MITEC Ethics Guidelines

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1 PURPOSE

Manukau Institute of Technology Limited (MIT) recognises the need for studies in which human participants may serve as research participants. MIT is also aware of its responsibility for ensuring that the privacy, safety, health, social sensitivities and welfare of such participants are adequately protected. In addition, researchers need to ensure that research is conducted in an environmentally safe manner for the researcher(s) as well as the participants.

In these guidelines, reference to the **MIT Ethics Committee** (MITEC) shall mean the following:

(a) MIT has engaged the Unitec Research Ethics Committee (UREC) to assess ethics approval applications.

(b) Recommendations from UREC are provided to MIT's Deputy Chief Executive (Academic) for a decision.

In line with UREC's guidelines, MITEC provides these guidelines to support and advise staff and students wishing to undertake research in which humans may be used as participants.

It is MIT policy that all staff or student research projects which involve human participants must receive the approval of MITEC before they start.

These guidelines are not a substitute for reading, interpreting and implementing the intent of MIT's Research Policy (AC7) and MIT's Research Procedures (AC7/1). People using these Guidelines should refer in the first instance to the policy and procedures, and in the case of conflict, the policy and procedures shall prevail.

For any ethics-related information, contact MITEC at MITethics@manukau.ac.nz.

2 APPLICATION AND SCOPE

These guidelines and associated policy and procedures apply to all staff and students at MIT undertaking research involving humans as participants, a Te Ao Māori or Te Tiriti o Waitangi dimension, or any use of MIT data which is not in the public domain.

3 GUIDELINES

3.1 Ethical Governing Research and Teaching Activities

MIT emphasises eight guiding ethical principles governing research and teaching activities using humans. These are:

1) Informed and voluntary consent.
2) Respect for rights and confidentiality and preservation of anonymity.
3) Minimisation of harm.
4) Cultural and social sensitivity.
5) Limitation of deception.
6) Respect for intellectual and cultural property ownership.
7) Avoidance of conflict of interest.
8) Research design adequacy.

These principles will be taken into account when considering applications for ethics approval. The Ethical Principles are explained in Appendix 1**.**

3.2 Application procedures and forms

Ethics approval will be required before any research activities involving direct or indirect human participation, Te Ao Māori or Te Tiriti o Waitangi dimension, or any use of MIT data not in the public domain are initiated by the staff member or student researcher. Researchers

should check what form of approval may be required using these guidelines. This will enable the researcher to decide whether a full application to MITEC or another ethics committee, e.g. the Health and Disability Ethics Committee, is required. Where ethical approval is required, research cannot begin until such approval has been received in writing.

3.3 Individual Application for Ethics Approval for a Research Project

3.3.1 MITEC Application Form – A

This is for research which *does not meet* all criteria for harm minimisation. Staff researchers are personally responsible for obtaining approval. For student research, research supervisors must co-sign the application and ensure that:

1) the application is submitted to MITEC;
2) students understand the principles and procedures set out by MITEC;
3) the project is appropriately supervised;
4) the project is of an acceptable standard for the discipline concerned.

3.3.2 MITEC Application Form – B

This is for research which does meet all criteria for harm minimisation (see section 3.7). Staff researchers are personally responsible for obtaining approval. For student research, research supervisors must co-sign the application and ensure that:

1) the application is submitted to MITEC;
2) students understand the principles and procedures set out by MITEC;
3) the project is appropriately supervised;
4) the project is of an acceptable standard for the discipline concerned.

3.3.3 MITEC Application Form – C

This application form is for ethical approval for a research component of a teaching programme. This application is to enable MITEC to delegate authority to the applicants to approve non-contentious research (i.e. normally submitted under 3.3.2, MIT Human Ethics Application - Form B) within a teaching programme. Approval for Research Components of a Teaching Programme can be for a maximum of three years. Teaching programmes cover:

1) student research projects;
2) courses that have a significant component of research;
3) research laboratories; or
4) class research exercises.

3.3.4 MITEC Application Form – D

An applicant will use this form for accessing MIT data and participants for research that is already approved by an external Ethics Committee. MIT's Deputy Chief Executive (Academic) or his/her nominee will review the application along with the submitted documents and make a decision. The decision will be communicated to the applicant, UREC Chair, Research Office and other stakeholders where relevant.

3.4 Submission of Applications

Applications that are incomplete or lack the appropriate signatures, or are submitted after the specified application deadline date will not be processed. This will mean delays for the project. Applications must be completed with all e-signatures and all supporting documents and emailed to MITethics@manukau.ac.nz by the due date and time deadline specified in order to be processed at the next meeting. UREC's meeting dates and deadlines will be published periodically. Late applications will be considered at the next meeting.

Note that email trails are unable to be accepted and are not considered valid in lieu of signature/s.

The applicant must send all completed forms plus attachments (i.e. survey instruments, information and consent forms) electronically to MITethics@manukau.ac.nz or the research supervisor, as appropriate.

The applicant is responsible for ensuring that the research supervisor and/or Head of School receive the application form and all relevant attachments in digital format. These people must personally sign the declaration page, after which the staff applicant or supervisor, as appropriate, is responsible for ensuring the signed copy is emailed to MITethics@manukau.ac.nz.

Reading of the application cannot commence until all documentation is received. The primary reader will send the feedback to MITethics@manukau.ac.nz for communicating to the applicants.

3.5 Approval by the MIT Ethics Committee (MITEC)

MIT has engaged the Unitec Research Ethics Committee (UREC) to assess ethics approval applications. UREC will assess MIT's ethics applications and communicate its recommendations to MIT's Deputy Chief Executive (Academic), who will decide on the outcome of each application and communicate the decision to the Applicant, Head of School and Research Office.

No research can be implemented until an ethics approval has been granted. Failure to comply with approval procedures can result in serious disciplinary action. Researchers must also comply with MIT's Research Policy (AC7) and MIT's Research Procedures (AC7/1).

Under certain circumstances, MITEC cannot approve some research projects. These include:

1) Research involving or affecting animals.
2) Research using genetic modification.
3) Some clinical trials using human participants, i.e. trials requiring completion of Statutory Declaration B (consult http://www.hrc.govt.nz or http://ethics.health.govt.nz/system/files/documents/pages/HDEC%20scope%20summary.pdf)
4) Research involving human remains.
5) Any clinical study requiring the approval of the Standing Committee on Therapeutic Trials (SCOTT), the Gene Technology Advisory Committee (GTAC) or the Environmental Risk Management Authority (ERMA).

For each of the above types of research projects, an application must be made, using the appropriate forms, to an accredited animal or regional Health and Disability Ethics Committee, details of which can be obtained from UREC via MITethics@manukau.ac.nz.

