practice.

Context—The integration of genetics and genomics information into all facets of health care provides the tools to treat patients as truly unique individuals and implement novel screening, diagnostic, and therapeutic interventions all aimed at improving population health. The gap between genetics/genomics in clinical care, and what the nursing community is equipped to

provide, grows larger day by day. A similar gap exists for medicine and other health professionals [16]. Understanding the implications of genetic/genomic changes associated with common diseases has the potential to improve the identification of individuals at risk for health problems, target risk reducing interventions, enhance existing screening, improve prognostic and treatment choices, develop individualized therapy, and influence treatment dosing and selection based on genetic variations that influence drug response. With the increasing development of practice guidelines, commercially available tests, insurance coverage, and legislative protection, genetic tests are already moving beyond specialty genetic services into the mainstream health care arena. The result is health care providers including nurses, not specially trained in genetic or genomics including implications of genetic testing, are assuming responsibility for all aspects of genetic/genomic service delivery. Further challenging the health care community is the fact that direct to consumer marketing of some genetic tests are already underway [17]. These discoveries have the potential to decrease the disease burden and morbidity, and present a unique opportunity to impact health care costs. However, this benefit will be limited by the lack of knowledgeable professionals who can help the public understand the risks, benefits, or value of such genetic tests.

Evidence continues to accumulate regarding the value of genetic/genomic information on health outcomes [18,19]. A significant barrier to assuring that patients and families benefit from this rapidly emerging knowledge is lack of recognition of the value of genetic/genomics on health outcomes across the health professions. There is a tremendous gap in the knowledge of practicing nurse about the relevancy of genetics/genomics to clinical care. Furthermore, there is an even greater knowledge gap associated with the sensitivity, specificity and clinical utility of the broad array of genetic tests available to the public. This gap can be closed through education about the relevancy of these discoveries and the translation to practice, education, and policy. In addition to balancing the point, it can serve as another way nurses can contribute to better decision-making for patients).

Current academic nursing education does not adequately prepare nurses for their evolving role in today's genomic era. Genetics/genomics didactic and clinical content are not standard in Registered Nurse (RN) preparatory programs, leaving a large nursing workforce insufficiently prepared to help people take advantage of genomic discoveries to improve their health. Previous research has revealed that many nurses have minimal training in genetics and genomics [20]. Recognized by nurse educators and professional nursing organizations as a problem, the American Association of Colleges of Nursing (AACN) revised The Essentials of Baccalaureate Education for Professional Nursing Practice, which now integrates genetic/genomic concepts as foundational for all baccalaureate nursing curriculum [21]. Some professional nursing organizations include genetics/genomics in annual education programs, and 49 professional organizations endorsed the U.S. genetic/genomic nursing competencies.

Although the preparation of nurses for today's genomic era is recognized by the academic community, faculty resources are meager and funds for educational programs to incorporate genetic/genomic into curricula are lacking. Public and private funds are needed to assure that all nursing faculty are able to acquire the knowledge necessary to initiate and sustain the integration of genetic/genomic content throughout all nursing programs.

Solutions—Efforts in transforming health care should focus on educating nurses to be competent in this new knowledge. Reaching the 2.9 million practicing nurses requires financial support to develop and update continuing education programs; to create workshops; and build, maintain, and update an educational portal that facilitates access and use of all available genetic/genomic educational resources. United States genetics/genomics nursing leaders have helped prepare the nursing profession by developing and disseminating guidelines for genetic/genomic practice (Genetics/Genomics Nursing: Scope and Standards of Practice) and

education (Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics). Nurses in several countries are devising solutions to incorporate genetic/genomic education into continuing education programs for clinicians and into traditional academic programs. The Competencies provide guidance to educators about required knowledge, skills, and abilities of nurses to assure quality care in the 21st century [22,23]. It is a tremendous challenge to address the learning needs of current faculty who themselves have not had this new science in their training. Efforts to provide the tools to facilitate education of faculty are ongoing (see Table 1) with: 1) publications to promote awareness; 2) development of educational programs to prepare faculty and researchers; and 3) tools to assist faculty in curriculum integration of genetics and genomics. The leadership nursing has provided in the area of competencies and education can serve as models to inform the work of other health care professionals. Four major areas need progress.

