# Living with data

You are invited to take part in a research project. Here you will find all you need to know about participating in this research including information on what the project is about, what is involved in taking part and what the significance of the research is to the wider community. Before you decide whether or not to participate, it is important for you to understand why the research is being undertaken and what it will involve. So please take time to read the following information carefully. Feel free to ask us if anything is unclear or if you would like more information (our contact details can be found below). You can download the information from this section as a pdf by clicking on this link [add link].

# 1. What is the project's purpose?

Living With Data is a research project run by a group of academics at the University of Sheffield and is – you guessed it – about data. Data is information stored on a computer, including personal information about individuals.

We are undertaking this research because the widespread collection and use of digital data is changing people's lives, positively and negatively. To ensure that data works for people and society and is a force for good, we need understanding of people's knowledge, experiences and perceptions of data practices, in particular what they think constitute 'fair' practices. *Living With Data* aims to produce such understanding.

We are working closely with data practitioners and policy makers. We will share what we learn through our research with them, so that future policies reflect the views of the public.

# 2. Why have I been approached?

Research has shown that different groups of people experience data practices differently. We are therefore carrying out our research with people from different places and communities to investigate whether this is the case. You have been chosen because you are a member of one of the groups / communities we want to talk to.

# 3. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to

It is completely up to you to decide whether or not to take part. If you do decide to participate, you will be asked to tell us a bit about yourself and to sign a consent form. You can withdraw from the project any time before 31<sup>st</sup> May 2021 with no negative consequences or questions asked. If you wish to withdraw from the research, please contact project researchers (our contact details can be found below).

## 4. What will I have to do if I take part?

You will be invited to participate in an online discussion which will last between 60 and 90 minutes. You will be invited to share your knowledge, experiences and perceptions of data processes (eg collection, analysis, sharing).

You will not be required to travel to take part in our research. You will need to have access to the internet and a device such as a phone, laptop, tablet, or desktop computer. We will discuss technical requirements with you, if you decide to take part.

Some of the online discussions will be one-to-one – just you and an interviewer. Some will be in small groups, of up to 4 or 5 people. We will usually arrange group discussions with groups of people who know each other.

### 5. What are the possible risks of taking part?

We do not foresee any disadvantages or risks to taking part in this project.

It is possible, however, that talking about your experiences and perceptions of data practices may remind you of negative experiences relating to this topic or other aspects of your life. If this happens, remember that participation is voluntary and you are free to withdraw without giving a reason or facing any negative consequences. You are also free to decline to answer any questons without giving a reason or facing any consequences. If you need support addressing negative experiences, we recommend that you contact professional organisations such as <u>Citizens</u>. Advice or <u>Samaritans</u>.

#### 6. What are the possible benefits of taking part?

On an individual level, taking part in this research gives you an opportunity to discuss and think about a relevant and important societal issue. We will also be sharing with you some of our findings from the project so far that reveal how some public sector organisations are currently using, sharing and analysing data- something which you might find interesting or useful in the future. You will also be given a £20 one4all voucher when you have completed the research to thank you for your participation.

On a broader level, you will be helping us to work towards the goal of making data work for everyone and be fair for all contributing towards shaping (and improving) existing policy and practice around how data about us is collected, analysed and shared.



# 7. Will my taking part in this project be kept confidential?

Yes. All the information that we collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the Living With Data research team. You will not be identifiable in any reports or publications unless you have given your explicit consent for this.

8. What will happen to the data collected, and the results of the research project?

The online discussions will be recorded. Immediately following the discussion, the recording will be transferred to a secure university server and deleted from the recording device. It will then be securely sent to a professional transcription company; a data confidentiality agreement will be signed prior to any data transfer. Upon receiving the transcript, a member of the research team will anonymise the transcript (that is, delete names and any identifiable personal features) and then delete the recording from the secure server. The results of this research will be published in reports and peer reviewed journal articles that will be publicly available. You will not be identifiable in any published results.

It is likely that other researchers may find the data we collect on this project to be useful in their future research. To make this possible, we would like to make the data available in a data archive. We will ask for your explicit consent for your data to be shared in this way. Only the anonymised transcript of the focus group will ever be shared.

Procedures for handling, processing, storage and destruction of study data meet the requirements of Data Protection Act 2018. All responses and information collected about you during the research will be stored on the University's password-protected, secure drives.



9. What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the <u>University's Privacy Notice</u>.

10. Who is organizing and funding the research?

The University of Sheffield is organising the study. This research is funded by the Nuffield Foundation.

11. Who is the Data Controller?

The University of Sheffield is the Data Controller for this study and is responsible for looking after your information and using it properly.

12. Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by the Department of Sociological Studies.

13. What if I wish to complain about the research?

If you have a concern about any aspect of this study, please contact Hannah Ditchfield or Helen Kennedy using the contact details below. If you feel your complaint has not been handled to your satisfaction you can contact the Head of Department Professor Nathan Hughes by email: <u>nathan.hughes@sheffield.ac.uk</u>, who will then escalate the complaint through the appropriate channels. If the complaint relates to how your personal data has been handled, information about how to raise a complaint can be found in the <u>University's Privacy Notice</u>.

14. Contact details for further information

Dr Hannah Ditchfield (hannah.ditchfield@sheffield.ac.uk)

Professor Helen Kennedy (h.kennedy@sheffield.ac.uk).

