

Evidence for Health

From Patient Choice to Global Policy

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CAMBRIDGE
UNIVERSITY PRESS

Cambridge University Press & Assessment
978-1-107-64865-4 — Evidence for Health
Anne Andermann
Frontmatter
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Shaftesbury Road, Cambridge CB2 8EA, United Kingdom
One Liberty Plaza, 20th Floor, New York, NY 10006, USA
477 Williamstown Road, Port Melbourne, VIC 3207, Australia
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103 Penang Road, #05–06/07, Visioncrest Commercial, Singapore 238467

Cambridge University Press is part of Cambridge University Press & Assessment,
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www.cambridge.org
Information on this title: www.cambridge.org/9781107648654

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First published 2013

A catalogue record for this publication is available from the British Library

Library of Congress Cataloging-in-Publication data

Andermann, Anne, 1972–

Evidence for health : from patient choice to global policy / Anne Andermann.

p. ; cm.

Includes bibliographical references and index.

ISBN 978-1-107-64865-4 (pbk.)

I. Title.

[DNLM: 1. Public Health. 2. Decision Making. 3. Evidence-Based Practice. 4. Health
Policy. 5. Outcome Assessment (Health Care) 6. World Health. WA 100]

362.1–dc23

201204120

ISBN 978-1-107-64865-4 Paperback

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Every effort has been made in preparing this book to provide accurate and up-to-date
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publication. Although case histories are drawn from actual cases, every effort has been
made to disguise the identities of the individuals involved. Nevertheless, the authors,
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material contained in this book. Readers are strongly advised to pay careful attention
to information provided by the manufacturer of any drugs or equipment that they plan
to use.

I have written this book for Lara and Ben, with the hope that promoting evidence-informed decisions will allow them to live in a healthier and more equitable world.

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Foreword

Tikki Pang

Visiting Professor, Lee Kuan Yew School of Public Policy,
National University of Singapore, Singapore and formerly
Director, Research, Policy and Cooperation, World Health Organization,
Geneva, Switzerland

In an age of financial crises, diminishing resources and competing priorities, Anne Andermann's book is very timely and fills an important gap in the critical area of developing sound and sustainable health policies. While many books and manuals have been written on the use of evidence in the development of clinical practice guidelines, there have been very few attempts at a treatise on the use of evidence in policy formulation. Written as a practical guide to evidence-informed decision-making, this book will be an invaluable tool for policy-makers and others, including health practitioners, enabling and empowering them to make rational decisions and better withstand vested interests and political, economic and even ideological pressures, which are so pervasive in the policy sphere.

Based on her own extensive experience, the author takes us systematically through the strategies commonly used to improve health, and the more difficult topic of how decisions are made which impact health outcomes. She then tackles the practical issue of producing evidence and the critical bottleneck which exists between the production and use of evidence. Often, a major challenge is the lack of understanding between researchers and policy-makers, which, I believe, can be overcome to a large extent by giving attention to the issues highlighted in this book. In the chapter on evidence production, the author highlights, for example, the increasing importance of implementation research, which aims to develop strategies for optimising the delivery, uptake and use of new or existing interventions by populations in need. This type of research is particularly important in supplying the kind of evidence which policy-makers appreciate and understand more readily than basic biomedical or even clinical research. The chapter also highlights the importance of evaluating the impact of policy, and how such research can feed back into the "knowledge loop" in an iterative, reinforcing manner. The final chapter cogently tackles the oft-neglected final step of how evidence-informed decisions are actually made, highlighting the necessity of coming up with various options which take into account ethical, social, legal and cultural issues, and the sensitivities and concerns of interested parties who may be affected by the decision.

This book is valuable for three reasons.

First, is its pragmatic, realistic and empathetic approach. Relating her ideas to her own personal experiences, which make the book feel vibrant and "alive", the author highlights the reality that policy-making is inherently complex and challenging, with evidence being only one factor which has to be integrated with a myriad of others. In the words of Sir Michael Marmot, the reality is that "scientific findings do not fall on blank minds that get made up as a result. Science engages with busy minds that have strong views about how things are and ought to be".

x	Foreword
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Second, is its implicit message that the need to understand the importance of evidence is as relevant and important for a doctor, a nurse, or an individual patient and consumer, as it is for senior policy-makers at national or global levels. All of these people must, ultimately, make decisions pertaining to the health of human beings, be it at the level of an individual or whole populations, both in developed and developing countries.

