



International Society of Nurses in Genetics

Privacy and Confidentiality of Genetic Information: The Role of the Nurse

(Approved: August 8, 2005, Revised: April 5, 2010)

Brief Statement of Need/Importance

According to the Genetic Information Nondiscriminatory Act (USA), "Genetic information" means information about: a person's genetic tests, genetic tests of a person's family members (up to and including fourth-degree Relatives), any manifestation of a disease or disorder in a family member; participation of a person or family member in research that includes genetic testing, counseling, or education. Genetic information does not include information about sex or age. An increasing amount of genetic information about individuals is becoming available because of advances in genetic technologies. While this information has the potential to provide health benefits, it may also increase risk of harm. Of major concern is the potential for misuse of genetic information resulting in any kind of discrimination or stigmatization. Assuring privacy and confidentiality of genetic information demands continued vigilance on the part of all nurses as genetic technologies and discoveries are translated into clinical application and practice.

It is the position of ISONG that a professional nurse should:

- Be aware of the provisions and protections afforded to individuals by any law pertaining to genetic information (e.g., Genetic Information Nondiscriminatory Act [GINA] in the United States);
- Safeguard a client's right to privacy;
- Adopt into her or his practice, guidelines for ethical practice, identified by one's professional nursing association, for example, the American Nurses Association in the United States, The United Kingdom Nursing & Midwifery Council, the Japanese Nursing Association; or the professional codes of conduct pertaining to one's own country regarding privacy and confidentiality, informed consent, truth telling and disclosure, and non-discrimination;
- Become familiar with legislation in their own state or country with regard to the nurse/client relationship, confidentiality of medical information and privileged status;

- Obtain and make a record of a client or their designee's informed consent prior to releasing genetic information to any third party;
- Understand that family culture, values, traditions, and relationships influence the sharing of genetic information;
- Recognize that each individual in the family is autonomous with respect to genetic matters that may be compromised by the decisions of other family members;
- Become aware of the potential for stigmatization and discrimination as a consequence of linking genetic information with ethnicity, race, gender, or other social variables;
- Educate clients and the public about the various ways in which tissues and cells might be used as a source of genetic information; and
- Collaborate with other health professionals to assure that clients receive the highest level of genomic health care.

In addition to the above, it is the position of ISONG that nurses who are prepared at an advanced level be able to integrate knowledge of privacy and confidentiality issues and psychological consequences of the use of genetic information into health care practice.

References

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