Understanding and Improving Human Data Relations

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1 Conclusion

"What drives and drags the world are not machines, but ideas." – Victor Hugo

In this chapter, I will reflect on my journey as a researcher, activist and innovator through this work, and contextualise the contributions of the thesis in terms of their legacy and future value.

1.1 Personal Reflection

[TODO write personal reflection using material from C1 plus new]

1.2 Legacy of This Thesis to The Future of Human Data Relations

This thesis offers a detailed understanding of individual needs around data interaction and data-centric service relationships [Chapter 6], backed by empirical participatory action research in both public sector and private sector Case Studies [Chapter 4; Chapter 5], providing a clear answer to the two primary research questions RQ1 and RQ2: People want visible, understandable and useable15 data, process transparency, individual oversight capabilities and involvement in decision-making.

Furthermore, based on a solid grounding in existing literature, policy and innovation around Data Access, Personal Information Management, Human

Data Interaction and Human-centric Innovation [Chapter 2], these needs are synthesised into a clearly-defined new field for future research and innovation, *Human Data Relations (HDR)* [7.2], encompassing four clear objectives for improving individual agency and societal power imbalances around data: (i) data awareness & understanding, (ii) data useability15, (iii) ecosystem awareness & understanding, and (iv) ecosystem negotiability.

With the inclusion of Chapter 7], the thesis goes much further than a traditional HCI PhD, drawing on the author's experiences with the practical pusuit of better Human Data Relations in four different real-world academic and industrial project settings [7.1.1]. This allows for additional insights, designs and implementation strategies that enable the thesis to offer more than just a theoretical contribution, but clear and actionable insights that could be immediately explored by researchers and innovators - an anthology of reference material, designs and strategies. This practical contribution of the thesis is delivered in four distinct parts:

- first, a map of the landscape for improving HDR [7.2.4], outlining the key obstacles that are likely be faced in pursuing HDR objectives [7.3], including illegible, immobile, scattered and unmalleable data; a complex ecosystem lacking metadata; exploitations of power by data holders, introspective practices, insufficient machine understanding of human information, and gaps in interoperability, investiment and demand;
- second, four detailed approaches for making progress in the pursuit of better HDR, illustrated with reference to real-world projects situated in the HDR space: (i) discovery-driven activism (ii) life interface design, (iii) protection of, and progressive action within, the information landscape and (iv) motivational efforts to make better HDR viable, investable and well-understood across society [7.4];
- third, through a series of specific insights that can aid the pursuit of better HDR, including conceptualisations around life information and ecosystem information, deep understandings of the ways in which service providers exert power over the data economy and at the seams of their products; practical trajectories for change including entity identification, individual and collective data activism; and methods for acquiring additional metadata, provenance and context so that systems can better understand and represent human information [7.3 and 7.4]; and
- fourth, an HDR glossary, located in the appendices, explaining key terms
 and making the findings, insights, obstacles, approaches and opportunities
 of this thesis, as well as the references to the relevant ideas and work of
 others where mentioned, easy to locate.

Through its Case Studies, this thesis has made additional contributions are made to the fields of Early Help and GDPR Data Access, as detailed in [1.2.3] and [1.2.4]. Nine publications, workshops and presentations of the work in this thesis have been delivered [1.3], and the research has contributed value to real-world industrial projects at BBC R&D in the UK, Hestia.ai in Switzerland and their

client Sitra in Finland.

Through the grounded practical references and examples provided and extensively detailed throughout Chapter 7, this work moves beyond simply conducting research to understand human personal data needs, and sets the scene for an progressive and activist agenda to realise those needs. It constitutes a call to arms for future research, innovation and activism in Human Data Relations, combined with a detailed guide to understand the data economy landscape, what needs to change, and an arsenal of design and implementation strategies for how that might be done by HDR reformers as they fulfil their role as a recursive public [7.2.5]. Armed with these insights, future HDR reformers can drive us towards a better future to deliver increased agency for individuals, greater data use capabilities, and a more balanced landscape around the use of personal data by service providers.

Bibliography