Understanding and Designing Human Data Relations

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# 1 Introduction

[Target 4,000 words]

## 1.1 Motivation & Problem

[Target 1,000 words]

## 1.2 Prior Work / Theoretical Frame

[Target 1,000 words]

## 1.3 The Research Question & My Approach

[Target 1,000 words]

*What role should people’s data play in their lives, and what capabilities do they need?*

Sub-questions:

* RQ1: How do people understand and relate to data?
* RQ2: What role do people have in the world of data?
* RQ3: What role does does play in people’s lives
* RQ4: What would an ideal world of humans and data look like?
* RQ5: What are the barriers and opportunities toward this ideal?

## 1.4 Contribution

[Target 500 words]

## 1.5 Thesis Structure

[Target 500 words]

## 1.6 Notes

# 2 Literature Review

## 2.1 Data-Centrism

### 2.1.1 What is Data?

Data is an oft-used word that carries multiple meanings. In everyday speech, it might refer to mobile phone bandwidth, a filled application form or a collection of files. Even experts have a variety of definitions of data, as well as the related concepts of information and knowledge(Zim, [2015](#ref-zim2015)). In this study, we refer to data by its accepted definition as information or knowledge stored in a form suitable for computer processing. Wellisch expressed this as ‘the representation of concepts or other entities, fixed in or on a medium in a form suitable for communication, interpretation, or processing by human beings or by automated systems’(Wellisch, [1996](#ref-wellisch1996)), which is a useful definition as it includes the fact that both humans and algorithms can use data, and that data is something that needs interpretation.

From a strict grammatical stance, ‘data’ is a plural of the singular ‘datum’ thus it is more correct to write ‘the data are correct’ - but this usage is rapidly declining from use(‘Data’, [n.d.](#ref-grammaristData)) and throughout this thesis I use the more widely adopted usage of treating data as a singular mass noun, as in ‘the data is correct’.

The concepts of ‘data’ and ‘information’ are closely related, so much so that they are often used interchangeably. Ackoff presented a model for distinguishing data, information, knowledge, understanding/intelligence and wisdom, in which he describes data as the physical symbols, effectively the 1’s and 0’s stored in a computer or the ink marks on a page, which becomes useful when humans or algorithms are able to deduce facts from those symbols to answer simple questions - at this point it becomes ‘information’. Being able to interpret deeper how and why questions allow information to become knowledge and understanding, towards the ultimate goal of wisdom(Ackoff, [1989](#ref-ackoff1989)). This is often represented as the DIKW pyramid (DIKW being shorthand for the data-information-knowledge-wisdom transformation that occurs as you move up through the layers), the origin of which is unknown(Wallace, [2007](#ref-wallace2007)). Figure 1 builds upon a representation by George Pór(Pór, [1997](#ref-por1997)) of the pyramid as a ‘wisdom curve’, showing how increasing meaning and value can be obtained from data as deeper questions can be asked of it. This theme of obtaining meaning and value from data is an important aspect of my research that I will refer back to.



REDRAW Figure 1: Making Data into Meaningful Information

This model that turning data into information can be thought of as using that data to answer questions is consistent with the idea that “information can be thought of as the resolution of uncertainty”(‘Information’, [n.d.](#ref-wikipediaInformation)). The exact origin of this definition is unknown but it is often attributed to mathematician Claude Shannon(Shannon, [1948](#ref-shannon1948)). Indeed from an etymological stance, one who is informed is one who has received knowledge or concepts as a result of what has been communicated to them. Thus we can consider that data is the material from which that information can be received. It follows also that data contains uncertainty that must be resolved in order for it to become meaningful information.

### 2.1.2 The Rise of Data-centrism

The earliest computer systems used data to store mathemical and scientific facts. Data processing allowed for previously manual operations to be performed with greater speed and accuracy, most famously the work of Alan Turing and the case of the Enigma code breakers during World War II(Hutton, [2012](#ref-hutton2012)). This work was the advent of general-purpose computing - machines that could be applied to any problem provided you could reduce that problem to data. Businesses over the following decades began to apply computers to myriad new problem areas in all different fields of work and life, and doing so began the encoding of information about people as data, be it for statistical purposes like censuses or research, or simply to enable the more efficient serving of customers by storing databases of customer records.

