

## **Understanding the Experiences of Individuals with Diabetes During the COVID-19 Pandemic**

### **Participant Information Sheet (PIS)**

You are being invited to take part in a research study that will look at posts on an online diabetes support group in order to understand the experiences of people with diabetes during the COVID-19 pandemic. This research is being carried out for a postgraduate student dissertation. 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?**

Helena Bilsborough, School of Health Sciences, The University of Manchester

Dr Sarah Peters, School of Health Sciences, The University of Manchester

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

This research is aiming to understand the experiences of people with diabetes throughout the COVID-19 pandemic. We are aware that the pandemic may have had affected the lives of people with diabetes, and we wish to understand peoples experiences to improve support provided in the future. We are looking at posts in online support groups so that we can look back at key time points during the pandemic.

We plan to look at posts around three different time points – from 11<sup>th</sup> March 2020 (when the COVID-19 pandemic began to get underway), 2<sup>nd</sup> April 2020 (in the middle of most countries' lockdowns) and 1<sup>st</sup> June 2020 (when many lockdown measures in different countries had begun to relax). Approximately 1050 posts will be collected, 350 per time point. Posts will be collected from each time point working forward until approximately 350 posts have been retrieved. We will not include posts from individuals if we can see that they are under 18 years old or if they do not have diabetes. For example, we will not include posts from people who appear to be family members or carers of people with diabetes.

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

The outcomes of the study will be written up for Helena Bilsborough's Masters thesis. Outcomes of the research study will be summarised and provided to the group moderators that they can then share with the online discussion group if they are happy to do so. The outcomes may also be published in a scientific journal and presented at a conference.

➤ **Who has reviewed the research project?**

The project has been reviewed by The University of Manchester Research Ethics Committee 5.

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

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

There will be nothing for you to do if you agree to take part. The data for the study will come from posts that have already been made on the support group.

### **➤ Will I be compensated for taking part?**

No payment is available for allowing your posts to be used in this research.

### **➤ 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 do not wish to take part you should email the researcher at [HELENA.BILSBOROUGH@POSTGRAD.MANCHESTER.AC.UK](mailto:HELENA.BILSBOROUGH@POSTGRAD.MANCHESTER.AC.UK) . Please contact the researcher within 2 weeks of the study being advertised if you wish to opt out. It will not be possible to remove your data from the project after this time as it will have been anonymised and we will struggle to identify your specific data. This does not affect your data protection rights.

## **Data Protection and Confidentiality**

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

We will only collect information that you have posted in the online support group. This may include your name/username that you use in the online group, but we will remove such identifying information and replace it with a number after we have collected the messages.

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

We are collecting and storing this personal identifiable information in accordance with UK 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 information that is already publicly available on the online support group will be collected for this study. When the researcher collects messages, she will remove any identifying details (e.g. names, online identities). Data will be securely stored on the secure University of Manchester computer server. It will be kept for 5 years and then deleted.

When we write up the study, no quotes will be used in the way they are written online – quotes will be carefully selected and altered (paraphrased) so that no one would be able to tell that you wrote them.

Only the project researchers (Helena Bilsborough and Sarah Peters) will access the study data.

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:

**DR SARAH PETERS:**

**EMAIL:** [SARAH.PETERS@MANCHESTER.AC.UK](mailto:SARAH.PETERS@MANCHESTER.AC.UK)

**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 306 8089.

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 wish to opt out of the study then please contact the researcher(s)

**HELENA BILSBOROUGH:**

**EMAIL: [HELENA.BILSBOROUGH@POSTGRAD.MANCHESTER.AC.UK](mailto:HELENA.BILSBOROUGH@POSTGRAD.MANCHESTER.AC.UK)**

**DR SARAH PETERS:**

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