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## Human Ethics Guidelines

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### 1. Purpose

- 1.1 These Guidelines provide detailed information on the conduct of ethical research at the University and the applicable procedures and processes when applying for Human Ethics Committee (HEC) approval.

### 2. Application of Guidelines

- 2.1 These guidelines are intended to support and clarify the Human Ethics Policy.

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## Guidelines Content

### 3. Application of Principles

#### 3.1 Respect and care for persons:

##### (a) Informed consent:

- (i) Informed consent has two basic components -
  - A) The decision is informed by adequate understanding of any information that is relevant to that decision; and
  - B) The decision is voluntary, and is therefore, free from undue influence such as manipulation or coercion.
- (ii) Participants have the right to decide whether they wish to participate in research, including the right to withdraw their participation. Participants do not need to provide reasons for not participating, nor for discontinuing their participation.
- (iii) When informing potential participants about the research, it must be made clear to them at what point in the research process it will no longer be possible to withdraw the data collected, for example, once data analysis has started.
- (iv) Students in a course being taught by the researcher are considered to be unable to give consent free of coercion. Consent should be solicited by an independent third party and no access to identifiable information provided until grades have been assigned.

##### (b) Limitation of deception:

- (i) Research projects that are based around any form of deception are considered to be ethically suspect until all rationales for the deception have been considered and judged justifiable. In particular, any research that is based on deception that could cause psychological, socio-cultural, or physical harm is unlikely to be acceptable to the HEC; and
- (ii) Wherever possible, projects involving a measure of acceptable deception should incorporate an appropriate debriefing of the participants as soon as is practicable after their participation is complete.

##### (c) Special care of potentially vulnerable participants:

- (i) Special care must be taken of potentially vulnerable persons. Vulnerability includes those that are particularly susceptible to harm. It also encompasses people whose ability to consent freely is compromised due to socio-cultural and environmental context, or a limited capability to make independent rational decisions;
- (ii) Potentially vulnerable groups include children and young people; older adults; people with mental illness; people with serious intellectual disability; people with English as a second language, or with a different cultural background to the investigators; people whose freedom to make independent decisions is restricted (for example prisoners, employees, students); and people whose health, employment, citizenship or housing status is compromised;
- (iii) Children (under the age of 16 years), and especially young children (under the

age of 7 years) are considered to be a particularly vulnerable group that must be carefully protected from exploitation during any research project; and

- (iv) Students are potentially vulnerable participants when participating in research undertaken by their teacher or lecturer.

(d) Respect for legal rights:

- (i) Researchers should respect the property of others. This includes their legal rights to land, goods, privacy and intellectual property.

(e) Conflicts of interest:

- (i) Researchers should ensure that the roles they occupy, and relationships they have with the people who are invited to take part in their research, do not compromise the participants' ability to freely consent or decline to take part in that research. See [Conflicts of Interest Statute](#);
- (ii) Researchers should be aware that their personal or professional interests (e.g., financial) may conflict or lead others to perceive a conflict with their ability to conduct research in an objective and professional manner;
- (iii) Researchers should design their research and relevant teaching activities, so far as possible, so that they are not in a position where their activities as a researcher (or teacher, in the case of teaching applications) could:
  - A) Conflict with other professional or personal interests they may have, or
  - B) Involve them recruiting participants with whom they have pre-existing personal or professional relationships (See 3.1(a) iv).
- (iv) Should any unavoidable conflicts arise; researchers must take appropriate steps to minimise the potential risks. If uncertain, researchers may seek advice from the HEC Convenor.