The personal computer revolution(‘The personal computer revolution’, [n.d.](#ref-britannicaPCrevolution)) of the late 1970s and 1980s put computers in every office and eventually every home too, and it soon became commonplace that each individual would have data stored about them in companies’ databases. In the subsequent years three factors have combined to accelerate this trend of storing data about people: i) labour costs have remained high and companies have sought ways to automate their businesses and to implement online services and call centres in place of in-person staff interaction, ii) computer processing and storage has become ever cheaper thanks to the advent of cloud computing, meaning that many business processes could be reduced to data processing tasks or entire businesses be moved online, and iii) the rise of smartphones and web-enabled devices have meant that the public are now ready and willing to conduct much of their daily business online through the web and apps. These factors have encouraged both commercial and civic providers to centralise their services and to ‘go digital’ to the greatest degree possible. In doing so they collect ever more data about people (now ‘service users’ or just ‘users’). Data is now seen as a resource which can be mined for value, and harnessed for profit and business efficiency - ‘the new oil’(Toonders, [2014](#ref-toonders2014)). Zuboff, in her 2019 book on ‘surveillance capitalism’, characterises this new digital world as the collection of human behaviour data so that it can be used as free raw material and converted into profit through hyper-personalised advertising and targeting by software platforms(Zuboff, [2019](#ref-zuboff2019)). This philosophy is also known as ‘data-ism’(Brooks, [2013](#ref-brooks2013)).

As a result of data-ism, the collection of data about people has become an inevitable part of modern life. We live ‘digital lives’(‘Our digital lives’, [2018](#ref-ted2018)) where we each interact directly and indirectly with hundreds of digital systems every day - as you shop, socialise, or browse online; as you listen to music or watch TV; as you interact with governments or healthcare services; as you travel, and many more. Every one of those interactions indicates the presence of data about you stored in a company database. Every aspect of our lives involves the input, processing and output of data – either provided by, collected from, or generated about, us. And the digital data we create and consume (whether consciously or not - data sharing is often unwitting(Crabtree & Tolmie, [2018](#ref-tolmie2018))) has a direct influence on our lived experience - from decisions about what we are entitled to and what opportunities we will be offered, to the advertisements and content recommendations we are shown while we browse.

Unfortunately, the large-scale systems which collect data about us now function as ‘data traps’(Abiteboul et al., [2015](#ref-abiteboul2015)) - where data about us is easily gathered but very hard to remove or even to access. This creates a lack of agency for the individuals living in this data-centric world. The World Economic Forum’s “Rethinking Personal Data” project recognised the critical role that data - specifically personal data - data created by and about people - now holds, and identified that ‘an asymmetry of power exists today […] created by an imbalance in the amount of information about individuals held by industry and governments, and the lack of knowledge and ability of the same individuals to control the use of that information’(World Economic Forum, [2011](#ref-WEF2011), [2013](#ref-WEF2013), [2014b](#ref-WEF2014context), [2014a](#ref-WEF2014lens)).

### 2.1.3 Data Protection & GDPR

Since as early as 1973, the need to protect individuals’ rights over their data has been recognised(US Department of Health Education and Welfare, [1973](#ref-USDOHEW1973)). The 37-nation organisation OECD in 1980 stated that “the right of individuals to access and challenge personal data is […] the most important privacy protection safeguard” and issued recommendations that individuals should be given basic privacy rights, including the right to be informed whether data is stored about them, and the right to an intelligible copy of that data(Organisation for Economic Co-operation and Development, [1980](#ref-OECD1980)).

Over the subsequent decades, lawmakers began to enact laws to deliver these rights to individuals, notably the UK’s Data Protection Act 1984 (which set up an independent body, the Data Protection Registrar (now the Information Commissioner’s Office) with which organisations were required to register their usage of personal data), Ireland’s Data Protection Act 1988 (which introduced the concept of a ‘duty of care’ for data collectors - that they are expected to avoid causing damage or distress to data subjects), the EU’s Data Protection Directive in 1995 and the UK’s Data Protection Act in 1998. However, such laws were generally found to be ineffective - in 2002 Simon Davies, director of Privacy International said that the UK’s DPA was “almost useless in limiting the growth of surveillance”(Millar, [2002](#ref-millar2002)).

It was only in 2018, when the EU’s General Data Protection Regulation came into force, carrying with it significant designed-to-hurt fines for non-compliance, that individuals have been able to practically exercise their data rights to any meaningful degree. The GDPR can be seen as the first serious attempt to rebalance the aforementioned power imbalance between citizens and organisations that the World Economic Forum identified and is generally regarded as a landmark piece of legislation and a strong template for individual data protection. Around the world, companies have overhauled their privacy policies and updated their business practices to comply with the GDPR and other similar legislation, such as Japan’s 2017 Act on the Protection of Personal Information, India’s 2019 Personal Data Protection Bill and the 2020 California Consumer Protection Act. In the USA, there has been no national privacy law yet, but ‘the GDPR’s protections can be found - albeit in weaker, less prescriptive forms - in U.S. privacy laws and in Federal Trade Commission settlements with companies’(Hoofnagle et al., [2019](#ref-hoofnagle2019)).

