# Participant Information Leaflet (Historical/Social/Economic/Scientific) – Guidance Note

The Data Protection Office in conjunction with the Research Ethics Policy Committee ( REPC) has prepared a Participant Information Leaflet Template to aid researchers who are **processing personal data** for their research studies in the fields of (historical, social, economic or scientific research). If your study relates to health research[[1]](#footnote-1), please do not use this template. You will need to use the alternative template available [here.](https://www.tcd.ie/info_compliance/data-protection/documents/TCD_Participant_Information_Leaflet_V.01.docx)

Please note that in relation to the use of personal data:

* Processing means (any operation or set of operations performed on personal data. This includes storing, collecting, retrieving, using, combining, erasing and destroying personal data, and can involve automated or manual operations);
* Personal Data means (any information concerning or relating to a living person who is either identified or identifiable). An individual could be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier (such as an IP address) or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that individual.
* Sensitive personal data (or special category personal data) means personal data revealing
  + racial or ethnic origin,
  + political opinions,
  + religious or philosophical beliefs;
  + trade-union membership;
  + genetic data,
  + biometric data processed solely to identify a human being;
  + health-related data;
  + data concerning a person’s sex life or sexual orientation.

The form provided is a template only: researchers will need to tailor this template to their own research studies. Any information leaflet should provide all information necessary in order to ensure researchers are fully transparent as to the use of participants personal data.

Researchers should pay attention to:

* The content of the leaflet particularly the importance of using plain English;
* The appearance of the leaflet particularly the font and font size used;
* The National Adult Literacy Agency have provided useful advice on how to ensure the leaflet is suitable for your target audience and is available at [www.simplyput.ie](http://www.simplyput.ie).

**INFORMATION LEAFLET TEMPLATE (Historical, Social, Economic or Scientific)**

**NAME OF STUDY: (INSERT TITLE HERE)**

IN THIS SECTION YOU MUST INCLUDE AN INTRODUCTORY STATEMENT

*SAMPLE TEXT: You have been asked to be involved in this research study because we are trying to find out ( insert purpose of research)*

*Before you decide whether or not you wish to participate in the study, it is important for you to understand why the research is being done and what taking part involves.*

*Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.*

# Background information to the study

In this section please explain the background context of the study explaining its relevance (i.e. why the study is being done and why this person has been asked to take part)

*SAMPLE TEXT: We plan to study x and to collect information relating to Y (include full list of any personal information.)*

# Benefits

Provide information on potential benefits if any, to the participant or others, through taking part.

If there is no direct benefit to the participant, then this should be stated.

*SAMPLE TEXT: There will be no direct benefits to participants, however we hope the results of the study will help us to understand ( please complete).*

# Disadvantages

Provide a fair and honest evaluation of the possible consequences of key research procedures

*SAMPLE TEXT: The interview will take approximately x There is a small risk of your personal data being breached and your identity being revealed.*

# Do I have to take part?

Explain the voluntary nature of the study and the right to withdraw without penalty

*SAMPLE TEXT: It is your choice whether you would like to take part in the study or not. If you do not wish to participate, you do not have to give a reason and you can change your mind at any time. If you decide that you do not wish to be part of the study, now or later, you will continue to receive the same level of (INSERT AS APPLICABLE). Please contact x if you wish to withdraw from the study at any time.*

# What happens if I take part?

Explain what taking part in the research will involve including a list of topics that you will discuss and the expected location and duration of participation.

Explain what will happen to the personal data provided by the participant (INCLUDING AUDIO OR VIDEO RECORDING)

State the length of time the personal data will be kept (in an identifiable or pseudonymised format) and why it is necessary to keep it for that period.

State the arrangements to be made for the personal data to be archived or destroyed.

State whether the personal data collected will leave the State and if so what countries it will go to and why; please be careful of data stored in the cloud and carry out due diligence as to where this data is stored).

