

Internship Report – Angela Ballantyne

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Throughout my time at the Human Genetics Programme (HGN) I worked both independently and in close co-operation with my supervisor Ayna Smith, HGN's Ethics Officer, and with its Communications Officer, Sameera Suri.

My work at HGN related to four distinct projects. First, I was involved in the review by international experts of an HGN report, which examines the impact of gene patents on access to genetic technologies in the developing world. I was involved in managing the review *process* and revising the *content* of the document, and I personally elected to continue my involvement with this project after I left HGN.

Second, Ayna and I designed the model for a database of regulatory documents relating to the ethical, legal and social aspects of Genetics (ELSI ReD), and wrote the Specifications Document which describes this database for potential contractors. This 20 page document includes details of the storage of the data, the search pathways, search options, presentation of search results, user interface for the data, and a series of drawings illustrating the desired design of web pages. In relation to the content, I researched and wrote summaries for 100 regulatory documents to be stored in the database. An interim version of ELSI ReD is now available on-line through the HGN Genomic Resource Centre web site (www.who.int/genomics). In addition, I wrote the guidelines for the maintenance of the database, which includes criteria for inclusion of documents in the database.

Third, I wrote a project plan for including a Best Practices in Genetics and Genomics (BPGG) section on the GRC. As part of this initiative I conducted independent research into the genomics industry in Brazil and presented this in a template form as the first entry for the BPGG section.

Finally, I worked on the "ethics and genetics" initiative which aims to prepare educational material for clinicians and patients in developing countries, relating to the ethical issues raised by genetics. My supervisor and I wrote a commentary, which was submitted for the JAMA Global Health Theme Issue. I also initiated background research on the topic, and the development of an international network of people interested in the project.

In addition to my regular work I had the opportunity to attend the Global Health Research Forum, the WHO Ethics Council meetings and the Executive Board of WHO meeting. I was also grateful to be invited to participate in the Consultation on Equitable Access to Care for HIV/AIDS, sponsored by WHO and UNAIDS. I felt that these gatherings added an important aspect to my internship experience as they allowed me to interact with a diverse range of international experts.

Overall, I appreciated the diversity of projects I was given to work on, and the challenging nature of many of the tasks. The design of ELSI ReD and the management of the review process for the "Gene patents and Access" document provided me with an opportunity to see the internal workings of WHO. With the genetics and ethics project (particularly the drafting of the JAMA article), the revision of content of the "Gene patents and Access" document and the research into the genomics industry in Brazil I was able to apply the research and writing skills I have developed at Monash. As a final compliment, the design of the BPGG allowed me to explore and better understand the aims and priorities of the Genomic Resource Centre.

The HGN team was a delight to work with – they were supportive, encouraging and fun. I would encourage Monash University to continue its support of the Fellowship.

I would recommend this experience to students seeking to:

- explore the difference between academia and policy;

- apply the theory and skills they have developed through the Masters in Bioethics program;
- diversify their experience in bioethics; or
- obtain a better understand of the workings of WHO and UN agencies in general.