Blockchain for Medical Research

Accelerating Trust in Healthcare

Sean T. Manion • Yaël Bizouati-Kennedy

CRC Press
Taylor & Francis Group
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CRC Press
Taylor & Francis Group
Boca Raton London New York

CRC Press is an imprint of the
Taylor & Francis Group, an **informa** business
A PRODUCTIVITY PRESS BOOK

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First published 2020
by Routledge
52 Vanderbilt Avenue, New York, NY 10017

and by Routledge
2 Park Square, Milton Park, Abingdon, Oxon, OX14 4RN

Routledge is an imprint of the Taylor & Francis Group, an informa business

Library of Congress Cataloging-in-Publication Data
Names: Manion, Sean T., author. | Bizouati-Kennedy, Yaël, author.
Title: Blockchain for medical research: accelerating trust in healthcare /
Sean T. Manion and Yaël Bizouati-Kennedy.
Description: Boca Raton: Taylor & Francis, 2020. |
Includes bibliographical references and index.
Identifiers: LCCN 2019053960 (print) | LCCN 2019053961 (ebook) |
ISBN 9780367347598 (hardback) | ISBN 9780367347468 (paperback) |
ISBN 9780429327735 (ebook)
Subjects: MESH: Computer Security | Healthcare Financing | Data Mining |
Electronic Health Records | Biomedical Research—economics |
Delivery of Health Care—economics
Classification: LCC RA440.85 (print) | LCC RA440.85 (ebook) | NLM W 26.5 |
DDC 362.10720285—dc23
LC record available at https://lccn.loc.gov/2019053960
LC ebook record available at https://lccn.loc.gov/2019053961

ISBN: 978-0-367-34746-8 (pbk)
ISBN: 978-0-367-34759-8 (hbk)
ISBN: 978-0-429-32773-5 (ebk)

Typeset in Garamond
by codeMantra

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Preface

What is blockchain? While many have talked or written about it, and while I've been writing on the topic for a while, the answers tend to vary—depending on where you are on the evangelists-to-skeptics spectrum. When Sean offered me the chance to work with him on this book, one of my drivers was the fact that I believe in blockchain and what it will achieve. I don't believe this technology is a magic wand which will resolve all the world's problems and cure all ills.

Rather, I believe blockchain is an accelerator, of vision, ideas and truth.

While conducting research for this book, I had the privilege of interviewing several experts from different fields—technology, science, medicine, finance, philosophy—who each shed a different light on the question: what is blockchain?

In every fascinating conversation I had (I want to thank everyone who took the time to help in this research), everyone brought a different facet or aspect to the surface.

The common thread though is that blockchain provides one single source of truth. In a world increasingly full of noise, where thoughts are constantly shared, tweeted and broadcasted, where everything and everyone is measured by "followers" and "likes," it's hard to decipher not only what is true, but what matters. It's hard to cut through the noise.

Blockchain achieves that.

The second driver for me was a personal one, and the topic of the book: how then can blockchain help the healthcare field and medical science? How can blockchain help bring faster miracles?

I lost my almost 18-year-old son to schizophrenia. From the day my beautiful boy was diagnosed (January 3, 2012) to the day he died (February 29, 2012), few weeks elapsed. And for both him and me, this was a nanosecond. There were no miracles fast enough for him. In these few weeks, while

I tried to reassure myself, hoping a cure would be found shortly, hoping a miracle treatment would erase his mental pain and he would attend college, follow his dreams and become a musician or a neuroscientist, or both, I was also faced with reality: research was not being done fast enough, communication between various doctors was not being done fast enough. Nothing was fast enough but the progression of his mental illness.

For every parent faced with a child's critical illness, time is obviously of the essence. It's the difference between life and death. And this is what blockchain can achieve: hasten everything. Because this precept of having one single source of truth, when applied to healthcare, translates—for one—in faster research. Research that is verified, shared and distributed in a more efficient way. In turn, this means faster clinical trials and faster treatments for patients. This could also help contain the opioid pandemic. It will help bring back patients at the center of medicine. And this is only one example of the many ways this technology can ameliorate healthcare. And by "ameliorating," I mean, making it more accessible, faster and to more people.

Blockchain can and will bring faster miracles.

—YBK

My mother, Thomasina, died of cancer in May of 2017. It was a sad, sometimes horrible, sometimes beautiful, but ultimately tragic end of a great life. Excellent doctors and advances in medicine gave us a little more time, some wonderful moments, a little more music and some better quality of life at the end. But the miracles weren't fast enough for more. I am not alone in this experience and cancer is not the only culprit. Our time is limited. A little more life, a little more experience, a little more achievement and a little better quality of life is the ultimate value. Money is great, but it is not enough. Steve Jobs died rich at 56, leaving humanity a little poorer, and his loved ones much poorer in their grief. In business, time may be money, but in life, money doesn't buy time.

What if we could speed up science, improve the quality of research for fewer wrong turns and wasted effort and reduce the overall cost of execution improving the return on investment of research? What if we could give more time, better quality of life and more chance of long-term reprieve to those families dealing with cancer? What if we could improve the quality of life and outcomes for the veteran with a traumatic brain injury and his spouse and three kids? What if we could extend the time a university professor with Alzheimer's could continue to teach our kids and enjoy time with

her family? What if we could cure childhood disease allowing kids to grow up, achieve their dreams and change the world?

That is the overarching goal of this book, to bring the worlds of science and blockchain together, advance medical research and improve health outcomes. It is not a deep dive into one subject, but rather a view across topics in simple language to allow experts in technology, science and medicine (along with everybody else) to understand the possibilities as exploration of this intersection gets underway in the real world. We offer cross visibility of where we are: the nascent power of this rapidly emerging technology and the complex challenges of medical research, and we unite them in a vision for the future where science is not only trusted, but also better because it is verifiable by blockchain.

—STM

Acknowledgments

I want to acknowledge some of the people who brought me into the blockchain space and guided me along the way. John Reusing of Bad Decisions/Baltimore Bitcoin fame first introduced me to the concept. Debbie Bucci and the dozens of contributors to the 2016 HHS ONC blockchain and healthcare white paper contest showed me the possibilities. Lauren Long led the first foray into blockchain for neuroscience research at Society for Neuroscience 2017. Reem El Seed introduced me to human centered design. Felicia Qashu helped me dissect research into its component parts, while building an analog trust network of research at Defense and Veterans Brain Injury Center. Loretta Polite helped me get my head around the regulatory challenges and possibilities. Heather Flannery helped me explore the blockchain for research vision and continues to pursue this shared vision on a parallel path. Samson Williams provided the much needed common sense and business perspective while reminding us that "blockchain isn't hot sauce, you can't just put that sh*t on everything." Nicole Tay was my New York City blockchain guide while providing technical and ethical perspective along the way. Natalie Marler gave me deeper publishing insights. Susan Ramonat, John Bass and Jose Arrieta shared their brilliant insights and inspired with their industry leadership. Thanks to Gilles Hilary and Georgetown University for hosting our Blockchain in Health Research conferences. Thanks also to Jacob Kean and University of Utah for facilitating the early real-world explorations of this tech for research.

These are just a handful of the hundreds of technologists, entrepreneurs, researchers, patients, providers, regulators, conference planners, attendees and everybody else that have informed my thinking and expanded the field and the possibilities for better science and faster miracles that helped make this book possible.