Third, is that it offers many universal lessons and recommendations on the importance and use of evidence, which are applicable beyond the health sector to other sectors that nonetheless have a direct or indirect influence on human health. The book thus speaks to the reality of an increasingly globalised world where health challenges are transnational, multidimensional and multi-sectoral.

In addition to its obvious value as a practical “A to Z” guide for decision-makers, the book should be compulsory reading at the postgraduate level in the fields of public policy and public administration, where future decision-makers need to be sensitized to the thoughts of Goethe, who famously said “knowing is not enough, we must apply; willing is not enough, we must act”.

I have no doubt that this landmark publication will go a long way in advancing the cause of evidence-informed decision-making, which is the foundation for creating and maintaining strong and sustainable health systems. Robust health systems can then achieve their ultimate goal of improving the health status and lives of the people they serve in an ethical, equitable and sustainable manner.

Preface

The idea for this book came to me when I was teaching a course on epidemiology to graduate students in the Health and Health Policy (HHP) Programme at Princeton University's Woodrow Wilson School for Public and International Affairs. Many of my students were completing a Master's degree in Public Administration (MPA) or Public Policy (MPP). They had already worked in government or for well-known international non-governmental organisations (NGOs) and had been involved in making decisions that could affect the health of hundreds of thousands of people. Yet for the most part they did not have any formal education or training in health sciences upon which to base these decisions. With undergraduate degrees in political science, management and economics, the process of producing, appraising and using scientific evidence was a "black box" that was unveiled during the course so that the students could be more critical readers of the research literature (or even of reports of the literature published in the media, which is where most people read about scientific evidence). Even health practitioners working on the frontlines – including doctors, nurses, midwives, lay health workers and others – are not always well versed in research methods and how research findings can be used to improve health. While evidence is certainly not the only "ingredient" that goes into decision-making for health, making decisions without evidence is like sailing the seas without a map and compass. Therefore, to foster more evidence-informed decision-making, I thought it would be important to write a book targeted towards practitioners and policy-makers that demystifies the process of knowledge production and illustrates the complexity of decision-making so that knowledge users are better able to incorporate the scientific evidence into decisions, to thereby influence health outcomes in a more strategic and informed way. This is by no means an epidemiology textbook, but rather a practical guide to evidence-informed decision-making with the goal of improving health and reducing health inequities.

My main argument throughout this book is that the health of individuals and populations is a product of the many decisions that we make on a daily basis. If our world has enormous (and some might say highly unethical) health inequities whereby some people can expect to die at age 40 whereas in other parts of the world people live on average to age 80, it is because we make it so and we allow these disparities to continue. These are not laws of nature. There are just people, like you and me, making a series of decisions that have consequences for health – even when these decisions are being made outside of the health sector. The flip side of this is that we also have the power to change the health landscape, or even our own health, but this depends upon using the best available scientific evidence to inform decision-making, and ensuring that decisions are not thwarted by vested interests or lack of political will.

Indeed, making evidence-informed decisions is not a straightforward process. I recall my experiences as a researcher in a health technology assessment (HTA) agency. The role of this organisation, at arm's length from the Ministry of Health, was to provide government with evidence-informed recommendations for improving health services, and ultimately for improving health. My role was to develop a process for evidence-informed decision-making

with regard to genetic screening that also made explicit the underlying value judgements and ethical considerations. However, there was a clash with the economist on the Board of Directors who strongly believed that all considerations can be incorporated into a cost-effectiveness analysis and who disagreed that cost issues are just one aspect – rather than the central aspect – of decision-making. On another occasion, there was a clash with a fellow researcher – a devout Catholic and anti-abortionist – who was developing recommendations for prenatal screening that would affect the entire population. To what extent should her own personal values be permitted to influence recommendations made in a multi-cultural society where citizens do not share the same values? How can we ensure that value judgements are made explicit rather than pretending that they do not exist? Even risk tolerance varies from person to person. How to choose a threshold for an entire population when some people would be comfortable with a risk of 1 in 100 of carrying an affected fetus, and others would be unable to sleep at night if they had a risk of 1 in 1,000? This book illustrates that decision-making for health is a highly complex and contentious area where even experts can disagree on the best process for making these decisions – and quite often, there isn't a systematic or explicit process being used at all.

While there is no single, universally accepted approach to decision-making, this book provides an algorithm that uses a series of questions for arriving at evidence-informed decisions that take into consideration the multiple complexities and value judgements involved. In many ways, the process (i.e. being participatory and involving stakeholders, as well as being explicit in justifying why a certain decision is made) is just as important as the product (i.e. the final decision made).