If applicable, state the existence of automated decision-making, including profiling and information about the logic involved, as well as the significance and the envisaged consequences of such processing for the data subject;

# Will my records remain confidential?

Explain that the interview will be recorded (audio or video) if applicable and outline the arrangements for storing the research data (where it will be stored, for how long, security arrangements, who will have access).

Provide details on how participants identity will be kept confidential in any analysis, publication and presentation of resulting data and findings.

*SAMPLE TEXT: Your privacy is important to us. Your personal information will be stored securely in x in Trinity College Dublin for up to x years.*

*Any information that leaves Trinity will have the name removed so that your identity remains confidential.*

*We will never share your audio or video files with any third parties.*

*Anonymised data may be shared with the scientific community and industry.*

NB: For students undertaking Masters programmes who have no intention of subsequently publishing their research the relevant paragraph should read:

*‘original audio recordings will be retained in [specify location, security arrangements and who has access to data] until after my degree has been conferred. A transcript of interviews in which all identifying information has been removed will be retained for a further two years after this.*

Include cautions about inadvertent discovery of illicit activities ((e.g. physical, emotional or sexual abuse, concerns for child protection, rape, self-harm, suicidal intent or criminal activity

*TEXT: Please note that by law we are obliged to report any inadvertent discovery relating to……*

**What will happen to the results of this research?**

Outline fully and realistically your plans for the dissemination of the research including conferences, publications and teaching use.

If your plans for the research only consist in submitting your dissertation then simply state this.

SAMPLE TEXT: *The information from this study may be published in scientific papers and on public registries. If this is the case, your identity will remain confidential and no one will know that you took part in the study.*

# What do I do if I have any further questions?

SAMPLE TEXT: Please ask the researcher that gave you this information sheet. They will be happy to answer any questions that you may have.

# THANK YOU

# DATA PROTECTION INFORMATION

|  |  |
| --- | --- |
| Data Controller | Trinity College Dublin |
| Data Protection Officer | Data Protection Officer  Secretary’s Office  Trinity College Dublin  Dublin 2  Dataprotection@tcd.ie |

|  |
| --- |
| What is the lawful basis to use my personal data? |

We will use the information you provide to us for this research study which is historical/social/economic/scientific research[[2]](#footnote-2) in the public interest*[[3]](#footnote-3). (Note this can be deleted if no personal or sensitive information is collected in the study)*

# What are my rights in relation to your use of my personal data?

You are entitled to:

* The right to access to your data and receive a copy of it
* The right to restrict or object to processing of your data
* The right to object to any further processing of the information we hold about you (except where it is de-identified)
* The right to have inaccurate information about you corrected or deleted
* The right to receive your data in a portable format and to have it transferred to another data controller
* The right to request deletion of your data

unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting the PI at x or the Trinity College Data Protection Officer (contact details above).

Please note that these rights relate to data which could identify you (personal data). If your data has been anonymized, we will not be able to access or delete it, as we will have no way of being able to link the data to you.

1. “health research” means any of the following scientific research for the purpose of human health: (i) research with the goal of understanding normal and abnormal functioning, at molecular, cellular, organ system and whole body levels; (ii) research that is specifically concerned with innovative strategies, devices, products or services for the diagnosis, treatment or prevention of human disease or injury; (iii) research with the goal of improving the diagnosis and treatment (including the rehabilitation and palliation) of human disease and injury and of improving the health and quality of life of individuals; (iv) research with the goal of improving the efficiency and effectiveness of health professionals and the health care system; (v) research with the goal of improving the health of the population as a whole or any part of the population through a better understanding of the ways in which social, cultural, environmental, occupational and economic factors determine health status; [↑](#footnote-ref-1)
2. *Article 9(2) (j)) Please note that this basis is only required if using sensitive personal data. Delete if not using sensitive personal data.*  [↑](#footnote-ref-2)
3. *(Article 6(1)(e)* [↑](#footnote-ref-3)