Also in 2018, the Cambridge Analytica scandal(‘Facebook–cambridge analytica data scandal’, [2014](#ref-wikipedia2018cambAna)) broke - the personal data of 87 million people, acquired from Facebook, was exploited with the apparent intent of influencing voting outcomes including the UK’s 2016 Brexit referendum and the USA’s 2017 election of Donald Trump. This combined with widespread public information campaigns about GDPR have led to a widespread awareness of personal data rights(European Union Agency for Fundamental Rights, [2020](#ref-EUAFR2020)) and at the time of writing in 2021, personal data protection laws and individual digital rights remain a rapidly evolving area.

From the GDPR and its antecedents, a number of key terms have been established which I will adopt in this thesis, specifically (Information Commissioner’s Office, [2014](#ref-ico2014); The European Parliament and the Council of the European Union, [2016](#ref-GDPR2016)):

* *Personal data* means any information relating to an identifiable natural person - one who can be identified directly or indirectly by reference to an identifier such as a name, identification number or location or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that person.
* The *data subject* is the identified individual, living or deceased, who the personal data relates to.
* A *data controller* is the legal entity (company, public authority, agency, individual or other body) which collects or stores personal data about an individual and determines the means and purposes for which it is processed. Legal liability for data protection compliance rests with the data controller.
* A *data processor* is a legal entity which processes personal data on behalf of the data controller. In this context processing refers to the technical aspects of data such as storage and retrieval. Interpretation or decision making in relation to personal data must be done by the data controller.

### 2.1.4 The Fight for Effective Data Access

[Target 400 words]

### 2.1.5 Research Gap: The Human Experience of Data

[Target 400 words]

## 2.2 Personal Data Interaction

[Target 2,500 words]

### 2.2.1 Computers as General Purpose Information Tools

[Target 300 words]

### 2.2.2 Personal Information Management

[Target 600 words]

### 2.2.3 Personal Informatics & The Quantified Self

[Target 650 words]

### 2.2.4 The Emergence of Complex Digital Lives

[Target 600 words]

### 2.2.5 Research Gap: The Data Beyond The Individual

[Target 350 words]

## 2.3 Human-Centric Computing

[Target 2,500 words]

### 2.3.1 Human Computer Interaction Foundations

[Target 400 words]

### 2.3.2 Data Transcendence & Human Data Interaction

[Target 600 words]

### 2.3.3 People In Context: Human-Centred Design

[Target 600 words]

### 2.3.4 The Personal Data Economy

[Target 600 words]

### 2.3.5 Defining the Research Agenda for Human-Centricity in Practice

[Target 350 words]

## 2.4 Research Gap

[Target 500 words]

# 3 Approach & Methods

[Target X words]

* this PhD comprises a number of studies conducted between 2016 and 2021.
* there are three strands of enquiry:

## 3.1 1. The Human Perspective on Data Centricism

The objective of this part of the research is to fain a rich understanding of what data IS to people as they live their lives in the modern world.

Epistemiology:

* Here and throughout this thesis, we take a subjectivist perspective, looking more at what people think than trying to discover a single objective truth.
* As Peirce’s pragmatic maxim says, the meaning of anything in the world is understood through the conception of its practical effects, and theories that are more successful at controlling and predicting our world can be considered closer to the truth.
* We take an inductive research approach, finding patterns and forming theories to explain them

Therefore the key approach to this research objective is to be able to meaningfully engage with people about the subject of data, and conduct considered conversations to uncover their points of view.

(insert concentric circles diagram: Your Life > Your Data > )

Using a general approach of leading people into the subject of data using meaningful representations or starting with things that they already know (the devices, software and companies in their own life) I found effective ways to engage with participants and then get them talking about their data.

The interviews I conducted were divided into two strands: - exploring families’ data in a civic context, as it might be used in the provision of care or other state Services - exploring individual ‘digital life’ - the data that participants hold, use, or live with (or is held about them) by the companies they interact with.

(do these need little subsections as in 2 below?)

in the former case, I modelled data types and produced data cards and designed other activities to help stimulate discussion. In the latter, I used sketch interviewing as a technique. Then used standard qualitative interviewing as a technique (how much do I need to say about this?)

### 3.1.1 Data Cards and Card Sorting Techniques

Describe and show Family Civic Data cards used in 2017 study Describe the card-sorting techniques used - the riskiness vs who-should-control-it corkboard technique used in 2017 study

Describe why chose this - boundary objects (REF Star)/things to think with (REF Brandt and Messeter)

### 3.1.2 Family facts

Describe the facts-on-poles technique used in 2017 study.

