

**UNIVERSITY OF AUCKLAND
HUMAN PARTICIPANTS ETHICS COMMITTEE
(UAHPEC)**

APPLICANTS' REFERENCE MANUAL

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Owned by: DVC(Research)
Approved by: Prof Jim Metson
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1. THIS DOCUMENT

1.1 Purpose

The UAHPEC Applicants' Reference Manual is written specifically for members of the University of Auckland involved in research with human participants. It is intended to provide guidance to researchers and ethics advisors on the ethical conduct of research projects, and on the process of applying for ethics approval from the University of Auckland Human Participants Ethics Committee (hereafter "UAHPEC"). The manual highlights issues to which particular attention needs to be paid during the design and conduct of research.

1.2 Aims

The aims of this manual are to:

- Provide a clear statement of the ethical principles and standards by which research involving human participants at the University of Auckland should be guided
- Draw attention to ethical issues that might arise in the course of a research project and suggest strategies for responding to them
- Provide examples of appropriate wording in the application form and research documents
- Provide information about further resources that may be helpful to the researcher.

Researchers should also refer to both the Guiding Principles for Conducting Research with Human Participants ([Guiding Principles](#)) and the [online ethics training modules](#) when designing research projects and applying to UAHPEC for ethics approval.

2. UNIVERSITY REQUIREMENTS AND ETHICAL PRINCIPLES

The University of Auckland has an obligation to ensure that all research conducted by members of the University conforms to the highest ethical standards.

2.1 Definition of “Research with Human Participants”

For the purposes of this document,

The University understands research to be ‘original, independent investigation undertaken to contribute to knowledge and understanding and, in the case of some disciplines, cultural innovation or aesthetic refinement’ (see Glossary for an expanded definition of the PBRF definition of “Research”).

Research with “human participants” is broadly defined. A research participant is a person with whom there is some intervention or interaction that would not be occurring, or would be occurring in some other fashion, but for the research. Research with human participants includes the acquisition and study of data through intervention or interaction with an individual (a participant), or from personal information even if acquired without direct interaction with the individual. It also includes research on human remains, tissues or bodily fluids. For the University, human participant research is understood to include research using anonymous questionnaires, research within teaching sessions and research carried out as part of coursework, conducted within and outside the University.

UAHPEC [Guiding Principles](#), (2020), p.5

2.2 Key Principles

The University requires research with human participants to be designed and carried out to the highest ethical standards.

To guide researchers in conducting their research to the highest ethical standards, the University acknowledges an ethics framework that encompasses two sets of principles sitting alongside each other. Te Ara Tika is a framework for researchers and ethics committee members developed by the Pūtaiora Writing Group with support from the National Ethics Advisory Committee (NEAC), the Health Research Council (HRC) and Ngā Pae o te Māramatanga (NPM). Te Ara Tika principles are drawn from tikanga Māori (Māori protocols and practices) and its philosophical base of mātauranga Māori (traditional knowledge), and integrate understandings from Te Tiriti o Waitangi, Indigenous values and Western ethical principles¹.

Alongside the tikanga principles is a set of Western bioethics principles shaped over many years in response to international events impacting research and the ethics landscape.

The partnership of these principles are more explicitly described in the National Standards for Health and Disability Research and Quality Improvement (National Ethics Advisory Committee, 2019)², and researchers are encouraged to use these Standards for

¹ Te Ara Tika Guidelines for Māori Research Ethics: A Framework for Researchers and Ethics Committee Members

² NEAC National Ethical Standards for Health and Disability Research and Quality Improvement

guidance to ensure that the ethical principles are reflected in their research projects, even if the project is not health-focused.

The value underlying these principles is respect for people.

2.2.1 Te Ara Tika Principles

i. Whakapapa

Whakapapa refers to relationships: the quality of relationships and the structures or processes that have been established to support these relationships. The relationship between researchers and participants (and New Zealand communities) must involve trust, respect and integrity.²

ii. Mana

Mana refers to power, prestige, leadership or authority bestowed, gained or inherited individually or collectively. It infers that each individual has the right to determine their own destiny upon their own authority.²

Shared knowledge upholds the mana of research participants. Mana relates to equity and distributive justice in terms of the potential or actual risks, benefits and outcomes of research.²

iii. Tika

Tika refers to what is right and what is good for any particular situation. Importantly, in the context of ethics it relates to the design of a study, and whether the research achieves proposed outcomes, benefits participants and communities and brings about positive change.

Tika requires respectful relationships with Māori in all studies, regardless of the research design and methods. Researchers should engage with communities about which research questions are important, and reflect on the ethical issues associated with their study.²

iv. Manaakitanga

Manaakitanga refers to caring for others, nurturing relationships and being careful in the way we treat others. Aroha (respect, love), generosity, sharing and hosting are essential to manaakitanga, as is upholding the mana of all parties.

As well as gathering data, researchers should collaborate with and give back to the community (for example, through koha and sharing ideas).²

2.2.2 Bioethics Principles

(i) Autonomy

The principle of autonomy requires that research participants' capacity for self-determination is treated with respect. Participants should freely consent to their participation in the research study, and their consent should be informed by relevant

information provided by the researchers. Autonomy may also refer to the autonomy of groups in society.

(ii) Beneficence

The principle of beneficence is about acting in the public good; it includes all actions which are intended to promote the good of other people. Researchers should consider how their research might be of benefit to participants, groups and/or wider society. There may be direct benefits to the participant; for example, through the intervention they receive, or to wider society through the results of the research.

(iii) Non-maleficence

Researchers have a duty to consider the harm that their research project might cause and must minimise and manage risks of harm, such as the risk of physical or psychological harm to research participants. The greater the risk of harm that might result from the research study, the greater the care that should be taken when addressing the ethical issues raised.

(iv) Justice

Justice is about treating others equitably and distributing burdens and benefits fairly. Researchers have a duty to ensure that the benefits of their research are achieved through just means; that the benefits and burdens of research are fairly distributed; and that there is fair treatment in the recruitment of participants.

2.3 Te Tiriti o Waitangi

The University recognises that all members of its community are encompassed by Te Tiriti o Waitangi with mutual rights and obligations. The principles of partnership, participation and protection underpin the relationship between the University and Māori under Te Tiriti o Waitangi.

Te Tiriti o Waitangi is a vital component of research ethics. Research proposals must incorporate, where appropriate, the spirit of Te Tiriti o Waitangi. This means that all parties involved in the research project must respect the principles of Te Tiriti o Waitangi and act accordingly whether Indigenous or not, respecting the mutual obligations and responsibilities of the two partners relationship and sharing implicit Te Tiriti o Waitangi.

2.4 The University of Auckland Human Participants Ethics Committee (UAHPEC)

UAHPEC's terms of reference are as follows:

- To ensure that research involving human participants conducted by members of the University community complies with the highest ethical standards
- To protect the interests of participants, the researcher and the University of Auckland
- To promote awareness within the University community of ethical issues relating to research with human participants
- To provide an avenue for handling complaints or queries made by any interested person.

See [University of Auckland Governance and committees](#) for Terms of Reference.

2.5 Membership of UAHPEC

The Committee membership profile reflects the requirements for the University and Health Research Council Ethics Committee (HRCEC) approval. As far as possible, the Committee aims to include the representatives specified in the [“Guiding Principles for Conducting Research with Human Participants”](#).

Overall, the Committee aims to have a balance of institutional and lay members; at least two Māori members; representation from the community at large; an appropriate ethnic and gender balance; and a balance of disciplines and expertise. UAHPEC operates with a two-tier structure, comprising an over-arching committee (UAHPEC) and two sub-committees (HPEC-A and HPEC-B), each serving a similar function and having the same roles and responsibilities.

2.6 Roles and responsibilities

The primary responsibility for maintaining ethical standards in research rests with the research team and, in particular, with the principal investigator/supervisor (PI). The ethical review process provides advice on appropriate ethical standards for specific research protocols, but applicants remain responsible for maintaining all ethical standards throughout the research project.

UAHPEC is primarily concerned with approving applications to conduct research involving human participants. It is not responsible for other ethical matters such as research involving animals or research misconduct.

UAHPEC expects that researchers respect and provide protection for participants at all times. It also expects that the research is conducted in accordance with the ethical guidelines and frameworks of the researchers’ respective professional or disciplinary societies.

UAHPEC’s key ethical principles are consistent with the Health Research Council’s ethics framework. UAHPEC is an HRCEC-approved ethics committee; continuing approval is dependent upon the HRCEC being satisfied that UAHPEC *“is able to offer sufficient protection to the research participants and can maintain the reputation of ethical review in general”*. See page 4 of [HRC Guidelines for Approval of Ethics Committees, 2012](#).

In reviewing applications, UAHPEC reserves the right to seek expert opinion, from individual experts or from relevant committees such as the Health Research Council Ethics Committee (HRCEC), Standing Committee on Therapeutic Trials (SCOTT), Gene Technology Advisory Committee (GTAC), Ethics Committee on Assisted Reproductive Technology (ECART), the National Ethics Advisory Committee (NEAC) and the Health and Disability Ethics Committees (HDECs).

2.7 Research requiring approval

All research involving human participants undertaken by University of Auckland researchers, as defined in the [University of Auckland Research Code of Conduct Policy](#) (hereafter referred to as “Research Code of Conduct”) must obtain ethics approval unless an exemption applies. Approval should be obtained from either UAHPEC, Auckland Health Research Ethics Committee (AHREC) or a Health and Disability Ethics Committee (HDEC). HDECs are the Ministry of Health ethics committees that review health and disability research. However, not all health and disability research requires review by an HDEC. Research exempted from HDEC consideration typically requires review by either

UAHPEC or AHREC.

All research that falls within the scope of AHREC, i.e., research that involves patients or staff from the Auckland DHB must be reviewed by AHREC. Please see Section [3.6](#) for more information about eligibility for AHREC review.

To avoid any doubt, in addition to research being conducted by, or under the direction of, University of Auckland staff, the following kinds of research require UAHPEC approval:

- Teaching involving student-led research within class teaching time with other students
- Student-led research with human participants who are not class members
- Research carried out as part of coursework, conducted within and outside of the University
- Research by any person seeking to conduct a University-wide student survey for research purposes, as defined in the University's *Student Survey Policy and Procedures*. Such applications must be submitted to, and endorsed by, the Planning and Quality Office, ext. 84642, prior to submission to UAHPEC
- Coursework proposals in which students take part as participants in research exercises, such as laboratories, in full or partial fulfilment of their course requirements.
- Audit investigations that have a research component (see Section [11.9](#))

Funded research projects, including those funded by external funding sources and commercial contracts via UniServices, are subject to the same ethical review as all other research projects.

Research projects can commence only after UAHPEC approval has been given. There are no exceptions to this rule and HRCEC approved ethics committees, including UAHPEC, do not grant retrospective approval.

2.8 Research conducted without ethical approval

Failure to obtain ethics approval when it is required, and failure to comply with the policies or conditions set out by UAHPEC, constitutes research misconduct and may give rise to disciplinary action according to standard procedures at this University.

Researchers who do not gain approval risk not being able to publish their research in reputable journals and other possible consequences, and, in the event of a complaint or legal suit, may not be covered by the University's indemnity insurance.

2.9 Research methodology

Researchers must ensure that the research methodology they have chosen is appropriate to answer their research question. Section 5.1 *Research aims and design* in the UAHPEC's [Guiding Principles](#) notes that:

To justify the involvement of human participants, studies must be well-designed. In requesting the time and input of participants, the researcher has an obligation to ensure that the research methods used are adequate to answer the research questions or to realise the research aims and objectives.

The researcher should also show consideration for the guiding principle of beneficence to ensure that research involving human participants has real or

potential value or benefit to participants or the community that justifies participants' time and input.

The Committee acknowledges that student research often has some weaknesses in methodology but that this is counterbalanced by the value of providing training in research methodology.

2.10 Exemptions

Any member of the University who conducts research with human participants must apply for ethics approval unless an exemption applies.

A list of exemptions from the requirement to obtain UAHPEC approval as approved by the University of Auckland Council, is included in Section 3.1.1 of the [Guiding Principles](#). Exemptions can only be approved by the University Council when the [Guiding Principles](#) is updated every three years.

Research that has been approved by another HRCEC-approved ethics committee or an institutional ethics committee may be exempt. See Section [2.7](#) for the ethics approval requirements when research is transferred from another institution and for collaborative research.

2.11 Transferring research and research collaborations

Previously obtained ethics approval: Where a new staff member brings with them a research project from another institution or where research is conducted in collaboration with a researcher from another institution, unless the project has been approved by one of the HDECs or AHREC, the original ethics application and approval must be submitted to UAHPEC for ratification. The Committee may either ratify the approval or require a full ethics application if the approved application from another University / Institution is significantly different from UAHPEC requirements.

If no ethics approval was previously obtained: A new application needs to be submitted to the UAHPEC, AHREC or an HDEC.

Ratification is delegated to the Chair who may refer the decision to a UAHPEC meeting. The researcher must obtain written approval from the UAHPEC Chair prior to undertaking the research. More detail of the ratification process is given in Section [2.12](#).

Where research is conducted in collaboration with a researcher from another institution where ethics approval has not been obtained, a full application for ethics approval must be made to UAHPEC, AHREC or an HDEC.

Where research is conducted with ongoing consultation with cultural groups, individuals and/or organisations, an amendment request must be requested if there is any deviation from the previously approved ethics application.

2.12 Ratification process

To seek ratification for the use of an approved ethics application from another University / Institution, the ethics committee and approval process of that organisation needs to be similar to that of UAHPEC.

The following documentation, written in English, is required to be sent to humanethics@auckland.ac.nz:

- Approval letter
- Approved application (to include all names of the research team)
- Relevant supporting documentation (including any documents for participants)

A University of Auckland academic staff member needs to be named on the approved application.

The University of Auckland requires confirmation that participants will only be those mentioned in the originally approved application and does not include the addition of any potential new participants. If the application does include new participants then a new application will need to be submitted for approval.

Once received, the approval letter and approved application will be sent to the UAHPEC Chair. The Chair has been delegated to review and ratify the application, or can require that a new application be submitted. The research can only start here in New Zealand once an approval letter has been sent to the applicant.

Ratifications are noted at the UAHPEC meetings.

If an amendment request has been made to the approved application of another University / Institution, then the amendment(s) requested and approval also needs to be submitted for ratification by UAHPEC.

If a University of Auckland student is involved then a new application is required through UAHPEC.

Permission for research from another University: If research from another University / Institution is to be carried out within the University of Auckland with no involvement of staff or students of the University in the research team, permission needs to be sought from the appropriate academic head as UAHPEC ratification of ethics approval does not include this.

2.13 Pilot studies

A pilot study is one in which preliminary research protocols are trialled. Since a pilot study involves human participants in research procedures, it requires the approval of UAHPEC. Approval from UAHPEC is required separately for the main study in a new application.

A pilot study should be distinguished from any preliminary discussions with key informants to assist with the development of the research aims or design. Preliminary discussions may lead to revisions of research processes or instruments, but are not intended to provide data for analysis in the study. Such preliminary discussions do not require the approval of UAHPEC.

2.14 Projects with multiple phases or years

If a project has multiple phases, this should be clearly indicated in the study design of the application. A pilot study is not considered to be one of the phases in the research. Separate applications for separate phases of a study may be required by UAHPEC.

If a project is taking place over multiple years, this should be clearly stated in the study design of the application. If any of the research team will no longer be active in subsequent phases of the research, or new research team members are to be included, it should be mentioned in the initial application that an amendment request will be submitted to notify the UAHPEC of these personnel changes.

Researchers should take note of any timeframes mentioned in an application and be aware that whilst applications are approved for a period of three years, the project duration will be as stated in the application and cannot be automatically extended to include other projects over the remaining period unless specifically part of the study design at the time of submitting the application.

2.15 Liability insurance

The University has professional indemnity cover in place that covers "all activities of a researcher" for and on behalf of the University of Auckland. This professional indemnity cover is designed to cover the University's (which includes the researcher's) legal liability to a third party subject to the terms and conditions of the policy. The researcher may not be covered by the University's indemnity insurance if ethics approval has not been obtained.

3. EXTERNAL COMPLIANCE REQUIREMENTS

3.1 New Zealand legislation

The University must ensure that research carried out by its staff and students conforms to various statutory requirements. The [Education Act 1989](#) requires the University to exercise its academic freedom in a way that is consistent with the highest ethical standards.

In exercising their academic freedom and autonomy, institutions shall act in a manner that is consistent with –

(a) the need for the maintenance by institutions of the highest ethical standards and the need to permit public scrutiny to ensure the maintenance of those standards (Education Act 1989, Section 161(3a))

Other legislation may also have an impact on the design and conduct of research projects involving human participants. These include the Privacy Act 1993, Health Research Council Act 1990, Accident Compensation Act 2001, Human Tissue Act 2008, Oranga Tamariki Act 1989, Children's and Young People's Well-being Act 1989, and Vulnerable Children Act 2014.

Researchers in the creative arts should be aware of the Films, Videos, and Publications Classification Act 1993 and consult the Office of Film and Literature Classification before presenting potentially objectionable art to the public.

[Appendix 1 – Associated Documents](#) provides a standard list of legislation. For further consideration, a complete list of New Zealand legislation can be accessed at the [University's Register of Compliance](#).

3.2 Compliance with Health Research Council Ethics Committee (HRCEC) requirements

UAHPEC must meet the HRCEC's requirements in order to maintain its status as an HRCEC-approved institutional ethics committee.

3.3 Compliance with professional codes

Professional codes can impose requirements on researchers in particular professions. Research should be conducted in accordance with professional codes. However, where there is inconsistency between the University's policy on research and a professional code, the researcher should inform, and seek advice from, UAHPEC.

3.4 Requirements of other organisations

A research project may have requirements imposed upon it by an organisation outside the University (such as a funding organisation or a journal in which the researcher wishes to publish). These requirements may affect the design of the study or use of research data and may raise particular ethical issues, such as conflict of interest between researchers, the University, and the outside organisation. Researchers should detail the requirements in their ethics application and explain how these will be met, within the guidelines and requirements of UAHPEC and the University. Any change requested by

another organisation after UAHPEC approval which will affect the conduct of the project as approved must be submitted to UAHPEC for approval before it can be implemented.

3.5 Requirements of the Health and Disability Ethics Committees (HDECs)

Research in the health and disability field may require approval from a Health and Disability Ethics Committee. The HDECs are Ministry of Health committees (established under Section 11 of the [New Zealand Public Health and Disability Act 2000](#)), whose function is to secure the benefits of health and disability research by ensuring that it meets or exceeds established [ethical standards](#).

According to the [Standard Operating Procedures for Health and Disability Committees](#) (August 2014) health and disability research is research that aims to generate knowledge for the purpose of improving health and independence outcomes. There are two main types of health and disability research:

- intervention studies, and
- observational studies

Currently there are four HDECs: Northern A, Northern B, Central and Southern. The online HDEC application system allows researchers to select review by the closest HDEC or to submit their application to the next available committee meeting (which may or may not be the nearest committee).

