**(NON-MEDICAL RESEARCH)**

**PARTICIPANT INFORMATION SHEET**

**Add in study title**

You are being invited to take part in research on [research topic]. [Name and position] at the University of Edinburgh is leading this research. Before you decide whether to take part it is important you understand whythe research is being conducted and whatit will involve. Please take time to read the following information carefully.

**What is the purpose of the study?**

The purpose of the study is to [summarise research focus and aims. Include the reason why the study is being conducted. Please ensure this is in lay language]

**Why have I been INVITED to take part?**

You are invited to participate in this study because you [give reasons for contacting the individual and/ or give inclusion criteria].

**Do I have to take part?**

No – it is entirely up to you. If you do decide to take part, you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect your xxx [e.g. healthcare, employment etc.] [amend this paragraph if you need to restrict or not grant the right to withdraw data].

Please note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to your withdrawal and so you are advised to contact the research team at the earliest opportunity should you wish to withdraw from the study. [Please amend if it is not possible to withdraw participants’ data e.g. if participation is anonymous]

**What will happen if I decide to take part?**

If you do decide to take part, please keep this Information Sheet. You will be asked to [sign/complete] an Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate. [Please amend to suit consent process, e.g. if online consent, how will this be done]

You will be asked a number of questions regarding [briefly describe the kinds of data you will require]. The questionnaire/interview/focus group [delete as appropriate] will take place in a safe environment at a time that is convenient to you. Ideally, we would like to audio record your responses (and will require your consent for this), so the location should be in a fairly quiet area. The questionnaire/interview/focus group [delete as appropriate] should take around [specify likely time duration] to complete.

**What are the POSSIBLE benefits of taking part?**

There are no direct benefits, but by sharing your experiences with us, you will be helping [researcher name] and the University to better understand … [key research focus]. [Amend if providing reimbursement for travel costs or gift voucher]

**Are there any risks or disadvantages associated with taking part?**

There are no significant risks associated with participation. [if there are any significant risks, these must be specified. Include amount of time taken complete questionnaires / attend interviews. If there is a possibility of criminal behaviour being disclosed, include the fact that you will need to break confidence. If there is a likelihood of upset/distress, contact information of support services should be provided at the end of this sheet]]

**Risks of participation (COVID-19)** [Only include for Face-to-Face research during Covid restrictions]

We have taken specific steps to minimise the risk of exposure to the Coronavirus during the study by adhering to the Scottish Government [guidance](https://www.gov.scot/coronavirus-covid-19/) (<https://www.gov.scot/coronavirus-covid-19/>)  Further, you will only interact with researchers who are well, and have had no known contact with COVID-19 positive individuals for the past 14 days.  However, even with these control measures, there remains some additional risk of exposure from participating in this study.

**What if I am unwell?**

If you feel unwell or have been in contact with a COVID-19 positive individual in the past 14 days, then please contact the researcher (Name and telephone), and we will postpone or cancel the research interaction.

**Will my taking part be kept Confidential?**

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.

**How will we use information about you?**

We will need to use information from [you] [from your medical records] [OTHER] for this research project.

This information will include your [initials/ NHS number/ name/ contact details - provide a bullet list of identifiers held by site and/or sponsor for the research].  People will use this information to do the research or to check your records to make sure that the research is being done properly.

**OPTION where applicable:** People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Unless they are anonymised in our records, your data will be referred to by a unique participant number rather than by name [amend as appropriate]. If you consent to being audio recorded, all recordings will be destroyed once they have been transcribed. Your data will only be viewed by the researcher/research team. [if the data are to be shared with 3rd parties, you must declare this here and name the parties concerned.] All electronic data will be stored on a password-protected computer file and all paper records will be stored in a locked filing cabinet. Your consent information will be kept separately from your responses in order to minimise risk.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

### What are your choices about how your information is used?

* You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
* **OPTION if follow up data will be collected after withdrawal:** If you choose to stop taking part in the study, we would like to continue collecting information about your health from [central NHS records/ your hospital/ your GP]. If you do not want this to happen, tell us and we will stop.
* We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

### Where can you find out more about how your information is used?

For further information about data privacy for research participants please refer to: <https://data-protection.ed.ac.uk/privacy-notice-research>

* our leaflet available from [X]
* by asking one of the research team
* by sending an email to [email], or
* [Add another option, if applicable]

**(Only relevant for Sponsored research)** The University of Edinburgh is the sponsor for this study based in [the United Kingdom/ country]. We will be using information from [you (and/or your medical records)] in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Edinburgh will keep identifiable information about you [for x years after the study has finished/ until x] and your anonymised data for a minimum of X years.

**What will happen with the results of this study?**

The results of this study may be summarised in published articles, reports and presentations. You will not be identifiable from any published results. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name. With your consent, your anonymised information may also be kept for future research [delete if not applicable] A summary of the findings from the study will be made available to participants who indicate they would like to receive this. This summary will be sent to participants by post / email. [delete if not applicable]

**WHO IS ORGANISING AND FUNDING THE RESEARCH?**

This study has been organised by [research team / student name and course] and sponsored by the University of Edinburgh (if applicable).

The study is being funded by [xxxx] (if applicable).

**WHO HAS REVIEWED THE STUDY?**

The study proposal has been reviewed by xxxx [School Ethics Committee and /or external approvals e.g. Council].

**WHO CAN I CONTACT?**

If you have any further questions about the study, please contact the lead researcher, [name, contact details].

If you would like to discuss this study with someone independent of the study please contact [name, contact details. N.B. This cannot be a member of the study team].

If you wish to make a complaint about the study, please contact:

[insert names and contact details of appropriate member of staff in School (this cannot be a member of the research team) or Research Governance Team (cahss.res.ethics@ed.ac.uk)]