Other examples of research projects that UREC cannot approve are given in the Standard Operating Procedures for Health and Disability Ethics Committees (SOPHDEC) (consult http://ethics.health.govt.nz/applying-review). In such cases, the ethics application must be made to a Health and Disability Ethics Committee using their (or the national) application form.

UREC may, from time to time, redefine these exempt and modified categories or determine new ones.

Retrospective approval will not be given for any research already underway. Research conducted prior to obtaining ethical approval is in violation of MIT's Research Policy and will be subject to disciplinary procedures.

Where MITEC has determined that research is not being conducted according to the protocol approved, MITEC can **withdraw** approval for the research.

3.6 Exceptions from Approval Requirements

While ethical considerations must still be upheld, the following do not require specific approval from MITEC:

a) research that does not involve humans or animals and is not foreseen to adversely affect humans or animals;
b) evaluations conducted within MIT for quality assurance purposes;
c) research involving existing, publicly available documents or data (e.g. analysis of archival records, which are publicly available);
d) preliminary interaction or discussion where the exact research aims have not yet been formulated;
e) research in which a single investigator is the subject of his or her own research, and where no hazardous outcomes are foreseen;
f) one-off interviews with public figures, e.g. politicians, prominent authors;
g) seeking a professional or authoritative opinion, except where this is part of a study of the profession or area of expertise;
h) where harm minimisation criteria are not exceeded, and where certain student research projects are covered by an approved Research Component of a Teaching Programme (MITEC Application Form - C).

3.7 Contentious and Non-Contentious Ethics Applications

If research could involve humans as participants and/or could potentially harm humans, ethics approval must be obtained from MITEC before the research is begun.

Humans are involved as participants in research if people:

1) Respond to surveys (e.g., questionnaires, interviews, focus groups).
2) Provide information about themselves, directly or indirectly.
3) Have some form of intervention imposed on them (e.g., medical, drug or physical treatment, physical manipulation, food or fluid supply/restriction, specific environmental conditions imposed, exercise regimes, other activities of an experimental nature).
4) Are the participants of certain observational studies which may not protect their anonymity or the confidentiality of information collected about them?

Applicants should use the non-contentious application, 'MITEC Application Form – B', if all of the following criteria can be met:

1) No vulnerable people or minors are involved as participants.
2) There is no deception involved in eliciting the information from participants.
3) There is no potential for harm or stress.
4) No interventional 'treatment' is imposed on the participant (e.g., drugs, physical manipulation, exercise regimes, environmental conditions, food/fluid supply/restrictions).
5) No body tissue or fluid sample is removed from any participant.
6) The participants remain anonymous and cannot be identified from the raw or published data, either directly or by inference.
7) No personal information on an individual participant is collected, and sensitive questions are not asked.
8) The researcher(s) has (have) no significant conflict of interest in the research.
9) Particular ethnic groups are not deliberately targeted as participants.
10) The research does NOT have particular relevance to, nor affect or impact on Māori.

Face-to-face interviews may be conducted by the researcher as long as the above criteria are upheld throughout the research. Researchers should use the contentious application, 'MITEC Application Form – A' if any of the above criteria cannot be met. If in doubt about which form to use, researchers may refer to the MITEC Applicant Questionnaire to assist them in deciphering which form to use.

3.8 Ethics Application for Research Component of a Teaching Programme

This application is to enable MITEC to delegate authority to applicants to approve non-contentious research (i.e. normally submitted under MITEC Application Form – B see above criteria) within a teaching programme. Approval for Research Components of a Teaching Programme can be for a maximum of three years. Applicants should use 'MITEC Application Form – C'. Teaching programmes cover:

1) Student research projects, or
2) Courses that have a significant component of research, or
3) Research laboratories, or
4) Class research exercises.

3.9 Clinical Trials

In cases where clinical trials are being conducted by MIT staff or students (for a definition and information on clinical trials, MIT adheres to the HRC Guidelines on Ethics in Health Research regarding compensation for research participants), see sections 3.5 and 5.6 of the HRC Guidelines on Ethics in Health Research (consult www.hrc.govt.nz). Compensation may apply (but is not solely restricted) to Accident Compensation Corporation and Insurance Corporation Cover.

3.10 Complaints Procedure

3.10.1 Complaints Concerning the Assessment of an Application

Complaints regarding the assessment of an application for ethical approval and/or the procedures and/or the decision-making process used by MITEC in reaching a particular decision will be investigated using the following procedures:

1) The complaint must first be submitted in writing to MITEC via MITethics@manukau.ac.nz.
2) MITEC will deliberate on the complaint. As part of its deliberation, MITEC may liaise with national or regional health bodies on services and treatment and with the Health Research Council (HRC) Ethics Committee on research and innovative treatment issues.
3) MITEC will provide a written response to the complainant detailing how the complaint was investigated and the result of their consideration of the complaint.
4) MITEC will provide the complainant with a reasonable opportunity to respond in writing and to attend a committee meeting for further discussion.
5) If the complainant responds in writing or attends a committee meeting, MITEC will provide a final decision in relation to the complaint in writing to the complainant.

3.10.2 Appealing a decision of MITEC

An appeal of a decision of MITEC can be submitted if a final decision (application has been withdrawn or declined by the committee) has been provided by MITEC and the grounds of appeal fall within the criteria outlined below. Appeals of a decision of MITEC shall be submitted to MITEC and will be conducted according to the following procedure.

Grounds for Appeal: That there has been a material irregularity in the assessment of the application or in the procedures adopted by the committee, or there is substantive disagreement in regard to a decision of MITEC.

Procedures:

