

## UoM Research Participant Information Sheet

### Covid-19: Attitudes towards pathogen-related data sharing during a pandemic

#### Participant Information Sheet (PIS)

You are being invited to take part in a research study which focuses on gathering information about pathogen-related data sharing and data licences, and how groups of software engineers and researchers approach challenges around data availability during a pandemic.

#### **About the research**

##### ➤ **Who will conduct the research?**

Yo Yehudi, EngD Student at School of Computer Science, The University of Manchester and Software Developer at the Department of Genetics, University of Cambridge.

##### ➤ **What is the purpose of the research?**

The world is currently experiencing lockdown in many countries due to the COVID-19 pandemic. Many efforts to "hack" solutions, models, informative graphs, etc. have arisen on very short notice. Despite the urgency of this issue, with thousands dead and millions confirmed infected worldwide, there are data sources with restrictive licences preventing people from effectively working with pandemic related data. This raises the following questions to be studied systematically:

In times of a pandemic or epidemic when rapid response is required, what are attitudes towards pathogen-related data sharing and data access? In particular:

- Are these data licenced in a way that permits re-use and redistribution?
- Are they made available in ways that are easy to download and re-use, e.g. API or bulk download, machine-readable with relevant metadata?
- What response do various communities have to these restrictions?
- **How are participants chosen?**
  - Participants are chosen based on a search for individuals who are experiencing difficulties gaining access to restricted COVID-19 data sources, or are circumventing the restrictions in some way (e.g. by using an alternative data source, encouraging data curation / submission to another source, or some other measure).
- **Will the outcomes of the research be published?**
  - Written-up results will be preprinted and published in an open access journal, and data/anonymised results will be published openly on a data depository such as Zenodo. These data will be drawn from one-on-one interview data discussing challenges and measures taken around COVID-19 data sharing.
- **Who has reviewed the research project?**

This project has been reviewed by The University of Manchester School Of Computer Science Division/School Ethics Committee.

## **What would my involvement be?**

### **➤ What would I be asked to do if I took part?**

If you take part, we will ask you to participate in a short informal interview with you via audio, video, or text chat. The interviews will take around 20-30 minutes.

During the interview, we will ask you about data sources you have worked with, what challenges you have faced in working with them, and what you have done when you meet these challenges. We will also ask about what your ideal data source might be like, and whether you've considered any possible ethical issues related to data sharing.

Your statements (either online or during the interview) would form part of a data corpus recording challenges, attitudes and behaviours in response to data sharing challenges.

Your name and other identifying details would be removed before publication, and we would share text of interviews / recorded statements with you before publishing or sharing any data.

After the study is complete, we will write-up and publish our results.

### **➤ What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part. If you wish not to take part you can either inform us verbally or email [yochannah.yehudi@postgrad.manchester.ac.uk](mailto:yochannah.yehudi@postgrad.manchester.ac.uk). If you do decide to take part in an interview, you will be given this information sheet and will be asked to indicate your consent. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised as we will not be able to identify your specific data. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further.

## **Data Protection and Confidentiality**

### **➤ What information will you collect about me?**

In order to participate in this research project we will need to collect information that could identify you, called "personal identifiable information". Specifically we will need to collect:

- Your name and job role(s) in relation to the pandemic.
- Your interview responses, which could potentially identify you, depending on what you say. In order to preserve your privacy, we will give you the chance to review your responses before anything is published, and we will anonymise all data to ensure that is not identifiable.

### **➤ Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

➤ **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research](#).

➤ **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

Only the study team at The University of Manchester will have access to your personal information, but they will anonymise it as soon as possible. Your name and any other identifying information will be removed and replaced with a random ID number. Only the research team will have access to the key that links this ID number to your personal information. If you participate in an interview, your consent form will be retained for 5 years on secure University of Manchester Research Data Storage.

When you agree to take part in a research study, anonymised and aggregated information about you may be provided to researchers running other research studies, or wishing to analyse the results of this study. Your information will only be used by this organisation and researchers to conduct research in accordance with The University of Manchester’s Research Privacy Notice.

This information will not identify you and will not be combined with other information in a way that could identify you.

If you wish for your contact details to be removed from the project database, please email [yochannah.yehudi@postgrad.manchester.ac.uk](mailto:yochannah.yehudi@postgrad.manchester.ac.uk)

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

### **What if I have a complaint?**

If you have a complaint that you wish to direct to members of the research team, please contact:

**YO YEHUDI – [yochannah.yehudi@postgrad.manchester.ac.uk](mailto:yochannah.yehudi@postgrad.manchester.ac.uk) (Research Student performing the study) or**

**CAROLINE JAY – [caroline.jay@manchester.ac.uk](mailto:caroline.jay@manchester.ac.uk) (Supervisor)**

**If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact**

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: [research.complaints@manchester.ac.uk](mailto:research.complaints@manchester.ac.uk) or by telephoning 0161 275 2674.

If you wish to contact us about your data protection rights, please email [dataprotection@manchester.ac.uk](mailto:dataprotection@manchester.ac.uk) or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner's Office about complaints relating to your personal identifiable information](#) Tel 0303 123 1113

### **Contact Details**

If you have any queries about the study or if you are interested in taking part then please contact the researcher(s)

**YO YEHUDI – [yochannah.yehudi@postgrad.manchester.ac.uk](mailto:yochannah.yehudi@postgrad.manchester.ac.uk)**