

Understanding and Improving Human Data Relations

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Abstract

Technologies including PCs, smartphones, and cloud computing have transformed the world: In our daily lives we interact with many businesses and public services who (to reduce costs) increasingly seek to rely on data collection and processing rather than face-to-face user interactions to inform their decisions. This creates

an *imbalance of power* between those who hold data and the individuals about whom data is stored, who cannot easily see their personal data or how it is used. This *Digital Civics* PhD research explores, from an individualist perspective, the topic of ***Human Data Relations***. Through two qualitative case studies across public and private sectors, it answers the question, ‘*What relationship do people need with their personal data?*’. Case Study One focuses on *Early Help* social care: Through four workshops with supported families, social workers and staff, a deep understanding of the individual perspective on civic personal data use is established. *Shared data interaction* is explored as a means to shift the balance of power towards the individual while maintaining an effective care relationship. Case Study Two is a three-month study exploring 10 participants’ experience of using *GDPR data access rights* to view their own data, resulting in insights into individual needs and the challenges of data-centric service relationships, and recommendations for improvement of policies and practices. With reference to literature from the fields of *Personal Information Management*, *Human Data Interaction* and *MyData* personal data ecosystems, these case studies contribute to a unified understanding of *six core needs* that people have in Human Data Relations. In the final chapter, the thesis discusses the *practical pursuit* of these goals, drawing on first-hand knowledge acquired from expert participation in industrial research projects at BBC R&D and Hestia.ai/Sitra, *mapping out the landscape for future research and innovation*.

Dedication

For my children Rosie, Joey, and Zach; my nephew Elliott; and my nieces Amy and Lyla. My wish is that that you and your generation might soon experience a future where technology can truly help people and empower them to thrive, and where personal data drives human flourishing more than corporate profit. I hope that this research can in some small way contribute to a better future for you all.

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No-one really knows how hard a PhD is until they are already well beyond the point of no return. It is demanding, challenging and often thankless and lonely work. You spend countless hours striving to find meaning among masses of data or iterating endlessly to concisely express complex, nebulous and elusive ideas. This endeavour is made even harder when you are a mature student with financial and parental responsibilities. At times, especially during the final unfunded writing-up period, the impacts upon my life and those around me have been huge and unreasonable. For this reason, the greatest thanks of all go to my wife Joni Bowyer, who has stood by me throughout, picking up the slack again and again where I could not. She has endured the impacts of money, time, uncertainty and divided attention that this unforgiving work has thrust upon our family. She has also provided practical help on countless occasions

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