

## PREFACE

Data permeate contemporary healthcare: everybody seems to be relentlessly asking for more data, of better quality, on more people. With this book, I explore the drivers for and implications of such intensified data sourcing. It has ended up as a treatise about *data paradoxes*. I think of paradoxes in the sense of opposing stories that are—each in their own way—true, although they superficially seem to preclude each other. People often use the same data to produce very different, sometimes opposing, stories about the state of affairs in healthcare. Besides paradoxical ways of telling stories *with* data, it is also possible to tell seemingly opposing stories *about* data—stories about why data are collected and how datafication affects healthcare. Although such stories appear paradoxical, they make sense when we accept that intensified data sourcing are transforming the way that we should think about data. Data are not simple pieces of information. They are ontologically multiple: parts of several coexisting networks, dynamics, and practices that simultaneously inspire and affect people in diverse ways. I invite readers to contemplate data paradoxes because I think that it can help both scholars and practitioners to use data wisely, with greater awareness of what data do and for whom.

It is impossible to study any social phenomenon without understanding it in a specific context. The stories I tell about data unfold primarily in Denmark. Why Denmark? The Danish healthcare system has one of the most advanced and integrated data infrastructures in the world. It is therefore the place to go when wanting to explore intensified data sourcing in practice. The integrated data infrastructures in that system create fantastic

research opportunities, ensure many seamless clinical interactions, and confer administrative benefits, and the data resources are increasingly seen by the medical industry as business opportunities. The Danish data infrastructures therefore inspire policymakers in healthcare systems around the world.

What is rarely spoken about, however, is that the Danish experience with integrated data infrastructures also gives rise to a number of concerns. Data integration is far from straightforward, and unintended consequences proliferate. My aim with this book, in all its simplicity, is to use the admittedly extreme Danish experience with data integration to inspire a longing for *better* use of data instead of the current global urge for just *more* use of data. The first step toward better use is to acknowledge the need to look *at* data practices, not just look *with* data at the world. The second step is to ask, “Better for whom?” and “Better according to which criteria?” and to seek answers by analyzing the diverse implications of intensified data sourcing for different people, or the same people over time. This book does just that.

The book is based on a project that has received funding from the European Research Council (ERC) under the European Union’s Horizon 2020 research and innovation program (grant agreement number 682110), as well as the Velux Foundation (grant agreement number 36336). The ERC grant allowed me to gather a group of excellent scholars to study data intensification as it unfolds in various health settings. This has provided a much more comprehensive understanding of the data politics involved than I could ever have achieved alone. I composed the ERC project so that I personally focused on the politics of integrating data infrastructures, while others engaged closely with a range of clinical practices affected by this data integration. In this way, we could combine breadth with depth and compare data intensification initiatives prompted by a range of actors, including researchers, clinicians, politicians, administrators, and people working with data for the pharmaceutical and medical device industry. We also covered initiatives among patients belonging to different age groups, literally from the newborn to the dead, and in different healthcare areas with different degrees of specialization, from municipal homecare to frontier genomic medicine.

The subprojects were carried out by an amazing group of scholars. Mette Hartlev took the lead on mapping legal controversies about data, partly in dialogue with Jens Schovsbo. With Sarah Wadmann, I studied data analysis initiatives covering general practice, hospitals, and psychiatry; and with Christoffer Bjerre Haase, I learned about the introduction of data tools in general practice.

Malene Nørskov Bødker helped me gain more knowledge about data practices in municipal home care. Through Francisca Nordfalk, I learned about data sourcing in the course of a newborn screening program. Together with Maria Olejaz, Francisca and I also explored an initiative to carry out genetic research on dissection donors. Francisca and I also looked at opt-out registries for research participation and how they work in practice. Without Francisca, I would not have experienced firsthand the thrill and dread of dealing with registry data. Anja MB Jensen shared her deep understanding of the organ transplant field and gave insight into the use of data in donation practices. With Lea Skovgaard Larsen, I have had the pleasure of studying public perceptions of data sourcing. Aaro Tupasela studied European integration initiatives and artificial intelligence (AI) projects. With Aaro, I also studied the enrollment of citizens in research through a genetic register tracking people with specific genetic variations. This research initiative involved samples from Pakistan, and Zainab Sheikh went into detail with this particular collection practice as an example of how a Danish urge for data provides opportunities and risks for people in a less affluent country like Pakistan. In its last stages, Sofie á Rogvi joined the project funded by an emergency grant from the Velux Foundation to help understand the COVID-19 pandemic as a data-political event. All this research informs this book, but the book is not a compilation of the articles we have produced. It is written as an independent argument, although I do sometimes reuse particularly telling quotes or passages from published articles.

