

WHO/HGN

Monash/WHO Fellowship
Report for Monash University

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During my time as an intern with World Health Organization's Human Genetics, my work primarily focussed on the report *The Ethical, Legal and Social Implications of Pharmacogenomics for Health in Developing Countries*. I was supervised by the Ethics Officer, Cathy Schapper and assisted by the Health Information Officer, Soleil Labelle and the Responsible Officer, Dr. Victor Boulyjenkov.

The major project that I worked on was the report on *The Ethical, Legal and Social Implications of Pharmacogenomics for Health in Developing Countries*. My role included researching, writing and editing the first draft of the report. The sections that I primarily focused on were related to Ownership, Patents, Liability, Equity, Education and various technical aspects related to pharmacogenomics. In addition to the writing of the report, I also researched and helped refine the list for the reviewer panel.

This research and writing involved literature surveys of numerous information databases, covering the WHO library database, medical research databases and databases concerned with medical issues and information relating to the developing world. As part of this research, I attended a number of different training sessions through the WHO library on effective researching, with a focus on medical and social issues related to ethics and the developing world.

The writing of the report was done in collaboration with the Ethics Officer, and though I primarily focused on sections outlined above, I was also involved in the other sections of the report, Informed Consent, Privacy, Confidentiality, Stigmatization, Racial and Gender Issues, and Benefit Sharing, Capacity Building and Technology Transfer. The Ethics Officer and I worked very closely and had many meetings and discussions relating to all aspects of the report.

I was involved in the editing of the first draft, and made changes and additions to the technical section of the report, which was written in parallel with the Joint Centre for Bioethics, Toronto. I researched appropriate professionals and people for the review panel, and was actively involved in the issuing and refining contact details.

In addition to the work on the report, I was also involved in evaluating and suggesting updates and improvements to the Genomic Resource Centre website. As part of that work, I identified new documents, reports, legislation and regulations to be included on the ELSI ReD database on the Genomic Resource Centre website. This section of my work was conducted with both the Ethics Officer and the Health Information Officer.

Outside of the work conducted directly with the Human Genetics, I also had the opportunity to observe and learn about the workings of a large international organization. I attended three meetings of the WHO Ethics Council, listened in to a number of sessions of WHO's 117th Executive Board, attended a variety of WHO seminars on topics including the pricing of pharmaceuticals and the history of yellow fever as well as a Chronic Diseases and Health Promotion department meeting.

Though my time here was short, I have gained many valuable skills involved not only in relation to pharmacogenomics, but also in the way in which reports and information are generated and disseminated within a large, multi-regional, multi-national non governmental organization. The seminars that I attended and the interaction with not only the Human Genetics' team, but with many other people from different cultural backgrounds,, areas of interest and expertise which has been particularly beneficial.

The level of independence and responsibility given to me has been a vital ingredient in giving me enough capacity to follow my interests, whilst ensuring that the work that I did was of use and was of a collaborative nature. I am indebted to the Human Genetics' team who have made my time here enjoyable as well as educational. They ensured that I was involved and supported in all ways, not just related directly to the work.

This experience has been excellent, and I would strongly support any Monash student considering the Fellowship to apply. I thank Monash, the Centre for Human Bioethics and the World Health Organization for the opportunity.

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