3.2 Acknowledgement of the Treaty of Waitangi (the 'Treaty'):

- (a) As researchers in Aotearoa New Zealand, the Treaty principles of partnership, protection, and participation should underpin our research relationships.
  - (i) Partnership: Where research focuses on tangata whenua, researchers should work with hapū, iwi, and other Māori communities – including Māori academic colleagues and bodies such as Toi huarewa and Māori research entities within the University – in designing their research. Where appropriate, researchers may need to consult with local tangata whenua;
  - (ii) Protection: Researchers should ensure that their research actively respects tangata whenua rights and culture;
  - (iii) Participation: Where research focuses on Māori participants, Māori should be involved in the design, management, analysis and outcomes of the research; and
  - (iv) Practice: For research focusing on Māori, researchers should provide space for Māori research practices, which includes the use of Te Reo Māori, and Māori ontology, epistemology and methodologies.

- (b) In all of the above, researchers must consult carefully with Māori whānau, hāpu or iwi concerning the correct protocols and practices that should be observed during any research that involves them.
  - 3.3 Minimisation of harm:
    - (a) To participants: It is unacceptable to expose participants or third parties to unnecessary harm. If significant harm (either physical, psychological, socio-cultural, or spiritual) is possible, research should not commence until steps have been taken to minimise or to eliminate any such risk of harm.
    - (b) To the researcher: It is important to ensure the safety of the researcher and those assisting, as well as the participants. The minimisation of harm includes obtaining HEC approval before commencing research. HEC approval must also be obtained before undertaking research with highly sensitive information.
  - 3.4 The principle of academic freedom is defined in the [Education Act 1989](#). It includes the freedom of academic staff and students to engage in research, and the freedom of academic staff and students, within the law, to question and test received wisdom, to put forward new ideas and to state controversial or unpopular opinions.
  - 3.5 Researchers have a responsibility to be sensitive to significant social and/or cultural practices of the communities to which individual participants may belong. This may include the principles of partnership, protection, participation and practice, referred to in the context of the Treaty in 3.2(a), to guide the development of the research project in a way that is empowering and culturally appropriate.
  - 3.6 All research proposed to the HEC must align with established principles of responsible research conduct, including:
    - (a) The project must have research and teaching merit;
    - (b) The benefits of the research weighed against the commitments required from its participants must be justifiable and not trivial;
    - (c) The researcher/supervisor must have appropriate qualifications and/or expertise to conduct and supervise the research;
    - (d) The research must be well designed, using appropriate methodologies and protocols. The research design must make it possible to meet the identified goals of the project; and
    - (e) Researchers should appropriately acknowledge the work of others and should not present the work of others without attribution appropriate for the medium of presentation or by omitting reference to the relevant published work of others.
  - 3.7 The [Staff Conduct Policy](#) also sets out standards of conduct at the University, definitions of research misconduct, and procedures to be followed in the case of misconduct in research.
- 4. General Procedures of the HEC**
- 4.1 Before commencing research, the lead investigator of a human research project (apart from those projects identified at 4.3) should complete the HEC's online screening questionnaire. This screening will determine the level of HEC review required.
  - 4.2 Certain research activities of negligible risk may not require review by the HEC. These activities may include:

