

Accounting for the worth of health data: Database shareholding and its effects on data valuation and governance

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Concepts like data trusts and data cooperatives have recently attracted interest as ways for the public to control data access and use for varied purposes. Some proposals not only investigate the value creation from digital health data, but also its redistribution (Savona 2019; Birch, Chiappetta, and Artyushina 2020). This article studies LunaDNA, a platform assigning “database shares” to its “members” to give back monetary value for people uploading their data. Following a valuographic approach (Dussauge, Helgesson, and Lee 2015), the article studies LunaDNA’s legal documents, website entries, and digital interfaces to describe how LunaDNA’s designers calculate and assign database shares to its member contributions, and how the resulting database shareholding model enacts different values, social relations, and entitlements between database shareholders and the managing company. The article suggests that database shares and its associated “database ownership” may be understood as a financial instrument that engineers industrial fairness and financial liabilities to bind people in research endeavors, while placing uncertainties around data-based value creation into the future. Invoking a vague public benefit and delaying remuneration shall erase moral concerns over undue inducement while increasing the overall value shareholders may receive from their investment. While appealing to transparency, control, and reciprocity, database shareholding must be understood as a way of entangling the public in research endeavors while disentangling it from the management operations of the company or decisions as to what kinds of research are permissible on the platform in the first place.