University of Auckland:
Human Participants Ethics Committee

Guiding Principles for Conducting Research with
Human Participants

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1. Introduction

The ‘Guiding Principles for Conducting Research with Human Participants’ provide the means by which The University of Auckland, (hereafter “the University”) meets its obligation to ensure that all research with human participants that is conducted by members of the University conforms to the highest ethical standards. In this way, research participants are treated with respect and dignity and their privacy, safety, health, and personal, social and cultural sensitivities are protected.

"Research with human participants" includes every interaction between a researcher and another human, research on human remains, tissue or bodily fluids, and the study of any information relating to a human. Included in this definition is research involving anonymous questionnaires, research within teaching sessions and research carried out as part of coursework, conducted within and outside the University.

The Guiding Principles set out the key ethical considerations that researchers should be guided by when designing and conducting their research projects. For more information about how the principles contained in this document should be put into practice, researchers should refer to the Applicant’s Manual. The manual gives detailed guidance on the mandatory items that must be included in the ethics application and includes other information essential for making ethics applications. The manual can be found at http://www.auckland.ac.nz/uoa/re-uahpec

2. Scope of this document

This document has been developed for members of the University involved in research with human participants. In particular, the document is intended to provide guidance to researchers conducting research with human participants, ethics advisors and members of The University of Auckland Human Participants Ethics Committee (UAHPEC). Researchers should refer to the Guiding Principles and the Applicant’s Manual when designing research projects and when applying to UAHPEC for ethics approval. The Guiding Principles are approved by Council and reviewed every three years.
3. Role, function and membership of the University of Auckland Human Participants Ethics Committee

3.1 Overview

The University recognises the need for research studies in which people serve as research participants. At the same time, the University is aware of its responsibility to ensure that the welfare, privacy, safety, health, and personal, social, and cultural sensitivities of participants are adequately protected. Thus, the University has established a committee – The University of Auckland Human Participants Ethics Committee (UAHPEC) - to review and approve the adequacy of protection for human participants.

It is the policy of the University that, prior to commencement of research, all staff or student projects and research within teaching sessions that involve human participants must receive approval from UAHPEC.

UAHPEC does not grant retrospective approval.

No project involving human participants can be carried out by members of the University without the approval of UAHPEC, unless an exemption applies. This is subject to the proviso that for health and disability research that falls within the scope of a Health and Disability Ethics Committee (HDEC) review, a Ministry of Health approved HDEC must approve the research.

The mechanism for applying for ethics approval can be found in The University of Auckland Research Guide which is located on the staff intranet at: https://www.staff.auckland.ac.nz/uoahome/staff-intranet/research-36/about-research-at-the-university-of-auckland/research-guide

3.2 Terms of reference

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.

http://www.auckland.ac.nz/uoahuman-participants
3.3 Function of UAHPEC

The function of UAHPEC is to review proposed research involving human participants that is conducted by members of the University.

The UAHPEC will:

- review and where satisfied that it is appropriate, approve submitted research for compliance with ethical principles
- provide advice and assistance to anyone undertaking such research
- receive, record and respond to information concerning adverse events
- from time to time, monitor approved projects to ensure that the research has been carried out in accordance with the ethics approval that was given.

In assessing applications, UAHPEC reserves the right to seek expert opinion, including 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).


UAHPEC will respond to requests for advice on ethical matters concerning research prior to application for ethical review and / or in relation to research that is ongoing and has been approved by the committee.

3.4 Membership of UAHPEC

The committee membership profile reflects the requirements of the University and Health Research Council (HRC) approval requirements. As far as is possible, the committee should include the representatives specified below. Overall, the committee will have a balance of institutional and lay members; at least two Māori members; representation of the community-at-large; expertise in clinical aspects of the social sciences; appropriate ethnic and gender balance; and a balance of disciplines and expertise.

