

# Understanding and Improving Human Data Relations

Alex Bowyer

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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 a pragmatic, individualist, constructivist 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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## **Bibliography**

Bowyer, A. *et al.* (2022) 'Human-GDPR interaction : Practical experiences of accessing personal data', *CHI '22*.

Marshall, M. (2020) 'Markdown thesis'. Available at: <https://gitlab.com/mrshll1001/markdown-thesis>.