1) An application for appeal shall be made in writing, summarising the relevant facts and setting out the grounds for appeal, no later than 90 days after the final decision by MITEC has been made.
2) MITEC shall forward the appeal to MIT's Chief Executive. Within ten days, MIT's Chief Executive or their nominee shall determine whether the Appellant has established grounds for an appeal.
3) If grounds for appeal are established, MIT's Chief Executive or their nominee shall advise by written notice to MIT's Deputy Chief Executive (Academic) that an application for an appeal has been received and include a copy of the Appellant's application for an appeal. MIT's Deputy Chief Executive (Academic) or delegate shall provide a written response relating to the Appellant's application to appeal and shall provide a copy of all relevant documents, including a copy of any committee minutes or file notes relating to the decision. A copy of this written response will be provided to the Appellant.
4) An Appeal Committee shall be established and provided with the appeal documentation and the MITEC response. The Appeals Committee shall consist of MIT's Chief Executive or their nominee, two senior academic staff, and at least one of whom is an HRC accredited ethics committee member from another institution. None shall be current members of UREC or MIT's Deputy Chief Executive (Academic).
5) The appeal hearing shall be held at a time convenient to all parties, including the Appellant. The Convenor of the Appeal Committee shall advise the Appellant of his/her right to appear at the hearing, to be accompanied by whānau or a support person, to appoint an advocate to speak on his/her behalf, to request an interpreter, and the right to request a Maori representative on the Appeals Committee.
6) The appeal hearing shall be an open consultative event with both parties to the appeal in attendance for each other's explanations. The hearing shall follow meeting rules as follows:
    i) All comments and questions are addressed or asked through the Convenor; the Appellant and/or advocate is invited to present his/her case, followed by an opportunity for members of the Appeal Committee to ask any questions;
    ii) MIT's Deputy Chief Executive (Academic) or his/her delegate is invited to explain and clarify the decision made and then speak to matters raised in the appeal, followed by an opportunity for members of the Appeal Committee to ask any relevant questions.'
    iii) Either party may ask questions, and the Convenor may also invite either party to present any additional information relevant to the hearing;
    iv) All parties apart from the Appeal Committee are then requested to leave the meeting;
    v) The Appeal Committee considers all the evidence presented and makes a decision.

Appeal Outcome:

The Appeal Committee shall either:

1) Reject the appeal, or
2) Uphold the appeal and require MITEC to reconsider its decision. The Appeal Committee shall provide MITEC with a detailed response and targeted advice on matters that require attention in considering the application.

3.10.3 Complaints Regarding the Ethical Conduct of Research

Complaints may be made to MIT's Research Office that research is not being conducted according to the protocol approved by MITEC. These will be investigated according to the following procedure.

1) The complaint must be made in writing to MITethics@manukau.ac.nz. This complaint will be treated as confidential.
2) The Deputy Chief Executive (Academic) will set up a subcommittee to investigate the complaint. This committee will include the Research Director and at least one internal and one external member of UREC. The Deputy Chief Executive (Academic) may seek advice from, or refer complaints to, other bodies as might be deemed appropriate.
3) The chair of the subcommittee will contact the researcher about the complaint. While the complaint is being investigated, the Research Director may request that the research be put on hold.
4) A written response will be provided to the complainant and the researcher detailing the committee's findings.
5) The researcher will be given the opportunity to provide a written response to the committee's findings.
6) The subcommittee shall submit the findings to the Chair of the Academic Committee.

Outcomes:

The Chair of the Academic Committee shall either:

1) Uphold the complaint and withdraw ethical approval for the research. All research must stop, and any data collected as a result of this research must be discarded and not used in future research or publications. Research may only commence again once a new application for ethical approval has been submitted and approved.
2) Uphold the complaint and issue a warning to the researcher. A request for variation to the application is to be submitted to MITEC if required.
3) Uphold the complaint and provide advice to the researcher on how to avoid ethical difficulties in their future research.
4) Find the complaint is unfounded with no evidence of misconduct identified in the investigation.

In all cases where any form of misconduct has been identified, appropriate parties at MIT will be notified for follow-up according to the relevant MIT policies.

4 GUIDELINES FOR COMPLETING AN APPLICATION FOR ETHICAL APPROVAL

4.1 Project Information

4.1.1 Approval by another Pathway or Institution

Research conducted in community agencies will, in most cases, not involve another ethics committee. However, written consent from the head of any agency in which research is being undertaken or who is a collaborator in the research will in most cases, be required. Exceptions can include where the subject of the research has no direct connection with the work of the agency or where participants are clients of the agency (e.g., the agency is where they live), rather than employees.

In cases where more than one school or practice pathway of MIT is involved in a research project, written approval must cover all relevant pathways.

In the case of projects where a student is the principal researcher, it is the responsibility of the principal supervisor to ensure all necessary consents are obtained from outside agencies and other pathways of MIT.

4.1.2 Approval by another Ethics Committee

Aspects of a research project may need ethics approval from another institution external to MIT. For example, if the researcher is using patients from a health service provider, ethics approval may be required from a Health and Disability Ethics Committee.

If the researcher is a student at another tertiary education institution (e.g., university or polytechnic) and ethics approval has been granted from that institution, MITEC does not require a second and separate application, but a copy of that application and a copy of the ethics approval must be submitted to MITEC as soon as it is available.

If the research is undertaken as part of a collaboration involving multiple organisations or institutions, then ethical approval should be obtained from the primary investigator's institution. Details of this approval should be provided to MITethics@manukau.ac.nz for noting by MITEC.

For approved research, liability will normally rest with the institution approving the research.

4.2 Project Details

This section covers information to consider when discussing project details, participants and data collection.

4.2.1 Methodological Considerations

When designing research and choosing methodology, there are a number of ethical considerations to take into account. Some of these key areas are discussed below.

4.2.2 Research Design Adequacy

Researchers must ensure that their research design is adequate to allow ethically robust research to be carried out. This includes consideration of the following elements:

1) The aims and objectives of the project.
2) The value and benefits of the project.
3) Appropriate project duration.
4) Appropriate sampling procedures.
5) The selection of a suitable methodology and suitable methods.
6) The development of rigorous data collection tools.
7) Appropriate data analysis and reporting.

In the case of student research, the research supervisor can assist with research design adequacy. All student research proposals should be considered and approved by the appropriate body.

In the case of staff research, staff should consult appropriately and seek peer-review for the proposal.

4.2.3 Anonymity

Generally, the best protection of the confidentiality of personal information and records is achieved through anonymity. Returned or recorded survey instruments (such as questionnaires and interviews) should not include information that may directly, or by inference, identify an individual or organisation without their prior written consent to this effect (e.g., name, address, email address, phone numbers, and detailed description of person or organisation). Often code numbers are used merely to track responses and follow up on this. In some instances, which must be justified by the applicant, personal identifying information may need to be collected in order to follow up on the responses made by individual participants. This may be required when, for example, further selection is made from questionnaire responses to select a subset of participants for more detailed interviews. It is recommended that in such circumstances, a separate file linking response form codes to individuals be maintained with access limited only to the principal researcher. In all cases, this intent should be provided on the information sheet and agreed to in advance by the return of

the questionnaire or signed consent form. Only the researchers in the project and their supervisors should have access to the data.

4.2.4 Limitations of Deception

Deception occurs when researchers represent their research as something other than what it is. This may take the form of deceiving participants as to the true purpose of the research, the methods that are being used to collect the data, the participants' actual role in the research, the uses to which the data will be put, or any other action that limits participants' understanding of what the research is actually about. Deception also occurs when a researcher omits data or analyses data in ways that reduce the validity of the research. The offering of inducements to potential participants may also constitute deception.