- (a) Some interviews which seek non-sensitive factual information (e.g. requests for statistical information or information about services from public agencies);
  - (b) Most research involving publicly available documents or information, apart from highly sensitive information, and apart from instances where individuals might be unwittingly identified from such information; see further comments relating to research with electronic data; and
  - (c) Public figures interviewed about their work or profession.
- 4.3 Certain preliminary or auxiliary procedures are exempt from HEC review, although they include participants or data. These procedures are exempt as they do not constitute research. Staff or students engaged in these procedures are not required to complete a screening questionnaire. Such procedures may include:
  - (a) Preliminary interaction or discussions which are not recorded and which are undertaken solely for the purpose of formulating research objectives; and
  - (b) Informal discussions with colleagues, family, and friends, or as a contribution to a class discussion or project, in either case where no formal publication of the data is intended and no identifying information is reported.
- 4.4 Reviews, evaluations, or surveys conducted within the University for the purposes of critically examining and improving education practices and University processes (e.g. management reviews of University processes, teaching staff, module, or programme evaluations, statistics, performance data of broad groups such as mature students, international students, staff and student surveys, etc.) are also exempt from HEC review. All such reviews, evaluations, or surveys must meet the University's ethical standards. For example, potentially sensitive data that is identifiable (such as comments collected via email) must be collated and de-identified by a neutral administrator. HEC approval is required before commencing any research where the data is identifiable and will be published outside the University, whether as academic research or otherwise.
- 4.5 Where access to personal information located outside the University has been granted by an agency holding the information, an application for ethical approval is still necessary.
- 4.6 Where researchers are collaborating with researchers at other New Zealand tertiary institutions, ethical approval should be sought from the ethics committee of the lead researcher, provided it is HRC accredited. If this is not the case, an application should be made to the Victoria University HEC. If the lead researcher is based at a tertiary institution in another country, and that institution has granted ethical approval, the research may be approved at the discretion of the Convenor of the HEC or sub-committee chair following review of the external documentation.
- 4.7 Each person named in an application must provide confirmation of their agreement to be responsible for the research and indicate they agree to conduct the research ethically and in a manner entirely consistent with the details supplied in the application. For more guidance, see the ethical principles outlined above.
- 4.8 Applications can only be made by:
  - (a) Academic staff of the University; Postgraduate research students, Honours students, and certain 300-level students (at the discretion of the HE Convenor) under the supervision of permanent academic staff. Student applications must be carefully reviewed and approved by supervisors before being submitted for review and approval, and supervisors must acknowledge their responsibility to

ensure that the research is conducted ethically and in line with the approval;

- (b) Visiting scholars and other persons having some formal association with the University; and
- (c) Members of independent bodies associated with the University.

## 5. Teaching Activities and Research

5.1 The Head of School should ensure that all School/Department/Centre teaching and learning activities adhere to the Human Ethics Policy. When designing courses course coordinators should consider whether any planned teaching activities that include research with human participants comply with the University's Human Ethics Policy. In particular, students' safety should not be compromised and coordinators must ensure that the privacy, rights and freedoms of students and community participants are protected.

5.2 Formal ethical approval is required for relevant teaching activities - that is teaching activities which pose specific ethical risk. These include activities which require students to:

- (a) Reveal personal experiences that may compromise their physical, cultural or emotional safety or result in the disclosure of sensitive information;
- (b) Utilise human tissue;
- (c) Engage directly or indirectly as learning subjects (e.g., observe self or others; engage in interventional projects such as taking blood samples, or any project in which the experimenter or lecturer intervenes to influence the behaviour of individual subjects through manipulation of the social, psychological or physical environment);
- (d) Engage directly or indirectly with members of the community as research subjects and
- (e) Utilise information about other identifiable individuals that is not available in the public domain.

5.3 Formal ethical approval can be given for individual undergraduate courses or for a programme. Programme approval can be utilised when the majority of courses in a programme require approval for similar research projects, otherwise individual course approval is required. Programme approval requires that the course coordinator ensures that all applicable courses in the programme adhere to the conditions of the HEC approval.

5.4 Where undergraduate students are engaged in learning about research activities, course approval is sufficient. Course coordinators must ensure that students engage in ethical research and that students read and are familiar with the HEC Policy and Guidelines before engaging in the research exercise.

5.5 Where postgraduate students are undertaking human research for an individual major project or thesis a specific human ethics application from each student is required in consultation with their academic supervisors.

## 6. Appeals and Complaints

6.1 Where an applicant is dissatisfied with the decision of a Convenor of a subcommittee with delegated authority from the HEC, the applicant may appeal to the HEC.

6.2 A complaint to the HEC may be lodged by any other person. Formal complaints are made in writing to the Convenor of the HEC. Complainants will be kept informed about the progress of

their complaint and will be informed in writing about the outcome.

- 6.3 Any person or body dissatisfied with a decision of the HEC may appeal to the Chair of the University Research Committee.
- 6.4 If the HEC becomes aware through a complaint that there is the likelihood of harm occurring to participants, the HEC may suspend approval of an application while the complaint is considered. During the period of suspension, no research involving human participants, as set out in the ethics application, may be conducted. The grounds for the suspension must be communicated in writing to the applicant.

