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Kathleen E. Carberry
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“Supporting people to live their lives to the fullest demands understanding, defining and measuring the health outcomes that matter most to individuals and their families. The book provides an excellent guide to this important journey written by one of the most practically experienced health care professionals in the field.”

Christina R Åkerman, MD, PhD, Exec. MBA
Former President of the International Consortium for Health
Outcomes Measurement (ICHOM)

“A must-read guide for anyone who is looking to start measuring and improving health outcomes. Written by one of the top experts in the field, this book offers practical advice that will help you overcome implementation challenges in different health care settings.”

Marcia Makdisse, MD, PhD, MBA, VBHC Green Belt, MSc
Academia VBHC, Brazil.

“To truly transform health care, we must understand the outcomes that matter to individuals and families and then measure those outcomes to know if we are helping. Kathleen Carberry’s *How to Measure Health Outcomes* provides a critical toolkit for anyone committed to delivering better health for each and for all.”

Alice Andrews PhD
Director of Education, Value Institute for Health and Care, The
University of Texas at Austin

“This handbook is essential for achieving high value health care. Measuring the outcomes that matter to patients enables clinicians to ensure that they achieve their purpose of helping and healing. Prof. Carberry brings deep expertise and offers specific and actionable steps for how to measure what matters to the people you serve.”

Elizabeth Teisberg, PhD
Professor, Cullen Trust Distinguished University Chair in Value-
Based Health Care, University of Texas, Austin

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“A dog-eared bookmarked version of this guide belongs in the hands of every type of clinician, health care administrator and QI enthusiast. Kathy Carberry’s decades of experience and work with the Value Institute provides an invaluable compass on the journey to creating value for patients in any health system.”

Shannon Jackson, MD FRCPC MSc(HCT),
Hematologist and Physician Lead for Value Based Health Care,
Providence Health Care, Vancouver, Canada

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How to Measure Health Outcomes

A Hands-On Guide to Getting Started

Kathleen E. Carberry

University of Texas at Austin



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Preface

This how-to guide is intended for a broad audience of people working in health care, from direct care providers (e.g., doctors, nurses, therapists) to health care administrators such as hospital executives and health insurance company employees. It is written from my perspective as someone who has helped individuals and teams in inpatient, outpatient, and health plan settings measure health outcomes. This guide focuses on practical advice for measuring outcomes in a variety of health care settings. There are other instructional resources about outcome measure development, conducting outcomes, and/or health services research. Over the years, I have watched people who want to measure outcomes get stuck because they didn't have basic information about how to get started – how to turn their aspiration of measuring outcomes into real information that they could use to improve their practice. My hope is that this guide becomes a regular reference for you as you embark on the process of measuring outcomes. This is a process and not a “one-and-done” undertaking.

I have written this guide as though I were giving advice to an individual. The tone, therefore, is conversational. The guide draws from different conversations I've had over the past 20 years about the nuts and bolts of measuring outcomes. I will share with you what I've learned from my measurement experience throughout my career – from measuring outcomes of relatively rare conditions to measuring outcomes of more prevalent ones – including the techniques that I applied in each setting, as well as strategies to scale programs within organizations. While different medical conditions and/or care processes may require specific data points, the general steps to measuring outcomes are the same. In Chapter 6, I will describe ways that health care provider organizations can enable outcome measurement for individual clinical providers.

In discussing outcome measurement, it is important to acknowledge that we are not just talking about biomedical data. Rather, this guide will teach you how to measure data in a way that tells a broader story about a person's health that includes their own perception and experience of what health means. While this guide does not focus on broad measures of public health, when thinking about measuring health outcomes it is important to keep in mind that health is largely impacted by factors outside of the health care milieu, such as where we live and what we eat.

You'll notice throughout the guide that I generally refer to patients as people. While the word “patient” reminds us of whom we serve, there are also connotations from which we should move away. One of the original meanings of patient was “one who suffers,” or “enduring without complaint,”

based on the word's Latin root, *patiens*, which implies a sense of passiveness.¹ Additionally, the word patient can imply a hierarchical and patriarchal social system that immediately puts the care provider a step above the patient as “more knowing.” In fact, *both* bring knowledge that is needed to improve the patient's health. While the care provider knows more about certain areas, such as the disease process and biology, patients know much more about how the condition affects their daily lives, what it keeps them from doing, and so on.

In the same way, using the word “member” to describe someone who is part of an insurance plan obscures a person's individual agency and contributes to a one-size-fits-all mentality. It can imply someone who incurs costs that the insurer or employer has to pay or not pay for. The word distances us from the person who needs the services to better their health and live the life that they want to live.

So, in this guide, I will refer to patients and members simply as “people” because, in fact, that is what they are: people like you and me. People whom we have the honor of caring for each and every day. People who need our help.

We are also going to consider the voices of family members and caregivers because measuring their outcomes is also critical. Poor caregiver outcomes can directly impact both patient outcomes and caregiving in and of itself by putting people at risk for higher levels of stress, depression, and anxiety.^{2,3}

And one final note, I am writing this from my experience working in the US health care system. My hope is that the nature of this how-to guide will lend itself to being adapted and applied within the health care system where you live and work, and I send you my very best wishes.

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Acknowledgments

How to Measure Health Outcomes: A Hands-On Guide to Getting Started is a reality thanks to many people who have helped me in countless ways. I was inspired to write it after reading a book about writing that my colleague, Victoria Davis, lent me. As I talked about the idea of writing this guide with my other colleagues, Amy Madore, Sarah O'Hara, and Kasey Ford, their enthusiasm and encouragement gave me the momentum to write a draft for the Measuring Outcomes That Matter course in the first year of the Master of Science in Health Care Transformation degree program. It was an ambitious goal. With their help and the support of Alice Andrews, the director of education, and Elizabeth Teisberg and Scott Wallace, the directors of the Value Institute for Health and Care, I am pleased to share this guide with you. I cannot thank Sarah O'Hara enough for being my thought partner on how best to organize this work and for asking the right questions that got me thinking more about what I needed to say, Elizabeth Teisberg for her thoughtful review of the manuscript, nor Amy Madore for her superb editing skills and ability to ask questions that stretch my thinking.

Vital to measuring outcomes is understanding what the outcomes are that matter most to people. Hence, I am thankful for the critically important work of Elizabeth Teisberg and Scott Wallace in developing the Capability, Comfort, and Calm outcome measurement framework. This framework anchors outcome measurement in the outcomes that matter most and refocuses the health care system on achieving better outcomes for the people it serves. From my clinical vantage point, this simple and elegant framework fills a void in the world of outcome measurement in health care. I am deeply grateful for their thought leadership, collegiality, and everything I have learned from them.

I am also so grateful to my colleague, Chris Ulack, who keeps me laughing; Joel Suarez, who taught me that writing is thinking; and the entire Value Institute team for being such encouragers and cheerleaders for these outcomes work.

There are several organizations mentioned in this guide that are exemplars of outcome measurement. My teammates and I at the Value Institute are grateful to them for sharing their stories and experiences with us so that they can be disseminated more broadly to drive much needed improvement in health care.

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And finally, I have to thank my family: my husband, Michael, for being my best friend and for all of the extra carpool he did and dinners he made so that I could focus on writing; my parents and sister for always believing in me; my in-laws for their encouragement; and my children, Brigitte and Daniel – thank you for your unconditional love and patience, even when there were nights I had to skip stories. I love you so much. You inspire me every day.