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 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.