### 3.1.3 Sketch Interviewing

Describe and show Sketch interviewing as used in the 2017 interviews and GDPR study.

### 3.1.4 Studies undertaken towards this research goal.

* 4 x 2 hr family ‘home visits’ (REF Mannay)
* 3 x 1hr ‘mobile phone/usefulness interviews’
* 5 x 1.5 hr ‘digital life sketch interviews (2017)’
* 11 x 1 hr ‘digital life interviews’ (2019)

## 3.2 2. The Lived Experience of A Data-Centric world

follow same pattern as above.

this time, importance of looking beyond the individual. looking at the way data exists and is used within relationships people have with organisations that hold data, within the data centric world.

additional Epistemiologies we draw on here are foucault’s thinking that meaning comes from discourse, and Deweyan pragmatism, that the purpose of research is to find solutions to real world problems in a manner that the solutions are generalisable.

here we move beyond people’s perspectives and thoughts to their actual lived experiences. our objective here is to understand the lived experience in a data centric world and how data can affect your life and relationships.

building on the prior research around attempts to model and interact with data in a more whole life, systemic way, we step up and look at data from the ‘life’ level - where we can see that, given the fact that most data is not directly held by individuals but by organisations - its role in relationships is key.

### 3.2.1 Early help

* explain the early help context and how it is a good setting to explore data relations especially w.r.t to empowerment

In order to fully explore this we conducted qualitative fieldwork with both sides of the early help relationship, exploring both current experiences of data use but also imagined future uses with different configurations that might be considered more human centric.

### 3.2.2 Card Sorting

### 3.2.3 Sentence Ranking

### 3.2.4 Ideation Grids

### 3.2.5 Group Poster Design

### 3.2.6 Storyboarding Cards

(participatory design) Quick explainer and reference to Golembewski

### 3.2.7 GDPR

* explain the GDPR context and how this is also a way to explore practical experience of real data processes

### 3.2.8 Privacy Policy interviews

as a starting point, having identified companies in people’s lives I start with the objective reality of what those companies say they collect, and use that as a way in to meaningful data conversations with participants.

### 3.2.9 View Your Data interviews

then to explore a real world process, I took participants on a journey of discovery of requesting, accessing and viewing their own held data.

### 3.2.10 Studies undertaken towards this research goal.

HDI in context of care study - 1 x 2h workshop with families (x participants) - 2 x 2h workshop with staff (x participants) - 1 x 2h workshop with staff and parents (x participants)

GDPR study - 10 x 1h+ privacy policy discussion - guiding through email etc - 10 x 2h view your data discussion

## 3.3 3. Uncovering and Exploring Design Constraints and Opportunities

Epistemiology: practical, pragmatism. What is possible. research through design.

This research goal starts from a different perspective, looking from the designer / technologists perspective, to gain an empathetic understanding of the current status quo of data systems and then applying human-centric system to reconsider the design of these systems. The goal is to uncover the barriers and challenges that must be overcome through design of systems and processes, and exploring the possible avenues of design that could be exploited

Here, research was conducted through embedding myself in projects aligned to the research objectives of building new data systems. Not empirical structured research but rather a process of acculturation to the world of building data systems and learning through participation and through research through design and through technical prototyping.

## 3.4 Research Through design

background on how this can be framed as research through design

## 3.5 Rapid prototyping

background on how prototyping is used to explore new ideas - pivoting etc.

### 3.5.1 Studies undertaken towards this research goal

two major projects:

* SILVER (ref early help as earlier)
* BBC R & D/PDS

two minor projects:

* web augmentation
* experimenting with using own data and getting usable data with GDPR

## 3.6 Structure of the following chapters.

Findings from the first research goal, The Human Perspective on Data Centricism, are written up in chapter 4, Understanding data

Findings from the second research goal, The Lived Experience of A Data-Centric world, are written up in chapter 5, understanding data relations.

Findings from the third research goal, Uncovering and Exploring Design Constraints and Opportunities are written up in chapter 6, understanding design constraints and possibilities.

In chapter 7, these findings are brought together to address the overall research question and suggest avenues for future research, design and development that can be applied to design better human data relations.

# 4 The Human Perspective on Data and Data-Centrism

[Target x words]

# 5 Living In A Data-Centric World

[Target x words]

# 6 Human-Centricity: Design Constraints and Opportunities

[Target x words]

# 7 Designing Better Human Data Relations

[Target x words]

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