Details of HDEC meetings can be found at: <http://ethics.health.govt.nz/about-committees/meeting-dates-venues-minutes>

In general, research requires HDEC review, if it involves one or more of the following:

- Human participants acting as consumers of health or disability services, or as relatives of consumers of these services, or as volunteers in clinical trials
- Human tissue, unless informed consent has been obtained for its use and it has not been made available to researchers in a form that could reasonably be expected to identify the individual concerned or there is a statutory exception to the need for consent
- Health information, unless its use has been authorised by the individuals concerned, or unless the researchers receive it in a de-identified form and it cannot be matched by the researcher to another dataset that could identify individuals. <http://ethics.health.govt.nz/operating-procedures>

The HDEC provides a [summary flowchart](#) for confirming whether a research study requires HDEC review.

If UAHPEC considers it necessary to pass on an application to an HDEC for review, the applicant will be advised. Sometimes it may be appropriate for an HDEC to refer an application to UAHPEC because it may fall outside the scope of review of the HDECs. However, a research project should be reviewed by a single HRC approved committee.

3.5.1 Sponsor authorisation

Before an HDEC application is submitted online, it requires authorisation by the University of Auckland as (host) sponsor/one of the sponsors.

A sponsor is defined in the HDEC Standard Operating Procedures as “the person or organisation with responsibility for the initiation, management and financing arrangements of a study”. The use of “sponsor” in this context should not be confused with a funding provider.

The study sponsor and the Coordinating Investigator have the primary responsibility for monitoring approved HDEC applications to ensure that their health and disability research is conducted lawfully.

This authorisation has been delegated to the Ethics and Integrity team, and will be given upon sighting of sign-off by the academic head or his/her delegate.

The required form is available from the website (see link below), and is added to the online HDEC form as an attachment (in the “Other” category).

Further information about how to apply to an [HDEC for review](#).

3.6 Auckland Health Research Ethics Committee (AHREC)

All clinical/health research conducted by staff or students of the University that is not within scope for HDEC review should be submitted to AHREC for ethical review. Clinical/health research is defined as:

“research in which people, or data or samples of tissue from people, are studied to understand health and disease. Clinical research helps find new and better ways to detect, diagnose, treat, and prevent disease. Types of clinical research include clinical trials, which test new treatments for a disease, and natural history studies, which collect health information to understand how a disease develops and progresses over time.”
[NIH National Cancer Institute].

Applications for such research submitted to UAHPEC may be required to be submitted instead to AHREC.

3.7 Requirements of the Ethics Committee on Assisted Reproductive Technology (ECART)

For the purpose of the HDECs, health and disability research does not include research that creates or uses a human gamete, human embryo or hybrid embryo. Such “human reproductive research” requires approval by the Ethics Committee on Assisted Reproductive Technology.

Further information and guidance is available at [ECART](#).

4. APPLYING FOR ETHICS APPROVAL

4.1 Infonetica Ethics RM online system

All applications for ethics approval to UAHPEC, including those for research as part of student coursework, must be made via the Ethics RM online system.

The application can be drafted using the Word copy of the online form on the [UAHPEC website](#), and the content of the final version then copied into the online form.

A number of Quick Reference Guides (QRGs) are available to guide applicants through the application and submission process. The QRGs can be accessed from [here](#).

4.2 Completing an ethics application

When completing the application form, applicants should use language that is free from jargon and is comprehensible to laypeople. If English is not the applicant's first language, seek advice from someone who can assist with grammar, syntax and spelling as necessary.

The ethics approval process requires disclosure of all known relevant information about the proposed research to UAHPEC. The Principal Investigator/supervisor (PI) needs to consider whether a particular piece of information is relevant to the ethics approval process even if the form does not specifically ask for that information to be provided.

4.3 Submitting the ethics application

Only the PI can submit an application for ethics approval. For Doctoral, Masters and Honours research, applications should be submitted by the primary supervisor who will be named as the PI.

If the PI will be unavailable to submit an application, please contact the Ethics Administrators for assistance.

All correspondence regarding individual ethics applications will be addressed to the PI. It is the responsibility of the PI to ensure that all research team members are aware of any relevant correspondence from UAHPEC.

After submission, applications are routed automatically by the online system to the appropriate person(s) for sign-off in each academic unit. Faculties may have additional requirements for the submission of ethics applications to UAHPEC, and applicants are responsible for checking with their faculty ethics advisor if this is the case.

Once academic unit sign-off has been obtained, the ethics application will be accessible to the UAHPEC administrators to include for Committee review. Applicants should ensure they have provided sufficient time to allow for the sign-off process.

UAHPEC will not review the application until it is completed to an appropriate standard. Incomplete and/or poorly constructed applications will be returned to the PI.

4.4 Online application support

For technical issues please raise a [service request](#) with the University Staff Service Centre or contact them on Tel + 64 9 923 6000 ext 86000 (Monday to Friday 7.30am – 6pm).

The Ethics Administrators can assist with phone support. Please contact: humanethics@auckland.ac.nz or ext. 83711.

4.5 Submission deadlines

UAHPEC meets fortnightly from February to December. The agenda closes three weeks prior to a meeting to allow for preparation of the initial application, for revisions to be made as a result of pre-screening and for a preliminary review of the application by UAHPEC members prior to the meeting. Appropriately completed applications received after the deadline are included in the agenda for the following meeting.

After an application has been submitted it is routed automatically to the appropriate person(s) for sign-off in each academic unit. Researchers should therefore **submit applications at least one week before the next submission deadline** to allow sufficient time for academic unit sign-off.

The Ethics team will not be aware of applications until they have been submitted online and signed-off completed. If you are concerned about the progress of your application, contact the Ethics Administrators at: humanethics@auckland.ac.nz or ext. 83711 as soon as possible.

The UAHPEC meeting dates and the deadlines for submitting applications for review are available online on the [UAHPEC website](#).

5. DOCUMENTS TO BE INCLUDED

Researchers need to include all recruitment material as well as data gathering documentation and material as attachments to their application. Information in these public documents must be consistent with information provided in the application form.

5.1 Documents for participants

Documents for participants may include Participant Information Sheet(s), Consent Form(s), advertisements, email invitations, questionnaire(s), list(s) of interview questions, web pages, and confidentiality agreement(s).

All documents intended for participants and/or third parties should be completed to a high standard of written English and must be submitted to UAHPEC in final format on the University of Auckland academic unit letterhead. Documents intended for participants should not include headers such as 'Appendix A'.

5.2 Advertisements for recruiting participants

Any advertisements for recruiting participants, including email invitations and all other electronic or social media invitations, must be submitted to UAHPEC in the format intended for viewing by prospective participants.

The advertisement must include enough information about the research so that potential participants can decide whether they might like to participate in the study. Any characteristics which participants must have, or any which would make someone ineligible to participate, should be stated clearly, for example, age requirements, or the kind of professional experience which may be needed for creative practice research.

When research involves participants with specific aesthetic criteria and professional experience such as used in creative practice, this should be signalled and clarified in the study research design in the application form, and the invitation included as an attachment.

The advertisement should include the source of research funding (if applicable) and contact details for the researcher(s), but does not need to be on University letterhead.

The advertisement should state that the research is being conducted by the nominated researcher(s) and not that the research is being conducted by 'the University of Auckland'.

The UAHPEC approval wording should be included on flyers, advertisements and email invitations. This should read:

Approved by the University of Auckland Human Participants Ethics Committee on for three years. Reference Number

The Committee does not encourage use of personal mobile phone numbers for recruitment purposes unless it is a phone dedicated to a research study. This should be clarified in section L:3 of the application form. University email addresses should be used rather than personal email addresses.

5.3 The Participant Information Sheet (PIS)

The purpose of the PIS is to give enough detail so that prospective participants can make an informed decision about taking part, or not taking part, in research. The PIS should be seen as an essential element, but not the *only* element, in the process of obtaining informed consent from participants. It is an aid to the conversations that form part of the process of obtaining consent and should be a stand-alone document that potential participants can take away to share with others and consider in their own time and place. This may involve them taking the PIS away and thinking about it or discussing it with someone else.

The PIS should use easy-to-understand (non-technical) language and contain sufficient information so that potential participants can understand the key aspects listed below. The amount of information needs to be balanced against the length of the PIS, which needs to be such that potential participants can read it in a reasonable amount of time. Key aspects to include are:

- What the study involves – what will be done by whom, what participants have to do and the purpose of what has to be done
- Potential benefits and risks and how risks will be managed, reported or compensated, including any payments that participants may receive

- The rights of the participant, including voluntary participation and the right to withdraw, the management and protection of their rights to privacy and confidentiality, and their rights to their own or new personal information
- What will happen after the study, including how the results will be communicated and disseminated, and the storage, retention and destruction of data and samples
- The PIS should be offered to the participant to keep and therefore should be presented separately from questionnaires, consent forms or other material that will be returned to the researcher.

Where the research involves different kinds of participant groups, participants of different ages, or different methodologies for different participant groups, it may be preferable to have separate PISs directed to the different groups.

5.4 Essential elements for the Participant Information Sheet

The following is a guide to what should be included in a participant information sheet (PIS). However, please bear in mind that different research projects require different kinds of information to be included. An example layout is shown in [Appendix 2](#) of this document.

5.4.1 Format and language

A PIS should not be written in the style of a letter.

The PIS must be written on University of Auckland academic unit letterhead that includes the full postal address, as well as telephone and email contact details of the PI's academic unit.

Layout should be as simple as possible with font in a style and size that is easy to read. The University style guide recommends Verdana.

The PIS should be written in the first and second person (that is, 'I' and 'you') as if the researcher is addressing the prospective participant. Where consent is required from participants who speak English as an additional language and have limited English language skills, the PIS must be translated into a language that the participant can readily understand.

Avoid jargon and academic terms as much as possible and use language appropriate to the participants (for example, to their age and expected knowledge of the subject). The following online tools may be of assistance in preparing suitable text: the [Oxford 3000™ Text Checker](#) can be used to check that forms use high frequency words from the 3000 word list. [Flesch-Kincaid Reading Ease level](#) of text can be checked using a readability tool.

5.4.2 Introducing the research project – a checklist

- Include a clear, unambiguous title for your research project (use the same title as for the application form)
- If your research has more than one kind of participant, address the document to the participant by role; for example, 'Participant Information Sheet (Manager)', 'Participant Information Sheet (Focus Group)'.

- Include the name(s) of all the researchers and whether they are a staff member or student. If a student, state the name of the degree and academic unit or faculty enrolled in, and include the name(s) of the supervisor(s).
- Include any current position the researcher holds so that potential participants can gauge for themselves if there are any possible conflict of interest issues (for example, if you are a University of Auckland student, but also employed at a different institution or company).
- Invite potential participants to be involved in the research and explain why and how they have been selected, and briefly say what you will ask them to do.
- State that participation in the research is voluntary and the invitation to participate can be declined without giving reason.
- State the rationale for the research.
- State the research methods and procedures to be used in the project, including the time requirement from participants.
- State the duration of the project (when it will happen and for how long).
- State the risks and benefits of the project.
- State if the project has any funding from any organisation and if any third party is involved in the research and/or will be privy to the data and results.
- If the research involves a group (such as students in a class) and some members of the group may decline to participate, indicate what these non-participants will do while the research is being conducted and indicate how the anonymity of non-participants will be preserved (e.g., if you are video-recording the class).
- If the primary researchers come from more than one institution provide all of the relevant institutional contact details.

At the end of the last page of the PIS, include the following:

- Contact details for the researcher, supervisor and academic head. This should include name, phone number, email and/or postal address for the University. Please do not provide any home phone numbers, or personal mobile numbers, email addresses or home addresses. A mobile phone number can be provided when the phone will be dedicated to the recruitment and managing of the project.
- UAHPEC Chair statement and contact details:
For any concerns regarding ethical issues you may contact the Chair, the University of Auckland Human Participants Ethics Committee, Office of Strategy Research and Integrity, University of Auckland, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711.
Email: humanethics@auckland.ac.nz
- UAHPEC Approval wording. This should read: Approved by the University of Auckland Human Participants Ethics Committee on for three years. Reference Number

5.4.3 Research in organisations

If the research is to be conducted in any organisation such as a business, government organisation or school, provide a separate PIS for the chief executive officer (CEO) or other relevant person of authority to ask permission to access the organisation's site and employees as participants.

The PIS should:

- Clearly seek their permission for access to the organisation's facilities and clients/employees/ staff. If the researcher needs the organisation's assistance to recruit the participants, this request should be added
- State that they cannot give permission on behalf of the employee to participate, withdraw their data or be recorded
- State what and when information will be reported to them, and how the confidentiality of participants will be protected. In most circumstances, it would not be appropriate for the CEO or other relevant person to have access to information that compromised the confidentiality of a client, employee, or member. Any proposed exceptions to this provision should be clearly explained in the application form
- Explicitly seek assurances that participation or non-participation will not affect the participant's relationship with the organisation or access to its services. Any proposed exceptions should be clearly explained in the application form.

Where the research is to be conducted with students in a school, separate PISs need to be provided for:

- The boards of trustees/Principals – seeking permission to access the teachers and site, (and for any other assistance required from the School), and requesting assurance that participation or non-participation will not affect the teachers relationship with the school or grades of the students
- Teachers – for access to their classrooms and any other assistance or participation in the research
- Parents of participating students under 16 years of age
- The students themselves

Additionally, the researcher must describe what non-participating members of the class/group will do while other students are participating and whether any information will be obtained about non-participants in the course of the research.

5.4.4 For children under 16 years of age

If participants are under 16 years of age, parents or guardians should first be asked for their consent.

The 'assent' of participants aged under 16 years of age is also required if they are of an age (usually 7 or above) to understand the project and their role in it. 'Assent' means agreement to participate in research by persons who are too young to give their informed consent but are old enough to understand the research project, the possible benefits and expected risks of the research and what they would be expected to do as participants. Even children younger than 7 may be able to understand a simple explanation of what you would like them to do, and agree to it (or not). **Please note that assent by itself is not sufficient**; if assent is obtained, consent must still be given by the participant's parent(s), or legal guardian(s).

In some cases, children under the age of 16 may be able to consent without obtaining parental consent. However, researchers must justify to the Committee why they would not ask for parental consent. In such cases, researchers will normally still be expected to inform parents/guardians of the research.

It is important that the language used in the PIS for under 16 year olds and/or in the assent form is at a level that can be understood by the child.

The researcher must also consider whether the language used in the PIS to describe the research is appropriate for the parent or guardian.

Researchers should consider how participants who are under the age of 16 years when they consent to the use of their data can be given the option to re-consent to the use of their data when they reach the age of 16.

5.4.5 Right to withdraw from participation

Participants have the right to withdraw from participating in the research at any time without giving a reason.

Participants have the right to withdraw their data from the research up to a specified date or period of time unless it is in a form where withdrawal is not possible (for example, the data are anonymised, or are part of a focus group). If data cannot be withdrawn, this must be clearly explained, for example:

Participants have the right to withdraw from a focus group meeting at any time without having to give a reason. However, they will not be able to withdraw their data because its' removal will affect the contextual meaning of the remaining data.

If participants cannot withdraw from participation, for example, participants with professional skills recruited for performance in creative practice research where they will be committing to a sustained process of rehearsals and performances and withdrawal 'at any time' would be contrary to the professional standards within the disciplines of dance, music and theatre, then this must be clearly stated in the recruitment documents and application form.

5.4.6 Anonymity and confidentiality

Please see Sections [8.12](#), [8.12.1](#), [8.12.2](#), [11.2.3](#) and [11.2.4](#) for detailed explanations of what is meant by 'confidentiality' and 'anonymity'.

If participants' and non-participants' identities cannot be kept confidential, it should be indicated and explicitly mentioned in the PIS (and acknowledged in the consent form (CF)) that neither anonymity nor confidentiality can be guaranteed.

If the research involves focus groups, interviews with small numbers of individuals, or interviews with well-known members of the community, researchers should emphasise that they will do their best to preserve the confidentiality of participants, but cannot guarantee that confidentiality will be maintained, and that others may identify participants by their comments.

If confidentiality is offered to participants, it should be made clear how the information that they provide will be reported or published.

It may be appropriate in some research situations to offer participants (for example experts, contributing performers, research taking place in creative practice) the option of being identified in reports of the research. This possibility should be made clear the PIS and CF.

If identifiable data will be seen by third parties, for example for translation or cultural comment, state who will see the data and why, and how the confidentiality of the participant will be preserved. A confidentiality agreement signed by the third parties must be submitted along with the application for ethics approval.

5.4.7 Use of audio, electronic or other media

If audio, video, electronic or other means of recording are involved this should be indicated.

If the recording is essential to the research and participants cannot ask for the recording to be stopped, the PIS should contain an explicit statement informing participants that the recording cannot be stopped.

If the recording is optional, the PIS should explain the option to participants. The PIS should also state: *Even if you agree to being recorded, you may choose to have the recorder turned off at any time.*

The Committee prefers that participants are offered an opportunity to review recordings (audio, video, or photographs) of their responses, and considers a two week timeframe from receipt of transcript appropriate. The process for doing this should be clearly explained in the application form and public documents.

Researchers should also consider how data on the recording device will be kept safe and secure.

If third parties are involved (such as for transcription, translation and/or editing), the researcher should explain to the participant how confidentiality of information and participation will be preserved, such as advising that the 3rd party transcriber will have signed a confidentiality agreement. The application form should include the unsigned confidentiality agreement in the attachments.

The PIS for third parties, such as CEOs, or boards of trustees/principals, should indicate that interviews will be recorded only with the consent of the interviewees (e.g., teachers or employees). Normally, recorded interviews of this type cannot be shared with these third parties, but if this is intended, it must be clearly explained to all concerned.

Participants can withdraw from focus groups, but recording devices cannot be turned off during the discussion or information subsequently withdrawn. You might like to use the following wording:

You may refuse to answer any questions and are free to leave the group discussion without having to give a reason. However, because of the nature of the group situation, the recording device cannot be turned off during the discussion and, if you withdraw from the research, information you have contributed up to that point cannot be withdrawn.

5.4.8 Research outside New Zealand

In general, local contact details for the research project at the overseas location should be provided (to enable participants to make contact easily), as well as contact details at the University of Auckland. If email contact is considered sufficient, this should be explained and justified in the application.

5.4.9 Distress and discomfort

If the research involves any procedure that may reasonably be expected to cause physical, psychological or social discomfort or incapacity, this must be indicated, as should plans for subsequent assistance or referral. Assistance or referral could include having a support person, someone present who has a first-aid certificate or who is medically qualified, and/or giving participants a list of counsellors who can be accessed

without any costs incurred by participants. (Please note, only enrolled students can access support from the [University Health and Counselling Service](#)).

5.4.10 Data retention and sharing

According to the [Research Code of Conduct](#), research data must be retained for at least six years, but preferably indefinitely.

Explain how, where and in what format data will be stored, how long it will be stored for and how it will be destroyed subsequently. Data can be stored in various forms, including tape recordings, discs, videos, computer files and paper records.