3.4.1 Membership profile

As a minimum, the committee will include:

- One member nominated by the Dean of the Faculty of Arts (Institutional)
• One member nominated by the Dean of the Business School (Institutional)
• Two members nominated by the Dean of the Faculty of Medicine and Health Sciences (Institutional)
• One member nominated by the Dean of the Faculty of Science (Institutional)
• One member nominated by the Dean of the Faculty of Education (Institutional)
• One member nominated by the Dean of the Faculty of Engineering (institut io nal)
• One member with legal expertise nominated by the Dean of Law (Institutional/Lay)
• Deputy Vice Chancellor (Research) or nominee (Institutional)
• One member who has expertise in the area of moral philosophy appointed by Council on the advice of the Head of Department of Philosophy (Institutional/Lay)
• Pro Vice Chancellor (Māori) or nominee (Institutional/Lay)
• One Student Representative nominated by Auckland University Students’ Association (AUSA) Executive Committee (Lay) and/or Postgraduate Students’ Association (PGSA) (Lay)
• Two lay members approved by Council (Lay)
• One member from the community-at-large (Lay)
• Additional coopted members as required to ensure the appropriate breadth of expertise.

3.4.2 Term of membership

The term of membership is two years with the exception of student representatives for whom the membership term is one year. Appointments may be renewed but no member shall serve more than four consecutive terms.

3.4.3 Chair

The Chair is appointed by Council, in consultation with the committee if necessary. Either the Chair or Deputy Chair is a lay person. The term of the Chair is two years. Appointments may be renewed, but no Chair shall serve more than four consecutive terms.

3.4.4 Reporting to Council

UAHPEC reports to Council annually, and at other times as requested by Council.
3.4.5 Quorum

A quorum consists of not less than 50% of the relevant committee membership.

4. Ethics framework for research with human participants

4.1 Introduction

The University requires research with human participants to be designed and carried out to the highest ethical standards. The four key principles of ethical research which UAHPEC requires to be applied to the design, conduct and ethics review of research are autonomy, beneficence, non-maleficence and justice. The value underlying these principles is respect for people.

4.2 Key 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 study 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. Research should 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.

4.3 Congruence with Health Research Council ethics framework

The above four principles are widely accepted as key principles that guide all research ethics communities. They are complementary and interdependent and how they apply, and the weight accorded to each, will depend on the nature and context of the research being undertaken.

UAHPEC expects that researchers will at all times respect and provide protection for their human participants. It also expects that the research will be conducted in a manner that conforms with the highest ethical standards and in accordance with the ethical guidelines of the researchers’ respective professional or disciplinary societies.

UAHPEC is an HRC-approved ethics committee; continuing approval is dependent upon the HRC Ethics Committee being satisfied that UAHPEC “is able to offer sufficient protection to the research participants and can maintain the reputation of ethical review in general.” (Health Research Council, 2012, p.4).

5. Applying the core principles to the design, conduct and ethics review of research

5.1 Researchers’ obligations

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. Poorly-designed studies are unlikely to justify the involvement of the research participants.

The researcher is also obliged to ensure that research involving human participants has a value, be that real or potential, theoretical or applied, direct or indirect, that justifies participants’ time and input.

5.2 Recruitment of research participants

The researcher should choose a method of approaching potential research participants that takes account of potential imbalances of power between researchers and participants.

5.3 Inducements, compensation and reimbursement

Where research participants incur costs, it is appropriate to reimburse them. The committee also considers that it is ethically acceptable to compensate participants in some way for their time. However, payments, or other forms of
compensation, should not be so large as to unduly induce individuals to consent to participate in the research.

5.4 Free and informed consent

Competent individuals should participate in research only if they have given their free and informed consent. Therefore, the researcher must provide participants with adequate information about the purpose of the research, methods of participant involvement, and intended use of the results. This information must be provided in a manner that most easily and effectively permits the potential participant to understand and voluntarily commit to participation in the project. Clear and comprehensible information that is appropriate to the particular context needs to be used in the Participant Information Sheet (PIS) and Consent Form (CF).

Special care in preparation of documents is required for children, persons with special needs and individuals with diminished autonomy. When dealing with these vulnerable individuals, the researcher must consider whether they are able to give free and informed consent or whether the consent of one or more guardians may be required.