The ERC group opened up our biweekly meetings to other colleagues who were also studying data practices ethnographically. We called ourselves the Data Group. It has made it possible to compare and contrast our ERC findings with other people's work. I have learned immensely from the discussions about data practices that unfolded in this group. Henriette Langstrup, Sara Green, Olsi Kusta, Anna Sundby, Nina Rud Rasmussen, Margit Anne Petersen, Aja Smith, John Brodersen, Rikke Torenholdt, Ivana Bogovic, Claudia Bagge-Petersen, Rosie Collington, Nikoline Nygaard, Line Egede Clausen, and Jette Holt have in various phases joined and fertilized discussions and debates. This book could not have been written had I not had the chance to learn from the Data Group. My first, deep-felt thanks therefore go to this marvelous group of scholars: the ERC project members and the wider Data Group.

Second, I wish to thank the many interlocutors in healthcare, in Denmark and beyond, who gave me their time to be interviewed and who

have enlightened me about their perceptions, practices, and priorities. I am truly grateful. Many of them have felt that it was a risk talking to an outsider about how data *really* are used, not just how they are *said* to be used. I appreciate your trust. Others have enrolled me as an interlocutor in their deliberations about new data initiatives, and I have learned a lot from these dialogues. I hope that those who have shared their hopes and concerns see them reflected in this book.

Outstanding international scholars have also joined our meetings for shorter periods, or sometimes just once, and helped us along with comments, questions, and suggestions. It has been incredibly stimulating and a true testimony to academic generosity! Among them are (listed in alphabetical order) John Burnett, Annamaria Carusi, Sarah Cunningham-Burley, Susan Erikson, Susi Geiger, Lisa Guntram, Ilpo Helén, CF Helgesson, Linda Hogle, Sonja Jerak-Zuiderent, Jane Kaye, Thomas Lemke, Jake Metcalf, Timo Minssen, Lynn Morgan, Anna Pichelstorfer, Katie Pine, Violeta Argudo Portal, Jenny Reardon, Minna Ruckenstein, Tamar Sharon, Karoliina Snell, Heta Tarkkala, Linnet Taylor, Sally Wyatt, and Teun Zuiderent-Jerak. Each visitor has been a great source of inspiration.

Sarah Cunningham-Burley and Mette Hartlev deserve special mention for their insightful advice in the early phases, when I was applying for the ERC project, and Mette for her continued help with understanding legal intricacies; Linda Hogle for encouraging me to pursue the idea of paradoxes and for being a continued source of inspiration; and Ina Willaing Tapager and Hans Okkels Birk for suggesting important case material.

I am also deeply indebted to all the people who have commented on earlier drafts—sometimes several times—and helped me articulate my arguments. The text has benefited so much from your careful readings. My colleagues at Section for Health Services Research, University of Copenhagen, commented on the introduction, and John Brodersen, Amy Clotworthy, Sara Green, Christoffer Bjerre Haase, Linda Hogle, Jette Holt, Dorthe Brogård Kristensen, Olsi Kusta, Henriette Langstrup, Steffen Loft, Francisca Nordfalk, Ezio di Nucci, Naja Hulvej Rod, Sofie á Rogvi, Zainab Sheikh, Lea Larsen Skovgaard, Sarah Wadmann, Ayo Wahlberg, Brit Ross Winthereik, and three anonymous reviewers have generously read and commented on various chapters, or even the whole book. I remain indebted to your immense generosity! I would also like thank the editor, Justin Kehoe, and series editor, Paul N. Edwards, for daring to take on board a book about data practices in a small European country.