## **7. Adverse Incidents**

- 7.1 If an adverse incident occurs in the course of the research, researchers are responsible for taking immediate action to protect participants. Following the event, an Adverse Incident Report must be submitted, following the template provided by the HEC, outlining immediate and subsequent remedial action to mitigate harms arising from the event. The HEC will review the report at a meeting of the HEC.

## **8. Ethics Approval for Health and Disability Research**

- 8.1 Health and disability research, or research using human tissue, may be required to be submitted for ethical review by a Health and Disability Ethics Committee (HDEC) established under section 11 of the [New Zealand Public Health and Disability Act 2000](#).
- 8.2 Researchers proposing such research will be directed by the university's HEC screening form to complete the Scope of Review Form provided by HDEC.
- (a) If the Scope of Review form reveals HDEC approval is required, the application must be submitted to HDEC using the online system provided by HDEC for that purpose (which differs from the HEC application form). The Convenor of the University HEC should be named as a sponsor on the HDEC application.
  - (b) If the Scope of Review form reveals that HDEC approval is not required, the applicant must continue applying for approval from the University HEC or the appropriate University human ethics subcommittee. A copy of the outcome advice received from the Scope of Review process and the documentation submitted to HDEC with the Scope of Review form should be attached to the application.
  - (c) The HEC should be notified when an application from the University has been approved by HDEC.

## **9. Ethics Approval for Research with Highly Sensitive Information**

- 9.1 Research into highly sensitive areas carries a risk of harm to human participants and/or a degree of personal risk for the researcher(s) involved. HEC approval is therefore required for all research with highly sensitive information. Researchers who wish to conduct research with highly sensitive information must indicate this on the screening questionnaire. Applications to human ethics subcommittees that include research with highly sensitive information must be referred to the HEC.
- 9.2 If HEC approval for research with highly sensitive information is granted, researchers are not permitted to deviate from the research design. If new research materials or areas of research are required, a new application for ethical approval is required.

- 9.3 HEC approval will allow the university to assist any external investigation into the research activities and will help demonstrate that the research activities are part of a legitimate research project. However, such ethical approval does not guarantee legal protection from investigation by external authorities. Researchers are advised to seek legal advice before commencing research with highly sensitive information.

## 10. Accessing, Storing and Transporting Highly Sensitive Information

- 10.1 Human Ethics application must specify the details of any datasets, web sites (including URLs) and/or activities which will be undertaken as part of the proposed research project.
- 10.2 Researchers who have received Human Ethics Committee approval to conduct research with highly sensitive information must contact ITS to set up provisions for the access and storage of such information. The HEC approval number must be given to ITS, along with any conditions imposed, before provisions for working with highly sensitive information can be made. Access to sexually explicit material is governed by the [Dealing with Sexually Explicit Material Procedure](#).
- 10.3 Researchers must be aware that any web sites associated with illegal behaviour (including extremism and terrorism) and/or the publication of secret, confidential, classified and trade-sensitive material may be subject to surveillance by security agencies. Access to these sites should only be done via the University network. However, this cannot guarantee legal protection from investigation by external authorities.
- 10.4 Researchers are strongly advised to avoid transporting or transmitting raw research materials connected to research using highly sensitive information. Researchers wishing to transport or transmit highly sensitive information should note this in their application. If approved by HEC, researchers will be referred to ITS for a solution or guidance.