5.5 Protection of research participants’ privacy and confidentiality

The researcher has a duty to safeguard participants’ privacy and confidentiality. The researcher must make clear to participants the extent to which their participation in the research will be known to others. This means that the researcher must store data and disseminate results in a manner consistent with what the researcher has told participants about their privacy. This duty extends to the appropriate use of third parties to provide information about potential participants.

For more information about the Privacy Act 1993 and associated Codes of Practice please see Appendix 1.

5.6 Limitation of deception

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, and there is no less deceptive means reasonably available. Participants must be offered a de-briefing session after the data-gathering in which the deception is explained. UAHPEC will very carefully review any study which proposes using deception and will require a clear justification from the applicant as to why the deception is considered necessary for the study and how participants will be safeguarded.
5.7 Minimising harm

All research studies carry some risk of harm, but it is the duty of researchers to minimise that risk. Researchers have a responsibility to assess their research and to discuss any potential for harm, to individuals or communities, in their application for ethics approval. Whenever there is risk of harm, they should give careful consideration to possible alternative procedures.

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 can never wholly guarantee the safety of research participants. Therefore, potential participants must be made aware of potential risks and agree to them before participating in the research; this can be done by means of the PIS and CF. In addition, the researchers must be mindful of their own safety and well-being. Appropriate monitoring and support procedures should be put in place during and after research activities.

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

The University's liability insurance programme includes the requirement to obtain ethics approval (see section 6.7). Further information on risk management and liability insurance is available from the University’s Risk Office (ext. 82746).

5.8 Conflict of interest

It is the duty of the researcher to avoid conflicts of interest and to declare in the ethics application form and PIS anything that could be perceived as a conflict of interest. The purpose, nature and funding of the research should be clearly stated. If the research is funded, the support and its source must be identified in the PIS and research reports. In addition, the researcher must be sensitive to possible conflicts of interest between the participants, such as those that might arise between parents and their children, principals or CEOs and their staff, or teachers and their students.

5.9 Social and cultural sensitivity

The researcher has a duty to treat all participants with dignity and respect. Researchers must ensure that their actions and intentions are appropriately sensitive to participants’ cultural and social frameworks. Where appropriate, the researcher will provide information in the first language of the participants. When research involves particular cultural or social groups, the researcher has a duty to find and use appropriate channels to seek permission to work with such groups and, where appropriate, consult with
them about the appropriate conduct of research.

5.10 Vulnerable participants and communities

Vulnerable individuals and communities are able to be included in research projects where appropriate, but special care needs to be taken when research involves vulnerable participants. The researcher should take special care to ensure that the interests of vulnerable participants and communities, whether participating in the research or affected by it, are protected. Furthermore, researchers should inform the committee as to how they will protect the interests of vulnerable participants and communities.

5.11 The Treaty of Waitangi / Te Tiriti o Waitangi

The 1989 Education Act specifically enjoins the University to give regard to the Treaty of Waitangi. The University recognises that all members of its community are encompassed by the Treaty of Waitangi with mutual rights and obligations. Research proposals must incorporate, where appropriate, the spirit of the Treaty of Waitangi. This means that all parties involved in the research project must respect the principles of partnership and sharing implicit in the treaty.

The researcher has a duty of care to approach research pertaining to Māori in a culturally sensitive way. When research focuses on Māori as a cultural group, or if the nature of the research is such that there are clear potential implications of direct interest to Māori, the researcher is required to show that appropriate consultation has taken place, such as discussing any issues relating to Māori cultural and ethical values with the whanau, hapū or iwi concerned.

The Pro Vice-Chancellor (Māori) has a nominee (Māori ethics advisor) in each faculty. Researchers who are conducting research pertaining to or involving interaction with Māori will require the sign-off of the Māori ethics advisor in their faculty.

