

**Monash/ WHO Fellowship**

Report for Monash University

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As an intern in the Human Genetics Programme (HGN), I worked both independently and as part of a small team supervised by Angela Ballantyne, HGN's Ethics Officer.

The major project I worked on was the report on *Medical Genetic Services in Developing Countries: The Ethical, Legal and Social Implications of Genetic Testing and Screening* (GTS report). I was extensively involved in many elements of the development of the report, including researching, writing, editing and proofing of the report. I worked particularly on *legal* issues, and helped draft sections on privacy and confidentiality regulations in developing countries; pharmacogenomics; genomic research; religious perspectives on genetic testing; prenatal testing regulations in developing countries and sex selection prohibitions. I was given the opportunity to make suggestions about the structure and approach of the report, and assisted in incorporating review comments from the 24 member international *Expert Review Panel*.

Another project I worked on was the ELSI regulatory database (ELSI ReD). I was involved in discussion identifying limitations of the current format of the database, and provided input into the development of the revised management strategy. However, as this process of revision was ongoing while I was at WHO, no analytical work was being done on the material currently held in ELSI ReD.

Therefore, I undertook an additional major project, in which I worked on two case studies on quality and safety in genetic testing in Australia and New Zealand that were subsequently published on the Genomic Resource Centre (GRC) website maintained by WHO ([www.who.int/genomics](http://www.who.int/genomics)). I worked closely with Amy Pearn, an HGN intern, on doing additional research to build on the primary work done by a previous intern. We also worked together on writing new material and editing the case studies on the way to their final form (the case studies were completed after I left WHO). The case studies covered laboratory practices to ensure quality in testing, ELSI in relation to quality assurance in testing, and provided an overview of the regulatory measures to ensure good laboratory practice that have been put in place in each country. We also examined the recent reviews of these regulatory measures and the steps that Australia and New Zealand have taken towards implementing recommendations that have been made for improvement.

As part of this work, Amy and I identified a need for a template to guide research and writing for future case studies on this topic for the GRC website. We developed a template in consultation with Angela and Sameera Suri, the HGN Communications Officer, which is now being used to write the next case study by another intern.

A decision was also made to work the case studies up into an article for publication, to be done collaboratively by myself, Amy, Silvana Bettiol and Angela Ballantyne. I worked on this article during my first term at WHO and was responsible for finalising the article during my second term. I have undertaken to act as corresponding author

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and to coordinate the writing team's responses to reviewer comments after I leave WHO.

In addition to these major projects, I worked on updating the genetic testing and screening page on the WHO GRC website and prepared a summary of the issues covered in the GTS report for the website. I also assisted Angela with the development of the HGN WHO Ethics Council presentation based on the findings of the report. Finally, I provided substantive and editorial comments on a range of other ELSI projects, particularly the new Gender and Genetics section of the GRC website.

During my time at WHO, I was able to observe some aspects of WHO's operations by attending two WHO Ethics Councils, a CHP departmental meeting and a number of HGN meetings to discuss ELSI projects with which I was not directly associated. This was very valuable, as I gained insight into the breadth of the projects being undertaken within my own unit, as well as a better comprehension of WHO structures and processes. However, this understanding was greatly increased by the time and effort taken by my supervisor Angela, who was always available to explain WHO structures, processes and projects to me.

WHO provides training workshops for staff and interns, and I was fortunate to be able to attend the yearly workshop on Health and Human Rights. This was a great opportunity for me to develop my knowledge of human rights law and its application to health, while I also learned about how WHO works to promote human rights within its own work.

I have thoroughly enjoyed my time at the WHO. I greatly appreciated the stimulating nature of the work I was given, and the level of responsibility afforded me by my supervisor. I always felt like a respected member of a team, and found working with Angela, Amy and the rest of the HGN group a very valuable experience. I've learned an enormous amount in my time at WHO, not only about the particular areas on which I worked, but also from engaging with the rest of the team and hearing their perspectives on the ELSI we were examining. I found my work satisfying, and it was a great experience to be able to see a project of this kind through from start to finish. It enabled me to see not only how WHO produces work of this kind, but also to gain knowledge about the management of such as project.

I am tremendously grateful to Monash University for giving me this fantastic opportunity. I'm also very grateful to the HGN team for being so supportive and enjoyable to work with. My particular gratitude lies, however, with Angela Ballantyne who made my time at WHO far more rewarding than I ever imagined it would be, due to the time, thought and effort she put into supervising and encouraging me.

To Monash students considering applying for the Fellowship, I would highly recommend it to anyone wishing to gain an inside view of how policy development at the international level occurs, as the Fellowship is a unique opportunity to obtain this kind of insight. It is also a great chance to broaden your understanding of the practical application of bioethics theory.

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