# Understanding and Improving Human Data Relations

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## Contents



# 1 Thesis Conclusion

> *"Our research should transform, not just inform, society."* —Kingsley ofosu-Ampong, Researcher & Lecturer in Digital Transformation

Section 6.3 concluded Part One's academic enquiry with a clear answer to the question [2.4] of what relationship people want with their personal data in order to be empowered. They want:

- visible, understandable and useable data, as well as
- process transparency, individual oversight and involvement in decision making.

Section 9.6 concluded Part Two's exploratory design work by summarising the outlook for improving Human Data Relations, through four strategic 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], 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* and *MyData* [2.3.4]. Collectively through these discoveries, I solidified my existing understandings and was able to contextualise my evolving learning against the established research landscape.

As my understanding from the Case Studies coalesced into a clear, cross-validated understanding of what people want 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 developed. This ultimately gave me the confidence to recognise that, in this body of work, I have identified something newly emergent, that deserved to be named, scoped, and explored—**the field of Human Data Relations**.

I was especially lucky 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 action research cycle [3.2.2; 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 Part Two 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 translate those impacts into tangible needs, and to be able to map out the landscape and possibilities for improving the way we relate to data. Through this research, I have discovered rich evidence to quantify and qualify the losses of agency I had observed, in a far greater level of detail than existing research. The programme has also given me space to experiment with 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; Figure ARI7.1]. 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, in particular:

- the five types of held data [Table 5.2],
- the two purposes of HDR [Figure 7.1], and
- the approaches to effecting change in the HDR landscape [Figures 9.1, 9.2, 9.19, and 9.21].

I hope these models, as well as the other contributions 1.2, can help others to develop their thinking in the same way, to become HDR-literate and contribute to the crusade for HDR reform that the world so desperately needs.

The collaborative opportunities have been significant. Without this PhD, 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.ai and the wider *MyData* community. Alongside these formal collaborations, I have 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 helped develop the models and my own learning further.

This opportunity has opened doors that have allowed me to pivot my career towards putting these learnings into action, working on important projects [7.2] 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, how 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 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 [3.3.1] and RQ2 [3.3.2]: People want visible, understandable and useable10 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)* [7.3], encompassing four clear objectives [Chapter 8] for improving individual agency and societal power imbalances around data:

(i) data awareness & understanding,
(ii) data useability10,
(iii) data ecosystem awareness & understanding, and
(iv) data ecosystem negotiability.

The inclusion of Chapters 7, 8 and 9 took the thesis much further than a traditional HCI PhD, drawing on the author's experiences with the practical pursuit of better Human Data Relations in four different real-world academic and industrial project settings [7.2]. Through additional insights, designs and implementation strategies [Chapter 9], the thesis offers not just a theoretical frame for this area of research, but clear and actionable insights that could be immediately explored by researchers and innovators - **an anthology of reference material, designs and strategies for HDR reform**. This practical contribution of the thesis is delivered in four distinct parts:

- first, a **map of the landscape for improving HDR** [7.7], outlining the key **obstacles** that are likely be faced in pursuing HDR objectives [Chapter 8], 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, investment 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 [Chapter 9];
- 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 [Insights]; and
- fourth, **an HDR index**, located after the Appendices, making the novel findings, insights, obstacles, approaches and strategies of this thesis easy

to locate, accompanied by a glossary explaining existing terms and nomenclature this thesis makes use of.

Through its Case Studies, this thesis has made additional contributions to the fields of Early Help and GDPR Data Access, 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 this body of 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 and detailed references and examples in Part Two, this work moves beyond conducting research to understand human personal data wants, and **sets the scene for an progressive and activist agenda** to take action in service of those wants, with the objective to 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 HDR reformers might fulfil their role as a recursive public [7.8]. Armed with these insights, practitioners of this new field of HDR 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 across society—in short, a better world for us all.

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# Bibliography