Researchers should consider carefully how deception will be avoided. MITEC considers any deception inherent in a research project to be very undesirable.

4.2.5 Storage and Access to Data

It is necessary for research projects to ensure that arrangements for the storage of data are at least as secure as the source from which the data was obtained. Access to data should be restricted to the researchers and their supervisors and participant identifiers should be removed as soon as practicable.

Research files may contain confidential information, and it is essential that researchers ensure that this information is stored and dealt with appropriately and that access to the information only be given to authorised persons. Research data and consent forms must be retained for a period of 10 years. Research data and consent forms for significant research findings must then be transferred to the public archive. Please contact the Records Management team if further guidance is required.

However, it may be that the conditions of informed consent to participate in a research procedure will themselves require that the data generated be destroyed once the research information is extracted. In presenting the results of the research, information that may directly, or by inference, identify an individual or organisation should not be given.

Consent forms should not be stored in the researcher's home. The expectation of MITEC is for these to be stored securely on MIT premises. In the case of student researchers, it is the responsibility of the supervisor to ensure both consent forms and the data obtained in the course of the research are secured adequately and retained for the correct length of time.

4.2.6 Withdrawing from a Study: Participants and Participant Data

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 a party of a focus group recording). If data cannot be withdrawn, this must be clearly explained.

4.3 Benefits/Risk of Harm

This section outlines issues to consider when discussing the benefits and risks of harm associated with the research.

4.3.1 Minimisation of Harm

The risk of harm is as important as actual harm. 'Harm' is defined as that which adversely affects the interests or welfare of an individual or a group. The types of harm extend to physical, psychological, economic and social harm. Harm includes discomfort, anxiety, pain, fatigue, embarrassment and inconvenience. MITEC adopts very strict criteria for harm minimisation. Listed below are the areas of concern.

1) Lack of anonymity for participants.
2) Lack of confidentiality of information.

3) Requests for sensitive information.
4) Use of deceit.
5) Use of medically invasive procedures.
6) Cultural insensitivity.
7) Use of 'vulnerable' participants or those unable to give fully informed and voluntary consent.

4.3.2 Harm or risk of harm

In general, there are three kinds of impact which a research procedure may have on those participating: physical harm, psychosocial harm, and the risk of either (as opposed to its actuality).

Physical harm	What is called for is the minimisation of the harm and the maximisation of the good that results. A change in procedure (even at more inconvenience to the researcher) might reduce or eliminate the harm while leaving the good to be produced unaltered.
Psychosocial harm	Psychosocial harm ranges from the invasion of privacy and the diminution of social reputation to the creation of enduring psychological fears and confusions. Procedures must be established to minimise psychosocial harm. The procedures extend to processing, publication, storage and disposal of information. All information generated in the course of the research may contain sensitive details of individuals' private lives or may contain information affecting their assessed medical status and so on.
Risk of harm	Often what will be involved is not actual harm of any sort to participants but the risk of some harm. As in the case of harm itself, what is called for is the minimisation of the risk and the maximisation of the good that results.

4.3.3 Permissible levels of risk

Copies of the questionnaires, focus group and interview schedules and/or protocols, and/or experimental protocols and procedures must be submitted with the application to MITEC. Where these are necessarily provided to participants in a language other than English, a translation into English of any such questionnaire must also be submitted if required by MITEC. Where translation has occurred, the researcher must submit evidence that the translation has been professionally verified.

Arguably, some participative research paradigms limit the degree to which methods and tools can be explicit at the point of application. In such cases, protocols describing the relationship of the participants to the applicants and letters of support from the participants or their representatives would be important.

4.4 Informed and Voluntary Consent

4.4.1 Informed Consent

Informed Consent is generally required in written form. It may be more appropriate to acquire verbal consent from individuals, whānau members and members of a hapu or iwi. This is acceptable as evidence for Informed Consent.

Verbal consent should be documented in the researcher's notes, indicating the time and place the verbal consent was obtained and who provided the consent. If possible digital

recordings of consent should be obtained.

4.4.2 Limitations to Consent

Any relationship between researcher and participants that may compromise Informed Consent or the truthfulness of participant reports must be stated. In some special cases, it will not be possible to obtain Informed Consent because those participating are not competent to offer such consent. In these cases, it is essential to ensure that there are caregivers who may speak responsibly on their behalf and to ensure that the Informed Consent of those authorities is obtained. All participants under the age of 16 require the consent of parents or caregivers, where appropriate (Appendix 3).

There are potentially other participants whose ability to give Informed Consent may be compromised or limited in some way or other, for example, students, employees, legal minors, persons with diminished capacity (e.g., having an intellectual or psychiatric condition), or people in institutional settings (hospital patients, prisoners).

4.4.3 Participant Information Sheets

It is easy to manipulate a person's 'voluntary' consent by exploiting their ignorance, fears and respect for experts or superiors. Applications for projects must therefore be accompanied by Participant Information Sheet/s that describe, in the participant's language, the essential points that any reasonable person would wish to know before agreeing to participate, including:

1) What the research is about.
2) What they are being asked to do.
3) What the likely consequences are for them should they participate.
4) That there are no disadvantages/penalties / adverse consequences to not participating or withdrawing from the research.
5) Any special conditions of the research that might affect their participation, e.g., that there will be audio-taping, videotaping or photography.
6) How confidentiality of information will be preserved.
7) A schedule for the destruction of personal identifying information and the disposal of any human tissue or body fluids collected.
8) The host institution for the research.
9) The researchers who will actually make direct contact with the participants.
10) The supervisor for the project.
11) A means (for example, a telephone number, emails) by which participants are able to contact the researchers, the supervisor and MITEC to ask further questions.
12) The MITEC Approval Statement.
13) Information on compensation available to participants if relevant.

It is essential that the MITEC Approval Statement be included as this clearly shows that the research has the approval of MITEC.

There are some cases where it is not appropriate to provide a written information sheet (for example, with young children), it would be more appropriate to provide them with a verbal explanation. A dialogue statement of the verbal information that will be communicated should be provided.

It is also important to consider what, if any, inducements might be offered to potential research participants and whether or not such inducements will influence the voluntary nature of participants' involvement.

4.4.4 Consent Forms

Wherever possible, written informed consent of the person is required. This should be done

using a Consent Form. Consent Forms must have a brief explanation of the research, MITEC Approval Statement and include statements about being fully informed, voluntary choice, confidentiality, and an appropriate time for consideration and understanding of the complaints process. (See 'Complaints Procedures' within this document). People from whom tissue or body fluids are obtained are regarded as participants in terms of Informed Consent.

