

Monash-WHO Bioethics Fellowship 2010-2011

Report for Monash University

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During my two and a half month internship at WHO I worked in the Ethics and Health Unit, a branch of the Department of Ethics, Equity, Trade and Human Rights (ETH). I was supervised by Dr Marie-Charlotte Bouesseau and Dr Andreas Reis, both of whom were very warm and supportive (the exact moment I realised I had gotten lucky with my supervisors was when, on my first day, after being invited back to Dr Bouesseau's house for the Unit Christmas party, I found myself drinking homemade mulled wine and getting beaten at cards by Dr Reis' six year old daughter). My time in Geneva was definitely one of the most exciting and inspiring periods of my life.

I worked on two main projects during my internship. Firstly, I produced a report that looked at the ethics of biobanking. Biobanks are collections of samples of human bodily substances (e.g., cells, tissues, blood or DNA as the physical medium of genetic information) that are or can be associated with personal data and information on their donors. Biobanks have become very important for certain types of research, particularly genetic research. The first step in this project involved conducting a literature review in an attempt to identify the main ethical issues in biobanking. I concluded that there were six main issues: informed consent, privacy, withdrawal of participation, benefit sharing, commercialisation, and data sharing.

I then completed a review of different National Ethics Committees (NECs) published opinions on the ethics of biobanking, focussing particularly on the six main issues I had previously identified. The WHO maintains a database of NECs for member states around the world and, in order to establish which ones had produced publicly accessible opinion papers on biobanking, I scoured dozens of NEC websites and sent a copious number of emails and follow-up emails. Internationally, 18 NECs (as well as international organisations such as UNESCO and the Council of Europe) have to date produced documents that contain opinions on one or more of the major ethical issues involved in biobanking.

My final report on biobanking was sent to the head of the Biobanking Working Group, which is one of four Working Groups that are responsible for organising the content and agenda of the 9th Global Summit of National Bioethics Advisory Bodies. My report was designed to help the head of the Biobanking Working Group to easily identify those ethical issues in biobanking that require further analysis and would be good topics for discussion and debate at the Global Summit.

The second project that I worked on saw me involved in the preliminary stages of a new publication that the Ethics and Health team are producing, which at the moment has the working title of "20 Questions and Answers on Ethics and Health". As the title suggests, this document will be in question and answer format. Each question and answer will be

roughly a page long, and will generally cover practical aspects of health ethics that are relevant to practitioners in the field (e.g., What is a valid informed consent process? What are the potential burdens of public health programs and research, and how can they be addressed? What is the relationship between ethics, human rights and the law? Is it ever justifiable to infringe moral considerations in the name of public health?). The document will be produced in collaboration with the WHO Collaborating Centers for Bioethics, who will each produce about three or four of the page long answers once the 20 questions have been decided upon. My task was to provide members of Collaborating Centers with information on this new paper, as well as a list of preliminary questions that Dr Bouesseau, Dr Reis, and myself developed. This was done in an attempt to elicit feedback on our preliminary questions, as well as to get ideas on other questions that members of the Collaborating Centers thought should be included in the document.

I found both of the projects that I worked on to be interesting and challenging, and I learned a great deal in the process of completing them. I knew very little about biobanks and nothing about the ethics of biobanking before I started work on that project, whereas now I could expound ad nauseum on the importance of biobanking or why “broad consent” is necessary if biobanks are to remain viable. I also greatly enjoyed learning about the ethics of public health and simply public health in general, which are both areas that I did not have a background in and wanted to learn more about.

Aside from the actual work, there was always a lot going on at WHO. I attended a number of very interesting lunch-time seminars. I saw a speech by the UN Secretary General, Ban Ki Moon. The WHO Director General, Margaret Chan, spent a morning with all of the interns (there were over one hundred when I was there), taking photos and fielding questions. She was funny, fiery, and candid. I was invited to attend a Research Ethics Review Committee meeting (i.e., WHO’s ethics committee), which, replete with privacy agreements, high-profile members, challenging research submissions, and heated debate, was one of the highlights of my internship. I also sat in on a couple of sessions of the annual Executive Board meeting. In these meetings delegates from every WHO member nation organise the objectives for the coming year and set the agenda of the upcoming World Health Assembly. It was quite amazing to sit in the stalls and use an earpiece to listen to real-time translations of the non-English speaking delegates’ speeches—I felt like I was watching a movie. Speaking of movies, they were filming one at WHO while I was there! Steven Soderbergh was shooting some scenes with Marion Cotillard for the upcoming film *Contagion*. There was much excitement among the interns on that day, especially when the rumour spread that Matt Damon and Gwyneth Paltrow were in the building! There is never a dull moment at WHO.

Looking back at my time in Geneva, I can see that the most important thing that I took away from the experience was a strong sense of inspiration. I found working at WHO to be inspiring in two almost opposing ways: it was both humbling and confidence building. It was humbling (and slightly nerve wracking) to be at the epicentre of world public health; to work on agenda setting projects, to attend high profile meetings, to witness people at the top of their games, and to attend speeches by people I had only ever seen on the television. On the other hand, it was inspiring to realise that I could be capable of

working professionally at this international level, that it would not be a pipe-dream to aim for work with a UN agency if that was what I wanted. My ideas of what I should reach for in my career definitely underwent revision while I was abroad. Things that seem unachievable or intimidating from a distance often appear much more achievable and realistic when you experience them up close.

Perhaps the most inspiring part of my experience at WHO, however, was meeting and getting to know other interns. You would be hard-pressed to find a group of more interesting, intelligent and switched-on young people than the interns I befriended at WHO. I made friends my own age who had worked in developing countries, who had studied at the world's top universities, who were passionate and realistic about changing the world for the better, and who had big dreams. And spending time with them influenced and inspired me immensely.

I am very grateful to Dr Justin Oakley and the Centre for Human Bioethics for establishing the Monash-WHO Bioethics Fellowship program and for allowing me this wonderful experience. Like others before me have said, if you are reading this because you are thinking about applying for the fellowship, then I implore you not to hesitate. Oh, and heed the warnings about accommodation being hard to find in Geneva!