

# Genomics and the Right to Health Autonomy: A Survey of International Health Policies

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# Disclosures

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# Objectives

- 1) The learner will be able to discuss three (3) international genomics and autonomy-related policies.
- 2) The learner will be able to describe the importance of international health policies for nursing.

# International Policy: Overview

- There are a wide range of organizations that contribute to international policy.
- International policies tend to be broad reaching and take on different forms.
- Panels of content experts and stakeholders across the globe are included in discussions
- Signing onto a policy is not equal to ratification or enforcement of policies by a country.
- This review examined focused on health and science-related policies.

# International Health Policy: Organizations

- World Health Organization
- United Nations
  - Educational, Scientific and Cultural Organization (UNESCO)
- European Convention For the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine
- Professional Organizations: International Council of Nurses, World Medical Association, Global Alliance for Genomics & Health

# International Health Policy: Mechanisms

- Treaties
- General Comments
- Statements
- Declarations

# International Health Policy: Genomics and Autonomy

- Important Early Steps
- Dealing with Genomics as a New and Evolving Science
- Preserving Human Rights and Autonomy in the Context of Genomics



# International Health Policy: Important Early Steps

The Universal Declaration of Human Rights (1948)

Article 27

- (§1) Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.
- (§2) Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

(United Nations, 1948)

# International Health Policy: Addressing Genomics a New and Evolving Area Dignity and Discrimination

Universal Declaration on the Human Genome and Human Rights (1997)

Article 2

- (§a) Everyone has the right to respect for their dignity and for their human rights regardless of their genetic characteristics.

(UNESCO, 1997)

# International Health Policy: Addressing Genomics a New and Evolving Area Dignity and Discrimination

Universal Declaration on the Human Genome and Human Rights (1997)

Article 6

- No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.

(UNESCO, 1997)

# International Health Policy: Addressing Genomics a New and Evolving Area Dignity and Discrimination

European Convention For the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (1997)

## Chapter IV-Human Genome

### Article 11-Nondiscrimination

- Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.

(COE, 1997)

# International Health Policy: Addressing Genomics a New and Evolving Area Safety

European Convention For the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (1997)

Chapter IV-Human Genome

Article 13-Interventions on the human genome

An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.

(COE, 1997)

# Autonomy

- ***Autonomy*** (in a genomic context) addresses a person's ability to choose what happens both in research and clinical testing. Additionally, it has been added that this concept can include the right to participate in testing without being required to have results disclosed to them.

(WHO, 1997; Wolf, Annas, & Elias, 2013)

# International Health Policy: Preserving Autonomy in the Context of Genomics

Universal Declaration on the Human Genome and Human Rights (1997)

Article 5

- (§c) The right of each individual to decide whether to be informed or not on the results of genetic examination and the resulting consequences should be respected.

(UNESCO, 1997)

# International Health Policy: Preserving Autonomy in the Context of Genomics

International Declaration on Human Genetic Data (2003)

## Article 10

- When human genetic data ... are collected for medical and scientific research purposes, the information provided at the time of consent should indicate that the person concerned has the right to decide whether or not to be informed of the results.

(UNESCO, 2003)



# International Health Policy: Preserving Autonomy in the Context of Genomics

The Universal Declaration on Bioethics and Human Rights  
(2005)

Article 16

- The impact of life sciences on future generations, including on their genetic constitution, should be given due regard.

(UNESCO, 2005)

# Genomics in Nursing: Key Areas of Concern

- Privacy and confidentiality of genetic information
- Stigmatization and discrimination
- Uncertainties associated with gene tests
- Clinical applications of genetics

(ICN, 2009)

# Nurses and International Health Policy: Next Steps

## Be Aware

- Genetic knowledge is important for the future of nursing
  - Find out what the standards are for genomics in your country.
- Better understandings of international health policies can be very important for nurses
  - See how your country helps to influence international health policies
  - Learn about how your country applies international health policies

## Be Active

- While international health policies address genetics and autonomy, there is still work to be done:
  - Nurses can help educate policy makers and influencers about genetics (WHO, 2014)
  - Take part in international policy making and shaping through professional organizations

## Be Advocates

- Regardless of international health policy—advocacy for patient is still a central part of the work of nursing
  - Learn what your organizations do to protect patients engaging in genetic testing and research

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