Where appropriate, the consent form used must be provided with the application to MITEC. The researcher should advise the participant that a copy of the information sheet and consent forms should be retained by the participant. Where these are necessarily provided to participants in a language other than English, a translation into English of any such questionnaire must also be submitted if required by MITEC. If translated documents are used in the research, then you must provide MITEC with confirmation that the translations are correct and have been professionally verified.

It is acceptable to present a consolidated information sheet/consent form as long as the participants are provided with a copy of the document and have been given an opportunity to reflect on the document before indicating their Consent. Consent forms should be held securely on MIT property (unless justification can be made for this not being the case), separate from the data until the latter is destroyed.

Exceptions to written Consent might be mass-distribution questionnaires and very simple procedures (e.g., hearing tests) and procedures where the participant's ignorance of the intended research objective is essential (this must be exercised with extreme caution and with proper justification). For some questionnaires (particularly anonymously returned questionnaires), the return of the questionnaire can be reasonably taken as an indication of voluntary consent to participate, and this fact should be clearly stated on the questionnaire and information sheet.

4.5 Conflict of Role/Interest Funding

4.5.1 Funding

Researchers must indicate whether the project is being funded in any way, either through cash or in-kind support by any person or organisation, both internal and external to MIT. Any financial interest of the researcher, the host institution and/or a sponsoring agency in the outcome of, or involvement in, the project should also be fully disclosed.

4.5.2 Avoidance of conflict of interest

It is important for the researcher to declare any special relationships that exist with the research participants, e.g., friends, whānau/family, colleague-colleague, and student-teacher. Aspects of the research design that will minimise the effect of such relationships must be carefully considered and clearly articulated to MITEC. Where the relationship involves power being exercised, or potentially exercised, by one person over another, e.g., employee-employer, principal-teacher, these considerations are particularly important. Issues of gender, ethnic group and age may also be relevant. Where this involves staff-student relationships specifically pertaining to intellectual property and authorship, please refer to MIT's Research Policy (AC7) and MIT's Research Procedures (AC7/1) and MIT's Intellectual Property Policy (AM10) for further information.

4.5.3 Commercial Relationships

Any benefits to the researcher, the host institution or a sponsoring agency that will or might arise from a particular research outcome or from involvement in the research must be disclosed. Where commercial relationships have the potential to influence outcomes, procedures must be adequately described so that an ethical judgement can be made as to the independence and transparency of the research.

4.6 Treaty of Waitangi

4.6.1 The Treaty of Waitangi (and Māori Participation in Research)

MIT states its commitment to the Treaty of Waitangi through the Partnership document, Te Noho Kotahitanga. This document includes values that support MIT in developing a meaningful partnership with Māori. In relation to research and research ethics, Te Noho Kotahitanga states that 'MIT accepts responsibility as a critical guardian of knowledge' or 'taonga mātauranga'; therefore, MITEC will act as kaitiaki to ensure that Māori knowledge and processes in research be protected. In the spirit of the partnership, all researchers have a right to include Māori in their research projects and with this right is the responsibility to consult appropriately and conduct research in a culturally sensitive and respectful manner.

MITEC has produced guidelines to assist researchers who intend to undertake research that may involve Māori participants (through random selection), involve Māori, Māori-centred research and kaupapa Māori research.

For further guidance, contact the Chair of the Te Komiti Tangata Whenua (TKTW) or his/her nominee or refer to the Guidelines for Researchers on Health Research Involving Māori (consult www.hrc.govt.nz).

4.6.2 Non-Māori Researching Māori

Non-Māori are able and encouraged to include Māori participants in their research so that all New Zealanders can benefit from the research. The inclusion of Māori in research gives Māori the right to benefit from a share in what is ultimately state-funded (tertiary) research. It is important that an appropriate education in cross-cultural research skills and cultural safety be available for the researchers. For further guidance, contact the Academic Lead (Research) and the Chair of the Te Komiti Tangata Whenua (TKTW) or his/her nominee.

4.6.3 Research that MAY Involve Māori

Researchers whose intended research project may involve Māori participants through random sampling, or involve Māori as participants where Māori data is sought and analysed, are asked to outline the protocols and processes used throughout the research. Researchers should identify the person/people who have been consulted and their role in this project. Advice from the Chair of the Te Komiti Tangata Whenua (TKTW) or his/her nominee can be sought. It is expected that at least preliminary consultation will occur before submitting your application for ethical approval.

4.6.4 Research that Involves Māori

Consultation with either the Chair of the Te Komiti Tangata Whenua (TKTW) or his/her nominee, appropriate members of the MIT community or the wider community will be required if the research proposals involve Māori as participants or where Māori data is sought and analysed. This should occur before your ethics application is submitted.

4.6.5 Māori-Centred Research

Consultation with the Chair of the Te Komiti Tangata Whenua (TKTW) or his/her nominee, appropriate members from the MIT community or from the wider community will be required if Māori are significant participants and where an analysis is undertaken which produces Māori knowledge.

4.6.6 Kaupapa Māori Research

Kaupapa Māori research is research where Māori are significant participants, where the research team is typically Māori, a Māori analysis is undertaken, and Māori knowledge is produced. Māori Tikanga (protocols) and processes are followed throughout the research from the beginning to the dissemination of results to participants. Consultation with TKTW nominee(s) will be required, or with appropriate staff members within MIT or appropriate members from the wider community.

4.6.7 Kaupapa Māori Workshops and Training

The Research Office, in collaboration with the Te Komiti Tangata Whenua (TKTW), will organise workshops on Kaupapa Māori research and methodologies for MIT staff. For more information about these workshops, contact the Research Office at research@manukau.ac.nz.

4.6.8 Supervision

It is advisable that Māori advisors/supervisors assist with research projects that include a Māori kaupapa or where Māori are significant participants.

4.7 Cultural Issues (Ethnic/Social Groups other than Māori)

4.7.1 Cultural and Social Sensitivity

It is important that issues of cultural safety are addressed when research involves participants from various ethnic or cultural groups, even when small numbers from each group are involved. Where a particular ethnic or cultural group is the subject of the research, consultations must be undertaken with appropriate parties, and this process is outlined in the application.

The Health Research Council has the following advice to consider in relation to health research, but the principles described here should be considered in all research.

People of different cultures hold differing basic beliefs, have different value systems and regard differing modes of behaviour as acceptable to them. Since health involves matters which are often deeply personal and private, procedures for health research can very easily cause offence both to individuals and to ethnic groups, even though none has been intended.

Not only must there be due recognition of the indigenous culture of the Māori as the tangata whenua (indigenous people) but also due allowance for the increasing diversity of culture and religious beliefs which is now appearing in New Zealand society.

