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Defining Data Donation After Death: Metadata, Families, Directives, Guardians and the Route to Big Consent

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This chapter explores what we actually mean by data donation after death, and what different types of data donation metadata are involved in the process. It then provides an analysis of the ethical ramifications of each of these different types of data, outlines the concepts of data advance directives and data donation guardians as one way of dealing with these issues, and considers alternative governance mechanisms. The degree of control given to the first data donors may need to be high in order to maintain trust, but over time attitudes may evolve towards everyone giving "big consent" to data donation.

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