

Understanding and Improving Human Data Relations

Alex Bowyer

Contents

Frontmatter	1
Abstract	1
Acknowledgements	2
Lists of Tables and Figures	2
Lists of Tables by Chapter	2
Tables in Chapter 3	2
Tables in Chapter 4	2
Tables in Chapter 5	3
Tables in Chapter 7	3
Lists of Figures by Chapter	3
Figures in Chapter 1	3
Figures in Chapter 2	3
Figures in Chapter 3	3
Figures in Chapter 4	4
Figures in Chapter 5	4
Figures in Chapter 7	4
Figures in Appendix C	5
Figures in Appendix F	5
Bibliography	6

Frontmatter

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, 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*.

Acknowledgements

Lists of Tables and Figures

Lists of Tables by Chapter

Tables in Chapter 3

- **Table 3.1** - Context One (Civic Data & Early Help): Participants involved in Research Activities leading into Case Study One.
- **Table 3.2** - Context Two (Digital Life): Participants Involved in Digital Life Research Activities Leading into Case Study Two.

Tables in Chapter 4

- **Table 4.1** - Example Categories of Family Civic Data
- **Table 4.2** - Case Study One Group Design Workshops
- **Table 4.3** - Theme 1 - Meaningful Data Interaction for Families: Sub-themes & Participant Quotes
- **Table 4.4** - Theme 2 - Giving a Voice to the Family: Subthemes & Participant Quotes
- **Table 4.5** - Theme 3 - Earning Families’ Trust Through Transparency: Subthemes & Participant Quotes

Tables in Chapter 5

- **Table 5.1** - Types of Data Holding Organisation Targeted for GDPR Requests by Study Participants
- **Table 5.2** - Types of Personal Data Potentially Accessible from Data Holders via GDPR Rights
- **Table 5.3** - Presence and Quality Assessments of GDPR Responses by Data Type (as Percentages)
- **Table 5.4** - Best and Worst Data Holders in Different Categories, According to Participants' Judgements
- **Table 5.5** - Participants' Hopes, Imagined Data Uses and Goals for GDPR, as well as Resultant Outcomes
- **Table 5.6** - Theme 1 - Insufficient Transparency: Subthemes & Participant Quotes
- **Table 5.7** - Theme 2 - Confusing & Unusable Data: Subthemes & Participant Quotes
- **Table 5.8** - Theme 3 - Fragile Relationships: Subthemes & Participant Quotes

Tables in Chapter 7

- **Table 7.1** - Eight Lenses on Personal Data

Lists of Figures by Chapter

Figures in Chapter 1

- **Figure 1.1** - Poster Presentation of Case Study One
- **Figure 1.2** - The Structure of This Thesis

Figures in Chapter 2

- **Figure 2.1** - The Wisdom Curve: Making Data into Meaningful Information
- **Figure 2.2** - Li *et al.*'s Stage-based Model of Personal Informatics Systems

Figures in Chapter 3

- **Figure 3.1** - My Action Research Approach
- **Figure 3.2** - "Family Facts" – What is Data?
- **Figure 3.3** - Walls of Data – Sensitising Participants to the World of Commercially-held Data and GDPR
- **Figure 3.4** - Sentence Ranking – Bringing Support Workers and Families to a Shared Problem Space
- **Figure 3.5** - Family Civic Data Cards – Things to Think With
- **Figure 3.6** - Personal Data Examples – Making Data Relatable
- **Figure 3.7** - Home Interviewing: Card Sorting With a Family in Their Living Room

- **Figure 3.8** - Ideation Decks – Combining Random Design Ingredients to Generate New Ideas
- **Figure 3.9** - Group Poster Design – A Participant-designed Poster to Advertise Features of Imagined Data Interface Products
- **Figure 3.10** - Storyboarding Cards – A Collaboratively-constructed Narrative Created through Discussion From a Palette of Possible Parent and Staff Actions
- **Figure 3.11** - Thematic Analysis of Qualitative Data using Quirkos for Case Study One
- **Figure 3.12** - Spreadsheet-based Quantitative Analysis of Interview Data for Case Study Two
- **Figure 3.13** - Pilot Study Recruitment Poster
- **Figure 3.14** - How the Case Studies and Peripheral Activities Contribute to This Thesis