State if data is to be transferred to a public repository or made available for secondary research. The conditions under which this is done must be acceptable to both the repository and the participant, and a copy of these conditions provided to UAHPEC.

5.4.11 Research within the University

If students in the academic unit of the PI or other researcher(s) involved in the project are prospective participants, there must be an explicit statement that neither grades nor academic relationships with the academic unit or members of staff will be affected by either refusal or agreement to participate. It should be made clear that participation is voluntary.

The assurance needs to be given by either the researcher, or academic head, or his/her delegate as explained below:

- a. If there is **a possibility** of the researcher recruiting their own students; for example, because they have advertised in the academic unit **and** in the rest of the University, only the PI has to give this assurance. The PI should direct participants to the academic head or his/her delegate if they feel that this assurance has not been met.

The PIS could say:

If you are a student of the researchers we give our assurance that your participation or non-participation in this study will have no effect on your grades or relationship with the University and that you may contact your academic head should you feel that this assurance has not been met.

- b. If the researcher is **specifically targeting their own students**, the assurance must be requested in a PIS for the academic head, making clear the nature of the research, and then given as an explicit statement by the academic head or his/her delegate in a consent form (CF (academic head)) or in a letter of support/permission.

5.4.12 Compensation and funding

State the terms and conditions of any compensation being offered.

Reiterate the absolute right of participants to withdraw at any time. Please note that it is the Committee's expectation that all participants must receive any compensation offered to participants, irrespective if they withdraw from participation.

If funding for the research is being sought or has been obtained, this needs to be stated, as does the funding source.

5.4.13 Approval wording

The UAHPEC approval wording should be shown at the end of the text on the last page of all documentation that will be used in the recruitment process and that will be given to potential participants. The approval date and reference number needs to be completed prior to distributing the documents to participants.

The approval wording should read:

Approved by the University of Auckland Human Participants Ethics Committee on for three years. Reference Number

5.5 The Consent Form (CF)

Typically, UAHPEC requires consent to be recorded on consent forms. The consent form must be written on University of Auckland academic unit letterhead that includes the full postal address together with general telephone and email contact details for the academic unit.

If alternative methods of consent, such as oral consent, are sought, this must be clearly explained and justified in the application. In such instances, the research process must include a procedure for documenting that consent has been obtained.

Where questionnaires are anonymous, UAHPEC accepts a submitted questionnaire as evidence of consent, provided that appropriate information about the research was provided to participants in a PIS.

The consent form must be retained by the researcher and stored (separate from the research data) on University premises under the control of the PI for a period of at least 6 years, or the duration of storage of identifiable or re-identifiable data.

Anonymous questionnaires do not require signing of a consent form, as the submission of the questionnaire is taken as consent to participate.

An example of a consent form can be located at [Appendix 3](#).

5.6 Questionnaires and surveys

5.6.1 Format

A questionnaire is a specifically designed set of questions that a participant completes independently and returns to the researcher. Questionnaires should be submitted to UAHPEC in the final format in which they will be viewed by participants or, in the case of an online questionnaire, in a format that is as close as possible to the proposed final format. Minor editing changes (e.g., correction of spelling errors) can be made after approval of the questionnaire, but any other changes to the wording of questions, or adding or removing questions, must first be submitted for approval by UAHPEC as an Amendment Request.

If an invitation email is being used to recruit participants, the email could contain a link directly to the online questionnaire. In that case the applicants must include in the attachments of their application form the email script incorporating the link address and showing the UAHPEC approval wording at the end of the email text.

Applicants must also attach a copy of the online questionnaire wording that they plan to use. This should include a front page of the online questionnaire providing a link to the PIS, and, if the questionnaire is anonymous, clarification in the front page text that submission of the questionnaire will be taken as consent. UAHPEC approval wording must also be included at the bottom of the introductory section or at the end of the questionnaire.

For all online questionnaires, researchers must ensure that participants are able to print and/or save the PIS section of the questionnaire for future reference.

If the questionnaire is only to be completed by adults, a tick-box should be added where participants can indicate that they are 16 years or older.

If a PIS is sent to participants prior to accessing the online questionnaire, the PIS could contain a link to the online questionnaire from where participants can access the questionnaire.

If participants will be invited to leave their contact details for a prize draw or to receive compensation after completing an online questionnaire, researchers must use an online tool that allows collecting this information separately from the questionnaire content.

If a printed questionnaire is to be used, researchers must ensure that there is a method of returning the completed questionnaires which protects the confidentiality of participants and of data they may have provided (for example, an addressed envelope).

If the questionnaire is anonymous, it should be clearly explained that submission constitutes consent to participating in the research. Any identifying information (for example an email address for future contact) must be detachable from and stored separately from the completed questionnaire.

5.6.2 Reminders

If the researcher wishes to send out a single reminder, a statement to this effect should be included in the original Participant Information Sheet. Multiple reminders are not encouraged. If a researcher is planning to use more than a single reminder, then a justification needs to be included in the study design of the application form.

5.6.3 Gender

The Committee recommends using [Statistics New Zealand's categories](#) to classify gender identity (i.e., the self-identification of an individual's gender): Male, Female, Gender diverse, unless there is a clear reason not to. An option for 'decline to answer' may also be included.

5.7 List of interview questions

If the research study includes interviews with participants, for example, structured or semi-structured interviews or focus groups, a topic guide or proposed list of interview questions must be provided for UAHPEC approval, and a clear indication of the kinds of questions that will be asked given for potential participants in the PIS.

5.8 Observation Schedule

If the research involves collecting data from observation of participants, whether personal observation or through electronic means, a clear statement of the nature of the observations and a list of the kind of data that will to be collected must be provided.

5.9 Confidentiality agreements

Individuals hired as 3rd party research assistants to conduct specific research tasks, such as transcribing or editing data, must sign a confidentiality agreement. Members of the research team do not need to sign a confidentiality agreement (unless this is required by other parties for them to access data).

Specific research tasks that require a confidentiality agreement include (but are not limited to):

- translating
- interpreting
- recording
- recording or editing sound or image data
- entering data
- destruction of data

The PI must provide the Committee with a copy of the proposed confidentiality agreement(s). The agreement should be kept simple and tailored to suit the research project. A statement about the confidentiality agreement needs to be included in the PIS.

An example of a confidentiality agreement for a transcriber can be located at [Appendix 4](#).

5.10 Translations of documents

Some research studies include participants who are fluent in languages other than English and who would prefer to receive written information about the research in that language. In those cases, documents such as the PIS and CF need to be translated into the language in which participants are fluent (usually their first language) so that they are able to understand the information provided and give informed consent.

UAHPEC approval is based on the documents submitted in English; it is the researcher's responsibility to ensure that translations are accurate. UAHPEC recommends using the services of a professional translation service.

UAHPEC also recommends that translations be completed after UAHPEC approval, as amendments to the documents may be required during the review process. Copies of the translated document(s) must be emailed to: humanethics@auckland.ac.nz. Whether translation will be used should be addressed in the application form.

6. APPLICATION PRE-SUBMISSION

To increase the chance of an application moving smoothly through the process, researchers should follow the help notes for specific questions in the online ethics training modules. These have been informed by the changes that are most commonly requested by UAHPEC.

6.1 Faculty ethics advisors

Faculties and academic units that submit a large number of applications have designated ethics advisors who are familiar with the requirements of UAHPEC and can assist applicants in identifying and addressing ethical issues related to their specific research project. Applications that have had ethics advisor input are more likely to proceed smoothly through the approval process and UAHPEC strongly encourages less experienced applicants to seek ethics advisor support.

Names and contact details of faculty and academic unit ethics advisors are available from the relevant academic units and faculties and can also be found on the [UAHPEC Human Ethics](#) webpage.

6.2 Māori ethics advisors

The Pro Vice-Chancellor (Māori) has nominated a Māori ethics advisor in each faculty. Applicants should ensure that they have consulted with a Māori ethics advisor at an early stage of planning their research to ensure that the guidance of the Māori ethics advisors is incorporated in the study design.

Names and contact details of faculty and academic unit Māori ethics advisors are available from the relevant academic units and faculties and can also be found on the [UAHPEC Human Ethics](#) webpage.

6.3 UAHPEC administration and advice

The Ethics Administrators can be contacted for advice and guidance on matters relating to the human ethics application process.

Researchers are also welcome to contact UAHPEC, via the Ethics Administrators, for advice on ethical issues as the need arises; for example, if an unforeseen ethical issue arises during the course of a research project.

The Ethics Administrators can be contacted on ext. 83711 or email humanethics@auckland.ac.nz

7. ETHICS REVIEW PROCESS

7.1 Human ethics review pathways

There are three pathways of ethics review at the UAHPEC: expedited review, full review and out of cycle review.

(i) Expedited review

An expedited project is one in which there is deemed to be a low risk of physical harm, psychological harm, exploitation or other potential adverse effect.

For all applications, an initial determination of the risk level is made on the basis of responses to questions in the application form. Applications that meet the criteria for an expedited review are initially assigned to the expedited ethical review pathway, but during the expedited ethical review an application may be referred to the Committee for full review.

The turnaround time for expedited applications is usually about three weeks from the time of submission of the application.

(ii) Full review

Any research considered to be more than low risk will be placed on the next UAHPEC agenda for full review. After each UAHPEC meeting, the Ethics Administrators will inform PIs of the results of the Committees deliberations, usually within five working days of the committee meeting.

(iii) Out of cycle review

An out of cycle review may take place outside the scheduled Committee meetings when the Committee has closed for the year. UAHPEC will consider a request for an out of cycle review only in exceptional circumstances. Requests for an out of cycle review must be made in writing by the PI to the Chair of UAHPEC, via the Ethics Administrators. An application accepted by the Chair for an out of cycle review will be reviewed by four committee members, including the Chair. Decisions will be ratified at the following Committee meeting.

7.2 Committee decisions

The Committee informs applicants of its decisions in an outcome letter. There are several possible outcomes:

(i) Approved

The ethics application is approved and the proposed research can proceed. The approval date and reference number should be inserted on all documentation intended for participants prior to the research commencing.

(ii) Approved with comment

UAHPEC has given ethics approval with comments or required minor changes.

The researcher can proceed with the study, taking into account these comments. However, when the Committee has requested any minor revisions to public documents such as the PIS and CF, these must be made prior to proceeding with the study, and copies of the revised documents forwarded to humanethics@auckland.ac.nz.

The approval date and reference number should be inserted on all documentation intended for participants prior to the research commencing.

(iii) Conditional approval

UAHPEC requires the researcher to make revisions or provide further information or documentation before the research is able to receive final approval.

PLEASE NOTE: The research cannot proceed until these matters have been addressed and final approval has been received.

The researcher must provide the requested revisions, modifications, clarifications, documents and indicate these in the text of the resubmitted documents using track changes. Each concern mentioned in the letter of outcome must be addressed in a covering memo with an explanation of the changes made and attached to the online form in the Attachment section.

The researcher must receive an approval letter from the Committee before commencing their research. The application does not have ethics approval until the PI has submitted the required responses and received an approval letter.

(iv) Pending resubmission

In this instance, UAHPEC has not granted approval; this is usually because there are substantive ethical issues that still need to be addressed or are unresolved. The applicant will be encouraged to seek (further) advice from an ethics advisor and, in the case of students, also from their supervisor. Expedited applications cannot receive a pending outcome directly, but instead will be referred for full review.

The revised application must be resubmitted within two weeks of receiving the outcome letter in order for it to be added to the next UAHPEC agenda for full review. Any changes made should be listed in a covering memo and changes to the documents clearly indicated using tracked changes.

(v) Empowered

The researcher must contact the nominated Committee member(s) and arrange a meeting/exchange of correspondence with them in order to clarify the concerns of UAHPEC. The researcher then makes the required changes and submits the revised documentation to the Committee member who has the delegated authority to decide the outcome of the application. When the Committee member is satisfied with the changes, the researcher updates the application and submits the revisions in the Ethics RM online system. The reviewer will inform the Ethics Administrators that the application is approvable. Once the researcher receives the letter of approval, the proposed research can commence and the approval will be noted at a UAHPEC meeting.

(vi) Declined

No approval is granted and the project cannot proceed. It is rare that an application is declined. The Committee aims to facilitate researchers in bringing their research proposals up to the standard required for approval.

(vii) Noted

The Committee considered that the proposed collection of data does not require approval from UAHPEC, and the project can proceed.

(viii) Referred to HDEC

UAHPEC cannot provide a review of the research because the proposed research falls within the health and disability research scope that requires review by an HDEC. The researcher must prepare an application using the HDEC online application form and submit it for HDEC review.

(ix) Referred to AHREC

The proposed research falls within the scope of Auckland Health Research Ethics Committee (AHREC) review and should be submitted to that Committee using the AHREC application form.

7.3 Period of ethics approval

Ethics approval is normally given for three years.

7.4 Extension of ethics approval

An extension of approval for a further three years can be requested. A researcher who wishes to request an extension of approval should submit an amendment request to UAHPEC through the Ethics RM online system at least one month before the expiry of the approval. If there are no changes to the research team or the documentation provided at the time of the original approval, this should be stated in the Amendment Request. If there are changes, however minor, resubmitted documents should clearly indicate the nature of the changes.

Requests for extension of an ethics approval that has expired will not normally be considered unless there are special circumstances and the expiry date is less than 6 months past.

If ethics approval is still required for a project after a three-year extension, a new application is required.

7.5 Changes to the research study after approval

Any changes to an approved application requires UAHPEC approval before the changes are implemented. These changes must be submitted to UAHPEC as an amendment request.

This also includes changes suggested to research projects with on-going consultations with external groups. Researchers must submit an amendment request for UAHPEC approval of these changes before they can be implemented. Changes must not be implemented until the amendment request is approved.

If a PI goes outside of the approval granted by UAHPEC it could detrimentally affect their project and ability to publish, and could be a disciplinary issue.

7.5.1 Amendment request

An Amendment Request must be submitted through the Ethics RM online system under the same project number as the approved application. A rationale as to why amendments are being made as well as an explanation of the nature of the change(s) is required. Any amended documents such as the PIS and CF should be attached to the Amendment Request form when applicable.

Minor changes are dealt with under delegation by the Chair. These changes include:

- Changes of research personnel
- Extension/renewal of projects with low-level participant–researcher interactions
- Requests for change that do not increase the demands on participants or introduce new risks.

If the change is substantial, the request for change will be put on the agenda for the Committee to consider, or a new application for ethics approval of the changed project may be required. When the changes are substantial, the request must clarify which sections in the original application will be changed and how it will impact participants and their recruitment.

8. ETHICAL CONSIDERATIONS IN RESEARCH DESIGN

8.1 Recruitment of research participants

In the application, the researcher must describe in detail how he or she will identify potential participants and the method by which participants will be invited to take part in the research.

Public records of names and addresses, such as the telephone directory, or the register of medical practitioners, may be used in the recruitment of participants.

Researchers can request that holders of records/databases that are not public forward information about the research to potential participants, for example, organisations from which the researcher wishes to recruit participants. Those indirectly contacted by this method can then approach the researcher to take part in the research if they are interested.

If the researcher has access to private records of names and addresses in a capacity other than that of researcher in the given project, or where the records are protected by the Privacy Act 1993, it is not acceptable for him or her to recruit participants on the basis of this access. In such a case, the researcher should seek the form of indirect contact described above, by formally requesting a senior administrator of those records to forward information to potential participants.

It will usually not be appropriate for the researcher to recruit members of their own family or friends. As an exception to this general rule, small-scale and minimal-risk research projects on topics that are not sensitive or controversial and conducted by students in the course of studying research methodology may involve the use of family and friends as participants, provided participants are aged 16 years or above.

See Section [11.4.1](#) for information about conducting University-wide surveys of University of Auckland students.

8.2 Audience Reaction in Creative Practice Research

Researchers who are planning to research audience reactions to a live performance or art work in a public venue need to ensure notification to the audience has taken place. This can be achieved with signage, the terms and conditions of entry to an event, or an announcement prior to the performance. The signage could include notification whether audience participants may be identifiable in any future publications of the research, if applicable.

Researchers need to consider if they are intending to use research data that would be published in a form that would not reasonably be expected to identify the individual(s) concerned. What is meant by “a form that could reasonably be expected to identify the individual concerned” will depend largely on the particular circumstances. It is ultimately up to the researchers to determine whether they reasonably believed or believe that the publication was not in a form that could reasonably be expected to identify the individual(s) concerned. If information collected might be published online or used for marketing/advertising purposes, this needs to be considered and made clear to the audience.

8.3 Snowball sampling and direct recruitment

Snowball sampling is an approach whereby current research participants are asked to identify additional potential participants who have expertise or interests relevant to the research project.

In such cases, UAHPEC considers that indirect recruitment should be used. Researchers may ask the current participants to contact other potential participants and pass on the researcher's contact details, and these potential participants can then contact the researcher if they are interested in learning more about the study.

In some studies, researchers may consider that it would be more appropriate to contact the identified potential participants directly to introduce the research. If contact details have been collected for a purpose by a third party, the Privacy Act 1993 prevents their use for other than that stated purpose. However, UAHPEC recognises that contact details held by individuals about other individuals, such as friends, relatives, workmates or schoolmates, are not typically covered by the Act. Where direct recruitment of potential participants is proposed, this must be clearly explained and justified to the Committee.

In some studies, the researcher will know the participants because they are recruiting them from a small pool of experts or leaders in a particular field. The recruitment method in this case may be a combination of direct recruitment and snowballing. In cases such as this, researchers should clearly explain in their application the recruitment method and rationale, any potential problems with this method and how they will address those problems.

UAHPEC requires that researchers consider the sensitivity of the data to be gathered from potential participants. Where these data are sensitive with the potential to cause harm to participants, it may not be appropriate to use snowball sampling.

8.4 Consent

The principle of autonomy requires that research participants' capacity for self-determination is treated with respect. This section outlines the requirements that must be met for consent to participate in research to be valid. Further information about aspects of consent is provided in the sections concerning research with children (Section [8.8](#)) and conducting research in schools (Section [11.11](#)). See section [Appendix 3](#) for an example of a consent form.

Explicit, prior, informed and voluntary consent is required from competent participants in research, with few exceptions. Researchers should keep in mind that it is the quality of the consent rather than the particular procedures or protocols that make the informed consent process ethical. This must involve truthful and respectful exchanges between researchers and potential participants, adequate opportunities for potential participants to ask questions, have their questions answered, and have time to consider whether to participate in the research or not. This means that seeking consent to research is a process, rather than a one-off event, and this process needs to be thoughtfully tailored to the individual research project. Researchers should explain how they have designed the consent process for a particular study, and why it is appropriate.

The Committee does not normally approve 'opt out' consent processes, as it considers that consent to participation in research should be a positive action and that people should not be expected to identify themselves for the sole purpose of refusing consent.

If enrolling participants in a non-medical research project who are not fully competent to give their consent, processes for gaining assent of a legal guardian, someone holding an enduring power of attorney for health and welfare, or someone with an equally valid legal authority to act on behalf of the potential participant must be clearly described, where relevant. Where participants are not competent to give consent, their assent to research should be sought where possible. Please see Section [11.5](#) for guidance for medical related research.

