

## BOOK REVIEW

# Genomics for policy makers and for researchers

Genomics and society—Ethical, Legal, Cultural and Socioeconomic Implication

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Genomics is a valuable tool for understanding biological development. It provides new technologies for use in medicine, animal breeding and food production. This book provides a remarkably broad overview of its implications in various sectors of the society, ranging from questions on how clinical genetics services may contribute to the empowerment of patients to questions about economic assessment of these genetic services and biotechnological applications. The challenges faced when genomics meet the local cultures and religious beliefs, for example, traditional Indian Ayurvedic and Chinese medicine, and sociocultural beliefs in South Africa are described with scholarly insight in a way that is not easily available in other contexts. As is common when scientists and scholars talk about the future, there is an element of speculation both regarding potential benefits and risks of harm. The contributors come from many different disciplines and it would sometimes have been helpful to include not only biologic terms in the glossary. I still do not understand what a 'sociotechnical expectation' is. Still, the editors manage to produce a comprehensive report that should be helpful for any policy maker interested to understand and assess genetic innovations in biotechnology, bioengineering and medicine.

I will not give an overview of all 19 chapters in this review. They are all worth reading. One chapter is in my view outstanding in scholarly insight and careful reasoning. Marion McAllister has examined the literature on how clinical genetic services may affect patients'

wellbeing. May genetic testing, counselling and risk information be something good for the individual besides the medical benefit? She uses the concept of *empowerment* as an umbrella for various concepts (coping, perceived personal control, emotional regulation) used in instruments for investigation of the psychosocial aspects of genetic testing and discuss in detail how these concepts then relate to each other. She draws on the seminal work by Katherine Payne and others in Manchester who identified a high degree of discordance between different instruments for measuring patient-related outcomes. She then shows with good references how this field may move forward by applying strict criteria for the assessment of psychometric properties of health measurement scales, and try to bring the different measurements together under the construct 'patient empowerment'. This is done in a way that goes far beyond just using 'empowerment' as a new catchword, something that seems to be quite common among policy makers, social scientists and ethicists today. She concludes that genetic information can be empowering for people. For high-risk genetic conditions many of the benefits relate to feelings of personal control, emotional regulation and hope. More research is needed and several challenges are identified where research is underway or specific issues need to be addressed. There is a lot of interest in seeking out patient perspectives and preferences today. I highly recommend this chapter by McAllister to all researchers engaged in this field, and for policy makers who should not base their recommendations on sloppy research or on speculations about benefits and risks associated with genetic testing.

### CONFLICT OF INTEREST

The author declares no conflict of interest.

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