
Public Comments

MS. BERRY: We're set to begin with the public comment section of our session. I'd ask that everyone be seated please so that we can begin the next section.

Let's get started, folks. One of our critical functions here is to serve as a public forum for deliberations on the broad range of human health and societal issues raised by the development and use of genetic technology.

So we greatly value the input we receive from the public. As you know, we set aside time each day of our meeting to hear from the public and welcome and appreciate the views that they share with us.

Today we will be hearing from Jean Jenkins, the International Society of Nurses in Genetics, ISONG.

DR. JENKINS: Good morning. I'm Jean Jenkins, and I value the opportunity to be able to present to you today the following public testimony on behalf of the International Society of Nurses in Genetics, or as you commonly know them, ISONG.

I also want to inform you about an effort of several federal agencies, including the Human Genome Research Institute, Office of Rare Disease, Health Resources and Services Administration, and the CDC in collaboration with the American Nurses Association and ISONG to address genetic and genomic competency of all nurses.

We have provided the written testimony, and at some points I may refer you to that document. As you know, genetic and genomic science is redefining the understanding and the continuum of human health and illness. Therefore, recognition of genomics as a central science for health professional knowledge is essential.

Options of care will increasingly include genetic and genomic information along the continuum of care for all persons, including prevention, screening, diagnostics, prognostics, selection of treatment, and monitoring of treatment effectiveness.

The clinical application of this knowledge has major implications for the nursing profession, and it caused essentially all conditions have a genetic or genomic component. Recipients of nursing care will be from any stage of life, and cared for in varied clinical settings.

You will hear of a number of different examples where pharmacogenomics information will be used in determining how individuals respond to drug treatments. I won't outline those for you today, because I know some of the presenters will be discussing those.

With that kind of information and the selection of specific medications based on an individual's genotype which has major implications for nurses, they must be able to competently integrate genetic and genomic knowledge and implications into health care delivery so that all individuals receive equal access to genetic and genomic health care.

The code of ethics for nurses which was developed by the International Council of Nurses and the American Nurses Association state that nurses have a shared responsibility with other health professionals and society to ensure initiation and promotion of community, national, and international efforts to meet the health and social needs of the public.

This includes the right to seek and receive genomic health care that is non-discriminatory, confidential, and private. As providers in all practice settings, nurses must be able to advocate for and fulfill a central role in the assessment, the policy development, and the assurance of universal access to genomic health care, including discrimination by all populations, regardless of genetic and genomic literacy, socioeconomic, or ethnic/cultural background.

ISONG recognizes the application of genetic and genomic practice at both basic and advanced practice levels. Genetic nursing is the protection from promotion and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis of human response, and advocacy in the care of genomic health of individuals, families, communities, and populations.

Nurses can fulfill these responsibilities by the identification of genetic and genomic risk factors, nursing interventions, information provision, services referral, and promotional health behaviors to enhance the health and well being of the individual or the family seeking care.

To fulfill the right of the public to access genomic health care without fear of discrimination, the nurse's responsibilities extend to the development with partnerships of stakeholders such as patients, health care providers, insurers, government officials and legislators, enlisting such outcomes of such partnerships are included in the written comments.

The public will increasingly expect that the registered nurse will use genetic and genomic information and technology when providing care, and these expectations have direct implications for the RN preparatory curricula, as well as for the 2.5 million practicing nurses.

The rate of progress for applying a genomic approach through the continuum of care depends not only on the technologic advances that we've been discussing, but also on nursing expertise.

In its report on genetics and nursing in 2000, an expert HRSA panel emphasized the importance of integrating genetics content into nursing curricula in order to provide an adequately prepared nursing workforce not only for today, but also for the future. To assume this role with persons, families, communities, and populations throughout the life span, the registered nurse will need to demonstrate proficiency with incorporating genetic and genomic information into their practice.

Examples of such indications of practice are provided also in the written comments. Under Tab 3 of your handouts, there is an indication of the collaborative meeting that I had mentioned at the beginning, which was an effort of several federal agencies, including NHGRI, CDC, HRSA, and the American Nurses Association and ISONG, where we provided an opportunity together for key nursing stakeholders to attend the meeting in September, 2005.

This meeting was held in Washington, DC, and representatives of key nursing organizations came to consensus, which is a major advance in the profession of nursing, on a document whose purpose is to define essential genetic and genomic competencies for all registered nurses.

This document is intended to guide nurse educators in the design and implementation of learning experiences to help students, learners, and practicing nurses achieve genetic and genomic competency. These competencies are not intended to replace or recreate existing standards of practice, but are intended to incorporate the genetic and genomic perspective into all nursing practice and education.

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The goal is to prepare the nursing workforce to deliver competent genetic and genomic focus nursing care. The essential competencies require that all registered nurses integrate genetics into their professional responsibilities, including the professional practice domain, nursing assessment, identification, referral, provision of education, care, and support. These competencies are listed in your document as well.

In closing, ISONG views genetics and genomics as integral to all nursing practice. Nurses will increasingly use genetic and genomic information such as pharmacogenetics and genomics to create and administer individualized treatment and care plans.

All nurses share in the responsibility to assure that all individuals have equal access to this kind of based health care, and that it is non-discriminatory. Thank you so much for the opportunity to share with you the progress that is being made in the education of nurses that begins to build upon this infrastructure that was mentioned yesterday as being key to be able to translate scientific innovations that we are witnessing into health gains for all. Thank you.

MS. BERRY: Thank you very much for your comments. I appreciate it.

Emily?