Some research studies include electronic recording of participants. If the recording is essential to the research, participants must be informed that they cannot ask for the recording to be stopped. If the recording is optional, the participant may choose to have the recorder turned off at any time.

8.5 Information for participants

Researchers must provide participants with appropriate information about the research in a comprehensible manner. What information should be provided and how best to do so will vary, depending on the specific research proposal.

Sections [5.3](#) and [5.4](#) indicate the essential considerations and information to be provided to participants. Researchers should carefully consider how best to provide information on these core topics, as well as what additional information, specific to their project, should be provided.

8.6 Voluntary participation

Consent to research must be voluntary, and participants can withdraw from research participation at any time (see Section [9](#)). Researchers should identify possible constraints on free decision-making, such as imbalances of power between researchers and participants, and describe how they can support participants to be able to make free and voluntary decisions. In some cases, for example, participants may feel more able to reach a voluntary decision about participating in a research study if recruited indirectly, rather than directly by the researcher.

8.7 Focus groups (interviews with more than one person)

Focus groups, or interviews with two or more participants at the same time present specific ethical considerations:

- It is not possible to guarantee confidentiality
- Withdrawing information contributed by a participant is generally not possible and risks compromising the integrity and contextual meaning of the data from other participants who do not wish to withdraw from the research
- When a focus group or interview with two or more participants is to be recorded, it is generally not possible for individuals to decline to be recorded. This needs to be made clear in the PIS and participants need to be advised that they cannot ask for the recorder to be turned off, but that they can choose to not answer any question (that is, they can stay silent) or they can leave the room. On the CF, a bullet point must be included where participants can acknowledge their understanding that the focus group will be recorded.

Researchers must advise participants of these issues during the consent process and actively encourage participants to maintain the confidentiality of information shared under such conditions. Focus group participants may be requested to respect

confidentiality of other participants and the group discussions. This should be explained in the PIS and explicitly agreed to in the CF.

8.8 Children

Children require special consideration if they are included in research. Research with participants under the age of 16 years should be undertaken only if there is a specific and demonstrable need for the research, and no other reasonable route to the relevant knowledge is available.

UAHPEC usually requires parent or guardian consent for participants under the age of 16, but it has some flexibility in this regard depending on the nature of the research project. The informed *assent* of the child is also required if he or she is of an age to understand the project. While the researcher should endeavour to obtain written assent, there may be situations involving children where oral assent is acceptable; for example, where there are language or literacy difficulties. Record should be kept of the fact that a child has given assent and how.

Where children are invited to participate in research they and their legal guardian, where required, must be given adequate information about the research and what the child will be asked to do. The researcher must be sensitive to potential conflicts of interest between the parent or guardian and the child. Children must be given information about the research in a form that they can understand. In addition, each child must be advised of his or her right to decline to participate and his or her right to withdraw from the research at any time without giving a reason. Researchers must give the child an opportunity to ask questions and have them answered to the child's satisfaction.

Usually it is sufficient for only one of the child's parents to consent to the child's participation in research. However, the Committee may require the consent of all the child's legal guardians in special circumstances, including where:

- the research is on a topic of particular sensitivity to the child and/or guardians
- there is any risk to the child's physical, emotional or psychological well-being
- the child will be asked to discuss any matter relating to their parents or guardians

In some circumstances, the consent of the child rather than the parent is sufficient. For this to be the case, UAHPEC must be satisfied that the potential child participant will be able to understand their part in the research and the requirements of participation. However, even when the child's consent is accepted as sufficient, the Committee often requires that the child's parent or guardian will at least be informed about the research, even where there are no perceived risks (unless special circumstances dictate otherwise).

In determining whether the consent of parents or legal guardians is required, UAHPEC gives consideration to the following:

- the nature of the research topic and whether it would normally be regarded as being within the comprehension of a child of the age and experience of the intended participants
- whether the research concerns a topic, or involves ascertaining the child's views on a matter, that a reasonable parent or guardian would wish to be informed about because it may affect the child's relationship with them or may cause the child some concern

- whether the research methodology enables the child to have the information, time and support required to give informed consent. In certain circumstances, a child's competence to consent may need to be individually determined
- whether the research is designed or supervised and carried out by people experienced in working with children
- whether the consequences (educational, social, emotional or physical) of participation might be of concern to the parent, guardian or carer

Where a child is not competent to give his or her own consent, the researcher should follow the following process:

- Inform the parent or guardian about the research and advise them of the child's right to decline to participate or to withdraw from the research at any time without giving a reason
- Give the parent or guardian an opportunity to ask questions and have them answered to their satisfaction
- Obtain the consent of the child's parent or guardian before the child is approached for their assent
- Obtain a child's assent to participate if they are able to understand the nature of the project and what participation involves. The researcher should check the child understands by asking them a few simple questions
- Provide a separate PIS for the child. The language used should be appropriate for the child's age and reading ability. Where appropriate, assent may be given orally. The researcher must keep a record of the written or oral assent given
- Respect the child's right to refuse to participate whether or not the parent or guardian has consented on behalf of the child.

If either the child or the parent or guardian declines consent, the child cannot participate in the project. The child's decision not to participate in the research takes priority over any other valid consent.

No financial compensation should be offered to parents or guardians to persuade them to allow their child or a child in their care to participate in a research project. However, children may be offered small gifts, so long as the nature of the gift has been described in the PIS. Compensation for expenses incurred by reason of participation may be offered to the parent or guardian.

In any research where children are videoed or photographed, there must be parental consent.

Please note that UAHPEC will not approve any research to be undertaken by a researcher on the researcher's own children unless exceptional circumstances apply.

8.9 Institutional approval

When conducting research within an institution, researchers should determine what forms of institutional authority for the research to take place are needed prior to recruitment of participants. Typically, executive officers must consent for the research to proceed in their organisation, but only the participant employees can give consent for their own participation.

If researchers consider that it is not appropriate to seek institutional approval, they must justify this in the application and ensure that they address how, in these circumstances, the employer's interests would be protected. An example might be where individuals

with specific expertise from a range of organisations will be recruited rather than research being conducted wholly or primarily within a single organisation. For more information about research within institutions, see Section [11.4](#).

8.10 Documenting consent

Typically, UAHPEC requires consent to be recorded on consent forms. See [Appendix 3](#) for an example.

If alternative methods of consent, such as oral consent, are used, this must be clearly explained and justified in the application. In such instances, the research process must include a procedure for documenting that consent has been obtained.

Where questionnaires are anonymous, UAHPEC accepts a submitted questionnaire as evidence of consent, provided that appropriate information has been provided about the research, for example, in the form of a PIS on the first page of the questionnaire.

Where consent is obtained electronically, researchers must be able to keep a record of participants' consent (except for anonymous questionnaires).

8.11 Privacy and the use of private information in research

Research with human participants involves the collection, use, disclosure and storage of personal information about research participants. At times, this information may be sensitive, particularly where research relates to health.

Privacy is different from confidentiality. It describes the way researchers must manage personal information throughout the information life cycle, whether or not they have made promises that the information will not be disclosed.

Researchers must meet relevant legal privacy requirements and, as members of the University, comply with the University's [Privacy Framework](#). This Framework requires the University to ensure:

- **Data minimisation** – *limiting the amount of personal information the University collects and retains*. Researchers should request from participants only that information which is necessary to their project and not retain information unnecessarily.
- **Transparency** – *being open and honest about what information the University collects and how it will be used*. As part of securing informed consent to participation, researchers should explain clearly in participant information what information they are seeking, for what purpose, and how they propose to use or disclose this information. Researchers can also provide research participants with a copy of the University's Privacy Statement, which includes general information on data security and rights to access or correct personal information.
- **Security** – *protecting the personal information the University holds from harm*. Researchers must ensure that research data is stored securely and not accessed by, or shared with, unauthorised persons. See Section [10](#) Storage, retention and eventual destruction of data for more information.
- **Use limitation** – *making sure the University uses and discloses personal information only when necessary and with a lawful basis*. Researchers must ensure that they use personal information only in the ways they have notified to the

research participants, and the participants have consented to. Any secondary uses of data must be managed in accordance with Section [8.22](#).

- **Privacy rights** – *helping the University's data subjects to exercise their privacy rights and maintain some control over their information*. Requests for access to, or correction of, personal information by research participants should be managed in accordance with the University's [Personal Information Request Procedure](#).

For more information about privacy, the University's Privacy Framework, and international privacy laws that may affect us (such as the EU General Data Protection Regulation), check the Privacy FAQs or ask the [Privacy Officer](#).

8.12 Confidentiality and anonymity

The key principles of ethical research are underpinned by the value of respect for persons. Inherent in this is the need for researchers and UAHPEC committee members to consider how the confidentiality of research participants' identities and data gained from them is protected.

Despite the importance of the terms 'anonymous' and 'confidential' in the context of research with human participants, the difference between them is not always well understood.

8.12.1 Anonymity

Anonymity in research means an anonymous record, biological sample or item of information can in no circumstance be linked to an identifiable person.

In other words, participation in a research study is 'anonymous' if it is impossible for the researcher or anyone else to connect a research participant with the data that the participant has provided.

If potential participants cannot be guaranteed anonymity, they must be told this in the PIS. It is likely that anonymity will not be able to be guaranteed where the number of participants is small, where the outcomes of the research will be released among a small group of informed persons or where research is being undertaken with identifiable members of a community. For example, in a survey of teachers in a school, it may be possible to identify respondents in the research report if sufficient details are given of age, gender, subjects taught and length of time at the school, even if the teachers did not provide their names in the survey.

A common practice in research projects is to assign codes to participants. A research study is not anonymous if the researcher assigns the codes to participants. Therefore, to preserve anonymity, a third party (someone other than the named researchers) must be used to separate the identifiers from the data which is then coded. The third party is required to sign a confidentiality agreement and must undertake not reveal the identities of participants to the research team.

Under normal circumstances, the anonymity of participants completing web-based questionnaires can be guaranteed, even when the IP address of the participant is known. The risks associated with anonymous online questionnaires are similar to those associated with anonymous paper-based questionnaires. However, there are some exceptions as explained in Section [11.2](#).

Research design should consider how to protect the anonymity of non-participants. For example, if a questionnaire is used in a class, ensuring anonymity may make it appropriate that those who have declined to participate should return a blank questionnaire.

8.12.2 Confidentiality

Confidentiality in research means that information is private to the researcher and participant; that is, the information is held by those who share the confidence. The data from the research study can still be linked to individual participants by members of the research team, but not by anyone else.

Where there is the intention, or desire, to make public the names of participants, this should be clearly stated in the PISs and consent gained in CFs.

If potential participants cannot be guaranteed confidentiality, this should be clearly stated in the PIS. For example, participants must be told that confidentiality cannot be guaranteed where participants meet together, such as in focus groups, or in public spaces. Researchers need to have strategies in place to protect confidentiality and must outline these strategies in their ethics application. Consideration must be given to how data will be represented in research reports and to the management, storage and destruction of data. All data should be stored securely, and identifying materials (including key words or codenames) should be stored separately from coded data.

It may be misleading to describe the information collected during the research as confidential if it will be reported or published. An appropriate phrasing for the PIS might be:

If the information you provide is reported/published, this will be done in a way that does not identify you as its source.

Or

If the information you provide is reported/published, this will be done in such a way that will not disclose your identity

Researchers can only give an assurance of confidentiality to the extent allowed by law. Some government agencies and departments, such as the Police, IRD, and Customs, and the courts of law have a legal right of access to certain information. A disclaimer should therefore be included in any stated guarantee of confidentiality that confidentiality will be maintained to the extent allowed by law.

Where third parties (that is, people other than the named researchers) are given access to data that is not anonymous (for instance, for the purposes of transcription or translation), they must sign a confidentiality agreement (see [Appendix 4](#) for an example). Also, the PIS for those who supplied the data should explain how confidentiality will be maintained. Any confidentiality agreement with transcribers or translators must be submitted with the application to UAHPEC.

Where the researcher is given information that reveals a reasonable possibility that the life or health of any person may be at serious risk, the researcher will most likely have moral and legal obligations to breach confidentiality and report that risk to the appropriate authorities and appropriate others. The PIS should inform the participant of this possibility.

8.13 Conflicts of interest

The researcher must address potential conflicts of interests, whether real or perceived, for example, a conflict of interest between their activities as a researcher and their professional and/or personal interests. The researcher must declare in the ethics application form and PIS anything that could be perceived as a conflict of interest, and explain what actions they propose taking to resolve, avoid or minimise the conflict.

Researchers need to be sensitive to potential conflicts of interest if they seek to enrol as participants:

- their students
- those who are (or may perceive themselves to be) dependent on the researcher
- family members
- friends

In addition, researchers must be sensitive to possible conflicts of interest between participants, for example, between parents and their children, principals or CEOs and their staff, or teachers and their students.

To avoid conflicts of interest, or the appearance of conflicts of interest, researchers may not recruit their own children as participants if they are under the age of 16, except in exceptional circumstances that must be justified to UAHPEC (see Section [8.1](#)).

The sponsorship or funding of a project must not compromise its research adequacy or ethical acceptability. If the research is funded, the support and its source must be identified in the PIS or PIS/questionnaire and research reports.

8.14 Minimising harm

Research may carry some risk of harm, and researchers have a duty to minimise that risk and give careful consideration to possible alternative procedures. Researchers should assess their research and discuss any potential for harm, to individuals or communities, in their application for ethics approval. In addition, researchers must be mindful of their own safety and well-being.

Researchers should consider both the seriousness of the harm and the likelihood of the harm occurring, and take account of the balance between these factors.

Researchers cannot completely guarantee the safety of research participants. Therefore, potential participants must be made aware of potential risks during the consent process and agree to them before enrolling in the research.

In their ethics application, researchers must stipulate what monitoring and resources will be available and what procedures will be followed should participants experience harm or distress as a result of participating in the study. If appropriate, the researcher should describe to UAHPEC the experience available in the research team to deal with potential harm.

In addition, researchers must be mindful of their own safety and well-being and if appropriate, describe to UAHPEC how they will manage this.

For further information please refer to Section [5.4.9 Distress and discomfort](#). Further information on risk management and liability insurance is available from the Manager, Performance and Risk (ext. 87834).

8.15 Deception

Some forms of research involve deceiving participants about the purpose of a research study until after it has been completed. For example, some information may be withheld from participants until study completion because giving them this information would jeopardise the validity of the research.

Any study which proposes to use deception requires a clear justification from the applicant as to why the deception is considered necessary and how participants will be safeguarded. Researchers must explain the proposed purpose of the deception in detail and how it varies from the information to be provided to participants in their PIS and CF. In addition, applicants must submit de-briefing material that will be provided to participants, preferably as soon as possible after the conclusion of their participation.

UAHPEC is unlikely to approve any deception of research participants unless:

- the reasons for it are well-justified, such as the significance of the potential knowledge to be gained
- there is no less deceptive means reasonably available
- the research is of minimal risk
- the extent of the deception is explained in the ethics application
- disclosure of the deception takes place as soon as practicable
- participants are offered a debriefing session after the data-gathering in which the deception is explained
- participants have the right to withdraw any data obtained from them by deception

It is never appropriate to deceive the participants about the procedures they will have to follow, or the time the procedures will take, when they take part in the research.

8.16 Review and editing of electronic recordings and transcripts

The Committee recommends that participants are offered the opportunity to review and edit transcripts of recordings and when possible, also to review and edit the recordings. Editing of transcripts is not usually appropriate for focus groups.

Only people who have been recorded should be given the opportunity to review their own recordings or transcripts. CEOs, for example, should not normally be given access to recordings made of their employees or to transcripts of the recordings. If such access is proposed, this must be clearly explained to participants during the consent process. If those who have been recorded are permitted to review recordings or transcripts, a clear description of the procedures, including a timeframe for the editing to be completed, should be given in the PIS. A timeframe must be specific, for example, two weeks after receipt of the transcript.

If participants are not being given the opportunity to review and edit their transcripts or electronic recordings this should be clarified in the application form.

8.17 Ownership and storage of recordings

Indicate in the PIS who will own the recorded data and how the data will be disposed of at the completion of the study. Options include: participants retaining the recording; participants agreeing that the recording will be destroyed; or participants consenting to

the recording being stored in a research archive. If the data have not been publicly archived, which requires the participant's agreement, stored data should be accessible only by the researchers.

8.18 Reimbursement and compensation (token gratuity)

Where participants incur costs from participation in a study, they can be reimbursed. However, compensation, payments, prize draws and gifts for research participants should not be so large as to unduly induce individuals to consent to participate in the research.

Researchers may reimburse research participants for reasonable expenses incurred as a result of participating in the research, such as transport costs. When there is evidence for actual costs, reimbursement should be processed through normal academic unit reimbursement procedures.

It is also acceptable to compensate participants for their time and to give participants a gift or token gratuity to thank them for participating.

Researchers should take into account the following conditions regarding compensation or reimbursement:

- No compensations that could be perceived as inducements should be offered to parents, guardians, or carers to persuade them to include children under the age of 16 in a research project
- No compensations that could be perceived as inducements should be offered to participants who are under 16 years. Small gifts, or opportunities to participate in modest prize draws by way of thanks for participation, may be appropriate
- Where the purpose of a gift or suchlike is to thank participants for agreeing to take part, the gift should apply to all participants, irrespective of whether they withdraw during the project
- The reason for, and the level of, reimbursement, compensation or gifts should be clearly explained in the PIS, CF and in any advertising or promotion of the research
- Participants should be given an opportunity to decline payment or seek recompense in an equivalent or culturally appropriate manner, such as a koha payment to an iwi
- The Committee prefers financial compensation or reimbursement to be given in voucher form rather than in cash

Researchers should be careful about how they describe a payment made to recompense participants for expenses incurred as a consequence of their participation in the research. The term 'remuneration' could imply that there is an employment relationship between the University and the participant and this is clearly not the intention of the University. The term 'reimbursement' means that the participant is being recompensed for their expenses. A 'reimbursement' is also an amount that should not be taxable to the participants. Terms such as 'compensation' (token gratuity) or 'gift' are preferable to make clear that a payment is to thank the participant for their willingness to contribute to a research study. Therefore, researchers might wish to use wording such as:

Research participants will be reimbursed for transport costs that they incur as a result of their participation in this research study.

Or

To recognise the costs involved in participating in this research, participants will be reimbursed \$20 for attending the two focus group sessions.

Or

To thank participants for their contribution to the research, each will receive a \$20 voucher.

The tax treatment of such compensation amounts or gratuities is not always clear and therefore researchers should make no assurances to participants that amounts are tax free to participants. In the documentation that will be provided to participants, participants should be referred to the [Inland Revenue website](#) page on amounts received by volunteers to enable the participants to determine their own tax treatment. Ultimately, it will be up to each participant to decide whether to include the voucher amounts in their annual tax return or personal tax summary.

