Digital phenotyping and the (data) shadow of Alzheimer’s disease | Big Data and Society

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In this paper, we examine the practice and promises of digital phenotyping. We build on work on the ‘data self’ to focus on a medical domain in which the value and nature of knowledge and relations with data have been played out with particular persistence, that of Alzheimer’s disease research. Drawing on research with researchers and developers, we consider the intersection of hopes and concerns related to both digital tools and Alzheimer’s disease using the metaphor of the ‘data shadow’. We suggest that as a tool for engaging with the nature of the data self, the shadow is usefully able to capture both the dynamic and distorted nature of data representations, and the unease and concern associated with encounters between individuals or groups and data about them. We then consider what the data shadow ‘is’ in relation to ageing data subjects, and the nature of the representation of the individual’s cognitive state and dementia risk that is produced by digital tools. Second, we consider what the data shadow ‘does’, through researchers and practitioners’ discussions of digital phenotyping practices in the dementia field as alternately empowering, enabling and threatening.

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