Elements of chapters 1, 2, and 3 have previously been published in *SSS* (Hoeyer 2019), in *Economy and Society* (Hoeyer and Wadmann 2020) and a chapter in a book edited by Susi Geiger (Hoeyer and Langstrup 2021). Special thanks go to Henriette Langstrup and Sarah Wadmann for allowing me to reuse elements of our shared work, but even more for being such extraordinary companions throughout all of these years in the quest to understand intensified data sourcing. Thank you!

Every project involves administration—a type of data work that rarely inspires happy feelings. With Janne Sørensen as project administrator, however, even these tasks have been a worthwhile enterprise. A group of excellent student assistants have been transcribing interviews and taken care of all sorts of relatively dull data work: Ida Ege Biering, Rosie Collington, Line Dyhr, Emilie Funch Nielsen, Nikoline Nygaard, Sofie Amalie Olsen, Nina Rasmussen, and Sif Vange. Sofie and Nikoline have also conducted some of the interviews for chapter 6, just as I have been allowed to quote an interview conducted by Sofie á Rogvi. Thank you for your dedication to even the less inspiring tasks involved in academic work. I am also grateful for Julie Dyson's efforts to correct my English.

Thinking is a social act. This book has been nurtured by all the brilliant minds of the people mentioned here, just as it has benefited from the ideas of many other scholars who have inspired and helped me over the years. I cannot mention every one of you. While each one of you deserves part of any praise this book might receive, I am very much aware that I retain the responsibility for all errors. I am grateful for your generosity and intellectual nurture, even though you might think I should have come to other conclusions.

There is another kind of nurture that it is also paramount for me to mention—that of the love and care of my family and friends. They have had to bear with me many times as I have posed insisting questions about mundane data practices, often in the course of us doing something completely different. They have allowed me to pursue my weird curiosities—and yet also brought me back into the circles of social life from which all important values arise. One man, more than anybody else, serves as such a point of gravity in my life: my husband, Jesper. While you never cease to support me in my work, you always also know how to make me put it aside. Thank you for sharing your life with me. Thank you for being the very center of mine!

Copenhagen, January 2022



This is a section of [doi:10.7551/mitpress/14926.001.0001](https://doi.org/10.7551/mitpress/14926.001.0001)

# Data Paradoxes

## The Politics of Intensified Data Sourcing in Contemporary Healthcare

By: Klaus Hoeyer

### Citation:

*Data Paradoxes: The Politics of Intensified Data Sourcing in Contemporary Healthcare*

By: Klaus Hoeyer

DOI: 10.7551/mitpress/14926.001.0001

ISBN (electronic): 9780262374156

Publisher: The MIT Press

Published: 2023

The open access edition of this book was made possible by generous funding and support from MIT Press Direct to Open



The MIT Press

© 2023 Massachusetts Institute of Technology

This work is subject to a Creative Commons CC-BY-NC-ND license.  
Subject to such license, all rights are reserved.



The MIT Press would like to thank the anonymous peer reviewers who provided comments on drafts of this book. The generous work of academic experts is essential for establishing the authority and quality of our publications. We acknowledge with gratitude the contributions of these otherwise uncredited readers.

This book was set in Stone Serif and Stone Sans by Westchester Publishing Services.

Library of Congress Cataloging-in-Publication Data

Names: Hoeyer, Klaus, author.

Title: Data paradoxes : the politics of intensified data sourcing in contemporary healthcare / Klaus Hoeyer.

Description: Cambridge, Massachusetts : The MIT Press, [2023] |

Series: Infrastructures series | Includes bibliographical references and index.

Identifiers: LCCN 2022019995 (print) | LCCN 2022019996 (ebook) |

ISBN 9780262545419 (paperback) | ISBN 9780262374163 (epub) |

ISBN 9780262374156 (pdf)

Subjects: LCSH: Medical informatics—Denmark—Case studies. | Medicine—Denmark—Data processing—Case studies. | Medical policy—Denmark—Case studies.

Classification: LCC R858.A3 H64 2023 (print) | LCC R858.A3 (ebook) |  
DDC 610.28509489—dc23/eng/20220830

LC record available at <https://lcn.loc.gov/2022019995>

LC ebook record available at <https://lcn.loc.gov/2022019996>