

PART I

Questions of Data Governance for Data from Digital Home Health Products

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INTRODUCTION

As Barbara J. Evans quotes from Daniel Solove in her chapter in this part, “[n]ot all privacy problems are the same.” Digital home health products are exciting because they use the massive amounts of data that can be generated within the home to monitor, address, and improve our health. But this powerful leveraging of data means that digital home health products raise unique privacy problems, unlike those raised by most other medical devices. Not only are these products harnessing an ocean of data about their users, but they are also uniquely drawing that data from the most sacrosanct of settings, the home. This only heightens the importance of intentional, thoughtful, comprehensive, and well-designed data governance.

The contributions in this part wrestle with questions of data governance, informed by the heightened sensitivity of recording from the home. Each chapter focuses on different questions regarding data governance. In that sense, each contribution touches on “part of the elephant.” By reading these chapters, the reader may be able to see the full elephant – in this case, the challenges and opportunities inherent in data governance for digital home health products. The answers to these questions can help articulate an overall vision of data governance for data coming out of digital home health products.

Barbara J. Evans opens this part with her chapter, “In the Medical Privacy of One’s Own Home: Four Faces of Privacy in Digital Home Health Care.” Evans’s contribution challenges the reader to deeply engage with the concept of privacy, especially as it is applied to digital home health products. She argues that digital