## 11. Recruiting Participants

- 11.1 All requests seeking potential participants in a research project must comply with the Human Ethics Policy and these Guidelines. Where a researcher proposes to use an organisation's internal systems to recruit participants, prior permission should be obtained from the organisation.
- 11.2 All potential participants must be provided with an adequate information sheet as part of the recruitment process.
- 11.3 The information sheet should contain the following information:
- (a) Description of who is overseeing the research;
  - (b) Options to refuse research participation;
  - (c) The possible risks and benefits to participants, their significance and likelihood;
  - (d) Provision of services to participants adversely affected by the research;
  - (e) The participant's right to withdraw from further participation at any stage, along with any implications of withdrawal, and whether it will be possible to withdraw data;
  - (f) How privacy and confidentiality will be protected, including data storage and access;
  - (g) Any expected benefits to the wider community;
  - (h) The amounts and sources of funding for the research;
  - (i) Financial or other relevant declarations of interests of researchers, sponsors or institutions;
  - (j) Any payments to participants;



- (k) The likelihood and form of dissemination of the research results, including publication or storage in an institutional repository;
- (l) Contact details of a person to receive complaints (normally the HEC Convenor);
- (m) Contact details of the researchers; and
- (n) Any other relevant information.

## 12. Consent

- 12.1 Consent to participate in research will usually be explicitly provided to researchers, following the provision of an information sheet. Consent will usually be in writing (including electronic), or orally, depending on the nature of the research and the participant's personal and cultural circumstances.
- (a) In some circumstances, consent may be implied by participation e.g. by the return of a survey, or the answering of a verbal question.
  - (b) The method of providing consent in qualitative research depends on various factors, including the type of research, its level of sensitivity, its cultural context, and the potential vulnerability of the participants.
  - (c) In all cases, information sheets must be provided to participants to ensure consent is fully informed; i.e. participants must know what they are consenting to.
- 12.2 Signed consent forms should be held for five years after research results are submitted for publication; however, these should be held separately from the research data itself, so that the identities of participants aren't linked to their contributions.
- 12.3 Organisations must be asked to provide prior written consent to their employees taking part in research projects that pertain to that organisation and also, if appropriate, to their organisation being identified in the research outputs.
- 12.4 Parents and caregivers must give prior consent for children under 16 to participate in research. The children must also give their assent; this should be facilitated in an age-appropriate way.
- 12.5 Consent must be obtained for the use of any visual images generated as part of data-gathering processes. Separate consent must be obtained for the use of these images if they are also to be used for public presentations, teaching and/or publication purposes. Participants must be informed if the visual images will be published in electronic publications, including these which are stored electronically.
- (a) Researchers must pay particular attention to the sensitivities of using images and video/film of children, and should address issues regarding privacy, access, and the retention of such research material.
  - (b) The period of time during which images can be used for teaching purposes or for public presentations should be stipulated at the time consent is sought. In the case of visual images of children and adolescents, it is recommended that this period is no longer than five years, at which point consent for continued use would need to be renegotiated with each subject of the visual images.
  - (c) Where participants themselves generate visual images as part of the research or teaching activities, ownership of the images needs to be negotiated and agreed on as part of the consent process.
- 12.6 Where possible, research findings should be conveyed in a comprehensible form to those who participated in the research. Consent forms and/or information sheets should include an opportunity for participants to indicate that they would like to be sent feedback when the project

is completed (e.g. by ticking a box). When formulating and/or publishing results, researchers must do so within the limits of the consent provided and with any HEC approval conditions.

12.7 Researchers using focus groups need to be aware of and plan for ethical issues which concern confidentiality and withdrawal.

(a) Maintaining confidentiality needs to be emphasised with focus group participants in information sheets and in focus group protocol information. Information sheets and consent forms need to have a statement for participants agreeing not to disclose confidential information from focus groups.

(b) Participants must be informed that withdrawal from the focus group is possible although, for practical reasons, any data collected from them before they withdraw cannot be removed.

