



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

### Brief Statement of Need/Importance

According to the *Genetic Information Nondiscrimination Act of 2008* ([GINA] in the United States of America [USA]), "genetic information includes information about: an individual's health history, including genetic test(s) results, of an individual's family members (up to and including fourth-degree relatives), any manifestation of a disease or disorder in a family member; participation of the individual or family member in research that includes genetic testing, counseling, or education. GINA (2008) provides a basic level of minimum protection of genetic information, but lacks enforcement power not only within the U.S, where it is a federal law, but also throughout the world.. 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, including whole genome sequencing. While this information has the potential to provide health benefits, it may also possess risks of potential harm due to revelation of a person's genetic information to parties that may use it in ways harmful to the individual or family members, either personally or economically, and via intended or unintended ways. Such potential for misuse of genetic information may result in genetic/genomic 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. Nurses throughout the world must be able to advocate for patients and maintain currency in understanding policies related to genetic information disclosure (Kasper, Schneidereith & Lashley, 2016).

The American Nurses Association (ANA, 2015, para. 1) revised *Position Statement on Privacy and Confidentiality* specifically stipulates that "the patient's right to privacy of individually identifiable health information, including genetic information, is established statutorily with specific exceptions" for individuals protected by laws in areas governed by the U.S. However, that does not cover all individuals thought to be covered in the U.S.

Section 206 of GINA (2008) serves as a document regarding the kind of caution that should be observed as there are many instances in which individuals and their relatives are not protected by this law:

### **SEC. 206. CONFIDENTIALITY OF GENETIC INFORMATION.**

(a) Treatment of Information as Part of Confidential Medical Record.--If an employer, employment agency, labor organization, or joint labor-management committee possesses genetic information about an employee or member, such information shall be maintained on separate forms and in separate medical files and be treated as a confidential medical record of the employee or member. An employer, employment agency, labor organization, or joint labor-management committee shall be considered to be in compliance with the maintenance of information requirements of this subsection with respect to genetic information subject to this subsection that is maintained with and treated as a confidential medical record under section 102(d)(3)(B) of the Americans With Disabilities Act (42 U.S.C. 12112(d)(3)(B)).

(b) Limitation on Disclosure.--An employer, employment agency, labor organization, or joint labor-management committee shall not disclose genetic information concerning an employee or member except--

- (1) to the employee or member of a labor organization (or family member if the family member is receiving the genetic services) at the written request of the employee or member of such organization;
- (2) to an occupational or other health researcher if the research is conducted in compliance with the regulations and protections provided for under part 46 of title 45, Code of Federal Regulations;
- (3) in response to an order of a court, except that--
  - (A) the employer, employment agency, labor organization, or joint labor-management committee may disclose only the genetic information expressly authorized by such order; and
  - (B) if the court order was secured without the knowledge of the employee or member to whom the information refers, the employer, employment agency, labor organization, or joint labor-management

committee shall inform the employee or member of the court order and any genetic information that was disclosed pursuant to such order;

(4) to government officials who are investigating compliance with this title if the information is relevant to the investigation;

(5) to the extent that such disclosure is made in connection with the employee's compliance with the certification provisions of section 103 of the Family and Medical Leave Act of 1993 (29 U.S.C. 2613) or such requirements under State family and medical leave laws; or

(6) to a Federal, State, or local public health agency only with regard to information that is described in section 201(4)(A)(iii) and that concerns a contagious disease that presents an imminent hazard of death or life-threatening illness, and that the employee whose family member or family members is or are the subject of a disclosure under this paragraph is notified of such disclosure.

(c) Relationship to HIPAA Regulations.--With respect to the regulations promulgated by the Secretary of Health and Human Services under part C of title XI of the Social Security Act (42 U.S.C. 1320d et seq.) and section 264 of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d-2 note), this title does not prohibit a covered entity under such regulations from any use or disclosure of health information that is authorized for the covered entity under such regulations. The previous sentence does not affect the authority of such Secretary to modify such regulations.

<https://www.eeoc.gov/laws/statutes/gina.cfm>

### **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 (as in GINA (2008) in the United States).
  - Safeguard a client's right to privacy, which is more than a moral duty, it is adherence to Federal law in some countries such as the United States, including the *Health Insurance Portability and Accountability Act of 1996* (HIPAA) as well as GINA (2008).
  - Adopt into nursing practice and teaching, guidelines for ethical practice, identified by one's professional nursing association, such as 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's, 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, including members of past, current and future generations, 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 their genotypes, mutations, polymorphisms, or any chromosomal changes could be used as a source of genetic information not only for themselves but family members that preceded them and also germline offspring of themselves and other family members
  - Collaborate with health professionals to assure that clients receive the highest level of genomic health care related to their needs as individuals and also the needs of extended family if appropriate. In the least of circumstances, family members' information should be kept strictly confidential.
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- 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 healthcare practice.

- “Ensure privacy when discussion genetic and genomic information, while maintaining confidentiality and awareness of the potential impact of revealed information (either by history or by genetic testing results) on the individual and other family members at all times (Consensus Panel, 2006; 2008).

## References

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ISONG EPP members contributing to the 2018 version include Sue Dickey, Mary Beth Steck & Leslie Darmofal.