8.19 Social and cultural sensitivity

Researchers must ensure that their actions and intentions are appropriately sensitive to participants' cultural and social practices and expectations. Where appropriate, the researcher will provide information in the first language of the participants.

Research may involve recruiting members from particular communities or groups be they based on culture, geography, special interests or goals, shared situations or experiences. In such cases, the researcher has a duty to find and use appropriate channels to seek advice and, where appropriate, permission to work with such groups, as well as consulting with them about the appropriate conduct of research.

8.20 Use of human remains, tissue and bodily fluids in research

All applications that involve research involving human remains, tissue and bodily fluids must be submitted AHREC for approval.

8.21 Hazards

8.21.1 General

Many procedures are potentially hazardous in terms of the equipment used (for example, electrical equipment) or the environment in which a study is conducted. Many chemical substances, including medicines, are hazardous or potentially so. Applicants should take account of the safety or otherwise of proposed studies. UAHPEC may refer proposals to appropriate safety experts, including the relevant safety committee, as it deems necessary.

8.21.2 Radioactive substances

The use of radioactive material or equipment capable of generating ionising radiation must be under the control of a person who possesses a licence issued by the National Radiation Laboratory.

Applications for approval for any research or other activity involving the administration of any radioactive substance, or exposure to ionising radiation, can only be undertaken after prior permission for the purpose has been obtained from the National Radiation Laboratory and a specific licence issued.

8.21.3 Biological safety

The use of hazardous micro-organisms or genetically modified organisms must have approval from the University of Auckland Biological Safety Committee. UAHPEC will expect approvals to be included in applications, and it reserves the right to approach appropriate experts.

More information is available from:

- The University Health, Safety and Wellbeing Manager on ext. 84896 for general advice on safety matters contact
- The University's Hazards and Containment Manager on ext. 89466.
Email: francesca.casu@auckland.ac.nz
- The [University of Auckland Biological Safety Committee](#) webpages on the staff intranet

8.22 Secondary data analysis

Some research studies make use of secondary data; that is, data that was originally collected for a purpose other than the current research purpose. Secondary datasets include censuses and clinical records. The same dataset can be a primary dataset to one researcher and a secondary dataset to a different researcher.

Ethical approval will sometimes be required for the use of secondary data. If the data is identifiable or re-identifiable, or if the data was acquired with participant consent which did not include use for the purpose of the proposed secondary analysis, then UAHPEC approval must be sought.

Ethics approval for proposed research may sometimes be required by custodians of data prior to providing access. Permission of the custodian of the data is required for access to secondary data which is not publicly available. Researchers must ensure that the agency that is hosting the research or allowing access to data it has collected has a lawful basis to share that information and has ensured the participants are aware of the ways in which they might use or share the data. Researchers considering giving access to data sets should be aware of the requirements of the [University's Privacy Framework](#).

If personal information collected for a particular research project is to be provided in de-identified form for statistical analysis or analysis in a second project related to the original research such that it would be reasonably seen to be covered by the consent by which the data was originally gained, no further ethical approval is required.

If the data for secondary analysis are identifiable or re-identifiable, an application for ethical approval from UAHPEC for the project will be needed.

If the personal information is to be used for research that is not related to the original research, even if the data re de-identified, you will need to obtain ethical approval from UAHPEC.

For more details on the circumstances permitting the use and disclosure of personal information of research participants refer to *Principles 10 and 11* of the [Privacy Act](#), 1993.

9. WITHDRAWAL OF PARTICIPATION

9.1 Withdrawal from participation in research

Agreeing to participate, and continuing to participate in research, must be voluntary. A research participant is entitled to withdraw from a research project at any stage without giving a reason and this must be explained to them during the consent process.

9.2 Withdrawal of data from research

As a general rule, a participant whose identity is known to the researcher is entitled to withdraw the data they have provided. The PIS must inform participants of this right and give a specific date or timeframe by which the right must be exercised, typically within a set period of time from the data being collected, or before the analysis of research results commences.

If the time constraints of the research or the method of recording data (for example, an audio recording of a focus group) make withdrawal of data by the participant impractical, this must be stated in the consent process and must be specifically consented to by the participant.

10. STORAGE, RETENTION AND EVENTUAL DESTRUCTION OF DATA

All data collected about research participants, including personal information, must be stored or disposed of securely in accordance with the University's policies, including the [Privacy Framework](#) and the [Research Code of Conduct](#).

Information should be handled in a way that protects participants' confidentiality and ensures the authenticity, integrity and safe custody of the data. Where research involves the use of audio, video or electronic recording, special attention is required to protect confidentiality and security of data.

Clear indication should be given to UAHPEC and to participants regarding the storage and retention of data. Data stored for the purpose of the original research should be accessible only by the researcher (and supervisor in the case of students). Identifiable personal information about research participants should be retained for no longer than the researcher, or the University, has a lawful purpose to use it. Data may be retained for longer periods where it has been meaningfully de-identified.

10.1 Storage considerations

The principal investigator/supervisor (PI) should consider where the information is to be stored, especially if it is in electronic format. Some kinds of storage, for example, in the Cloud, may have particular issues to consider. The PI needs to address considerations such as where the Cloud is located, who 'owns' the data, and what happens when the data are deleted. The PI also needs to consider the format in which the data are stored. The software will need to be something fairly stable and widely accessible, otherwise it may not be possible to access it in a few years' time. Removable media such as USB sticks are easily lost and corrupted and therefore are not recommended.

Storage of data for posterity and future research that involves transfer to a public repository requires a suitable release form negotiated with the participant that clarifies conditions of future access.

Researchers are expected to advise the UAHPEC in their application of their intention to use such storage and the place and kind of access involved, and to include this in the PIS and CF for participants. For advice on such storage, see the Code of Ethical and Technical Practice devised by the [National Oral History Association of New Zealand](#).

In considering storage or disclosure of data, researchers should consider whether material is subject to copyright provisions and ensure compliance with the University's [Copyright Materials Policy](#). Participants should be informed in the PIS of any copyright conditions that may affect their contribution to the research.

10.2 Retention and destruction of research data

The [University's Research Code of Conduct](#) states that:

Original research data should preferably be kept indefinitely. At an absolute minimum, research data should be kept for at least six years, but where research data form the basis of a patent, they should be kept for a minimum of 21 years from the date the patent application was filed. In cases where an ethics committee approval requires data to be kept for a specified minimum period, this must be adhered to. It is important to keep data which have resulted in publication for sufficient time to allow reference to the data by other researchers and interested parties. For published research data, this may be for as long as interest and discussion persist following publication (p.5).

Unless it is intended to keep data indefinitely, a fixed term should be stated rather than 'at least 6 years'. If data are to be kept indefinitely, this intention and the reasons should be made clear to potential participants.

If data are to be disposed of or destroyed this must be done securely. Clear indication should be given to UAHPEC and research participants regarding the timing and manner of data destruction. If data are not to be destroyed, this must be indicated to participants along with the purpose of retaining them.

Destruction of electronic data involves more than just 'deleting'. The PI should seek advice as to the best method of complete destruction.

10.3 Storage of Consent Forms

The University requires that Consent Forms be retained in secure storage, separately from research data the PI for a defined period of at least six years, or as long as identifiable or re-identifiable data is stored. This is the responsibility of the PI. Information relating to storage period must be shown on the Consent Form directly under the "Consent Form" wording (e.g., "This form will be kept for a period of six years").

10.4 Practical steps to ensure secure data storage

Practical steps to ensure the security of the data might include:

- coded storage of information
- identification of participants through the use of key words or codenames
- separate storage of recorded information from transcripts or other identifying material
- where the material is in both paper and electronic format, there should be a link in each part referring to the existence of the other part to make sure that the complete data set is being managed
- having an audit trail to show who, if anyone, has accessed or attempted to access the data

10.5 Contingency plan

The PI needs to have a contingency plan in the event that a researcher leaves the University before the end of the stipulated storage time or in the event that the storage area is no longer available or accessible (this applies to electronic data as well).

University of Auckland data will remain the property of the University and become the responsibility of the academic unit involved.

11. Research design – particular types of research

11.1 Research by students

Research activities involving human participants that are to be undertaken by students as researchers require UAHPEC approval.

Student projects for theses or dissertations for credit of 90 points or more must be submitted as individual research applications for UAHPEC approval. Applications are to be submitted by the supervisor, who is the PI. The student researcher must be named and included in the research personnel of the application form.

UAHPEC may consider approval of smaller student projects (less than 90 points credit) in an enrolment-based group, as a coursework application, as indicated below. Student research which is not eligible for approval through a group application submitted by a course or cohort coordination must make an individual application through their supervisor.

UAHPEC recognises that as well as independent research projects for a thesis or dissertation, research and research training activities may be undertaken by students as part of coursework. Student research as part of coursework, and research activities undertaken in class time with students acting as participants or researchers also require UAHPEC approval, using a 'Coursework Application'.

11.1.1 Research for coursework

Ethics approval for laboratory-based courses or other student research projects that involve human participants and are part of undergraduate or graduate coursework requirements should be obtained from UAHPEC by the course coordinator(s). The same UAHPEC application form is used for both research projects and student coursework. When completing the form, the applicant is asked to select whether their application is for a 'Research Project' or 'Coursework Application'.

The completion of a single application form to cover multiple research projects or laboratories can be acceptable in some circumstances, as long as the application relates to a single course and a detailed description is given of all projects.

Coursework applications are for class research projects that either:

- have a common set of research questions and procedures that do not vary from student to student (for example, in laboratories), or
- allow students to choose their own research questions and procedures, as long as these do not vary significantly from those of other students in their course

Course coordinators are responsible for ensuring that students understand and observe the ethical principles and requirements applicable to such projects and for ensuring compliance with UAHPEC requirements.

Where there is a relevant course book or laboratory manual, this may be appended to a Coursework Application, but in any case the nature of the research activities should be clearly described in the application.

(i) Laboratory-based coursework

Laboratory participation is a formal requirement of the course and is stated to be a requirement for the course in the University calendar, academic unit handbooks and other course descriptions. Students may be involved as research participants and/or researchers. The research activities are explicitly pedagogical, contributing directly to the course content and objectives, and the information collected is not for dissemination beyond the course. Acquiring research skills may be one objective of laboratory or course-based research. Individual students are not required to give written consent for their participation, as their enrolment in these courses is taken as consent.

(ii) Students as participants for other students

Some courses include a research or research training activity that takes place in class time, with students from the course acting as participants. UAHPEC requires that participation in these types of research exercises remains voluntary and that alternative activities are provided for students who choose not to participate. Consent to participate should be obtained from each student participant.

A student does not have to participate in any particular research activity should he or she choose not to. UAHPEC requires that participation in a given research exercise remains voluntary. Alternative activities should be provided for students who choose not to participate. Consent to participate should be obtained from each student participant.

Potential class participants should be informed about:

- the purpose of the research activity and its relevance to class objectives
- what the information they provide will be used for
- the extent to which their participation and information will be kept confidential
- any potential risks
- health and safety provisions as appropriate
- that participation is voluntary and what alternatives there are should they choose not to participate

(iii) Performance and creative work courses

In some disciplines (e.g., Dance Studies, Fine Arts, Theatre) students may be expected to act as models or performers for work of other students, as part of learning the skills of the discipline. These are not regarded as involving research or needing UAHPEC approval. Course Coordinators and academic staff are responsible for ensuring the safety of all students involved in these activities and that the activities are not such as to cause embarrassment or distress to students. Course descriptions should make clear prior to enrolment what the expectations of students in the course are. Where coursework involves students seeking participants (including performers or models) outside those enrolled in the course, or asking participating students to provide personal information (e.g., about their life, or personal experiences) the coursework should be submitted to UAHPEC for approval. Where coursework is specified as a research project, it falls under (iv) or (v) below.

(iv) Student research in courses

As part of research training, some courses include small student research projects where either there is a common set of research questions and procedures that do not vary from student to student, or students choose their own research questions and procedures as long as these do not vary significantly from those of other students in the course. It is the responsibility of course coordinators to ensure that students understand and observe the ethical principles and requirements applicable to such projects and for ensuring compliance with UAHPEC requirements.

(v) Some student research projects and dissertations, which are either for course credit or a research component for less than 90 points credits, may be treated as coursework for the purposes of UAHPEC ethics approval, provided that these have a common set of research questions and procedures, or a specified range of research questions and procedures within which students may choose their project. Student projects outside the specified choices, or which raise substantive ethical concerns (such as using child or vulnerable participants, or presenting a risk of more than minimal harm to participants) must be submitted for UAHPEC approval as an individual research application. The Course co-ordinator or designated responsible academic is responsible for ensuring that students understand and observe ethical principles and work within the constraints and requirements of the UAHPEC approval.

11.1.2 Staff Research in class time

Research undertaken during class time for research purposes of a staff member or student who may or may not be a member of the teaching staff of that course must be submitted for UAHPEC approval.

It is University policy that research in class time is only permissible under the following three conditions:

- the research is directly related to course content, and
- the express written consent of the course coordinator is given to conduct the research in class time, and
- the course coordinator is satisfied that the students will be debriefed as to the aims, hypotheses and, where possible, results of the research. Such assurances should be included in any application to UAHPEC

If a research project meets these criteria, the ethics application must be completed as a research application and not a coursework application.

11.2 Internet research with human participants

The Internet is a communication medium in which both social use and technology change rapidly. It is important that applicants using the Internet for research show awareness of the ethical implications of any technology they may use. The recommendations from the [Association of Internet Researchers \(AoIR\)](#) Ethics Working Committee highlight the complexities of Internet research involving human participants, and may help applicants to frame the ethical issues that arise in their own research.

All staff and students contemplating use of the Internet should ensure that their research observes the principles and requirements of UAHPEC. Applicants should also be aware that members of the committee may not be familiar with any given technology, so care should be taken to explain technical details in lay terms.

To avoid confusion, the term 'public sphere' is used in this document to refer to all data that are visible to members of the public. However, although the data are visible, copyright and intellectual property rights may be retained by the owners of the data, and these rights must be respected. Research involving data that would normally be treated as 'personal' or that deals with sensitive issues should be considered particularly carefully.

11.2.1 Research involving data obtained from the ‘public sphere’

Works that are visible to a public audience (that is, in the public sphere) are not necessarily in the public domain. Formally, works in the public domain are those whose intellectual property rights have expired or are inapplicable. The term is not normally applied to situations where the creator of a work retains residual rights. Many of the works available digitally through the Internet (such as websites created and maintained by commercial organisations) are publicly available, but they are not in the public domain since the creator of the work retains copyright. Researchers should ensure they seek appropriate legal advice before they use any of the material from those sites.

Researchers are normally exempt from the need to obtain UAHPEC approval for research where the data are collected from the ‘public sphere’. However, there are a number of situations involving data in the public sphere that need careful consideration by researchers:

- a. Digital data can be searched much more easily than more traditional media, and it is frequently possible to link data in a way that would be practically impossible with non-digital data. This introduces additional risks for contributors to the public sphere since it may be possible to identify the source of ‘anonymous’ posts through search engines. If data obtained from the public sphere are reported in such a way that the author of the data may be unintentionally identified, UAHPEC approval should be sought.
- b. The provenance of data in the public sphere is typically unknown. The data may have been obtained illegally, or (more likely) have been shared without the permission of the original owner. This is particularly problematic for social media sites in which photos that identify individuals, or an individual’s personal data, are shared publicly without their consent. Researchers should avoid using data suspected of being released without permission of the owner.
- c. In some cases, automated search engines are able to access material, even when access for humans is restricted through a registration or log-on process. This makes the material sourced directly from search engines available to a wider audience than intended by the original authors/owners. Researchers collecting information directly from search engines should attempt to determine if such information has been obtained from restricted websites. If this is the case, it does not properly belong in the public sphere and permission would need to be sought from the owner of the data, and UAHPEC approval obtained.
- e. Data collected from the public sphere in which the researcher has participated, or has interacted with the participants, are considered to be problematic. Such research is not considered to be simply an analysis of publicly available archival data, but rather research in which the researcher influences the responses of participants in some way. For all such research, UAHPEC approval should be explicitly sought.

11.2.2 Consent for online research

- a. If data are not in the public sphere, such as sites in which registration is required prior to access, consent would be required from the organisation that manages access. However, consent may not be required from individual participants if the research is considered to be archival in nature.
- b. Researchers performing research that requires online consent should be aware of issues around identity and should make an attempt to address these issues in their application where possible; for example, minors, impaired and vulnerable subjects cannot be readily eliminated from the research.

11.2.3 Confidentiality of data

a. A guarantee of confidentiality is problematic for researchers who wish to use quotations in research because of the relative ease by which text can be tracked to the original source by users who have access to the data. This is especially the case if the researcher does not control the data source (for example, the data source is a forum that is internal to an organisation) or does not control access to the data source (for example, the administrator of a forum may change the access to the forum from private to public).

b. Encryption of data transferred via the Internet is not typically required, although it is more secure than unencrypted data. However, for sensitive data, such as financial data, health data, and other highly personal data, encryption is expected as a normal part of data management to reduce risk.

11.2.4 Anonymity

As discussed in Section [8.12 Confidentiality and anonymity](#), under normal circumstances, the anonymity of participants completing web-based surveys can usually be assured, even when the Internet Protocol (IP) address of the participant is known. However, there are some exceptions.

a. In cases where data are sensitive and the preservation of anonymity is paramount (such as questionnaires involving illegal activities), researchers should take additional steps to ensure IP addresses are not tracked and to inform UAHPEC of these additional steps.

Where the researcher is using a standard third party provider (such as Qualtrics) they should check that the provider guarantees, and can provide evidence, that the IP addresses will not be collected during the course of the survey. As an added precaution, researchers can check that the data are encrypted during transfer.

If the researcher has created their own website to collect responses, they can (for example) assure UAHPEC that the server has been set to NOT record logs of access, or perhaps set up a proxy server to make the results anonymous.

b. In the specific case where a researcher is administering a survey within an organisation and has access to the network within that organisation, the IP address may reveal the identity of the participant. It is possible that other circumstances may arise in which the IP address reveals the identity of the participant. In such cases, anonymity cannot be guaranteed.

11.2.5 Respecting the wishes of participants and organisations involved in Internet research

Much of the information available on the Internet is hosted through companies that may impose additional restrictions on use. Researchers using these services should be aware of the terms and conditions of use and adhere to them. Researchers who want to vary the terms and conditions of use could contact the owner and seek approval to use the information in the way their research requires.

11.3 Telephone research

Where research is conducted by telephone interview, the researcher should:

- Provide UAHPEC with a copy of the research questions to be asked and a script of the information to be given verbally to participants, or make it available on a web platform.
- Confirm the potential participant is aged 16 years or over (by asking them if they are).
- Give the potential participant a verbal explanation of the research, and ask them whether they agree to participate in the research under the terms specified. Audio-record oral consent if at all possible.
- Thank the participant, and provide a contact telephone number at the University in case of any complaints.

In some circumstances (for example, where potential participants are readily identified, their addresses are known, and the sample is not large) it may be appropriate to send an information sheet before conducting the research. This should state that the participant will be telephoned to be invited to participate in the research, or that, if interested, the participant can telephone the researcher.

