

Measuring understanding of biological data models

Participant Information Sheet (PIS)

You are being invited to take part in a research study measuring the differences in mental models of biological data between people of different backgrounds. This study forms part of Yo Yehudi's EngD degree research. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

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 purpose of this research is to investigate what differences people perceive in biological data models. We anticipate that this might vary depending on a person's educational background and experience within biology and programming. The results of this study may allow us to present data in ways that is easier for people to understand and interact with, particularly in computer applications.

Participants are chosen based on their background and experience in biology and programming, with the aim of providing a broad spectrum of participants ranging from people who specialise in wet labs with little computational experience, to people who write code regularly.

➤ **Will the outcomes of the research be published?**

The outcomes of this research (analysis of anonymised and aggregated data) will be published in an open-access journal, and anonymised result data will be deposited in a data repository where it will be available for others to re-use. Video and audio recordings will be deleted once they have been transcribed.

➤ **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?

During this study:

1. We will find somewhere quiet to conduct an interview.
2. We will then ask you to fill out consent forms and a short questionnaire about your background and work experience.
3. Finally, we will begin a short interview. The interview will be recorded, ideally via video but audio-only if you prefer. The interview will involve a few short tasks:
 - a. A card-sorting activity where there are no wrong or right answers.
 - b. The interviewer may ask some questions about the results of your card-sort.
 - c. We will also ask you to look at some biological data files and answer a few short questions. Again, there are no right or wrong answers – we want to know what **you** think.

This process will take between 30 minutes and an hour, and there are currently no follow-up interviews planned.

➤ 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. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. 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.

You are free to decline video recordings, but audio recordings and photography of the results of the card-sorting activity are essential to participation in the study. You should be comfortable with the recording process at all times and are free to stop recording at any time.

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:

- Video or audio recordings will be taken during the interview and will consist primarily of the results of the card-sort itself, but may also include the surrounding environment or your face if you move into the field of view of the camera. Still photographs of the card sort activity and data file activity may also be taken, especially if you prefer for the recording to be audio-only. Recordings will be deleted once they are transcribed into text format and have been verified.

➤ **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 may hold about you, including recordings or photographs.

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, available at http://documents.manchester.ac.uk/display.aspx?DocID=37095](http://documents.manchester.ac.uk/display.aspx?DocID=37095).

➤ **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. 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, unless you consent to sharing identifying information openly.

For audio/video:

Recordings will be used to create transcripts, which may be reviewed or verified by other researchers at the University of Manchester, who will also sign a copy of the Confidentiality Agreement. Personal identifiable information will be removed in the final transcript.

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?

➤ Contact details for complaints

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 (Research Student performing the study) or

CAROLINE JAY – 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 Governance and Integrity Officer, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: 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 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, available at <https://ico.org.uk/make-a-complaint/>
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

Consent Form

If you are happy to participate please complete and sign the consent form below

	Activities	Initials
1	I confirm that I have read the attached information sheet (Version 5, Date 04 July 2019) for the above study and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.	
2	I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to myself. I understand that it will not be possible to remove my data from the project once it has been anonymised and forms part of the data set. I agree to take part on this basis.	
3	I agree to the interviews being audio recorded and transcribed.	
4	I agree to outputs of the interview being photographed. This may include sketches I have made or cards I have sorted.	
5	I agree that any data collected may be published in anonymous form in academic data repositories, reports or journals.	
6	I understand that data collected during the study may be looked at by individuals from The University of Manchester or regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	
7	I agree that any personal/anonymised data collected may be shared with researchers/researchers at other institutions.	
8	I agree to take part in this study.	
9	(OPTIONAL) I agree to the interviews being video recorded and transcribed	
10	(OPTIONAL) I agree to share transcripts of my interview recordings publicly	

Data Protection

The personal information we collect and use to conduct this research will be processed in accordance with data protection law as explained in the Participant Information Sheet and the [Privacy Notice for Research Participants](#).

Name of Participant

Signature

Date

Name of the person taking consent

Signature

Date

Copies:

1 Copy for the participant

1 Copy for the researcher records