Practices and beliefs of an ethnic and/or religious nature must be fully respected. Research must be undertaken in a culturally sensitive and appropriate manner, in full discussion and partnership with the research participants, whatever their ethnicity or religious affiliation, and the results of any investigation should be appropriately disseminated in a full and frank manner.

Participants have the right to receive, in language that they will easily understand, information about proposed research in which they are being invited to participate. Where large numbers of participants from an ethnic group are being recruited, a translation of the participant information sheets and the consent form should be provided. In seeking Informed Consent, the involvement of a trained interpreter is highly desirable. If the number of participants from any ethnic group is small, the use of trained interpreters to read and discuss the information sheet with the participant may obviate the need for a printed translation. However, a translation of the consent form should be provided. In certain circumstances, verbal consent is considered appropriate (p. 21, HRC Guidelines on Ethics for Health Research, 2002 – consult www.hrc.govt.nz).

Where participants are sought from a particular social group, e.g. rest home residents, people with English as an additional language, the particular needs of these participants must be considered, including how harm minimisation concerns might be best addressed.

4.7.2 Pasifika Research

MIT's Pasifika Academic Sub-Committee (PASC) is available to provide support in many ways, including academic assistance.

Please see Research Guidelines for Māori and Community Social and Cultural Responsiveness for information on gaining appropriate cultural consultation.

4.7.3 Consultation

The purpose of a consultation is to ensure that the research practices are appropriate and that research will be conducted to ensure safety for the participants, the researcher and MIT. Appropriate consultation endeavours to establish a foundation for a collaborative relationship between researchers and participants.

Please see MITEC Guidelines for Māori and Community Social and Cultural Responsiveness for information on gaining appropriate cultural consultation.

4.8 Sharing Research Findings

4.8.1 Intellectual Property

Researchers should check MIT's Intellectual Property Policy (AM10) for guidelines on intellectual property ownership.

4.8.2 Cultural Property

Researchers should check MIT's Intellectual Property Policy (AM10) for guidelines on intellectual property ownership.

Researchers should carefully consider how the results of their research will be shared with and used by the participants and by the wider group(s) to which the participants belong. Where research information is disseminated in inappropriate or untimely ways, harm may be caused to participants. Consultation with participant groups should direct the researcher to the most appropriate processes in this regard.

Researchers should consult with Māori members of MITEC if issues of intellectual and cultural property ownership of Māori are likely to arise in the context of their research. The Health Research Council publication Guidelines on Health Research Involving Māori (1998) provides detailed advice on these matters (consult www.hrc.govt.nz).

4.9 Invasive Procedures/Physiological Tests

4.9.1 Definition of Clinical Trial

The definition of a clinical trial varies depending on the context in which it occurs. A 'clinical trial' is defined by the Ministry of Health as "a pre-planned, controlled clinical study designed to evaluate the safety, efficacy prospectively, or optimum dosage schedule (if appropriate) of one or more diagnostic, therapeutic, or prophylactic drugs, devices or interventions in humans".

The definition adopted in the context of the accident compensation legislation defines a clinical trial as "any research on human participants conducted to gain new knowledge into mental and physical health and disease" (Ministry of Health and ACC, 1993). It would exclude research based on the analysis of secondary sources of health information. Clinical trials often involve a wide range of health professionals with different qualifications, skills and expertise and would usually be conducted in hospitals, other health care settings, the community and academic host institutions. This definition is somewhat broader but is acceptable for the purposes of government-sponsored compensation to participants.

For ethical review by MITEC, the broader interpretation is preferred to ensure the protection of participants' rights, safety and welfare. Therefore, declarations for Accident Compensation coverage may need to be completed by the applicant.

4.9.2 Medical Research Involving Human Tissues or Fluids

MITEC may approve research that involves routine and simple methods of tissue or fluid collection, involves only minimal risk in obtaining such samples, and which it has the expertise to review. Any significant medical research or clinical trial will require ethics approval through an accredited Health and Disability Ethics Committee. In either case, the use of any invasive medical procedures or use of drugs must be identified, along with the safeguards that will ensure against infection, damage or risk to health. Declarations for Accident Compensation coverage may need to be completed.

Where the researcher intends to use tissues or body fluids, details of storage and the manner of disposal must be described. Issues of cultural sensitivity and accident compensation should also be addressed. Research involving human remains must be referred directly to a Health and Disabilities Ethics Committee for approval. Contact either the Health Research Council Ethics Committee or a Health and Disability Ethics Committee for the full procedures for ethical approval of such health research.

4.10 Declaration and Indemnity

All applicants are required to sign a declaration guaranteeing the accuracy of the information provided, and that the ethical conduct of the research as approved by MITEC will meet the requirements of MIT's Research Policy (AC7) and MIT's Research Procedures (AC7/1).

Any significant departure from the project approved, particularly around issues of consent, confidentiality, sensitivity and potential harm to participants, must be notified to the committee and approval sought before proceeding with the changes.

Provided the research is properly conducted within the limits of the approval, the researcher is indemnified against an accident or misadventure that may occur.

5 REFERENCE DOCUMENTS

1) Guidelines on Ethics in Health Research (consult www.hrc.govt.nz)
2) Guidelines for Researchers on Health Research Involving Māori (consult www.hrc.govt.nz)
3) Guidelines for Institutional Ethics Committees to Refer Research Studies to a Health and Disability Ethics Committee (consult www.hrc.govt.nz)
4) MITEC Application Form - A
5) MITEC Application Form - B
6) MITEC Application Form - C
7) MITEC Application Form - D
8) MIT's Research Policy (AC7)
9) MIT's Research Procedures (AC7/1)
10) MITEC Guidelines for Māori Social and Community Social and Cultural Responsiveness
11) MITEC Template - Participant Information Sheet
12) MITEC Template - Participant Consent Form (Organisation)
13) MITEC Template - Participant Consent Form (Adult)
14) MITEC Template - Participant Consent and Assent Form (Under 16yrs)
15) MITEC Template - Participant Confidentiality Agreement
16) MITEC Applicant Questionnaire
17) MITEC Applicant Checklist

6 DOCUMENT DETAILS

Version:	1.0	**Issue date this version:**	04/08/2022
This version approved by:	Academic Committee	**Date of approval:**	03/08/2022
Document owner:	Research Director	**Document sponsor:**	Academic Committee
Date of next review:	August 2025		
Date first version issued:	August 2022	**Original approval body:**	Academic Committee

APPENDIX 1: ETHICAL PRINCIPLES

The following eight principles govern all research at MIT involving human subjects, a Te Ao Māori or Te Tiriti o Waitangi dimension, or any use of MIT data which is not in the public domain. Additional considerations for research involving children or young persons (under the age of 16 years) or other vulnerable participants are explained in **Appendix 3**.

