

World Health Organization (WHO)

Topic 1: Genetic Testing

It is well established that genetics play a role in the onset of many diseases. Consequently, genetic testing¹ presents a unique opportunity for individuals to become informed about their genetic predisposition to certain diseases, thus offering them the option to prevent and manage them. Genetic testing is advantageous in its informative potential; however, some critical ethical, legal, and social issues (ELSI)² emerge, as well. While some of the issues raised by genetic testing arise globally, there are other concerns which are specific or more prevalent in developing countries.³

Two moral theories to consider when approaching the aforementioned concerns regarding genetic testing are utilitarianism and libertarianism. Utilitarians believe that moral decisions should be decided by calculating the burden/benefit ratio from a societal perspective. This perspective promotes the good of the society over the individual. Factors taken into consideration include the following: informing at-risk family members, delaying the onset of symptoms, increasing quality of life through adequate planning, and preventing the passing on of the disorder. Knowing of a disorder or preventing the passing of a genetic disorder by a couple deciding not to have children (or not in the natural way, if financially capable) could save large amounts of money for treatments often paid for by society. Libertarians believe that personal autonomy has the highest moral value and each person has the right to make his/her own informed decisions. Social stigmatism is also attached to the topic of genetic disorders. Individuals diagnosed with a genetic disorder are often discriminated against by members of society or even family and friends. Libertarians believe people have the right to live without such discrimination and fear. In matters of public health, these two perspectives often conflict.

How can the WHO prevent discrimination and stigmatization which presents informal barriers to health care access worldwide? Or is the world not ready yet to undergo the change from Libertarian views?

Questions to consider:

- How will the WHO fund genetic testing and education on the topic in underdeveloped countries?
- Many international and national reports on genetic testing have focused extensively on the potential for discrimination in relation to health insurance and employment. What can be done to reduce this form of discrimination by the WHO?

¹ <http://www.who.int/genomics/en/>

² <http://www.kumc.edu/gec/prof/geneelsi.html>

³ <http://www.who.int/genomics/publications/GTS-MedicalGeneticServices-oct06.pdf>

- An additional concern regarding stigmatization relates to the discrimination of female mutation carriers in communities with a high prevalence of autosomal recessive genetic diseases and a cultural preference for arranged marriage.
- How will the WHO respect cultural diversity? Especially in countries where certain genetic diseases are more common.
- When should small benefits to a large number of persons be prioritized over large benefits to a small number of persons (for example: where rare genetic conditions cause severe suffering and hardship within a limited number of affected families)?

Your research and position papers should not be limited to just these questions; I encourage you to use these questions as guidance, not as a strict outline. The goal of the WHO⁴ is to broaden the discussion of some of the major ethical legal and social issues specific to medical genetic services in developing countries, and to suggest principles of effective management of the issues raised by genetic testing in these contexts. I reiterate that when you write your position papers, you are writing about the position of the nation you are representing and not a personal view on the matter. If you have any questions feel free to reach out to me at sweller@mail.yu.edu. Best of luck and I am looking forward to reading your papers and meeting all of you!

Shelby Weller
Chair of WHO

⁴ <http://www.who.int/en/>