### 13. Electronic Observational Research

13.1 Researchers proposing to use electronic media as a source of data for research purposes should consider the following ethical and legal issues when designing their projects:

- (a) Whether the persons who posted the data would realistically be aware of its availability to third parties;
- (b) The sensitivity, including illegality, or the potentially embarrassing nature of the data;
- (c) The vulnerability of those persons or groups who may have posted the data;
- (d) Whether anonymity in regard to reporting the data in a research project can be guaranteed, including whether the data will be aggregated or whether individual quotations will be reported (and could potentially be traced back to an identifiable individual);
- (e) Whether personal images will be used in the research project;
- (f) The terms and conditions of the relevant website or social media platform; and
- (g) The withdrawal process online – whether if a person deletes data they have posted online that data will also be withdrawn from the research project.

13.2 In general, unless it is clear that the nature of the online data, its creators, and the purpose of the website indicates that its creators would reasonably expect it to be available to third parties, comments and information posted on many publicly available forums should not be used without seeking further permission.

13.3 In the case of lists and forums which are only available to members of an association, or who have applied to become subscribers and have been subject to some form of vetting, the permission of the moderator to use data from the forum must be sought.

13.4 Individual contributors should not be identifiable in any use of the data, unless permission has been sought and granted from each individual to be cited. Such permission must conform to the informed consent principles, and other relevant principles of this policy.

13.5 Researchers creating new lists, electronic forums or social networking sites for the purpose of their research must inform all participants when the forum is established, and advise any new participant joining the forum, that comments and information posted to the forum are intended to be used for research purposes. Researchers must also advise what is expected of participants, and what level of confidentiality applies. The information given to participants should state explicitly how the data will be reported (i.e. de-identified, or attributed), where and how the

research may be published, and state clearly that it will not be used for any other purpose. Approval from the HEC or a subcommittee is required before the list or forum is established.

- 13.6 Researchers soliciting participation in research through any electronic list or forum should ensure that their research is relevant to the wider purposes of the list, and provide a brief explanation of the purpose of the research and its benefits in the invitation.
- 13.7 Research involving the posting of false or misleading information is subject to the provisions regarding deception. The HEC application must explain how the benefits of the research outweigh any harm done by the deception involved, any risks to the reputation of the University, and how participants will be debriefed after the research is completed.

#### 14. Compensation for Participants

- 14.1 It is not University policy that participants in research must be paid for their involvement in research. However, there are occasions where koha/small gifts or compensation for time and/or travel may be provided. Researchers are reminded that:
- (a) If a payment of any kind is offered for research involvement, then it must be available to all participants equally and without prejudice. The amount of compensation must be in proportion to the time and /or travel commitments required from participants. Furthermore, the exact nature of or reason for the payment should be made explicit on the information sheet, any advertising, and verbally, if necessary, before any data gathering commences.
  - (b) Participants may decline such payments and request an alternative method of compensation such as a koha/gift payment or payment to a defined organisation or service. In such cases, local protocols and practices should be carefully observed.
  - (c) At no time should payments for research participants be so large as to amount to a perceived inducement to take part in research, or to undertake any act that is likely to cause participants unease, distress, or injury.
  - (d) In any instance where a research participant is deemed to be dependent on others (e.g. children) any payment must be discussed and consented to by those persons responsible for their care and welfare before the commencement of the research.

#### 15. Data identifiability

- 15.1 Researchers should be aware of the level of identifiability of research data.
- (a) Identifiable data allows a specific individual to be identified. This may include direct identifiers such as the individual's name, date of birth or address, but also indirect identifiers, such as particularly distinctive or unique information. Identifiable data is synonymous with personal information.
  - (b) De-identified data is data from which direct and indirect identifiers have been removed or manipulated. This removal or manipulation can be permanent or reversible, partial or complete.
  - (c) Anonymous data has been collected without direct or indirect identifiers, and no personal identifier can be inferred from it.
- 15.2 Researchers may describe their research as 'anonymous' or 'confidential'.
- (a) In anonymous research, the identity of participants is deliberately concealed during the

process of the research, including from the researchers themselves. Data collected is either anonymous or de-identified, and no attempt is made to re-identify participants.

