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

Section 6.3 concluded the academic inquiry part of the thesis with a clear answer to what sort of relationship people need with their personal data in order to be empowered - they need visible, understandable and useable data, as well as process transparency, individual oversight and decision-making involvement.

Section 7.5 summarised the outlook on improving Human Data Relations, through four approaches or trajectories for producing change in the HDR landscape - discovery-driven activism, building human-centric life interfaces, defending and exploiting the seams of the information landscape, and championing and teaching the HDR vision.

In this brief concluding chapter, I will bring the two parts of the thesis together, reflecting on my journey as a researcher, activist and innovator through this work, and contextualising the contributions of the thesis in terms of their legacy and future value.

1.1 Personal Reflection

As an experienced software engineer, power user and technology blogger, who had considered the loss of digital agency for many years [1.1.1], my journey into this research space was an unusual one; I arrived with **already-formed ideas** about the nature of the problem. This was not an ideal match for

the traditionally participant-led approach of HCI, where ideas and insights normally arise solely from one's participants. However, through the discipline of the Digital Civics programme and the experience of publishing peer-reviewed papers I successfully found ways to explore the research questions objectively. Recognising that HDR issues would be unlikely to surface organically, I was able to use careful sensitisation [3.5.1], balanced and open questioning and neutrally-designed stimuli [3.5.2] in a way that elevated **participant experience to be the primary source of data**, to produce findings and discursive conclusions that are as much the participants as my own.

Along the way I discovered **vital areas of literature and existing work,** most notably the foundational work of Weiser, Abowd, Crabtree and others [2.3.1; 2.3.3], the sub-discipline of Human Data Interaction [2.3.2] and the emergent innovation around Personal Data Ecosystems [2.3.4]. Collectively, I now knew where to position my existing and newly discovered understandings into the existing research landscape.

As my understandings of Human Data Relations informed by the Case Studies coalesced into a clear, cross-validated understanding of what people want and need from data and from data holders [Chapter 6], this gave me the confidence to **grow and evolve as a researcher**; moving from investigatory or theoretical research to more **practical, activist work** on how to begin to work towards delivering these new capabilities in practice, enabled by the models and ideas I was developing throughout the research.

I was especially lucky to be able to find peripheral activities, especially with the BBC and Hestia.ai, that fitted so well alongside my research agenda. These activities slotted perfectly into the existing action research cycle [3.2.2; Figure 3.14)(#figure-3.14)] of my thesis, producing **a powerful feedback loop** where findings from the academic inquiry became immediately applicable in practical settings, while experiences of the real-life barriers to pursuit of the HDR goals helped to challenge and evolve the theoretical models, such as Shared Data Interaction, emerging from the Case Studies.

This dual research-and-practice approach has allowed me to push this thesis further than a traditional HCI study would allow, and underpins the two-part structure of this thesis, where in Chapter 7 I leave behind the traditional researcher-as-observer stance and step forward into **taking an active role as an expert** in user-centred design (UCD) 3.2.1 and practical software interface and process design and innovation.

It has been a tremendous privilege to spend six years understanding in great detail the nature of the problems facing our data-centric society, to map those impacts into to tangible needs, and to be able to map out the landscape for improving the way we relate to data. As well as allowing me to find rich evidence to quantify and qualify the losses of agency I had observed, in a far greater level of detail than has been discovered previously, this programme has given me space to experiment with using using both GDPR and web-scraping to access

data and push boundaries, to really **embrace my role as an HDR activist** and adversarial designer [3.2.1]. It has allowed me design and prototype new models and views of data and of information which have **transformed the way I look at digital information** and how we relate to it - most notably the five types of data [Table 5.2], the two purposes of HDR [Figure 7.1], and the understandings of how to effect change in the HDR landscape [Figures 7.3, 7.15, 7.16, 7.32, and 7.34]. which I hope can help others in the same way.

The **collaborative opportunities of this PhD** have been significant. Without this thesis I would never have had the opportunities to discuss and develop models for personal data interaction and improved ecosystem negotiability with experts at the BBC, Hestia and the wider MyData community. Alongside these formal collaborations, I have also disseminated ideas through blogs, tweets, workshop papers and lectures, which has helped to refine and clarify ideas but also to stimulate valuable discussions with interested people to gain feedback that helps develop the models further.

This opportunity has opened doors that allow me to dedicate my future career to **putting these learnings into action**, working on important projects [7.1.1] to explore how data interaction reforms can be realised in practice, and how we can become not just innovators but social data activists. I now **know how to begin to have an impact** and to work on building that better HDR future I and my participants have imagined. It is the journey of a lifetime, and also one that is in many ways just beginning. I hope that my work and this thesis can, in some small way, contribute to a better, more human-centric digital world, and I can't wait to see where this leads.

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 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 useable**13 **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 useability13, (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 [7.1.2]. 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 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 already 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 and reconfigure society to one where those human-centric needs are better met. 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