- Relevant genetics/genomics content is needed across nursing continuing education programs to assure quality care.
- Nursing education programs must emphasize the genetic/genomic concepts and skills needed to assure quality care.
- Genetic/genomic knowledge and skills need to be integrated into student clinical experiences across the life span and throughout the health and illness spectrum.
- Resources to prepare faculty and to support ongoing changes are needed to assure that all faculty are able to implement and sustain the integration of genetic/genomic content throughout all nursing programs.

Disparities/Insurance/Reimbursement

- The nursing profession has a key role in assuring that genetic/genomic health care does not enhance racial and ethnic health inequities.

Context—Race and ethnicity are currently potential indicators for those at risk for or protected from a disease, as well as for different treatment responses [24]. However, reliance on these proxies should diminish as technology improves our ability to identify and interpret an individual's combination of genetic variations associated with particular health outcomes [25,26]. This will require appropriate use of new scientific knowledge, but also a continued emphasis on caring for each patient as an individual [27]. Interpretation of genetic information in a sensitive and appropriate manner requires accurate awareness of all the influencing factors affecting health care outcomes including genetics/genomics—but also includes the socioeconomic, lifestyle, and environmental influences that affect disease occurrence and treatment decisions. Nurses can assist policy makers to understand differences between labels that have societal implications versus individual characteristics that may increase risk for disease, affect the management of diseases and disease prevention or adverse drug reactions in order to provide individualized and safe health care.

Solutions

- Nursing education programs and curricula must increase emphasis on the cultural, language, family values, traditions, health beliefs and religious perspectives that impact access to and use of genetic/genomic information, technology and services.
- Effective continuing education programs will prepare practicing nurses to consider influencing variables related to the use of genetic/genomic services.
- Cultural assessment, knowledge, and skills must be integrated into nursing curricula and clinical experiences.

- Funding will support genetic/genomic research that investigates the influence of human genetic/genomic variation on health care outcomes.
- Application of nursing research on health disparities to research on genetic and genomics and health outcomes for patients and their families.

Policy

- Nursing contributions improve patient and family health outcomes and strengthen the practice of all health care professionals.
- Nurses have engaged in informing policy of genetics and genomics for decades by serving on committees to develop and institute policies, standards and practices that assure the highest possible levels of health care for all Americans.
- Policies that promote inclusion of genetics and genomics as an essential component of nursing education and delivery of health care, regardless of setting, are essential to accelerate the work of translation and application of genetic and genomic advances for promoting and protecting the health of the public.
- Current genetic and genomic [0]issues are [0]all of concern to nurses as they bring a biobehavioral perspective to the table with an emphasis on prevention and health promotion in the context of the patient, family and community. This fundamental perspective provided by nurses is crucial when these are being debated.

Context—Genetic testing is at the forefront of genomic health care applications with availability of testing for over 1,600 genetic disorders ranging from single gene disorders, such as cystic fibrosis, to complex disorders, such as diabetes. Family history is a valuable tool to identify those who may benefit from genetic services including genetic counseling and testing. The importance of obtaining an accurate family history as the critical entry point for those with genetic risks for disease, disability, or adverse drug effects cannot be overemphasized.

Currently, limitations of genetic testing generally include analytic validity, clinical validity, and clinical utility—all of which influence the accuracy and usefulness of the genetic test. Specifically, one concern related to genetic testing and its limitations is encompassed by a concept known as genetic determinism. Genetic determinism is the idea that an individual who undergoes a genetic test and is shown to be ‘at risk’ for a genetic disorder will ultimately be diagnosed with the disorder. While this may be true for disorders such as Huntington disease and early onset Alzheimer disease, most predisposition genetic tests are not sensitive or specific enough to allow prediction with certainty that the disorder will occur. Furthermore, when the family disease associated mutation is not known, testing negative on a genetic test does not rule out a disorder occurring in the future. These are complex concepts that may be difficult for the lay public to understand. Nurses regularly provide patient and family education and have the understanding and skills to anticipate and meet the educational needs of clients.

Current genetic/genomic policy issues being debated by policymaking groups can benefit from the biobehavioral patient/family/community centered perspective of nursing. A partial list of current challenges to safe, quality care for the U.S. public includes:

- Personalized health care: What models will emerge? Will there be access for all individuals regardless of demographics? Specifically, will genetic and genomic tests be available to all or to only a select few?
- Racial/ethnic disparities: Will genetic/genomic information diminish or increase disparities?

