

Book Review

Equitable Access to Human Biological Resources in Developing Countries: Benefit Sharing Without Undue Inducement

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Publisher: Springer International Publishing, Switzerland

DOI: 10.1007/978-3-319-19725-8

Print ISBN: 978-3-319-19724-1

Online ISBN: 978-3-319-19725-8

Pages: XIX, 197 (hardcover)



As a social scientist, a social activist, and an ethics committee member on a research ethics committee in a medical institution in India, I grapple with the issue of what a research participant gets out of participation in research. To me, it is a matter of justice, of fairness against exploitation and of equitable returns to ensure that participants ‘get back’, particularly in genetic/genomic research since (in the words of the Human Genome Organisation HUGO, stated in the year 2000), “companies investing in genomic research have a huge potential of translating genetic research into new products such as vaccines and drugs and can reap large commercial benefit”. The UNESCO Declaration (2003) takes this issue beyond individuals and states in Article 19 that “benefits resulting from the use of human genetic data... for medical and scientific research”, “... should be shared with the society as a whole”, but the question that remains is, substantively how can this be done, and what does ‘sharing’ mean.

There are the counter arguments that benefit sharing is unnecessary and would lead to the commodification of human biological material on one side and an undue inducement to participate on the other. Or, that there is no exploitation because people give their biological samples with altruistic motives for the common good and that genetic material is a common heritage resource.

This book takes these arguments head on and addresses them by combining bioethics with jurisprudence. It systematically deals with the questions of whether and in what circumstances benefit sharing is

appropriate for human genetic research and whether benefit sharing could in fact coerce or induce potential participants to participate in research, and finally whether concerns of 'indigenous peoples' being singled out for genetic research are being addressed by the current guidelines.

Chennells began this journey as a lawyer of the San community of Southern Africa which he has detailed in earlier writings also published by Springer.¹ He brings into this book extensive research on other cases of perceived exploitation of indigenous communities, including the islanders of Tristan da Cunha, whose 275 inhabitants descended from just fifteen original families and who show a high incidence of asthma. Academic research, with support from a genomics company identified a predisposing asthma gene in these peoples. This information was then sold to a German pharma company, to develop a genetic diagnostic test. The higher gains of these companies contrasts with the hypothetical potential benefits that the islanders had been promised of free pharmaceutical treatment if drugs were developed based on their research. Similar stories exist of the Nuuchanulth tribe of Vancouver Island in Canada, the Hagahai tribe of Papua New Guinea, and the Havasupai Indians in Arizona, among others. The angst is well expressed by this quote of an Aboriginal leader, John Little who says, "Over the last 200 years, non Aboriginal people have taken our land, language, culture, health and even our children. Now they want to take the genetic material that makes us Aboriginal people as well" (p.21).

Apart from the millions of dollars reaped as commercial gain, there are scholarly papers, dissertations, career path enhancements, institutional grants, and awards, among others, linked with these studies, which prompts Chennells to write: "There are clearly many forms of values locked up in the human genetic resources of certain populations". (p.23) He goes on to examine the concept of 'exploitation' and how the case of Henrietta Lack and the highly profitable cell line derived from her cancerous tumour, challenged the notion of exploitation in that it caused 'no harm'. This also forces us to reflect on the moral issues of 'wrongs' and 'harm' and also of 'theft' and 'blackmail'. We are also challenged to consider a broader dimension of 'beneficence' that goes beyond a person's fundamental wellbeing untethered to health and economic considerations but which can include matters of culture, beliefs, values, of dignity exploitation and injustice.

The proposition of a common heritage of humankind has been beautifully exposed in the moral simplicity of the Law of the Sea and Moon Treaty

(1979). Complex socio-political issues of state sovereignty, bioprospecting and biopiracy are discussed with examples (including cases from India of the well known neem tree and its medical property and turmeric powder as a wound healing medicine). The conclusion is that there is a close similarity in moral and ethical constructs of human and non human DNA, that patenting leads to commodification of human biological material with an unfair ownership pattern and that the common heritage of humankind can no longer be applied to human genetic resources in a meaningful way.

The 'altruism argument' has been shown to have value in affluent or developed countries where the benefit to the contributor of the new knowledge, products and services coming out of the research is ensured by a more open and fair access to health and education. However, this is not true in developing countries where poverty, poor access to health care and a disparity in basic health indicators creates an unequal, inequitable and incomparable situation.

An important issue discussed in the book is whether 'benefit sharing' amounts to inducement or coercion of vulnerable populations to provide genetic resources for research? Chennells plainly establishes that it is the narrow manner in which consent to a transaction is carried out that leads to unfairness and coercion. He takes us through the realms of justice, from Roman law and Aristotelian justice to a modern analysis of justice by Thomas Pogge. While we are more familiar with procedural and substantive justice from the ethical point of view, we are informed about the lesser known form of material justice, namely 'commutative justice'. This is the justice of voluntary exchange between two parties and would be key in guiding benefit sharing. In his words, it "features the restoration of a notional form of equality" (p.88). This is operationalised through the law of contract in which material benefit is a key consideration.

Clarity of ideas, substantiated with theoretical evidence and actual cases, unfolding in a logical, engaging manner is the cornerstone of this book. Each chapter is like a standalone article with an abstract, a conclusion, and its own set of references. It might seem that concepts are repetitive with this form of structuring I found that it helped me get clarity on the concepts and appreciate the newer evidence provided. The closing chapter presents, in a sense, the final arguments and is akin to the closing of a case in court; the representative of the San tribe reiterates the need to be treated fairly and with respect, and to be explained the details of the research and its outcomes

so that an understanding of harm can be clear from their perspective. This is followed by a summary of the arguments of earlier chapters which convincingly support the claim for benefit sharing. One thing that the book lacks is an index at the end of the book which would have been made the search for a specific subject easier.

In my view, the value of the book goes beyond DNA related research and provides thought for ethics committees, researchers and policy makers in developing countries to consider benefit sharing or ‘paying back’ in all forms of research, and the need for this to be stated clearly in contractual terms.

This book is a ‘must read’ for academics in the fields of law, ethics, genetic research and international relations and for policy makers, research ethics committee members and community rights advocates, among others. It empowers the “lambs to hold their own against the might of the lions” (attributed to Woody Allen and contextualised by Roger Chennells)!

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Endnote

- ¹ Chennells, R., V. Haraseb and M. Ngakacaja (2009). “Speaking for the San: Challenges for Representative Institutions” in R. Wynberg, D. Schroeder, and R. Chennells (eds.), *Indigenous Peoples, Consent and Benefit Sharing: Lessons from the San Hoodia Case*. London: Springer.

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