11.4 Research in organisations

Where an organisation, or part of its operations, is the subject of research, and the researcher proposes to include members of the organisation as participants, the researcher should usually approach the CEO or other relevant person in the organisation for permission for the research to take place. Where potential participants have different levels of status or authority within the organisation, the researcher needs to establish the most appropriate way of gaining access to them.

- While the organisation needs to give permission for the research to take place, each employee has the right to decide whether to participate or not, and to have their participation or non-participation kept confidential from their employers.
- Participants have the right to have the content of their participation kept confidential to themselves and the researcher.
- Participants have the right to an assurance, given by their employer, that their decision to participate or not in the research will not impact on their employment situation or relationship with their employer.
- Employers have the right to withdraw access to their employees at any time, but do not have the right to withdraw participant data already given to researchers as part of the study. This data can only be withdrawn by the participants (when data is identifiable).
- In situations involving participant observation, all potential participants should be informed of the observation and given the opportunity to minimise their participation if they so wish. If researchers propose not to provide such information, this must be justified to the Committee.

Deviations from these rights need to be justified. At all times, the fact that employees are in a dependent relationship with their employers should be borne in mind.

If the organisation or any other party with an interest in the activities of the organisation or participants sponsors the research, this must be stated in the PIS. If a report is to go to the organisation, this must also be stated in the PIS. When participants' comments are reported to the organisation, this should be done in a non-identifiable way if possible. During the consent process, participants must be informed if non-identification

will not be possible.

At times a researcher may want to speak with a person within an organisation because they may be a particular expert in a field, in which case they may be approached externally or separately to their organisation and in these instances there is no need to obtain consent from the CEO.

11.4.1 University-wide surveys of University of Auckland students

The University carefully regulates University-wide questionnaires/surveys aimed at the students. The [Student Survey Policy and Procedures](#) outlines the guidelines that govern such surveys.

Researchers should ensure they check the policy and procedure and reporting guidance prior to submitting an ethics application.

11.5 Research with vulnerable participants

Vulnerable individuals and groups may be included in research projects. Indeed, it is unethical to exclude vulnerable people from research simply because of additional difficulties that this might cause. To do so may restrict their access to research that may be of benefit to them. But it is also unethical to carry out research on vulnerable individuals if this could be carried out just as effectively on non-vulnerable individuals who are able to give informed consent to participation. Research with vulnerable participants requires both special care to avoid possible harms and special care with respect to obtaining informed consent.

Vulnerability may be the result of limited capacity (such as mental capacity) or limited access to social goods such as rights and power. Both individuals and groups may be classified as vulnerable. Vulnerable people potentially include those with mental health issues, children under the age of 16 years, prisoners, the elderly and those with a diminished capacity for self-determination.

Vulnerable research participants will usually need to be treated with special care to ensure that their interests are protected. Researchers should also consider what measures they need to take to protect the interests of vulnerable individuals and groups who are not participating in the research but may be affected by it. Researchers will need to convince the committee that they will be able to protect the interests of vulnerable participants and communities.

Before a vulnerable person can participate in any research study, the researchers will need to obtain the individual's consent if they are competent to give this. The ability to give consent may not be an all or nothing situation, and some people with diminished capacity may be able to give consent to some kinds of research participation, perhaps with assistance from an appropriate support person to understand what is involved.

Where a vulnerable person lacks the capacity to give consent for themselves, a legal guardian or someone holding enduring power of attorney for health and welfare or someone with an equally valid legal authority to act on behalf of the potential participant may give consent for the person's participation in non-health research. This should be accompanied by the individual's assent, if possible. If a vulnerable person decides not to participate, or to withdraw their participation, their decision takes priority over the consent another may have given for their participation.

A welfare guardian or person with power of attorney does not legally have the capacity to consent for the enrolment of someone without capacity to consent if it is a “medical experiment” (i.e. interventional health research), unless the purpose of the research is to save the individual’s life or prevent serious damage to their health.

Health research studies that include vulnerable participants will most likely require review by HDECs. The HDECs use the definition of vulnerable people from the NEAC [“Ethical Guidelines for Intervention Studies”](#).

11.6 Overseas research

Where research is conducted overseas, i.e., the researcher and participants will be located overseas, the researchers must demonstrate in the ethics application that the following aspects have been considered:

- the safety of researchers and participants. Information about risk management in relation to research away from the University can be found at [Health and Safety Risk Management](#)
- the contexts in which the research will be conducted and their relevance to the ethical conduct of research
- local ethics approval (from the overseas country) requirements where necessary or appropriate
- the relevant local regulations, including those relating to the protection of privacy and data as well as requirements for a research visa

A statement that the researchers will comply with local regulations is usually expected in the relevant question on the application form.

Skype, email and similar means of communicating with participants in other countries are not counted as overseas research if the researcher is located in New Zealand. Researchers, however, should ascertain that the countries in which the participants are physically located have no restriction on the use of Skype, email or similar means of communication. Researchers should also ensure that any legislative requirements of the country in which participants are located are met.

11.7 Research into illegal activities

Research involving the study of illegal activities and research that incidentally uncovers illegal activities raises complex ethical, moral and legal questions. The foremost consideration of researchers is the principle of avoiding harm to participants and third parties and to act within the law at all times.

Private citizens have no legal obligation to report illegal activities to the relevant authorities. While the legal obligations of a researcher are the same as private citizens, academic staff and students have additional obligations under the academic freedom provisions of the *Education Act 1989* to act in a manner consistent with “*the highest ethical standards*” (section 161).

Where a researcher collects personal information from participants, the researcher must protect that information from disclosure, whether or not it includes information about illegal activities. However, where a researcher uncovers information about unlawful activities that has not been collected from participants, the researcher may be morally obliged to report such activities. For example, if a property owner has given permission

for research to be undertaken on their property, information about unlawful activities on the property should be reported to the property owner (unless the information was given to the researcher in confidence by research participants). This may include such activities as the cultivation of cannabis or breaches of health and safety legislation. It is up to the property owner to take any subsequent action required.

The PIS and CF must include and acknowledge that if the researcher uncovers any illegal activity that poses a serious threat to the health and safety of an individual or the public, the researcher is required to disclose that information to the appropriate authority.

Participants must also be informed when relevant, that where there is any risk that criminal activities will be disclosed, the researcher will make every effort to ensure confidentiality, but that such communications are not protected in the same way that those with a lawyer or priest acting in their professional capacity are. While confidentiality will be protected from disclosure, the researcher remains a compellable witness. If researchers refuse to testify, they may be in contempt of court and face a prison sentence. They may also be charged as party to the offence if there is any suggestion that they aided and abetted the offence.

While a researcher may be a compellable witness, the standard of proof required by a court of law, particularly in criminal proceedings, is unlikely to be met by information that may be in the possession of a researcher. Unless a researcher has actually seen an offence being committed, or can offer other hard proof of criminality, such as knowledge of the location of proscribed drugs, illegal weapons or stolen goods, most information that is garnered as research data would probably fall into the category of hearsay, if tested in court.

Researchers conducting forensic research and/or who may need to access objectionable publications must be aware of the provisions of the *Films, Videos and Publications Classification Act 1993/Amendment Act 2015*. Publication is widely defined to include anything with images or words imprinted on it. Objectionable material is banned. Objectionable is defined in section 3 of the Act in general terms as sex, horror, crime or violence likely to be injurious to the public good. If a researcher requires access to material that is likely to be regarded as objectionable, application should be made to the Department of Internal Affairs Te Tari Taiwhenua for a publication to be classified, or if already classified, reclassified with restrictions so the researcher can use it. The Department can reduce or waive a fee for a member of an educational organisation on application. If there are a large number of publications for classification, these can be grouped together under one application.

Researchers conducting research into activities that promote or encourage criminal acts or acts of terrorism, such as the manufacture of methamphetamine or explosives, sexual abuse or bioterrorism, need to get clearance from the Department of Internal Affairs Te Tari Taiwhenua (dia.govt.nz) to access certain publications unless they are conducting research on behalf of a crown agency, such as the Police. They may also have to have their research outputs/ publications embargoed to avoid breaking the law.

11.8 Clinical trials

“A clinical trial is any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes” (as defined by the World Health Organization and New Zealand Ministry of Health, and adopted by UAHPEC).

Ethics approval for a clinical trial that does not fall within the scope of HDEC review must be obtained from AHREC.

11.9 Audits

Audit investigations examine practice and outcomes in a particular time and place, and then compare the results with explicit predetermined standards. An audit is typically a retrospective analysis of de-identified data for comparison with previously set standards.

The primary aim of an audit is to inform and improve the delivery and management of a service rather than to add new knowledge. Audit of this kind does not require approval of UAHPEC. However, an audit may sometimes produce results that are of sufficient interest to be further analysed and may become the basis of a research publication. Thus the process of audit merges with research and an audit may be regarded as a type of research, albeit one with more limited ethical concerns, and in these cases, an application to UAHPEC for ethics approval will need to be made. Researchers should seek advice from an ethics advisor or the Chair of UAHPEC if they are unsure whether UAHPEC approval is required.

When a researcher plans to analyse de-identified data from an audit for the purposes of research, or compare de-identified data from an audit with data collected by the researchers, the UAHPEC applications must contain details of how permission for, and access to, audit data will be achieved, and how audit data will be used in the study.

The [*NEAC Ethical guidelines for observational studies \(2012\)*](#) identify 10 main types of audit and associated activities in the area of health and disability services as follows:

1. **Audits** involve the systematic evaluation of aspects of health or disability support service delivery by considering measurable indicators of performance and/or quality.
2. **Programme evaluation** is a type of audit where a whole programme is evaluated, rather than specific interventions.
3. **Evaluation studies** aim to determine the relevance, effectiveness and impact of activities in the light of their objectives. Several types of evaluation are distinguished, including evaluation of the structure, process and outcome of an activity.
4. **Quality assurance activities** aim to improve health and disability support services by assessing the adequacy of existing practice against a standard.
5. **Outcome analyses** involve the assessment of health and disability support service quality by reviewing health care information to evaluate outcomes without comparing them against a standard. For example, clinicians may retrospectively examine health care notes and perform descriptive analyses to determine the outcome of medical treatment or course of a particular illness.
6. **Benchmarking** aims to improve practice through the comparison of two or more health and disability support services.
7. **Public health investigations** explore possible risks to public health, are often of an immediate or urgent nature, and are often required by legislation. Examples are investigations into outbreaks or clusters of disease, analyses of vaccine safety and effectiveness, and contact tracing of communicable conditions.
8. **Public health surveillance** involves the monitoring of risks to health by methods that include the systematic collection, analysis and dissemination of information about disease rates.
9. **Pharmacovigilance** (post-marketing surveillance) involves monitoring the adverse effects of pharmaceuticals after their introduction into the general population, by such methods as the spontaneous reporting of adverse events

and the monitoring of all adverse events for a restricted group of medicines (prescription event monitoring).

10. **Resource utilisation reviews** evaluate the use of resources in a particular health or disability service activity. For example by reviewing health records to determine health care inputs such as chest X-rays for patients with a particular diagnosis.

Comparable activities to many of these occur in other areas, for example in educational practice, in commercial activities and in social and public policy. Where any such activities are combined with research aims or projects, UAHPEC review is required.

Audits and related activities are typically minimal-risk activities. Where they involve retrospective review of data which is de-identified and not potentially re-identifiable they present few ethical issues. The permission of the custodian of such data is usually required for access to the data. Where researchers propose to access identified, partially de-identified, or potentially re-identifiable (e.g., key-coded) data, the issues relating to consent, privacy and confidentiality must be addressed.

UAHPEC requires that applications for approval of audit-based research provide evidence of permission to access data from the custodian of that data, and that either the data provided to the researcher is de-identified and not re-identifiable, or that the researcher(s) who have access to it meet or observe appropriate confidentiality requirements.

11.10 Research in your own work setting

Research in one's own work setting is often beneficial for students and other service users may benefit from providers who are engaged in reflective practice with a view to enhancing and improving the services. However, research in one's own work setting brings with it discrete ethical demands and raises particular issues with regard to ethical approval such as power imbalances and/or conflicts of interest.

In cases where research in one's own work setting will occur, applicants for ethics approval must consider all the ethical concerns that this raises and how they intend to address them. If it will not be possible to resolve these issues when the research is planned in one's own setting, the Committee recommends that the research is then performed in a different setting. The questions below may aid in explaining to the Committee how these issues will be resolved and should be added to the application form.

Please make a clear statement about whether or not the research will be conducted in your own setting. The following questions should be copied and pasted into the Study Design section of the online application form, and the response provided directly below each question:

1. If you are in a position of authority (of any kind) in your setting, how will you manage potential power relationships, conflicts of interest and protect others from the possible or potential negative consequences?
2. Apart from convenience, justify why you should conduct this research in your own settings. Also state the potential benefits to your colleagues, clients, employees.
3. What are the potential or possible risks to the participants now and in the future?
4. How, particularly in settings with small numbers of participants, will you retain confidentiality and/or anonymity?
5. How will you mitigate the conflict of interest in information you are able to access as a staff member as opposed to information you gather as a researcher?

6. How will you ensure that participation is voluntary and that potential participants do not feel under any pressure to participate?
7. When working with colleagues, how will you incorporate ways that your participants can withdraw from your study without any negative effects upon their employment or their relationships with their employer, you, and other colleagues?
8. When working with your own clients or students, how will you incorporate ways that your participants can withdraw from your study? How will you ensure that they are free to withdraw without any negative effects upon their grades or future status with you as someone who may continue to work with them once the research is concluded?

You should attach copies of any permissions and agreements that have already been secured from the setting to do the work.

11.11 Research in schools

When researching in schools, researchers need to give due consideration to the vulnerability of children and the importance of instructional time and activities. In order to make the best use of school time and the participation of the students, and for the research to have maximum relevance and validity, educational researchers need to work cooperatively with schools to ensure that:

- the integrity of on-going school activities is maintained and principals are alerted to possible disturbances that may result from the conduct of the research
- research aims are communicated clearly to parents/guardians, students, boards of trustees/principals
- parents/guardians, students, boards of trustees/principals are updated about any significant changes in the research programme
- research findings and the practical significance of the research are communicated in clear, straightforward and appropriate language to relevant research populations, institutional representatives and other stakeholders as appropriate
- use of research techniques such as experimental interventions that might deprive students of important parts of the standard curriculum, and in this way have the potential for negative social consequences, are minimised.

11.11.1 Discipline-based Professional Inquiry (Education)

In the field of education, it is recognised that teachers working in schools are required as part of their professional responsibilities, to reflect on and inquire into aspects of their current practice with a view to improving their practice. This principle is made explicit in The New Zealand Curriculum that governs work in schools, and is framed as ‘teaching as inquiry’. Such inquiry, which aims to determine evidence-based strategies to support student learning in different contexts, may be conducted with peers and/or students as part of a collective, professional review or development exercise. The latter may include a research aspect, but in this context it is important to recognise that different types of research may be employed to reach this goal. For the purposes of this manual, “research” will be taken to be the PBRF definition of “Research” as discussed in Section [2.1](#) and inquiries falling outside this definition will be termed “professional inquiries”.

11.11.2 Requirement for ethics approval

Usually, professional development or inquiry take place in contexts of pre-existing ethical expectations and regimes. That is, schools act with a duty of care to students, and teachers are bound by the ethical requirements of the Education Council and are expected to act ethically. Also, when taking place in the context of normal classroom

work, the primary purpose of which is to 'practise the profession', they are forms of professional inquiry and evaluation, and are not classified as research (using the definition of "Research" used by UAHPEC, see Section [2.1](#). As such, ethics approval is not required).

However, when such inquiry is being undertaken as part of a wider research project or for a research qualification (honours, masters or doctorate) UAHPEC approval is required.

11.11.3 Professional inquiry

Occasionally 'teaching as inquiry' coincides with, and is an expectation of, studies in professional qualifications (for example, students in pre-service teacher education programmes may be required, when working as teachers during practicum placements in schools, to undertake inquiry into their own work as members of a school community, and to report on outcomes). In these circumstances UAHPEC approval is not required. However, such inquiries must meet the following considerations:

- data are derived from normal processes; that is, information to inform the evaluation of teaching and learning for purposes of professional development (which may include asking students for feedback on the work) is derived from what goes on in the classroom as part of the normal functioning and work of the class
- confidentiality is maintained; that is, in any subsequent reporting on the outcomes of the inquiry, whether to colleagues or others, the identity of class members and the school, if the principal so wishes, is protected from disclosure
- the safety and welfare of all participants are protected
- the use of the collected information is primarily intended to benefit those receiving input in the professional setting (that is, the primary purpose of the inquiry is to improve students' learning outcomes and teachers' teaching)

The intention to report on, or publish, the results of such inquiry does not mean that UAHPEC approval is required for undertaking the inquiry. However, informed approval for public reporting of the outcomes of the inquiry should be obtained from appropriate authorities (e.g., the school principal).

When such inquiry is being undertaken in the context of a professional qualification (such as a Graduate Diploma of Teaching), it is the responsibility of the course director to ensure that the inquiry to be undertaken meets the considerations above. If a course director is unsure whether UAHPEC review of any particular activity is required, he or she should seek advice from an ethics advisor or the Chair of UAHPEC.

Further information about research in your own work setting is available in Section [11.10](#).

11.11.4 Consent process in schools

In all research studies where consent is sought, parents or a person who has the legal authority to consent on behalf of a participant should be sent Participation Information Sheets and Consent Forms for each project.

The information given in Section [8.8](#) *Ethical considerations in Research design, Children* is applicable to research undertaken in schools. That is, students aged 16 years and over are usually deemed to be capable of providing consent in their own right; students

between 14 and 16 years of age may be deemed capable of doing so, depending on the nature of the project.

Where parental/guardian consent is required, the PIS must request parents/guardians to discuss the research invitation with their child. The PIS needs to explain that even when parents'/guardians' consent to their child participating in a research project is obtained, the final decision is the child's.

Issues of anonymity and confidentiality need to be clearly explained in the PIS.

When parental/guardian consent is required, it is not acceptable to include children in the research in the absence of written consent being returned by parents/guardians. The presumption of consent in the absence of a signed CF is not acceptable. The Committee does not normally approve 'opt out' consent processes as it considers that consent to participation in research should be a positive action and that people should not be expected to identify themselves for the sole purpose of refusing consent.

The law does not allow schools to give consent for students in place of their parents/guardians.

11.11.5 Research on teacher practice within schools

When a research project involves only observing teacher practice in the classroom, there is no need to obtain student and parental/guardian consent. However, the students and parents/guardians should be informed in a PIS that researchers will be observing the teacher and that the focus will be on the teacher only.

11.11.6 Recruitment and participation in research in schools

If children in a classroom or other group setting are asked to participate in a research project, procedures must be put in place to protect the anonymity of those children who do not wish to participate, or whose parents/guardians do not wish them to participate.

Prior arrangements should be made with the school to provide alternative activities for children not participating in the research. These should be clearly specified in each appropriate PIS.