- Economic cost/value: What is the cost and value to individuals, families, and society of genetic/genomic applications—specifically genetic testing, genetic/genomically sensitive supportive care, and pharmacogenomics [28]?
- Direct to consumer marketing of genetic tests: What is the appropriate oversight? How to assure adequate consumer education pre- and post-genetic test results? Are the genetic test results sensitive, specific, and quality controlled?
- Health and related genetic/genomic information: How will information be stored, shared, and kept private? New models are emerging and usefulness and benefits are yet to be addressed. How will electronic medical records affect documentation privacy and confidentiality?
- Potential discrimination: The Genetic Information Nondiscrimination Act (GINA) H. R. 493 has been passed by Congress. However, there are significant gaps including 1) it excludes military personnel; 2) it does not apply to life, disability or long term care insurance; and 3) it does not prohibit medical underwriting based on current health status [29]. Other issues not addressed in this legislation may also emerge.
- Support for interdisciplinary health care education as a model that promotes effective use of genomic information integrated across disciplines [30,31].
- Provider reimbursement for genetic/genomic services: This complex issue involves nurses, other health care providers, as well as the consumer.
- Funding to support the incorporation of genetics/genomics into:
 - Nursing education at all levels.
 - Research and research training, specifically through funding of the National Institutes of Health programs. Examples include: National Institute of Nursing Research Summer Genetic Institute, National Human Genome Research Institute (NHGRI) programs (including Ethical, Legal, and Social Implications), institutional training grants (T32) in genomics, and individual funding.

Solutions—Nurses have made important contributions as members of former President Clinton’s Secretary’s Advisory Committee on Genetic Testing (SACGT) and President Bush’s Secretary’s Advisory Committee on Genetics, Health, and Society (SACGHS)—and individually and as representatives of organizations, presented testimony on topics ranging from genetic/genomic education of health care professionals to rights for protection from genetic discrimination.

The Evaluation of Genomic Applications in Practice and Prevention (EGAPP) initiative, sponsored by the Centers for Disease Control and Prevention (CDC), was implemented in 2004. The EGAPP initiative includes a working group with the primary goal of writing and informing others of recommendation statements for use of genetic tests. A nurse serves on the EGAPP Working Group. Building from her contributions two nurses were appointed to the Evaluation of Genomic Applications in Practice and Prevention Stakeholder group (ESG) for EGAPP. Nurses are active participants in EGAPP initiatives since their inception and as a result have been able to disseminate the genetic/genomic recommendations to the nursing community as well as provide feedback to the working group.

However, these efforts alone are not sufficient to address the multiple strategies that are needed to fully engage nurses. The following are examples of nursing’s contributions to genetics/genomics. If we are to truly leverage nursing’s role in improving the outcomes of care, more of these initiatives and efforts must include nursing:

The Institute of Medicine has instituted a Roundtable on Translating Genomic-Based Research for Health with the overarching mission to advance the field of genomics and improve the translation of research findings to health care, education, and policy. This multi-disciplinary effort, which includes nursing, has identified six priority areas: evidentiary issues and method; systems for research and evaluation; service delivery; innovation; education and; coordination. A nursing leader chairs the Education Committee.

The International Council of Nurses (ICN) is a federation of national nurses' associations from more than 128 countries. The ICN represents the world's widest reaching international organization for health professionals. In 2004, the ICN published the *Genetics in Nursing* Monograph providing a vision for nursing nationally and internationally in global, scientific, practice, education, social, information, ethical, and political contexts.

Genetic/genomic information is becoming widely available through research and testing. There is a movement toward widespread sharing of vast amounts of genetic/genomic data in an effort to research, prevent, and treat common disorders of adulthood, such as diabetes, cardiovascular disease, and Alzheimer Disease. Concerns exist regarding the ability to match individuals to their genetic/genomic information even when traditional identifiers (i.e., name, social security numbers) are removed. Nurses are well positioned to guide policies on the emerging issues related to use of genetic/genomic information as they have experience in monitoring research protocols through participation on Institutional Review Boards (IRB) and other groups who monitor these issues.

