Information Letter to Participants

Requirements

Letterhead
The first sheet of the Information Letter to Participants should generally be printed on ECU letterhead paper prior to distribution to participants. This is appropriate for all student projects.

However, if the project is being conducted in collaboration with another agency (e.g., research conducted in hospitals) or is part of a multicentre research project, it may be more appropriate to use that agency’s letterhead. However, the involvement of researchers from ECU should be mentioned in the information provided to participants.

Title of the project
The title of the project should be clearly printed on the letter. The title used is usually the same as that provided on the ethics application, but in some cases it may be appropriate to use a short title or lay title.

Researchers and Contact details
Student projects
The name and contact details of both the student and the supervisor should be provided. The School should be included. Participants should also be informed that the research project is being undertaken as part of the requirements of a degree. An example of a statement to be included is as follows:

“This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.”

Staff projects
Members of the research team and their contact details should be provided, with the Chief Investigator clearly identified. The School should be included.

Sources of Funding
Where the research project is funded, the National Statement on Ethical Conduct in Human Research requires researchers to disclose the source of funding to potential participants. In general, this would apply to staff research projects, funded from an external or commercial source. In clinical trials, the funding source must always be identified.

Description of the research project
Participants should be provided with a concise statement, using language that is easily understood, which includes the following items:

- the aims of the project
- a statement informing participants why and how they were selected as potential participants
- an explanation of the stages involved in the project (e.g., screening of potential participants, surveys, interviews, video-taping, audio-taping, blood testing, etc)
- a clear statement of what stage(s) the participants are being requested to participate in
- a description of what participants are expected to do, including an estimate of the time involved
- a clear explanation of any potential discomfort or inconvenience involved in participation and, if appropriate, an explanation of any alternatives to participation
- a description of any benefits of participation
- a description of any possible risks, and an explanation of any plans to minimise or avoid these risks
- instructions for participants about what they should do if they would like to participate, e.g., sign the Consent Form and return it to the researcher

If children and/or young people are the potential participants in research, information should be provided for them in language they can understand as well as providing a separate Information Letter suitable for their parents/guardian (see later section).
Confidentiality of information
Participants should be informed of the following items:
• how the information they provide will be used
• who will have access to the information they provide
• measures taken to ensure the confidentiality and privacy of the information collected, e.g. the use of pseudonyms or codes, erasure of tape recorded interviews following transcription
• participants should also be informed that there are legal limits to confidentiality unless completely anonymous data is to be collected
• arrangements for the storage of data, e.g. how the information will be stored, and the period of storage
• what will happen to the information after the research project has finished, i.e. plans for the destruction of the data (if this is intended) or plans for ongoing storage (e.g. for longitudinal studies)
• any information that may be required by Privacy legislation

Results of the research study
Participants should be informed of how the results of the study will be disseminated, e.g. in reports, at conferences, in publications. Participants should be assured that results will not include any information that may identify individual participants, unless specific consent for this has been obtained. Participants should also be informed if they will receive any feedback regarding their specific results, or the results of the study.

Voluntary participation
The Information Letter should clearly indicate to potential participants that participation is voluntary. No explanation or justification is needed if they choose not to participate. In some cases, it may be appropriate to inform potential participants that a decision not to participate will not disadvantage them, or involve any penalty.

Withdrawing consent to participate
Participants should be informed that they are free to withdraw their consent to further involvement in the research project at any time. Participants should also be fully informed of the consequences of exercising their right to withdraw from the research, including the withdrawal of information or material that has already been collected. If it is initially intended that a sample or data not be withdrawn after a particular stage in the research process, then this should be made clear on any information sheet or consent form given to potential participants.

Questions and/or further information
Participants should be provided with the name and contact details of the researcher(s) willing to be contacted regarding any questions or requests for further information. The following statement (or similar) should be included:
If you have any questions or require any further information about the research project, please contact: [researcher’s contact details]

Independent contact person
Participants should be provided with the name and contact details of the Research Ethics Officer, who can act as an independent person willing to be contacted regarding any concerns or complaints about the conduct of the project.

The following statement should be included:
If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact:
Research Ethics Officer
Edith Cowan University
270 Joondalup Drive
JOONDALUP WA 6027
Phone: (08) 6304 2170
Email: research.ethics@ecu.edu.au

Approval by the Human Research Ethics Committee
Participants should be informed that the project has been approved by the ECU Human Research Ethics Committee.
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Other issues

Information Letter for parents and/or guardians
Where children and/or young people (people under 18 years of age) are potential participants, an Information Letter should be prepared explaining the study to parents and/or guardians, and separate additional consent should be obtained from parents and/or guardians.

The Information Letter provided to parents and/or guardians should contain all the required elements listed but should be structured and worded so that it seeks consent from the parents and/or guardians for the participation of the child or young person in the research project.

Data collection involving audiovisual recording
If the research project involves audiovisual recording as part of the data collection procedures, participants should be informed. A specific statement should be included in the Information Letter to Participants indicating to participants what recording method will be used, who will have access to the recordings, what the recordings will be used for and what will happen to the recordings after the completion of the project.

If it is possible to participate in the project without being recorded, this information should be provided to the participants and they should be given this option.

Researchers should also be aware of situations where groups of participants may be recorded. In some circumstances, e.g. classrooms of children, it may be the case that only some of the group has consented to participation in the research project. Information provided to participants may need to provide an explanation of how this situation will be managed.

In addition, researchers should also consider the possibility that a participant may withdraw consent once a recording has already been made. In some cases, withdrawal of information already provided may be impossible e.g. if a tape has been transcribed and the identity of the participant removed. However, in other cases, withdrawal of information may be possible but difficult, e.g. erasure of one participant on a videotape of a group. If it is initially intended that a sample or data not be withdrawn after a particular stage in the research process, then this should be made clear on any information sheet or consent form given to potential participants.

Further use of information, data and/or samples collected
In general, information, data and/or samples collected from participants should only be used for the purposes for which they were originally collected. However, there may be cases where researchers may wish to use the information, data and/or samples for future research projects, for other purposes, or to make it available for other researchers.

If researchers wish to have this option, this should be explained to the participants in the Information Letter and specific consent should be obtained, giving the participant the option of how their information, data and/or samples will be used.

Collection, disclosure and use of personal information from other agencies or institutions
Where a research project involves access to personal information about participants from another agency or institution (e.g. access to medical records), the following applies:
• the Information Letter to Participants needs to indicate to participants what information will be accessed, in what form, how the information will be used, and who will have access to the information
• the Consent Form needs to specifically indicate that participants have given their consent for this access and for the use of the information (as described in the Information Letter to Participants)

Where a Commonwealth or private sector organisation is involved, legislative guidelines apply. It is recommended that researchers consult the information available on the website of the Office of the Federal Privacy Commissioner.