5.12 Human remains, tissue and bodily fluids

All human remains, tissue and bodily fluids, such as blood samples, must be treated with respect and, in general terms, samples collected for one purpose must not be used for another without the consent of the donor. Further information is available in the Health Information Privacy Code 1994, see especially Rule 10 “Limits on the use of Health Information”: [http://privacy.org.nz/assets/Files/Codes-of-Practice-materials/HIPC-1994-incl-amendments-revised-commentary.pdf](http://privacy.org.nz/assets/Files/Codes-of-Practice-materials/HIPC-1994-incl-amendments-revised-commentary.pdf)

The Human Tissue Act 2008 regulates the collection, storage, and use of human tissue in research. Researchers working with human tissue need to demonstrate to UAHPEC that they have understood and taken account of the
Human Tissue Act. For further information see Appendix 2 or: http://www.health.govt.nz/search/results/human%20tissue%20act

5.13 Incidental findings and discovering illegal activity

Research occasionally gives rise to findings that are unexpected and unrelated to the original purpose of the research, but which may have implications for the well-being and interests of participants. The most common examples of such incidental findings are when a study discovers a medical condition in a participant, or when a participant reveals that they are party to illegal activity in the course of the study. UAHPEC uses the standard of more-than-minimal risk to identify incidental findings: if a contingency is more likely to arise due to participation in the study than it would be in everyday life outside of the study, then it deserves special attention.

The University expects researchers to 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 advance. If participants do not want to be informed of such a finding, they should be excluded from the research.

In the case of discovering illegal activities, what should happen will depend on the circumstances. UAHPEC requires the researchers to give consideration to this issue for research where this may be a concern. The researcher/s must explain to UAHPEC (and participants where necessary) how they intend to handle such discoveries.

When there are incidental findings, 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, researchers have a moral obligation to breach confidentiality where the life or health of any person may be at risk. There may be legal requirements to report certain kinds of discoveries, and it is the researchers’ responsibility to be aware of these.

5.14 Adverse events

An important part of UAHPEC’s responsibilities is the evaluation of events in which research participants have been unexpectedly harmed. In order to fulfill its responsibility to protect all research participants, to the extent that it is possible to do so, UAHPEC requires written reports to be submitted to the committee describing any unanticipated problems involving risks to participants or unexpected serious harm to participants. It is the
responsibility of researchers (in the case of students, through their primary supervisor) to report adverse events to UAHPEC. The form for reporting adverse events is available from the Research Integrity Unit in the Research Office.

Where there is an adverse event, the affected participant must be put in contact with appropriate assistance by the researcher.

5.15 Storage, security, destruction and retention of data

Information should be handled in a way that protects participants’ confidentiality and ensures the safe custody of the data. Care should be taken to protect the legitimate privacy of individuals, institutions, communities and ethnic groups. 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 by the researcher and supervisor only. Researchers should consider how participants who are under the age of maturity 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 maturity.

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. For advice on this see the Code of Ethics devised by the National Oral History Association of New Zealand at [http://www.oralhistory.org.nz/code.htm](http://www.oralhistory.org.nz/code.htm)

If data are to be destroyed, clear indication should be given to UAHPEC and to participants regarding the timing and manner of this. If data are not to be destroyed, this must be indicated to participants along with the purpose of retaining them.

The University requires that Consent Forms be retained in secure storage by the researcher (in the case of students, through the primary supervisor) for a period of six years. Information relating to storage must be shown at the top of the Consent Form.

5.16 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 is obliged to do this if they have given the participant the opportunity to receive results and the participant has requested them.
5.17 Complaints procedure

A person wishing to raise a matter of concern or a complaint about research approved by UAHPEC and relating to the ethical standards of research on human participants conducted by members of the University, may do so in writing to the chair of UAHPEC. The complaints procedure is set out in full in Appendix 2. Researchers are obliged to inform research participants of the complaints procedure as outlined in the Applicant’s Manual.

6. Applying for ethics approval

6.1 Overview

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

Where approval for a research project has been given by an ethics committee not approved by HRC, the researcher will need to make a full application for ethics approval to UAHPEC or an HDEC. Where approval has been given by an ethics committee approved by HRC, the researcher must submit evidence of ethics approval to UAHPEC and the committee may either ratify the approval or require a full ethics application.

Where research is conducted with a researcher from an institution whose ethics committee is not approved by the HRC, a full application for ethics approval must be made to UAHPEC or one of the HDECs.

When a new staff member brings a research project to the University from another institution, the original ethics application and approval should be submitted to the chair of UAHPEC who will decide whether it should be submitted to UAHPEC for ratification or not. In either case, the researcher must obtain written approval from the chair.

