Living with **data**

Public understanding and perceptions of data practices: a review of existing research (January 2020)

1. Introduction

The ubiquitous collection and use of digital data (sometimes referred to as 'datafication' (Mayer-Schoenberger and Cukier 2013)) is said to have wide-ranging effects: benefits such as more effective service provision, and harms such as more surveillance, less privacy, and new forms of inequality and injustice. Concern about potential harms has led to measures to influence data governance, such as the establishment of the government Centre for Data Ethics and Innovation (CDEI) and the independent Ada Lovelace Institute (Ada) in the UK, alongside parliamentary inquiries (eg into data ethics, responsible uses of data, AI and digital government); social and civil society initiatives (eg doteveryone's Society In the Loop event, the Open Data Institute's 'data trust' pilots); and practical experiments with ethical data-driven systems (eg the work of Projects By IF, amongst others).

As datafication expands, interest in how the public perceives 'data practices' (that is, organisations collecting, analysing and sharing data and the outcomes of these processes) has begun to grow, amongst academic researchers interested in public/citizen views of the new role of data in society and amongst policy-makers and professionals keen to establish positive perceptions of their data-related policies and practices. Indeed, understanding public views is said to be at the heart of initiatives like CDEI and Ada, to ensure that data works 'for people and society' (Ada's mission) and is 'a force for good' (a CDEI aim). Consequently, research into public understanding and perceptions of datafication has flourished in recent years, and this has advanced understanding of these matters.

The emerging body of research into public understanding and perceptions of datafication is therefore in need of review. We need to synthesise existing evidence and evaluate whether patterns or generalizable findings emerge from existing research. We need to assess the claims that are made on the basis of existing research, reviewing methods, analyses and reliability of findings. We need to identify limitations and gaps in the existing research that future research can address. This document provides such a review. It will inform the original empirical research to be undertaken on *Living With Data: knowledge, experiences and perceptions of data practices*, a research project funded by The Nuffield Foundation (https://livingwithdata.org/current-research/).

This document is a review of original empirical research into public understanding and perceptions of, attitudes towards and feelings about data practices and related phenomena (such as AI and facial recognition). It reviews academic and grey literature published in that time period. By grey literature, we mean literature produced by independent, civil society, third sector, governmental or commercial organisations (as such, our definition differs from Defra's (2015), which excludes commercially published information).

Because of the proliferation of research on this topic in recent years, we have limited the research that we review in this document in the following ways:

- 1. **By dates:** given the fast pace of change in our field of enquiry, we review literature published between 2015 and 2019 (inclusive) only.
- 2. By geography for grey literature: because of the proliferation of surveys and polls in our field of enquiry in recent years, and because grey literature often aims to have a national impact, the grey literature we review is UK-focused (either UK-only or based on international research which included the UK). Relevant research has been undertaken elsewhere in the world (for example by the Pew Research Center's Internet & American Life project (https://www.pewresearch.org/internet/)) but we do not include it in our analysis. There is less academic research that is UK-focused. There are, however, a number of international collaborations in this field. Because of this, and because academic research contributes to an international conversation, we include selected international studies in the academic literature we discuss.
- 3. **By populations researched/research subjects:** we exclude literature about children's understandings and perceptions of data practices because the study of children (and digital media) is a specialist field outside the remit of our own research, although studies of adults' perceptions of data practices relating to children are included.
- 4. By domain, especially with regard to research about public perceptions of health data: research into public perceptions of uses of health data and the ethics of health data re-use is more advanced than in any other domain. As a result, more is known about public perceptions of datafication in health, and high quality syntheses have already been undertaken, for example by Understanding Patient Data (2018). We therefore focus this review primarily on domains other than health.
- 5. **By subject matter/focus:** a large proportion of the research into public attitudes and perceptions that has been undertaken focuses on privacy, surveillance and security. We largely exclude this from our review, except where there is an obvious focus on attitudes to data practices included in the research.
- 6. Existing evidence syntheses and reviews: A small number of evidence syntheses and reviews have been published in ths field. Some of these cover publications outside our timeframe (eg Bakir et al 2015 draws on publications from before 2015). Others cover domains that are not our focus (eg Understanding Patient Data 2018 on health data). For these reasons and in order not to reproduce work already undertaken, we do not carry out analysis of the literature covered by these syntheses in this document.

The research and reports that we review in this document were identified through two main search strategies:

- We carried out a **systematic search** of online citation databases, using multiple keywords relating to how people feel about data practices and what happens to their personal data. We focused this search primarily on Web of Science;
- We carried out a manual search that began with grey and academic literature with which we were already familiar, and then snowballing out (eg searching bibliographies, relevant websites, observing Twitter discussions and building on word-of-mouth recommendations).

The literature that we identified through these processes was reviewed iteratively by us, the authors of this report, according to one principle inclusion criteria: does it report empirical research about how people feel about data practices and what happens to their personal data? Answers to this question are likely to be subjective, and so is the existing knowledge which formed the starting point for the manual search. Searching databases also has limitations: different databases show different results from searches (see Martín-Martín et al 2019 for a detailed discussion of this), searches will only produce results from the Web of Science databases to which the host university subscribes, and of course, search keywords shape what is and is not found. In short, all literature and evidence searches are partial, and ours is no exception. In the final, published research review, we will discuss these issues in greater detail.

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- 2. Methodology
- 3. Main content

4. Bibliography

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