From my later experiences working as a public health consultant for another government agency that provides technical assistance to local health regions, I witnessed first-hand how decisions made by government can be very poorly received when certain stakeholders do not understand how these decisions were made and feel that the decisions are unfair. Quite literally there were fists thumping on tables and cries of injustice, followed by vehement accusations that the government was simply trying to save money and ration services. This was true decision-making in action. Not for the faint of heart. My role was to chaperone the process of revisiting the decision, which was done in a systematic, evidence-informed and participatory way. Everyone walked through the process together and various experts were called in as needed to clarify certain issues. The key was that everyone was on the same page and could appreciate the multiple complexities and considerations involved. While the local stakeholders still wanted to lobby for their cause, they were much more understanding the second time around when the government made the exact same decision – because this time there was also a clear explanation and understanding of why this decision was made. Of course, this does not mean that it was a straightforward case. Indeed, when the policy-maker from the Ministry asked for my opinion prior to making their decision public, I had to admit that it was a bit of a grey zone. On the one hand, offering this new preventive service to the region could be justified on the basis that this region has a somewhat higher prevalence of the health problem in question. On the other hand, this would be one of the first jurisdictions worldwide to offer such a service outside of a research context, there are many known technical and ethical ramifications involved in introducing this service, and the health problem is also fairly common in other neighbouring jurisdictions (although not quite as prevalent), which would lead to inequities in terms of access to services (also known as the “postcode lottery”). Thus, there were reasons given that clearly explained why the government chose not to go ahead with the introduction of this service – it was not simply a case of

rationing health care and saving money. Moreover, as the knowledge base and the context evolve, this decision could certainly be revisited over time to see whether these reasons still apply in future. The more I am involved in decision-making at a political level, the more I empathise with the challenges involved in integrating so many diverse considerations and viewpoints, and the more I believe in the value of a systematic approach that makes these multiple factors explicit.

Reflecting these experiences, the scope of this book is very broad, from the personal decisions that individual patients make about their own health to global policy decisions that can impact the health of millions of people worldwide. As a graduate student at Oxford University, the focus of my doctoral research was to better understand the expectations and information needs of women presenting to primary care, and what factors could promote evidence-informed patient choice. Later, as a family doctor, I experienced the daily challenges of helping my own patients make difficult decisions about their health: for instance, whether to undergo surgery that can improve quality of life but entails a certain risk of dying during the procedure or to forego surgery and live as long as possible with increasingly impaired function. As a public health physician working to promote the health of an Aboriginal population in the North of Canada (for public health physicians, the “patient” is the population), I was involved in examining the Health Impact Assessments of economic development projects and making recommendations on how to balance the needs of various disadvantaged populations in the North in a way that is fair and maximises benefits while minimising harm. As well, while working at the World Health Organization (WHO) in Geneva, I advocated for universal access to primary health care worldwide as an important method of social protection and lever for tackling health inequities. Currently, I combine public health practice at the local and national level, clinical work in a university-affiliated teaching hospital serving a diverse multi-cultural community, supervision and training of medical students and residents, and global health research aimed at empowering frontline health workers to tackle the social causes of poor health. I therefore write this book wearing several “hats”: as a policy-maker, a researcher, an educator, a health practitioner and even as a patient.

As one moves from patient choice to global policy, the level of complexity increases significantly. Yet, all decisions fundamentally entail various trade-offs when considering the different options and balancing the overall benefits and harms of choosing one option over another. Through this book, I hope that I can help policy-makers and practitioners to make more evidence-informed decisions for improving health. In particular, with the growing emphasis on the upstream social determinants of health, I hope that this book will also reach decision-makers outside of the health sector, as decisions made in areas such as education, employment, housing, gender equality and so forth are fundamental to tackling the major health inequities of our time. To make progress in reducing these inequities, we need evidence-informed decisions that consider the health impact of all policies, not just those involving the health care system. Better-informed decisions can lead to healthier and more equitable societies. It is up to us to choose.

Endorsements

“To enable individuals to be in control of their lives, action is needed on the social circumstances in which people are born, grow, live, work, and age. Evidence for Health: From Patient Choice to Global Policy is an innovative and timely book that provides important insight on how to make more transparent and informed decisions that will result in healthier individuals and more equitable societies.”

Professor Sir Michael Marmot, Director, UCL Institute of Health Equity, London, UK, and formerly Chair, WHO Commission on the Social Determinants of Health

“Evidence for health seems self-evident, however, Andermann in her thought-provoking book, points not only to the value of evidence, but also to the imperative to learn how to integrate it more systematically in all decisions related to health from local to global. Progress on this front would certainly contribute to better decisions and better health.”