1. Informed and voluntary consent

1.1. Involvement of participants in any research should be voluntary and based on an understanding of adequate and appropriate information about what participation will involve.

1.2. Researchers have a responsibility to provide prospective participants with all information relevant to their decision to participate, in a manner that is comprehensible to prospective participants.

1.3. In most cases, it is desirable that information and participants' consent is in written Form.

1.4. Whenever a participant may be identified from the information collected during their participation, the requirements of the Privacy Act should be met (see **Appendix 2**). Information should be collected directly from the participant, unless the specific exceptions outlined in Principle 2 of the Privacy Act 2020 apply. Specific consents may be required to collect information about participant(s) from other people.

1.5. Coercion of any sort to secure someone's participation in research is totally unacceptable. Reasonable compensation for taking part in research is permissible, but should not be of a kind to induce people to participate against their better interests. Researchers whose prospective participants are in any sort of dependent relation to them (e.g., their students, patients or clients) need to be particularly careful about the possibilities of implicit coercion.

1.6. The right of individuals to decline to participate in research or to withdraw from participation at any time, without penalty of any kind and without having to provide reasons, should be recognised and respected. Individuals may also withdraw identifiable information that they have provided at any time prior to the completion of data collection. In some contexts it may be desirable to submit texts or transcripts of dialogue, or analyses of data, to participants for final approval. Where the information is about identifiable individuals, their rights to access and / or correct such information is laid down in Principles 6 and 7 of the Privacy Act 2020 (see **Appendix 2**).

1.7. MITEC emphasises the right of individuals to determine whether or not they will participate in research, but recognises that there may be situations of cultural sensitivity in which it is appropriate to approach the leaders of some groups of persons for consent to the involvement of members of the group in research. It may also be necessary in certain circumstances to obtain the permission of relevant authorities to approach potential participants. Researchers should be sensitive in such cases to the possibilities of conflicting interests and wishes between authorities or leaders and individual group members.

1.8. Where prospective participants are not capable of giving informed consent to their own participation (e.g., children under 16 years of age or mentally infirm adults), this should be obtained from those with legal responsibility for them (see **Appendix 3**).

2. Respect for rights to privacy and confidentiality (see Appendix 2)

2.1. Rights to privacy and confidentiality should be respected. The identity of participants is to be protected at all stages of a research project, unless prior consent has been obtained from each participant.

2.2. Participants have the right to stipulate that information they provide be kept confidential and researchers should inform participants of this. The confidentiality of information obtained incidentally during research should also be respected.

2.3. Researchers are responsible for keeping information (including the identity of participants) confidential and secure from interception or appropriation by unauthorised persons or for purposes other than the approved research. This will often require coding of data and removal of identifying material from questionnaires and other documents. Researchers are also responsible for the safekeeping and confidentiality of signed consent forms. Collection and storage of information should comply with Principles 1-5 of the Privacy Act 2020.

3. Minimisation of risk

3.1. Participants should not be exposed to unnecessary risk. Risks include such things as pain, stress, emotional distress, fatigue, embarrassment, cultural dissonance, and exploitation. Researchers should make every attempt to identify and minimise any risks - physical, psychological, social or cultural - attendant on participation by individuals or groups in a research project. It may be helpful also to consult the participants to ascertain what risks they see or concerns they have.

3.2. Unavoidable risks, including inconvenience and discomfort to participants, should be balanced against possible benefit to the participants and the community in judging the ethical acceptability of research. Compliance with Principle 4 of the Privacy Act 2020 (see **Appendix 2**) is required here. Information about an individual cannot be collected by means that are unlawful or unfair, or intrude to an unreasonable extent upon the personal affairs of the individual concerned. Research or teaching involving risks to participants should be supervised by appropriately qualified personnel.

4. Limitation of deception

4.1. Deception of participants conflicts with the principle of informed consent, but in some areas of research it may be necessary to withhold information about the purposes and / or procedures of the research.

4.2. Researchers should make clear to MITEC the precise nature and extent of any deception, and why it is thought necessary. Emphasis on the need for consent does not mean that covert research can never be approved. Any departure from the standard of properly informed consent should be acceptable when measured against possible benefit to the participants and the importance of the knowledge to be gained as a result of the research or teaching session.

4.3. It should also be considered in light of Principle 4 of the Privacy Act 2020 (see **Appendix 2**) which prohibits collecting information about an individual by means that are unlawful and unfair, or intrude to an unreasonable extent upon the personal affairs of the individual concerned. There are no specific exemptions to this principle of the Act.

4.4. Researchers have a responsibility for ensuring that subjects of covert or deceptive procedures are provided as soon as possible with a sufficient explanation of the true purposes and nature of the research and reasons for the deception.

5. Social and cultural sensitivity

5.1. Research procedures should be appropriate to the participants involved in the study.

5.2. Researchers have a responsibility to inform themselves of and take steps necessary to respect the social and cultural sensitivity of all participants. Meeting language preferences of participants in the provision of information is particularly important.

6. Research adequacy

6.1. Research is not ethical if it does not meet appropriate standards of adequacy. MITEC recognises that different research paradigms may inform the conception and design of research. It does, however, adopt the following minimal criteria of adequacy:

- the research should have clear research goals
- its design should make it possible to meet these goals
- it should not be trivial, but should potentially contribute to the advancement of knowledge to an extent that warrants the cost to participants.

In the case of student projects, the contribution of the work to the student's own education is taken into account.

7. Avoidance of conflict of interest

7.1. Any sponsorship of research should not compromise its research adequacy or ethical acceptability.

8. Respect for property rights

8.1. Processes of research and publication should not violate or infringe legal or culturally determined property rights. These may cover such things as land and goods, works of art and craft, spiritual treasures, information and works of the intellect.

APPENDIX 2: COMPLYING WITH THE PRIVACY ACT 2020 IN RELATION TO RESEARCH

6.1 Introduction - Privacy Act 2020 requirements

Any collection of information about **identifiable individuals** must comply with the requirements of the Privacy Act 2020.

The Privacy Act 2020 lays down thirteen "information privacy principles" which should be observed in dealing with information about identifiable individuals. Most of these principles apply to the collection of personal information in the course of research investigations.

1. Principle 1: Purpose of collection of personal information (summarised)

1.1. Information about individuals should only be collected for a purpose necessary to a function or activity of MIT. Authorisation of the research by MITEC would imply that the research being carried out was necessary to a function or activity of MIT.

