
1. *Introduction*
   The sequencing of the human genome has opened up unprecedented possibilities for healthcare, but also ethical and social dilemmas about how these can be achieved, particularly in developing countries. UNESCO addresses such issues through its Bioethics Programme, established in 1993. Chapter 1 gives an overview of how the book analyses the Programme’s three international declarations on genetics and bioethics and its related capacity building activities. Drawing on international relations theories of governance and fieldwork conducted in Kenya, South Africa, France and the UK, the book assesses the Programme’s efficacy at international and national levels.

2. *Bioethics: human genetic and biomedical research ethics at UNESCO and beyond*
   Genetics presents new ethical problems, or at least new perspectives on existing ones. At the same time, understandings of what constitutes a bioethical concern are broadening. As inequalities in health between North and South enlarge, what should be the focus of research becomes in itself an ethical question, aside from how it should be carried out. These are some of the issues that the UNESCO Bioethics Programme seeks to address. Chapter 2 introduces the Programme’s efforts in the context of existing bioethical norms. It also reviews the ethics of human cloning and the current international regulatory framework in this area.

3. *Global governance: a conceptual framework for analysing bioethics at UNESCO*
   Chapter 3 provides a conceptual framework for the analysis of the UNESCO Bioethics Programme, derived from specific approaches to international relations theory. Regime theory attempts to explain why and how, in a world of sovereign states, collective action occurs. As regimes often entail bargaining, concession and compromise, scholars have proposed models of networked governance and cosmopolitan democracy to encourage meaningful global deliberation and enhance implementation of international norms. The book draws on these different theories and models to explain the evolution of the Bioethics Programme and suggest ways in which it could become both more democratic and more effective.

4. *Deliberating bioethics: UNESCO’s standard setting activities*
   Chapter 4 examines relationships between states and other actors during the drafting of the three UNESCO declarations on genetics and bioethics and in the debate over human reproductive cloning. Of particular concern are the bargaining power of developing countries and the relative influence of other UN organisations, independent experts and civil society actors. Power differentials between North and South surfaced in spite of formal procedures aimed at containing these and several non-state actors felt excluded from the process. UNESCO’s insistence on decision-making by consensus meant that only uncontroversial issues could be agreed upon, in generalised and non-binding formats.
5. Implementing bioethics: UNESCO’s efforts to realise and enforce the declarations

Chapter 5 examines the content and strength of the three UNESCO declarations on genetics and bioethics and the organisation’s efforts to ensure they will be realised in policy and practice. Much of the language in the declarations is deliberately vague and non-committal and controversial ethics issues receive little mention. Direct uptake by states, in legislative terms, has been poor. Nevertheless, UNESCO has made considerable headway in promoting ethics worldwide through dissemination of the declarations and other resources and capacity building initiatives aimed at research ethics committees and ethics teachers. The potential overlap with the WHO’s ethics programmes must be addressed.

6. Contextualising bioethics: the declarations in Kenya and South Africa

In Chapter 6 the analysis steps back from the international level, to see how Kenya and South Africa worked out their negotiating positions on UNESCO’s Universal Declaration on Bioethics and Human Rights (UDBHR), adopted in 2005. Kenya sought out expert views, but not those of civil society. In South Africa consultation was minimal. The chapter also outlines how far all three UNESCO declarations on genetics and bioethics are reflected in the laws, regulations and policies of both countries. Kenya has drawn explicitly on the UDBHR in developing its ethics systems, whereas South Africa’s efforts have been independent of UNESCO.

7. Contextualising bioethics: mapping progress in Kenya and South Africa

Chapter 7 assesses progress in bioethics in Kenya and South Africa from 2005 to 2012. Both countries have made significant strides in several areas of bioethics governance. Some initiatives have tackled issues that are of particular concern to the UNESCO Bioethics Programme, such as community preparedness, social responsibility in research and ethics training and education, yet few have drawn on UNESCO resources. Other areas—protection of vulnerable populations, sample shipping and public understanding of genetics and bioethics—remain a serious challenge. As these are also priority areas for UNESCO, it may be able to offer support on these issues.

8. Conclusion

The conclusion draws on theories of governance to suggest ways in which the UNESCO Bioethics Programme could operate more effectively, in the deliberation and implementation of ethical norms. It examines how relations between developed and developing countries could be made more equal; how stakeholders could be better engaged; and how states could be encouraged to adopt the provisions of the genetics and bioethics declarations. It also considers the implications of the book’s findings for the future governance of human cloning. As international consensus on the issue is unlikely, there will continue to be a legislative “black hole” on this issue.

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