- (b) In confidential research, the identity of participants is known (or potentially known) to the research team during the course of the research. Data collected may be identifiable, but is completely de-identified when published, and no participant's identity is revealed to anyone other than the researchers (except as may be necessary due to a risk of harm to any person or as required by law).

## 16. Privacy and Research Data

- 16.1 All human research which involves the collection of information about an identifiable individual ('personal information') must comply with the [Privacy Act 1993](#). Privacy considerations pertain to every stage of the research project.
- 16.2 Personal information should be collected directly from the individuals concerned, not a third party.
- 16.3 Where a project involves the collection of personal information researchers must take reasonable steps to make participants aware of:
- (a) the purpose for which the information is being collected;
  - (b) the intended recipients of the information;
  - (c) where and how the information will be stored; and
  - (d) the rights of access to, and correction of, personal information.
- 16.4 Personal information collected for one purpose shall not be used for any other purpose without the explicit written consent of any person who is the provider of that information.
- 16.5 Personal information should not be kept for longer than is necessary. In research projects, this means that personal information should not be kept beyond when it is needed to complete the research. The HEC expects data to be de-identified as soon as practicable. Where it is proposed to keep personal information for a longer period than necessary to complete the research this must be justified in the application for ethical approval and participants must give explicit prior consent.
- 16.6 Care should be taken to remove any personal information before publication (including direct and indirect identifiers), unless consent has been explicitly given by the provider of that information. It is essential that photographs and other visual media do not disclose identity information, unless consent has been explicitly given.
- 16.7 The ownership, cultural practices and access to data relating to Māori, Pasifika and other ethnic groups must be respected.
- 16.8 Researchers have an obligation to prevent research data from being lost, mislaid or accessed by unauthorised people. These considerations apply to all kinds of data, but particularly to personal information.
- (a) Personal information must be handled in a way which protects the identity of participants (unless they have consented to being identified in the research outputs) and ensures the secure custody of data. The HEC requires that personal information will be held only on protected systems supplied by the University (not on personal or portable devices or in unauthorised cloud storage, such as Google Drive or Dropbox).

- (b) Researchers, supervisors and teachers must ensure that all data is protected by safeguards against unauthorised access, use, modification, disclosure and other misuse. Appropriate security and backup systems should be used to protect against loss of such data. Particular safeguards may be required for sensitive information.
- (c) The application to the HEC must set out clearly who is entitled to have access to information, including personal information and sensitive information, if applicable. The HEC requires the principal investigator to take responsibility for ensuring data access is managed in line with what is stated in the application.
- (d) The application to the HEC must set out the security provisions proposed in regard to information storage.
- 16.9 The destruction of electronic data requires expert assistance. Professional advice on the most appropriate process must be sought from the University's Information Technology Service.
- 16.10 Privacy requirements must be supplemented with the need for responsible research conduct. That is, data collected and produced through the research process may also need to be archived in an institutional repository for the purposes of preservation, review, replicability and reproducibility. Archiving must be done with the explicit consent of participants to all conditions of the archiving, including the identifiability (or re-identifiability) of the data.

## 17. Definitions

For the purpose of these Guidelines, the following definitions apply:

Adverse incident	Instances of potential or actual physical harm to participants or researchers; potential or actual mental or emotional harm or distress to participants or researchers; and any other unforeseen events that raise ethical issues.
Cultural sensitivity	An awareness of, and appropriate response to, the cultural backgrounds, beliefs, and practices of members of a group or community.
Electronic media	Data in the form of opinions and information posted by individuals to any electronic forum, such as discussion boards, electronic lists, and social network sites.
Personal information	Information about an identifiable individual.
Potentially vulnerable person	Persons with a restricted ability to make independent decisions about their participation in a study and/or persons who may be particularly susceptible to harm because of their health status, physical or mental capacity or employment status, or as a result of imprisonment.
Publicly available information	Information in the public domain.

Sensitive information

Information about illegal activities or behaviour. Private information that could, if made public, offend, cause commercial or emotional damage or embarrassment.