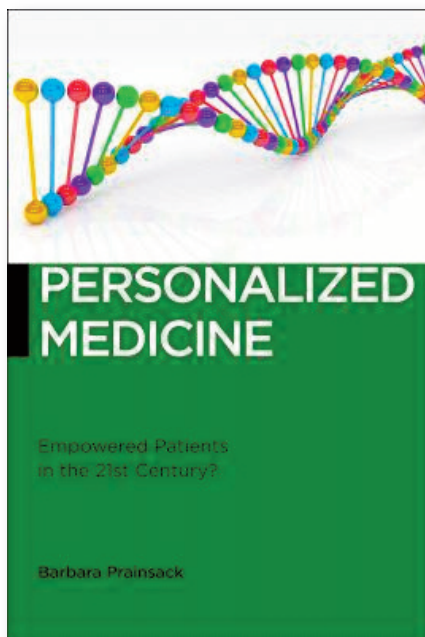


# Personalized Medicine

Empowered Patients in the 21st Century?

BARBARA PRAINSACK



"Barbara Prainsack raises deep questions about the ethics and politics of personalized medicine. In this rigorous and engaging book, she explores the cutting edge of health care, critiques several popular visions of patient empowerment, and offers a novel and compelling account of what truly democratic, responsive, and fair deployment of new health technologies would require. Displaying a mastery of diverse literatures in social science, law, and health services research, *Personalized Medicine* is a must-read for anyone interested in the future of patient participation in health and wellness initiatives—ranging from self-tracking to biohacking, and well beyond."

**Frank Pasquale, author of *The Black Box Society***

Inside today's data-driven personalized medicine, and the time, effort, and information required from patients to make it a reality

Medicine has been personal long before the concept of "personalized medicine" became popular. Health professionals have always taken into consideration the individual characteristics of their patients when diagnosing, and treating them. Patients have cared for themselves and for each other, contributed to medical research, and advocated for new treatments. Given this history, why has the notion of personalized

medicine gained so much traction at the beginning of the new millennium?

*Personalized Medicine* investigates the recent movement for patients' involvement in how they are treated, diagnosed, and medicated; a movement that accompanies the increasingly popular idea that people should be proactive, well-informed participants in their own healthcare.

While it is often the case that participatory practices in medicine are celebrated as instances of patient empowerment or, alternatively, are dismissed as cases of patient exploitation, Barbara Prainsack challenges these views to illustrate how personalized medicine can give rise to a technology-focused individualism, yet also present new opportunities to strengthen solidarity. Facing the future, this book reveals how medicine informed by digital, quantified, and computable information is already changing the personalization movement, providing a contemporary twist on how medical symptoms or ailments are shared and discussed in society.

Bringing together empirical work and critical scholarship from medicine, public health, data governance, bioethics, and digital sociology, *Personalized Medicine* analyzes the challenges of personalization driven by patient work and data. This compelling volume proposes an understanding that uses novel technological practices to foreground the needs and interests of patients, instead of being ruled by them.

**Barbara Prainsack** is Professor of Political Science at the University of Vienna, and Professor of Global Health and Social Medicine at King's College London. She is the co-editor of several volumes as well as co-author of *Genetic Suspects: Global Governance of Forensic DNA Profiling and Databasing and Solidarity in Bioethics and Beyond*.

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