Dr. Timothy Evans, Dean, BRAC School of Public Health, Dhaka, Bangladesh, and formerly Assistant Director General of the World Health Organization, Geneva, Switzerland

“Public health has too often focused on making recommendations about what people ought to do rather than considering what changes behaviours and policies. Drawing from multiple disciplines, Andermann thoughtfully addresses this challenge, reviewing how we make decisions that affect health – from the individual to the global level – and detailing how we can generate and best make use of evidence to reduce health inequities and improve people’s health.”

Dr. Kumanan Rasanathan, Health Section, United Nations Children’s Fund (UNICEF), New York, USA

“This book addresses key questions confronted by policymakers, health practitioners and the population at large. Written in a very simple and user-friendly manner, Evidence for Health will be a highly valuable tool for understanding and addressing health inequities in both developed and developing countries.”

Mr. Saeed Awan, Director, Centre for the Improvement of Working Conditions & Environment, Department of Labour and Human Relations, Government of Punjab, Lahore, Pakistan

“A fresh, thoughtful, and panoramic look at the role of evidence in health. This book should be of interest to any student of public health or public policy.”

Dr. Peter Singer, Professor of Medicine and Director, Sandra Rotman Centre, University Health Network and University of Toronto

“Decision-making is a complex process, particularly in medicine and public health. It frequently implies the simultaneous display of technical abilities, political appraisals, and moral judgements. Anne Andermann’s book, Evidence for Health: From Patient Choice to Global Policy, makes this process accessible to all. I have no doubt that it will become an invaluable tool for health professionals working in clinical, management, and public health settings.”

Dr. Julio Frenk, Dean of the Faculty, Harvard School of Public Health, and former Minister of Health of Mexico

About the author

Dr. Anne Andermann is a family physician, a public health specialist and a former Rhodes Scholar. Her doctoral studies at Oxford University focused on the impact of new genetic and genomic technologies in primary care, and she later worked for the Quebec Health Technology Assessment Agency (formerly AETMIS) on developing guidance for population-based genetic screening policy-making. Dr. Andermann has also worked at the World Health Organization (WHO) in Geneva on research capacity strengthening in low- and middle-income countries. During that time, she was a member of the WHO Research Ethics Review Committee and a main contributing author to the *World Health Report 2008* on increasing universal access to primary health care. Dr. Andermann is currently an Associate Professor in the Department of Family Medicine at McGill University, Regional Medical Officer for Health Canada's First Nations and Inuit Health Branch (FNIHB), Public health physician for the Cree Board of Health and Social Services of James Bay Northern Quebec (CBHSSJB), Chair of the public health theme for the new undergraduate medical curriculum at McGill's Faculty of Medicine, practising physician and Chair of the Community-Oriented Primary Care (COPC) Committee at St Mary's Hospital, and founder of an international research collaboration that aims to provide guidance and support for frontline health workers so that they can play a greater role in addressing the social causes of poor health and reducing health inequities. Her main area of interest is promoting the health of vulnerable and marginalised populations, including women and child health, Aboriginal health, global health and the health of families with rare and orphan genetic diseases. In 2011, she received the Canadian Rising Stars in Global Health Award from Grand Challenges Canada. This is her first book.

Acknowledgments

I would like to thank my colleagues, friends and family members who have helped me over the years in preparing this book, from debating the merits of vertical versus horizontal approaches to reading and editing draft chapters. In particular, I would like to thank Eva and Fred Andermann, Itamar Katz, Lilah Moore and Jean-Francois Boivin for their helpful comments. As well, I am grateful to Nisha Doshi and Richard Marley at Cambridge University Press for their guidance, to Tikki Pang for kindly agreeing to write the foreword, and to Marguerite Pigeon for doing a final read-through of the completed manuscript. I am greatly indebted to Karen and Kayleigh since without high-quality child care this book would not have been possible. Finally, I would like to thank my husband, Carlos Fraenkel, who encouraged me from the start to take on this project and stood by me through to its completion.

* * *

I have written this book in memory of my late grandmother, Dr. Mina Deutsch, who instilled in me a strong sense of social justice and taught me that even seemingly insurmountable challenges can be endured and overcome. I have also written this book in memory of my late DPhil (PhD) thesis supervisor, Dr. Joan Austoker, who set me on the path of public health and evidence-informed decision-making.

People themselves must have responsibility for the development and change of the world in which they live.

Amartya Sen

If our goal is to improve health, those within the health sector must move outside classrooms, laboratories, and hospital walls to embrace a broader approach to health.

Mary Ann Mercer