
Appendix 2

Methodology

In November 2003, the Human Genetics Programme commissioned the writing of a background paper on the “impact of DNA patents on access to genetic technologies and services for the control and management of non-communicable diseases in low to middle income countries”, by McGill University’s Centre for Intellectual Property Policy, Montreal, Canada.

This background document formed the basis for a three-round electronic review process, initiated in January 2004. Twenty-two individuals were selected as Scientific Review Panellists, on the basis of recommendations, demonstrated expertise, and their record of publications in the area of genetics or intellectual property rights. This work sought to explore and to highlight the crucial issues relating to intellectual property (particularly patents) through the lens of public health, rather than to produce official policy; the Scientific Review Panel therefore comprises chiefly academics, rather than policy-makers. Each of these individuals formally agreed to participate in the review process, and submitted a Declaration of Interests form. Table 1 presents a complete list of the members of the Panel.

The goal of the review process was to obtain critical feedback from academics, representing a balanced distribution across regions, and between sexes, on the document. During the first round of the review

process, extensive feedback was received from several reviewers, which led to a dramatic re-shaping of the document. In general, the first round of comments reflected a desire for a more detailed exploration of the ethical issues relating to the patenting of DNA sequences, and concrete linkages between the issues addressed and the specific needs of developing countries. The aim of the review was not to achieve consensus at all costs, or to privilege particular viewpoints; rather, it was, as much as possible, to present the important issues, including points of ongoing disagreement. The report was re-drafted in line with the comments received during the first round, and was sent back to the reviewers. The second round of comments were, in general, more specific—for example, pointing to technical matters, and to the need to clarify various arguments, as well as suggestions for the inclusion of a glossary and list of acronyms—rather than proposing the re-framing or substantial alteration to the report. Changes were again made by the editors on the basis of this feedback, and a third version of the document was sent out electronically for final review, including to several WHO staff. This third and last wave of comments comprised largely minor proposals for clarification of terms, and alternative language for some portions of text. These comments were incorporated, and the final report underwent professional editing and publication.

Table 1
Scientific Review Panel

Name	Institutional affiliation
Shaikha Al-Arrayed	Gulf Genetic Center, Ign Al Nafees Hospital, Kingdom of Bahrain
Amir Attaran	Centre for International Development & Kennedy School of Government, Harvard University, United States of America
John Barton	Law School, Stanford University, United States of America
Kare Berg	Institute of Medical Genetics, University of Oslo, Norway
José Maria Cantu	Genetics Division, Centro de Investigacion Biomédica de Occidente, Mexico
Jean-Jacques Cassiman	Center for Human Genetics, Campus Gasthuisberg, Belgium
Mildred Cho	Center for Biomedical Ethics, Stanford University, United States of America
Carlos Correa	University of Buenos Aires, Argentina
Abdallah Daar	Joint Centre for Bioethics, University of Toronto, Canada
Prabuddha Ganguli	"Vision-IPR", India
Cathy Garner	Centre for the Management of IP in Health R&D, United Kingdom
E. Richard Gold	Centre for Intellectual Property Policy, McGill University, Canada
Vladimir Ivanov	Research Institute for Medical Genetics, Russian Federation
Patricia Kameri-Mbote	International Environmental Law Research Centre, Kenya
Darryl Macer	Eubios Ethics Institute, Japan
Patricia Aguilar-Martinez	Laboratoire d'Hématologie, Hôpital Saint Eloi, France
Sisule Musungu	South Centre, Switzerland
Victor Penchaszadeh	Mailman School of Public Health, Columbia University, United States of America
Sandy Thomas	Nuffield Council on Bioethics, United Kingdom
Lap-Chee Tsui	University of Hong Kong, China
Ishwar Verma	Department of Medical Genetics, Sir Ganga Ram Hospital, India
Huanming Yang	Beijing Genomics Institute, Chinese Academy of Sciences, China