Research findings about the appropriate use and interpretation of genetic and genomic information and technologies are needed, and these would provide the foundation for our policymaking bodies [32]. Yet, the desire to create a 'one size fits all' policy has been a challenge when developing health policies for an extremely diverse population such as that in the United States [31]. Nurses are conducting research ranging from ethical issues of genetic testing to conducting microarrays on tissue samples. Findings from these studies and others have provided a foundation for ethical and social policies.

Professional organizations and foundations such as the Robert Wood Johnson Foundation (RWJF) provide advanced leadership fellowships for nurses who are aspiring to lead and shape the U.S. health care system of the future. The American Academy of Nursing (AAN) supports the RWJF's "Nurse Leaders in the Boardroom" effort, which seeks to place nurse leaders on non profit health care boards, by identifying candidates and mentors, and assessing key national health policy/decision-making bodies to identify those that have no or insufficient nursing representation, including those who represent genetics/genomics interests.

International Perspectives

- Preparing nurses to provide genetic/genomic-based health care is an international concern and by working together, nurses are finding answers.
- Policies that enable genetic/genomics to be an essential component of nursing education and delivery of health care regardless of setting are essential to accelerated translation and application of genetic/genomic advances to the health of the public.
- Nursing is recognized as providing leadership in educational programs nationally and internationally these programs can serve as models for all health professionals.

The need for a genetically literate workforce that can lead and assure nursing's ongoing participation in translation of genomic discoveries into day-to-day health care is not limited to the United States. Although the task of achieving genetic literacy for the over 2.9 million U.S.

nurses projected to be needed by 2020 [33] is one of the largest challenges faced by the profession; U.S. nurses are not alone in devising ways to meet this challenge.

Globally, nursing leaders look to each other for guidance to develop new strategies and nurses learn from colleagues who are implementing national education programs [30]. In 2001, the United States developed the National Coalition for Health Professional Education in Genetics (NCHPEG) competence statements. These were the template for United Kingdom (U.K.) nursing competencies [34]. The U.K. nursing program in the National Health Service National Genetics Education and Development Centre uses the U.K. nursing genetics competencies to raise awareness of the relevance of genetics, work collaboratively with policy stakeholders, and to provide practical help to integrate genetics and genomics into curricula and courses [35]. The 2003 U.K. White paper, *Our Inheritance, Our Future* [34], has had a substantial impact on nursing practice and genomic health care in the U.K. with an increase in trainee posts and education for nurses and other clinical practitioners. The goal of the National Health Service, to make the best use of advances in genetic/genomic knowledge, has resulted in increased investment in genetic services, research, and development of capacity across the entire health care system. This increased investment helps to harness the potential and involve the public in continuing debate regarding genetic developments and health care [34]. Similar efforts to develop the capacity of nurses to participate in genetic/genomically competent health care are ongoing in Japan where developments in genetic nursing have recently occurred [36, 37].

Concurrent analysis of nursing education's efforts by U.S., U.K., South African, and New Zealand members of the International Society of Nurses in Genetics (ISONG) facilitated collaboration among countries in identifying the most pressing obstacles to development of genetic/genomic health care [38]. Genetic/genomic nurse leaders from the United States, the United Kingdom, Brazil, Japan, Taiwan, Ireland, and Australia recently identified lack of effective presentation of genetics/genomics in nursing curricula and obstacles within health care settings as major barriers to integration of genetics and genomics into all aspects of nursing practice [39]. The lack of a genetically informed nursing workforce along with health care systems that are not prepared to implement genetic/genomic information into holistic care delivery are major obstacles to transforming health care. These are obstacles for the U.S. public that limit their opportunities to receive accurate and timely identification of genomic contributions to their risk for disease, management of symptoms, and support to individuals and families.

United States nurses have accomplished important milestones by creating practice guidelines and competencies with support from professional organizations including ISONG and the American Nurses Association [40,41]. These efforts advanced through federally funded projects that support nurse training, development of education resources, and research to build knowledge of genomic health care. However, the resources have not kept up with the need, and current resources are not sufficient to sustain even these initial training efforts. Education resources to prepare faculty, students, and practicing nurses are needed. Resources are also necessary to fund basic, clinical, and translational research to build the evidence base that will guide practice for today's and tomorrow's nurses. The scope of these guidelines will continue to broaden, as genetic/genomic discoveries become critical components of health promotion and disease prevention assessment and treatment management options for a larger spectrum of health concerns.