2. Principle 2: Source of personal information (summarised)

2.1. With certain exceptions, information about an individual should be collected directly from the individual. For research purposes, compliance with this principle is not required where:

a) the information is publicly available

b) the participant authorises collection of the information from someone else (it would be advisable to include this authorisation on consent forms if required)

c) the interests of the individual concerned would not be prejudiced

d) compliance would prejudice the purposes of the information collection (careful consideration of this exception could be undertaken in conjunction with justifying necessary deception or covert investigation)

e) compliance is not reasonably practicable in the circumstances

f) information will be used for research purposes in a form that could not reasonably be expected to identify the individual concerned.

3. Principle 3: Collection of information from participant (summarised)

3.1. When personal information is collected from an individual, or as soon as practicable after it is collected, reasonable steps should be taken to advise the individual of:

a) the occurrence of information collection

b) the purpose for which information is being collected

c) the intended recipients of the information

d) the name and address of the agency collecting and the agency holding the information

e) rights of access to and correction of personal information provided under the Act.

This information should be included on consent forms. "Reasonable steps" may include ensuring that information on the consent form is in appropriate language and that barriers to understanding such as language or cultural difference, physical or mental disability or reading difficulties are provided for.

3.2. Where information collection is an on-going process, and information of a similar kind is being collected on each occasion, only one notification is required.

3.3. For research purposes, compliance with this principle is not required where:

a) non-compliance is authorised by the participant

b) the interests of the individual concerned would not be prejudiced

c) compliance would prejudice the purposes of the information collection

d) compliance is not reasonably practicable in the circumstances

e) information will be used for research purposes in a form that could not reasonably be expected to identify the individual concerned.

4. Principle 4: Manner of collection of personal information (summarised)

4.1. Information about an individual shall not be collected by means that are unlawful or unfair, or intrude to an unreasonable extent upon the personal affairs of the individual concerned.

4.2. There are no specific exceptions stated in the Act to this principle. It appears to have been aimed at unauthorised surveillance and browbeating, but may have implications for the use of deception or covert means of obtaining research information. Not "intruding to an unreasonable extent" may involve concerns for privacy during collection and sensitive handling of potentially embarrassing information.

5. Principle 5: Storage and security of personal information (summarised)

5.1. Reasonable steps should be taken to prevent unauthorised access to and use of personal information.

6. Principle 6: Access to personal information (summarised)

6.1. Individuals are entitled to access to all readily retrievable information about them held by the researcher.

6.2. Part IV of the Act details specific exemptions to this principle. Most concern commercially sensitive information or information subject to professional legal privilege but Part IV also lists good reasons for refusing access which include: disclosure would involve unwarranted disclosure of the affairs of another individual; disclosure of evaluative information would breach an express or implied promise to the supplier of the information not to reveal the information and / or its source; Note: "evaluative material" relates to staff appointment, promotion or dismissal or to awarding a contract, award, honour, scholarship or other benefit.

7. Principle 7: Correction of personal information (summarised)

7.1. Individuals may request that information held about them is corrected or is attached to a statement of the correction sought but not made. Where disclosure of the information was previously made to others they are to be informed if reasonably practicable. Although aimed at personnel records and credit information, this principle may have implications for published case studies, where information is subsequently corrected.

8. Principle 8: Personal information to be checked before use (summarised)

8.1. Information about an individual should not be used without taking reasonable steps to ensure it is accurate, up-to-date and relevant.

9. Principle 9: Time information is kept (summarised)

9.1. Information about individuals should not be kept longer than necessary.

10. Principle 10: Limits on use of personal information (summarised)

10.1. Information about individuals should not be used for a purpose other than the one for which it was obtained or a directly related purpose, or another purpose that falls within a permitted exception, including:

a) if the use of the information for that other purpose is authorised by the individual(s) concerned

b) if the agency (in this case, MIT) believes on reasonable grounds that the information:

(i) is used in a form in which the individual concerned is not identified

(ii) is used for statistical or research purposes and will not be published in a form that could reasonably be expected to identify the individual concerned.

11. Principle 11: Limits on disclosure of personal information (summarised)

11.1. Personal information may only be disclosed to another party in specified circumstances. For research purposes, these circumstances include situations where:

a) disclosure is one of the purposes for which the information was obtained or is directly related to this purpose

b) the information is publicly available

c) the participant authorises disclosure of the information to someone else (It would be advisable to include this authorisation on consent forms if required)

d) disclosure is necessary for law enforcement reasons or because of risk to public health or safety or individual life or health

e) information will be used for research purposes in a form that could not reasonably be expected to identify the individual concerned.

12. Principal 12: Disclosure outside New Zealand (summarised)

Personal information may only be disclosed to an organisation outside New Zealand if the receiving organisation is subject to the Privacy Act 2020 because they do business in New Zealand, they will adequately protect the information (ie, by using model contract clauses) and/or they are subject to privacy laws that provide comparable safeguards to the Privacy Act 2020.

13. Principle 13: Unique identifiers (summarised)

13.1. A unique identifier may only be assigned if it is necessary for an agency to carry out one or more of its functions efficiently.

APPENDIX 3: CONSIDERATIONS FOR RESEARCH INCLUDING CHILDREN, YOUNG PEOPLE OR OTHER VULNERABLE PARTICIPANTS

In addition to the Eight Ethical Principles, the following additional considerations should be taken into account where research involves children, young people (under the age of 16 years), or other vulnerable participants (e.g., those unable to give consent, lacking mental capacity, in care or otherwise vulnerable etc.).

1. Careful consideration must be given to establishing and monitoring consent, the use and communication of findings, and the potential disruption (emotionally or practically) caused by the research.
2. Wherever possible, informed consent should be actively and directly sought from children, young people, and vulnerable participants using communication methods that maximise their understanding of the research. Informed consent must also be obtained from those with legal responsibility for them.
3. Consent should be monitored (e.g., through non-verbal cues) to ensure it is understood and ongoing.
4. The maintenance of anonymity and confidentiality are particularly important.
5. Researchers should make themselves aware of relevant services (e.g., counselling), in case support needs emerge during the research.
6. Researchers must inform participants that any information they provide which suggests a possibility of serious danger to the participant or others cannot be treated confidentially. Where such information is provided by a participant, researchers should disclose this to the relevant authorities and inform the participants and their parents, guardians or caregivers etc. of their intentions and reasons for doing so. Notes should be kept in case a complaint arises.
7. Participation in the research should be made as enjoyable as possible.
8. Interviews should be undertaken by two researchers or in areas where a researcher and the participant are not entirely alone to protect the researcher as well as the participant.
9. Where appropriate, the gender of interviewers should be taken into account, for example in research involving people who have been abused.
10. Feedback on the findings from the research should be given in ways that are meaningful to the participants.
11. Research that involves working with children or young persons aged 0 to 17 years must also take into account the requirements of the Children's Act 2014.