To the fullest extent possible, alternative activities should be of equal educational value and without social implications for the children.

In some cases it will not be possible to protect the anonymity of children; for example, where there are separate activities for those who wish and do not wish to participate. If the research topic is of a sensitive nature, the researcher must explain what arrangements they will put in place for students who might suffer emotional harm or psychological discomfort.

See Section [5.4.3 Research in organisations](#) for guidance on obtaining organisational consent.

11.11.7 Research within District Health Boards and healthcare settings

If the application relates to research within the health and disability field but does not require HDEC approval (see Section [3.5](#)) or AHREC approval (see Section [3.6](#)) then please consider the following issues when completing the UAHPEC application.

1. Organisational research approval

Each DHB has a research office that must provide approval for the research to be undertaken in the clinical setting. Other organisations (General Practice, Aged Care etc) will also have a process to be followed to allow the research to be undertaken. It is recommended that the applicant obtain advice within the clinical setting to ensure that the necessary organisational approval is obtained. It is usual practice within a DHB to notify the DHB research office of the research and to then provide evidence of UAHPEC approval once that is obtained.

2. Consent to undertake the research in the DHB unit or other healthcare setting

Please provide a letter of support from a suitable person in a position of leadership within the relevant clinical area (for example Director of Nursing, Clinical Director, Operations manager, Practice manager) stating that they give permission for the study to be undertaken in the setting and providing the necessary assurance statement (that their decision to participate or not in the research will not impact on their employment situation or relationship with their employer (see Section [5.4.3](#))). The person providing the letter of support must not be a member of the research team.

11.12 Research in areas of creative practice and performance

While the ethical principles governing creative practice research are no different from other kinds of research with human participants, there can be complexities about how these apply in different kinds of creative practice contexts.

Some creative practice research involves human participants in activities which are not directly or obviously providing personal data for analysis, but where people are invited to give their time, skills and information to a researcher's project, their free and informed consent is required and ethical approval of the research may be necessary.

It may be necessary in some cases to distinguish parts of the overall creative project or production in order to be clear about which involve human participants and require ethical approval, for example, differentiating the conception and framing of a piece of music, dance or theatre from its performance, though both can be seen as part of one research product.

There may be additional complexity when the performers are contributing to the development and understanding of the work, in similar fashion to participant or action research in other disciplines. It may be important also to provide separate information (for the UAHPEC and for participants) about participation in a creative product and in the textual report/thesis which may be part of the overall project (e.g., participants may not be identified in the thesis, but will be in the accompanying video or performance). In most situations, the primary requirement is that what will happen where, when and why is made clear to prospective participants, so that they can give informed consent to their involvement.

a. Who counts as a participant?

The contributions of people other than the researcher(s) themselves to creative work may make it difficult to distinguish assistants or collaborators from participants.

From the point of view of the UAHPEC, if someone is invited to contribute to a research project by providing information (e.g., about themselves or their response to a creative work) then they are a research participant.

Collaborators are those persons who share in the design, collection of information, and credit for a work. They are co-investigators and should be recorded as part of the research team in an application for ethics approval. People may also be consulted about aspects of the design or production of a work but be neither participants nor collaborators.

'Co-producers' as recognised in the 'Co-Production Form' for Doctoral work that contains co-produced creative practice components could be either co-researchers or participants with respect to UAHPEC applications.

Research assistants may be part of the research team or 3rd parties (who are neither part of the research team nor participants) who provide specific technical skills (such as translation, recording or editing) needed for part of the research. Where 3rd parties will be in contact with participants or information provided by participants, they will need to complete a confidentiality agreement. Research assistants (unless named in the application as part of the research team) also need to complete an agreement in which their role and any confidentiality requirements are set out and formally agreed to. In some situations such assistants may also be covered by an employment agreement or contract.

Where a person is involved simply to perform a work (e.g., a music, dance or theatrical piece) or to be a model (e.g., for a photograph or other art work) and no information is sought from them for the research, UAHPEC does not consider them to be a 'participant'. Hence their recruitment and information provided about their role does not require ethical approval from UAHPEC. They must of course still be treated ethically. There are forms of contract available which may be appropriate to such situations which specify the expectations of both parties in these situations.

Where research involves seeking or recording the responses of an audience/viewer/performer, the person is considered a participant and the research will require UAHPEC approval. Informed consent will be necessary, and should be tailored to the kind of participation. For example, recording an audience's response during a performance may require no more than clear signage explaining that this will happen and the possibility of withdrawing images where these are identifiable. Incorporating audience or viewer responses into the research would need more elaborate processes of informed consent.

b. Recruitment

Recruitment of participants for creative and performing research projects is no different in its requirements from other kinds of research. It is not usually appropriate to recruit family members or friends, except for small-scale and minimal risk student projects. Research with children (aged under 16) should be undertaken only if there is a specific and demonstrable need to perform it and children of the researcher should not be recruited. Researchers should consider carefully how to mitigate any aspects of coercion or pressure to participate that might be felt by those approached. See Section [8.1 Recruitment of research participants](#) for further information.

Advertisements should make clear if there are any specific requirements from participants, such as performance skills or experience or aesthetic qualities, and the time commitment involved. See Section [5.2 Advertisements for recruiting participants](#) for further information.

If special features (such as aesthetic qualities) will be used in selecting from interested participants, it should be made clear in information for potential participants that a selection process will take place, and the basis for this indicated if possible. A copy of the 'rejection' letter for those who were willing but not selected should be provided with the application for UAHPEC approval. The application should make clear for UAHPEC what kinds of features are likely to be used in the selection process.

c. Participant's rights

As well as informed consent, the rights of research participants include the right to withdraw at any point without giving a reason. This can pose a problem for performance of creative works, but while prospective participants may be informed that participation includes their presence at rehearsals and performances, and that they should not consent to participation if they think they may not be able to meet this need, they cannot be told that they cannot withdraw. See Section [9. Withdrawal of participation](#) for further information.

Information for participants should also make clear where recording (audio or visual) is planned, and for what purpose it will be used (e.g., for publicising a performance, as part of the final work, or as illustrative material to accompany the test of a thesis).

Participants may also have rights with respect to the use of images of themselves, both in the production of a work and afterwards. Researchers may need to consider carefully both their proposed use of images and to what extent they can retain control of future use (e.g., if images are published on-line). The situation with respect to any editing rights, or control over the nature and use of images must be made clear in the PIS and acknowledged in the CF.

Where interviews with participants are recorded (e.g., as part of a documentary project), UAHPEC expects that individual participants will be able to view what is to be included in the final cut and may at that point withdraw from the research or ask that something be modified. Where images are of more than one participant, or of some group activity, the same considerations apply as in focus groups – individuals cannot withdraw something if this would affect the contribution of others.

In general, UAHPEC will not approve of deception in research (such as hidden cameras or participants being misinformed about what their participation involves or images will be used for). Any application proposing deception will need to provide strong justification for this and explain how and when debriefing would occur. Debriefing should normally include the possibility that the participant may choose to withdraw from the project at that point. See Section [8.15 Deception](#) for further information.

d. Identifiability and confidentiality

The assumption that participants' identities will be protected may not be appropriate for creative and performance research. For example, it would be normal for performance participants to be named and probably not possible to conceal their identity. However, where participants provide personal information such as responses to a work intended to be used in informing analysis and development, it may be appropriate that this is not be attributed in a way that will identify the person (i.e., the participant's contribution will be confidential). This will depend on the nature of the project and the participation. Whatever is to be the case, participants should be clearly informed about it in the PIS and agree to it in the CF. See Section [8.12 Confidentiality and anonymity](#) for further information.

e. Protection from harm

Researchers are responsible for identifying and minimising possible harms to participants. As well as physical harm, possible harms include psychological and social harms, such as embarrassment. While creative works may push boundaries of acceptability, participants should not be exposed to such harms without their informed consent and appropriate support resources being in place. See Section [12 Conducting the research](#) for discussion.

f. Creative practitioners and researchers need also to be aware of legal constraints or requirements on their actions, particularly with respect to dissemination of objectionable images.

11.13 Māori research

11.13.1 Overview

Researchers should ensure that research projects that involve Māori, or that have clear potential implications of interest to Māori, are developed and conducted in a culturally appropriate way and in a way that is responsive to Māori.

Te Tiriti o Waitangi formalised the relationship between Māori and the Crown. It established the basis on which the partnership between Māori and the Crown was to endure by conferring a set of rights and obligations on each Tiriti partner in recognition of each party as equals. The University recognises that all members of its community are encompassed by Te Tiriti o Waitangi with mutual rights and obligations.

The Education Act 1989 specifically enjoins the University to give regard to Māori. These principles have been developed through successive legislature, Waitangi Tribunal findings and policy development to guide the application of Te Tiriti within a contemporary context, and to address areas of disagreement between the Māori and English versions of the treaty texts. There is much discussion as to what these principles mean, but no comprehensive or definitive set of principles have been created. However, over the years the following principles have become well established:

- Partnership
- Reciprocity
- Protection
- Autonomy
- Mutual benefit
- Equity
- Equal treatment
- Redress

Research proposals must incorporate, where appropriate, the spirit of Te Tiriti o Waitangi. This means that all parties involved in the research project must respect the principles of Te Tiriti and act accordingly whether Indigenous or not, respecting the mutual obligations and responsibilities of the two partners relationship and sharing implicit Te Tiriti o Waitangi.

Te Tiriti o Waitangi is a vital component of research ethics. The principles of partnership, participation and protection underpin the relationship between the University and Māori under Te Tiriti o Waitangi.

Partnership involves working with iwi, hapū, whānau, and Māori communities to develop research design and delivery. Participation, where appropriate, requires Māori to be involved at all levels of the research programme and in the decision-making process.

When research focuses on Māori, or if there are clear potential implications of direct interest to Māori and for Māori, the researcher is required to show that appropriate consideration of the principles has occurred and that consultation has taken place, such as discussing any issues relating to Māori cultural and ethical values with the whānau, hapū or iwi concerned.

11.13.2 Guidelines

Researchers proposing to carry out research involving Māori participants, issues of significance to Māori or Māori research methods are advised to consult the following guidelines:

Te Ara Tika – Guidelines for Māori Research Ethics

This document outlines a framework for addressing Māori ethical issues within the context of decision-making by ethics committees. The framework was developed by Pūtaiora (Māori members of ethics committees) and the National Ethics Advisory Committee (NEAC). The framework draws on Tikanga Māori (Māori protocols and practices).

[Te Ara Tika Guidelines for Māori Research Ethics](#): A framework for researchers and ethics committee members. Te Ara Tika is also included as an appendix in the HRC Guidelines.

Guidelines for Researchers on Health Research involving Māori

These guidelines were produced to assist researchers planning to undertake clinical, biomedical or public health research involving Māori participants or research on issues relevant to Māori health. The guidelines are specifically for applicants for HRC funding but will also assist researchers applying for funding from other sources. The guidelines inform researchers about consultation with Māori and the processes to follow when initiating consultation with Māori.

The Health Research Council's [Guidelines for Researchers on Health Research involving Māori](#):

11.13.3 Further advice

The Pro Vice-Chancellor (Māori) has a nominee (Māori ethics advisor) in each faculty.

12. Conducting the research

12.2 Incidental findings

Research occasionally results in findings that are unexpected and unrelated to the original purpose of the research and which have implications for the well-being and interests of participants and the duties of researchers. The most common examples of such incidental findings are when a research discovers a medical condition in a participant.

When incidental findings are revealed, researchers are expected to advise participants within the limits of their expertise and put participants in contact with appropriate assistance. Nothing in regard to incidental findings should normally compromise participant confidentiality or privacy. However, where the life or health of any person may be at risk researchers may have a legal obligation to breach confidentiality. In recognition of this, the Privacy Act permits the disclosure of personal information in certain situations. See Principles 10 and 11 of the [Privacy Act 1993](#) for further details.

Researchers should have clear policies and procedures in place before the start of a research project to enable them to deal with incidental findings. The researcher must indicate how likely an incidental finding may be, and how large the impact of the finding may be to the participant. If researchers believe there is a reasonable probability of incidental findings, they have a responsibility to inform the participant of this in the PIS. The PIS should also state that if a participant does not want to be informed of such a finding, they should not participate in the research.

12.3 Unexpected Harm

Assessing the safety of research procedures for participants and others is central to the design and implementation of ethical research. Well-considered research will identify possible negative effects for participants together with ways of minimising these and addressing any which may occur. Responding appropriately to an adverse event and reviewing participants' risk is a primary responsibility of researchers.

In their application for UAHPEC approval researchers must identify possible harms or negative effects, and describe procedures for dealing with these. These should also be described in the participant information sheet (PIS) and consent form (CF).

12.3.1 Adverse Events

Adverse events or other unexpected problems can arise in both biomedical, social and behavioural research. Serious adverse events are those that result in death, are life threatening, require hospitalisation, cause persistent or significant disability/incapacity, or other conditions which, based upon appropriate medical judgement, represent significant hazards to the participants. Also included is psychological or emotional disturbance, or infringements of privacy or other rights (for example, from unauthorised access to identifiable personal information or disclosure of confidential information).

Where there is an adverse or serious unexpected event, the first priority is that the researcher ensures that the affected participant(s) immediately receives care and assistance appropriate to the event or outcome.

If an adverse event affects researchers, then the University Health and Safety reporting procedures should be followed.

See the University of Auckland guidelines and procedures for [Responding to and reporting incidents and accidents](#)

12.3.2 Unanticipated Problems

Research occasionally gives rise to findings that are unexpected and unrelated to the original purpose of the research but may have significance for research participants' health or wellbeing. These are referred to as incidental findings.

The expectation of the UAHPEC is that adverse events, serious negative effects and unanticipated problems are recorded, evaluated and monitored by the primary investigator and their research steering committee. If a steering committee has not been assembled for a study, the Director of the Clinic or Laboratory or equivalent senior colleague will fulfil the role of the research steering committee.

Unanticipated problems are to be taken particularly seriously, and it is the responsibility of researchers (in the case of students, through their primary supervisor) to report all unanticipated problems to the UAHPEC on the 'Report Form for Adverse Events and Complaints'. This form is available from the Ethics Administrators: humanethics@auckland.ac.nz or ext. 83711.

As well as reporting the Unanticipated Problem, the researcher should consider:

- what the research participants need to know about the problem and how this might best be communicated
- whether changes need to be made to the research design
- whether or not a change in description of risk is warranted in the protocol, PIS and Consent Form

Where a breach of privacy of any kind has occurred during the conduct of research, the University's Privacy Officer must be notified and may specify requirements for handling the response to the breach.

It is a requirement of the University that work-related incidents or accidents be reported to the Health, Safety and Wellbeing Manager within 24 hours of the event, using the HR Accident/Incident Report form.

See the University of Auckland guidelines and procedures for [Responding to and reporting incidents and accidents](#)

12.3.3 UAHPEC responsibilities

UAHPEC will assess all reported adverse events or unanticipated problem in order to address immediate issues of safety for participants, and any changes in protocol design and implementation needed to protect the interests of current and future research participants. When evaluating an adverse event report, UAHPEC will consider:

- how serious the event is
- the relationship of the event to the research
- the expectedness (or otherwise) of the event
- the appropriateness of the action taken or proposed by the researcher

- the need to inform current or future participants, either by change to the research documents or by written or verbal communication

When appropriate, the UAHPEC will consult experts from within the University of Auckland to provide advice on the above considerations.

12.4 Complaints procedure

An important part of UAHPEC's responsibilities is the investigation of complaints received as well as the evaluation of events in which research participants have been unexpectedly harmed or placed at risk or approved processes were not followed.

1. Lodging complaints:

a. Complaints made by members of the public or participants:

A member of the public wishing to raise a matter of concern or a complaint about research approved by UAHPEC and relating to ethical standards of research on human participants conducted by members of the University, may do so in writing to the UAHPEC Chair by contacting the Ethics and integrity Manager (the Manager) in the first place via email (humanethics@auckland.ac.nz).

The complaint, or expression of concern, should be set out in sufficient detail to enable the Chair to understand both the research study and the issues of concern.

b. Complaints made by a member of the University:

A member of the University wishing to raise a matter of concern or a complaint about research approved by UAHPEC and relating to ethical standards of research on human participants conducted by members of the University must complete a Report Form for adverse event and complaints. The form can be requested from the Ethics Administrators using humanethics@auckland.ac.nz, and the completed form submitted to the Ethics and integrity Manager at the same email address.

c. If the complaint is about the Chair, or if any complainant/informant is dissatisfied with the Chair's response, the complainant/informant should, in the first instance, write to the Ethics and Integrity Manager who will then direct the complaint or concern to the DVCR.

d. Complaints concerning another ethics committee must be made to that committee.

2. Investigation process:

The Ethics and Integrity Manager will co-ordinate the investigation in consultation with the Chair. If the Chair is a subject of the complaint, then the DVC Research will take the Chair's role.

To protect the privacy of the complainant or informant, the researchers, and research participants, all information about a complaint or alleged adverse event will initially be treated as confidential to the Chair and the Ethics and Integrity Manager. The Manager, in consultation with Chair, will determine the appropriate levels of confidentiality throughout the proceedings.

A complainant or informant may request confidentiality, but must understand there will be circumstances where such a request will mean the complaint cannot be investigated. The complainant or informant will be advised if this is the case.

If the Manager, in consultation with the Chair, considers there are good reasons to protect the identity of the complainant or informant, and the investigation can still proceed in a procedurally fair manner, the identity of the complainant or informant may initially remain confidential.

Procedural fairness will normally require that details of the complaint or concern and sufficient information about the source of the complaint or concern will be made available to those about whom the complaint is made.

The Manager will ask the subject of the complaint or concern for a written response, if this is not the Principal Investigator.

In all cases, if the reported alleged adverse event or matter of complaint is of a serious nature and an investigation needs to be conducted urgently, the Manager and the Chair will take whatever steps they consider necessary.

After considering the response from the Principal Investigator and in consultation with the Chair, the Manager may seek such further information as may be necessary to pursue the resolution of the matter.

If the Manager, in consultation with the Chair, comes to the view that there has been a breach of conditions set by UAHPEC or there is evidence of research misconduct, a response will be sought from the researcher.

Complainants/informants will be kept informed about the progress of their complaint.

At any stage of the investigation, the Manager and the Chair may determine that in the interests of the welfare of research participants, it is necessary for a disclosure to be made to specific persons who can assist those research participants.

3. After conclusion of the investigation:
 - a. At the end of an investigation where the matter is resolved, the Chair will advise parties of findings and will, where necessary, refer the findings to the appropriate person or agency for any consequential action.
 - b. Where the investigation determines that there may be a breach of the University's Code of Conduct for Research, the Manager, in consultation with the Chair, will refer the matter to the Deputy Vice-Chancellor Research (DVCR). In such circumstances, the Chair will inform the complainant or informant and the subject of the complaint or concern accordingly.
 - c. Where the matter is not resolved through this investigation, the Manager will inform the DVCR and advise the complainant/informant and the Principal Investigator accordingly. The DVCR shall determine if further steps are to be taken within the University to address the matters raised by the complainant/informant.