Figures in Chapter 4

- **Figure 4.1** - Participants' Shared Values Deduced from Sentence Rankings Data
- **Figure 4.2** - Current Model of Data Interaction, and Proposed Model of Shared Data Interaction

Figures in Chapter 5

- **Figure 5.1** - A Journey Map of Each Participant's Study Progression
- **Figure 5.2** - An Example Life Sketch from Interview 1, with Data Handling Companies in Red, Data Types in Blue, and Feelings in Green
- **Figure 5.3** - Sankey Overview of Participants' GDPR Requests
- **Figure 5.4** - Longitudinal Distribution of Net Changes in Participants' Perceived Power and Trust Scores
- **Figure 5.5** - Perceived Power Balance Between Individual and Data Holder at Different Stages of the GDPR/Study Process
- **Figure 5.6** - Participants' Perceived Trust in Provider at Different Stages of the GDPR/Study Process

Figures in Chapter 7

- **Figure 7.1** - The Two Motivations for HDR: Controlling Your Personal Data Ecosystem and Utilising Your Information About Your Life
- **Figure 7.2** - Mapping the Six Wants into Objectives for the HDR Opportunity Landscape
- **Figure 7.3** - Obstacles and Resulting Insights in the HDR Opportunity Landscape
- **Figure 7.4** - Life Concept Modelling
- **Figure 7.5** - Mockup of a Unified TV Viewing History Interface
- **Figure 7.6** - SubsCrab: An Example Application for Ecosystem Detection and Visualisation

- **Figure 7.7** - Some of the Many Aspects of Metadata that Might Exist About a Datapoint or Dataset
- **Figure 7.8** - The Panopticon Structure of the Illinois State Penitentiary
- **Figure 7.9** - Human Values, as Identified in BBC R&D Research Funded by Nesta
- **Figure 7.10** - A Contact-and-Calendar-centric PDS Approach
- **Figure 7.11** - The Scattered Data Relating to a Vacation
- **Figure 7.12** - Mockup of a Unified Interface for a Vacation
- **Figure 7.13** - Annotating Data with Semantic Context
- **Figure 7.14** - Theory of Change [ToC]: The Four Dimensions of Change
- **Figure 7.15** - HDR Approach 1: Discovery-Driven Activism
- **Figure 7.16** - HDR Approach 2: Building the Human-centric Future
- **Figure 7.17** - Conceptual Model for a Personal Data Store System
- **Figure 7.18** - High Level Data Types
- **Figure 7.19** - Life Information Modelled as Happenings
- **Figure 7.20** - A Simple PDS Life Information Presentation Model
- **Figure 7.21** - Mockup of Life Information Presented in a PDS Interface
- **Figure 7.22** - Life Partitioning Analogy using a Cluedo™ board
- **Figure 7.23** - Mockup: Browsing By Areas of Life
- **Figure 7.24** - Identifying Entity Associations in Data
- **Figure 7.25** - Facebook's World2vec Model, Semantically Modelling Human Information from Social Media Posts on Facebook
- **Figure 7.26** - Identifying the Attributes of Data
- **Figure 7.27** - Determining The Nature of a Piece of Data
- **Figure 7.28** - Attributes of Data
- **Figure 7.29** - Actions One Might Perform on Life Information
- **Figure 7.30** - Questions One Might Ask of Life Information
- **Figure 7.31** - Example Taxonomies For Life Information Navigation
- **Figure 7.32** - HDR Approach 3: Defending User Autonomy and Hacking the Information Landscape
- **Figure 7.33** - The Modern 'Black Box' View of Technology
- **Figure 7.34** - HDR Approach 4: Winning Hearts and Minds: Teaching, Championing and Selling the Vision
- **Figure 7.35** - SILVER Health Data Viewing Interface
- **Figure 7.36** - Summary of Generalised Change Strategies for Pursuing Better HDR, Using the ToC Model

Figures in Appendix C

- **Figure C.1** - Screenshot From Quirkos During Coding Process
- **Figure C.2** - Screenshot From Quirkos at End of Coding Process
- **Figure C.3** - Screenshot From Workflow During Theme Construction

Figures in Appendix F

- **Figure F.1** - Private Data Viewing Monitor with Viewing Glasses

Bibliography