Summary of Current and Future Policy Issues

- Nurses and representatives of professional nursing organizations bring a biobehavioral perspective to the table with an emphasis on prevention and health

promotion in the context of the patient, family and community. Nurses are integral to the policymaking process that affects health care practice in the area of genetics/genomics.

Bringing the entire U.S. nursing workforce (over 2.9 million) to the forefront of genetics/genomic health care practice is appropriate, as one role of the nurse is to elicit health related information, recognize what is important, and subsequently act upon that information. Public policies that affect health care practice in the area of genetics/genomics will be stronger with inclusion of nurses and professional nursing organization representation in the policy making process. Successful application of genetic/genomic discoveries to transform health care requires:

- an infrastructure for assuring quality oversight of genetic/genomic testing laboratories
- a plan to more quickly integrate new genetic/genomic applications into practice for effective clinical application
- a prepared workforce that recognizes the risks, benefits and limitations of genetic/genomic information
- an infrastructure that provides resources to faculty who prepare this workforce, and
- policies that support integration of genetic/genomic information and services into health care.

Based upon the growing body of increasingly rigorous research, there is strong evidence that genetics/genomics is having both a national and global impact on health care. Nursing, as the largest and most trusted health care profession in the United States recommends the following to transform health care utilizing genetics and genomics:

- systematic inclusion of genetic and genomic information in all nursing education
- funding to train and support nursing faculty to integrate genetics and genomics into nursing education.
- funding to implement continuing education programs in genetics and genomics for nurses and other health care providers in order that they may maintain and expand a health care provider genetic/genomic knowledge base.
- evidence of genetic/genomic competency for every health care provider as a requirement for health care institutional accreditation by organizations such as Joint Commission
- documentation of genetic/genomic continuing education at the time of license renewal
- reimbursement for nurses and other healthcare providers from third party payers for assessments that include a genetic/genomic family history
- funding to establish a nursing research priority plan based on a systematic evaluation of the current state of the science in order to stimulate research that increases the knowledge base for genetic/genomic nursing through advancing cutting-edge, critical priority areas of research, and priority populations for study; and which serves as a model for other health disciplines
- increased funding to conduct nursing research in genetics and genomics
- policies that require genetics/genomics to be an essential component of nursing education and delivery of health care, regardless of setting, are essential to accelerate the work of translation and application of genetic/genomic advances for promoting and protecting the health of the public, and

- active participation by nurses when genetic/genomic [0]policy issues are being debated.

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Figure 1.
2005 Top Ten Leading Causes of Mortality in the U.S.[4] National Center for Health Statistics.
<http://www.cdc.gov/nchs/fastats/deaths.htm>

Table 1

Leadership in Genetic/Genomic Nursing Education *

Resource	Location
Genetic/genomic nursing publications to promote awareness	
American Association of Colleges of Nursing Revised Baccalaureate Essentials	http://www.aacn.nche.edu/Education/pdf/BEdraft.pdf
Essential Nursing Competencies and Curricula Guidelines for Genetics and Genomics	http://www.genome.gov/17517037
Journal of Nursing Scholarship Article Series	http://www.genome.gov/17515679
United Kingdom Nursing Competencies in Genetics	http://www.geneticseducation.nhs.uk/learning/nursing.asp?id=16
United Kingdom Nursing Standard Series Genetics: Building Nurses Knowledge	http://www.geneticseducation.nhs.uk/publications/nursing_professions.asp
Education programs to prepare faculty and researchers	
Cincinnati Children's Hospital Genetics Education Program for Nurses	http://gepn.cchmc.org
National Institute of Nursing Research Summer Genetics Institute	http://www.ninr.nih.gov/Training/TrainingOpportunitiesIntramural/SummerGeneticsInstitute/
University of Iowa Online Continuing Education Program: Ethics and Genetic Testing for Nurses - CEU	https://www.continuetolearn.uiowa.edu/ecommm/ccp/10Expand.asp?ProductCode=096cegenetic
Tools to assist faculty in curriculum integration of genetic/genomic	

Resource	Location
Nursing Faculty Tool Kit	http://www.genome.gov/27527634
United Kingdom Telling Stories, Understanding Real Life Genetics'	http://www.geneticseducation.nhs.uk/tellingstories/
U.S. Surgeon General's Family History Initiative	http://www.hhs.gov/familyhistory/

* With application to all health care professionals.