- d. Where the complaint remains unresolved at the University level, the complainant/informant may refer it to the Health Research Council Ethics Committee for an independent opinion.
- e. UAHPEC will be informed of the outcome of the investigation, normally only of the identity of the researcher and the research project where the complaint (or parts thereof) is upheld, or if it can be established that an adverse research event did indeed occur.

13. AFTER COMPLETION OF THE RESEARCH

The principal investigator must advise UAHPEC in writing that the research is complete.

Please email humanethics@auckland.ac.nz

13.1 Dissemination of results

The researcher must give due consideration to the dissemination of research results. Whenever possible, the findings should be conveyed in a comprehensible form to those who participated in the research. The researcher must do this if they have given the participant the opportunity to receive results and the participant has requested them. Whenever possible, a summary of the findings should be offered to participant(s). If providing a summary of findings is not possible, e.g., for retrospective data analysis, researchers must consider an alternative way of disseminating the results to participant(s) and/or the wider community. Publication in newsletters, etc. could alternative ways of making research findings known.

13.2 Publication of results

Researchers should be aware that there is an ethical dimension to the formulation and publication of results and loss of copyright. The researcher must remain sensitive to the uses to which the research findings may be put.

14. GLOSSARY

ACC

ACC refers to the cover and entitlements people in New Zealand have under the Accident Compensation Act 2001.

Adverse events in research

Adverse events can arise in both biomedical, social and behavioural research. Serious adverse events are those that result in death, are life threatening, require hospitalisation, cause persistent or significant disability/incapacity or other conditions which, based upon appropriate medical judgement, represent significant hazards to the participants. Also included is psychological or emotional disturbance, or infringements of privacy or other rights (for example, from unauthorised access to identifiable personal information or disclosure of confidential information).

Anonymity

Research participants are anonymous when neither the researcher(s) nor other participants are aware of who is participating. Research can be described as anonymous when the researcher gathering or analysing participant's data is unable to trace these to any individual participant. A questionnaire is not anonymous if it is coded in such a way that the researcher can trace it to the participant. It is preferable to use more precise descriptions when referring to identifiability of data.

Assent

Assent is the agreement to participate in research offered by someone able to understand what is required but not of an age or ability to give his or her consent. For UAHPEC, assent is required for participants 15 years and younger. Assent may be given orally, and the researcher should record the oral assent where possible and store the recording in the same way as written consent.

Audit

An audit involves the planned and systematic evaluation of a set of known variables, and/or a system or set of procedures, and/or documents against a set of criteria.

Child / Young person

UAHPEC regards young persons aged 16 or above as usually able to give consent for their own participation in research.

Clinical / Health Research

Clinical Research is research in which people, or data or samples of tissue from people, are studied to understand health and disease. Clinical research helps find new and better ways to detect, diagnose, treat, and prevent disease. Types of clinical research include clinical trials, which test new treatments for a disease, and natural history studies, which collect health information to understand how a disease develops and progresses over time. *[NIH National Cancer Institute]*

Clinical trials

UAHPEC adopts the definition of clinical trial of the World Health Organization and New Zealand Ministry of Health. That definition is “a clinical trial is any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes”. The National Ethics Advisory Committee (NEAC) provides guidelines in their [Standard Operating Procedures for Health and Disability Ethics Committees \(SOPs\)](#) that determines the whether ethical review is by an Institutional Ethics Committee like UAHPEC or AHREC, or an HDEC.

Collaboration: co-author

When University staff and students are involved in research or the preparation of a research output, the PI should ensure that the research team has clarified with the co-investigators and with the students in terms of their role and whether the student will be acknowledged as an author on any resulting publication. The ethical procedure for co-author outlined in the University of Auckland's [Authorship Guidelines](#) and includes reference to the international standard for authorship, the Vancouver protocol.

Confidentiality

Research participation may be described as confidential when the participant's identity is known to the researcher, but will not be disclosed to third parties or in any discussion or report of the research. This means that any report or discussion of the information given by the participant will be done in a way that does not identify, or allow identification of the participant as the source of the information.

Research data provided by a participant should not be described as confidential if it may be shared, reported or published, even when the participant will not be identified. Instead the way in which it will be stored, reported or shared (e.g., non-identifiable or coded) should be clearly stated. Personal information about participants may be described as confidential if it will not be reported.

Consent Form (CF)

A consent form is a document stating the terms upon which a person agrees to participate in research. It is signed by the participant and retained by the researcher. UAHPEC may give permission for consent to be obtained orally where there are cultural, safety or other special reasons.

Guardian of a child

A legal guardian of a child is the person who has legal responsibility for the day-to-day care and decision-making in relation to a child.

Identifiability of Data

Identifiable data is data from which it can reasonably be assumed that it is possible to identify a specific individual involved in the research. Identifying information includes, but is not limited to, names, addresses, birth dates, phone numbers, email addresses, identifying numbers (for example, National Health Index number or Inland Revenue number), employment details and photos.

To de-identify data is to remove from it all identifying information. It should be made clear to the Committee and participants whether this has been done in a way which allows re-identification or not.

Re-identifiable data is data from which researchers have removed identifiable information and assigned a code, but it remains possible to re-identify a specific individual, for example, using a code-key or linking different data sets.

Non-identifiable data is data that has never been labelled with individual identifiers or from which identifiers have been permanently removed, and for which there is no reasonable basis to believe that a specific individual can be identified. A subset of non-identifiable data is the data that can be linked with other data so it can be known that the two sources are about the same data participant, although the person's identity remains unknown.

Intervention study

An intervention study is where a researcher instigates a change in actions or processes for the purpose of studying the results. Please note that all medical and health interventions must be submitted to the [Health and Disability Ethics Committee](#). Please also note that the term “intervention study” is often used interchangeably with the term “clinical trial” (see Sections 2.4 and 2.5 of the NEAC [Ethical Guidelines for Intervention Studies](#) for the definition of intervention study and intervention). Non-health related interventions include, but are not limited to, changes to educational practices.

Interview schedule

An interview schedule is an outline of the topics, themes or questions to be discussed at an interview. The purpose of this schedule is to enable UAHPEC to determine whether the participant information sheet (PIS) adequately informs the participants of the nature of the interview. The schedule must be attached to the application.

Observational study

In health research, observational studies are distinguished from intervention or experimental studies as those where no intervention other than recording, classifying, counting and analysing of data takes place. The investigator has no control over study variables and merely observes outcomes. Most observational health research is epidemiological or health services research. In Social Sciences and some other disciplines, observation is a particular research methodology which may be included alongside other research activities.

Participant Information Sheet (PIS)

The participant information sheet (PIS) is the document that informs a potential participant about the research and the nature of the involvement required. The participant retains it. Generally, the PIS must be in a written format. However, in the case of telephone research, or in research in predominantly oral cultures, a researcher may make a case to present the information verbally. In these cases, a copy of the information to be presented verbally must be submitted to UAHPEC for review.

For online questionnaires, the PIS can be the first page of the questionnaire, and in those cases, applicants must ensure that the PIS can be down-loaded by participants to keep for future reference.

Questionnaire

A questionnaire is a written or electronic list of questions to be answered by participants. (This is distinct from a survey where the researcher asks the questions to participants face to face).

Research

UAHPEC follows the University's definition of research based on the definition issued by the Tertiary Education Commission (TEC) as part of the assessment of the research performance of staff (PBRF).

The 2018 PBRF definition of research is taken from the TEC's Guidelines for tertiary education organisations participating in the 2018 Quality Evaluation:

For the purposes of the PBRF, research is original, independent investigation undertaken to contribute to knowledge and understanding and, in the case of some disciplines, cultural innovation or aesthetic refinement. (The term 'independent' does not exclude collaborative work).

Research typically involves inquiry of an experimental or critical nature driven by hypotheses or intellectual positions capable of rigorous assessment by experts in a given discipline.

Research includes work of direct relevance to the specific needs of iwi, communities, government, industry and commerce. In some disciplines, research may be embodied in the form of artistic works, performances or designs that lead to new or substantially improved insights. Research may include:

- contributions to the intellectual underpinning of subjects and disciplines (for example, dictionaries and scholarly editions; the term 'scholarly' is defined as the creation, development and maintenance of the intellectual infrastructure of subjects and disciplines, in forms such as dictionaries, scholarly editions, catalogues and contributions to major research database).
- the use of existing knowledge in experimental development to produce new or substantially improved, materials, devices, products, communications or processes
- the synthesis and analysis of previous research to the extent that it is new and creative

Research findings must be open to scrutiny or formal evaluation by experts within the field. This may be achieved through various forms of dissemination including, but not limited to, publication, manufacture, construction, public presentation, or provision of confidential reports.

Research participant

A research participant is a person with whom there is some intervention or interaction that would not be occurring, or would be occurring in some other fashion, but for the research. Research with human participants includes the acquisition and study of data through intervention or interaction with an individual (a participant), or from personal information even if acquired without direct interaction with the individual. It also includes research on human remains, tissues or bodily fluids. For the University, human participant research is understood to include research using anonymous questionnaires, research within teaching sessions and research carried out as part of coursework, conducted within and outside the University.

Surveys

Generally the UAHPEC prefers more precise wording than "survey", such as "questionnaire", "interview", "review".

Vulnerable people

Vulnerability is a broad category. It describes people who have restricted capability to make independent decisions about their participation in the study. It also encompasses people who may lack the ability to consent freely or may be particularly susceptible to harm either

because of their health status, physical or mental capacity or employment status, or as a result of imprisonment (based on Chapter 6 (Ethical management of vulnerability) of the NEAC National Standards for Health and Disability Research and Quality Improvement 2019).

Appendix 1: Associated Documents

Researchers intending to undertake research involving human participants also need to spend time reading and understanding the following associated documents and their requirements.

Document Title & Location	Document Purpose
<u>Films, Videos and Publications Classification Act 1993</u>	This is an Act to consolidate and amend the law relating to the censoring of films, videos, books, and other publications; and to repeal the Indecent Publications Act 1963, the Films Act 1983, and the Video Recordings Act 1987.
<u>Guiding Principles for Conducting Research with Human Participants</u>	This describes UAHPEC, the ethics framework for research with human participants, the key ethical considerations that researchers should be guided by when designing and conducting their research projects, and applying for ethics approval.
<u>Health Information Privacy Code 1994</u>	This code of practice recognises those expectations that health information should be treated differently. It applies specific rules to agencies in the health sector to better ensure the protection of individual privacy.
<u>Mental Health (Compulsory Assessment and Treatment) Act 1992</u>	This would seem relevant for anyone undertaking research with people who are under compulsory treatment and orders.
<u>New Zealand Legislation</u>	There are also other pieces of legislation which have an impact on the design and conduct of research projects. These include the Privacy Act 1993, Health Research Council Act 1990, Human Tissue Act 2008, Protection of Personal and Property Rights Act 1988. For a list of relevant New Zealand legislation, refer to the University's Legislative Compliance Register.
<u>Oranga Tamariki Act 1989 Children's and Young People's Well-being Act 1989</u>	This is an Act to reform the law relating to children and young persons who are in need of care or protection or who offend against the law.
<u>Policy on Ethics Review of Research Proposals involving Human Participants (2011)</u>	This defines research and human participants, outlines UAHPEC policy on approval for projects involving human participants, and lists relevant legislation/university statutes or regulations.
<u>Student Survey Policy and Procedures</u>	The purpose of the Student Survey policy is to ensure a coordinated cross-university approach to surveying student opinion.
<u>The University of Auckland Research Code of Conduct Policy</u>	This briefly outlines the guiding principles and responsibilities of research, along with relevant examples.
<u>Ethics RM online system Quick Reference Guides</u>	These user guides provide information about using the <u>Ethics RM online system</u> .
<u>Vulnerable Children Act 2014</u>	This Act supports the Government's setting of priorities for improving the well-being of vulnerable children; and ensure that children's agencies work together to improve the well-being of vulnerable children.

Appendix 2: Example Participant Information Sheet

The following pages contain an example of information required in a PIS.

The intention is for the text to guide your thinking in making sure that you have provided your participants with sufficient information for them to make informed consent.

All public documents (PIS and consent forms) must be placed on academic unit/faculty letterhead which includes the new University of Auckland logo and address details. This can be provided from your academic unit administrator or downloaded from the [staff intranet](#).

PARTICIPANT INFORMATION SHEET

(Address by category, e.g. Manager)

Project title:

Name of Principal Investigator/Supervisor (PI):

Name of Co-investigator(s): (Additional research staff members)

Name of Student Researcher(s):

Researcher introduction

Include the name of the researcher and appropriate identifying information, whether a staff member or a student. If a student, state the name of the degree and the academic unit or faculty in which the researcher is enrolled. If a staff member, state the academic unit and position.

Project description and invitation

Invite potential participants to be involved in the research. State the rationale and aims for the project, using simple language appropriate for your audience. Explain why and how they have been selected. If the research involves a group (such as students in a class), members of which may decline to participate, indicate what these non-participants will do while the research is being conducted and indicate how the anonymity of non-participants will be preserved. It should be made clear that participation is voluntary.

Project Procedures

Explain the procedures in which the participants will be involved (e.g., interviews, focus groups). Explain the length of time involvement, including any travel the participant may have to undertake. If the research involves any procedure that may reasonably be expected to cause physical, psychological, social discomfort or incapacity this must be indicated, as should plans for subsequent assistance or referral. If students in the academic unit of the researcher (or supervisor) are prospective participants there must be an explicit statement that an assurance has been given by a person in appropriate position of authority that neither grades nor academic relationships with the academic unit or members of staff will be affected by either refusal or agreement to participate. If compensation or reimbursements are offered the terms and conditions should be stated. If funding for the research is being sought or obtained, this needs to be stated, as does the source

Data storage / retention / destruction / future use

Explain how, where, for how long and in what format data will be stored and subsequently destroyed. If data will be retained beyond the completion of the research for which it was collected, explain why. State if data is to be transferred to a public repository.

If audio, video, electronic, or other means of recording are involved this should be indicated, including a statement that the participant has the right to have the device turned off at any point (during interviews, but not during focus groups). If such recording is optional, the PIS should indicate this. If it is intended that a participant's recordings (audio, video, or pictures) can be reviewed by the participant, the researcher should explain the process. If third parties are involved (for example, in transcription, translation, editing or cultural comment), indicate who will view the data, for what purpose, and how confidentiality of information and participation will be preserved.

The PIS for third parties, such as Chief Executive Officers, boards of trustees/principals should indicate that interviews will be recorded only with the consent of the interviewee. Recorded interviews of this type cannot be shared with third parties. If this is intended it must be clearly documented for all concerned. The PIS should also include an explicit request for an assurance that participation or nonparticipation of employees/patients/students will not affect their employment/health care/grades or their relationship with the organisation.

Right to Withdraw from Participation

Participants have the right to withdraw from participation at any time without giving a reason. Participants must be given the right to withdraw their data from the research up to a specified date or period of time. (Note: This cannot happen with anonymous questionnaires or focus groups.)

Anonymity and Confidentiality

Ensure it is made clear to participants when one of the following applies:

- If anonymity with respect to the participant's identity cannot be guaranteed
- If anonymity with respect to the identity of non-participants cannot be guaranteed
- If confidentiality with respect to the participant's identity cannot be guaranteed

If confidentiality is offered, it should be made clear how the information provided by the participants will be reported or published.

If the research involves focus groups, interviews with small numbers of individuals, or interviews with well-known members of the community, it must be indicated that confidentiality with respect to the participant's identity cannot be guaranteed.

If the research is web-based, if encryption is used, or if some other method is used to preserve the anonymity of participants this should be described.

Contact Details

Include an invitation to contact the researchers or the academic head or his/her delegate. Provide the contact details of the researcher(s), supervisor (if applicable) and academic head for participants to use if they require more information about the study. Include name, email and /or postal address, and phone and extension number.

- If the PI is also the academic head, the contact details for their Head of School or Dean should be provided.
- Only use a mobile phone number if it is specifically for use in the study, and not a personal mobile phone number.
- If the research is conducted outside New Zealand, provide local contact details, as well as those of contacts at the University.

UAHPEC Chair contact details:

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, Office of Research Strategy and Integrity, The University of Auckland, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711. Email: humanethics@auckland.ac.nz

Add the UAHPEC Approval Wording

Approved by the University of Auckland Human Participants Ethics Committee on for three years. Reference Number

Appendix 3: Example of a Consent Form

The following page contains an example of information required in a consent form. The consent form must include acknowledgement of having read and understood the PIS and a specific statement of agreement to participate.

It must also state any other issues requiring specific consent. It may include statements explicitly acknowledging understanding of significant aspects of the research.

No information should appear in the consent form (CF) which is not included in the PIS. Simplified versions of a CF may be used (titled 'Assent Form') for recording children's assent to participate.

All public documents (PIS and consent forms) must be placed on academic unit/faculty letterhead which includes the new University of Auckland logo and address details. This can be provided from your academic unit administrator or downloaded from the [staff intranet](#).

CONSENT FORM

(Designated by category, e.g., "Manager")

THIS FORM WILL BE HELD FOR A PERIOD OF 6 YEARS [or specify a longer period if appropriate]

Project title:

Name of Principal Investigator/Supervisor (PI):

Name of Co-investigator(s): (Additional research staff members)

Name of Student Researcher(s):

I have read the Participant Information Sheet, have understood the nature of the research and why I have been selected. I have had the opportunity to ask questions and have had them answered to my satisfaction.

- I agree to take part in this research.
- I understand that I am free to withdraw my participation at any time, and to withdraw any data traceable to me up to a specified date (give an actual date / period) [include only if appropriate]
- I agree / do not agree to be audio recorded. [include only if appropriate]
- I wish / do not wish to have my recordings returned to me. [Include only if appropriate, and include a space to provide an email or postal address.]
- I wish to receive a transcript of my interview for editing. [Include only if appropriate, and include a space to provide an email or postal address.]
- I wish / do not wish to receive the summary of findings. [Include only if appropriate, and include a space to provide an email or postal address.]
- I agree to not disclose anything discussed in the focus group. [include only if appropriate]

Name: _____

Signature: _____

Date: _____

Approved by the University of Auckland Human Participants Ethics Committee on
for three years. Reference Number

Appendix 4: Example Confidentiality Agreement

Please note, the following is only an example and must be tailored to reflect the work undertaken in your research study:

All public documents (PIS and consent forms) must be placed on academic unit/faculty letterhead which includes the new University of Auckland logo and address details. This can be provided from your academic unit administrator or downloaded from the [staff intranet](#).

TRANSCRIBER CONFIDENTIALITY AGREEMENT

Project Title:

Researcher(s):

Supervisor:

Transcriber:

I agree to transcribe the audio-recordings/video-recordings (delete one as appropriate) for the above research project. I understand that the information contained within them is confidential and I agree that I will not disclose or discuss it with anyone other than the researcher and his/her supervisor(s). I shall delete any copies that I may have made as part of the transcription process.

Name: _____

Signature: _____

Date: _____