Failure to obtain ethics approval when it is required, and failure to comply with the policies established by UAHPEC, constitutes research misconduct and may occasion disciplinary action following standard University procedures. See the University of Auckland Code of Conduct for Research (2012) which can be found at https://policies.auckland.ac.nz/policy-display-register/code-of-conduct-research.pdf.

The researcher will not be covered by University indemnity insurance in the event of a complaint or legal suit by a participant if ethics approval has not been obtained.

Researchers should also note that many outlets for the dissemination of research results, such as academic journals, will not accept research results for publication if ethics approval has not been obtained.
6.2 Disclosure

The ethics approval process requires disclosure of all known relevant information about the proposed research proposal to UAHPEC. The principal investigator needs to consider whether a particular piece of information is relevant to the ethics approval process even if the Guiding Principles do not specifically ask for that particular piece of information to be provided.

6.3 Overseas research

Where research is conducted overseas, the principal investigator must demonstrate that they have considered the safety of the researchers and participants and taken into account ethical conditions appropriate to the area in which the research will take place. They must pay attention to contextual issues and show how they have addressed these.

UAHPEC also requires that local ethics approval is obtained if necessary or appropriate, and that local laws are complied with. A researcher must be familiar with local law, including in relation to the protection of privacy and data, and assure UAHPEC that they will comply with local law.

6.4 National Institutes of Health (NIH) funded research

Research on human participants conducted at the University that is supported by U.S. Federal Funds, or research where this institution is a part of a multi-centre study with NIH funding, is subject to special requirements. In order to fulfill the terms of the Federal-wide Assurance with the Office of Human Research Protection, researchers should contact the Human Ethics Administration, ext. 83711, for advice prior to taking up the research grant.

6.5 Coursework-based research

UAHPEC recognises that research may take place in class time with students acting as participants. Such research is usually applied for in a ‘Coursework Application’. There are two kinds of coursework-based research:

(i) Laboratory and other course-based research – such research is explicitly pedagogical; it contributes directly to the course content and objectives, and the information collected is not for wider dissemination. Students may be involved in this research as research participants and/or researchers. Acquiring research skills may be one objective of laboratory or course-based research.

(ii) Research in class time – this kind of research is undertaken for the research purposes of a staff member or student who may or may not be a member of the teaching staff of that course. It is University policy that research in class time is not permissible except under the following three conditions:
• the research is directly related to course content
• 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.

6.6 Funded research

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.

6.7 Liability insurance

The University maintains a liability insurance programme which extends to the performance of clinical trials. The policy conditions include the requirement to obtain ethics approval and to adhere strictly to the approved protocol. For more information please contact the University’s Risk Office.

References


Appendix 1: The Privacy Act 1993

The protection of privacy is both a legal requirement and also a significant ethical concern. Naturally, UAHPEC does not provide legal advice on these matters; nor can we provide anything more than basic guidance. The Privacy Commissioner provides a significant amount of information, including on Codes of Practice which supplement the Act (and in some circumstances these may set out more stringent requirements). For more information visit www.privacy.org.nz.

The University’s policy relating to privacy can be found at http://www.auckland.ac.nz/uoacad/home/privacy. This policy gives guidance on the collection, use, disclosure and correction of data held by the University. The University has a Privacy Officer who deals with the policy and issues arising.

The UAHPEC looks to ensure that both legal requirements relating to the Privacy Act and ethical standards relating to privacy issues are met as part of its process of reviewing whether to grant ethical approval. For that reason, the following points should be noted, as they may be important in a particular case.

In the first place, compliance with the requirements of the Privacy Act and any relevant code is relevant to ethical approval in two separate ways. Firstly, there is the requirement that researchers collect and store information in a manner that complies with legal and ethical requirements relating to privacy. Secondly, where the research involves reviewing data that has been obtained by another organisation, it is necessary for researchers to ensure that the organisation that is hosting the research or allowing access to data it has collected is complying with its privacy obligations in allowing access to that information for research purposes.

Of the ‘information privacy principles’ set out in the Privacy Act 1993, some are of particular relevance to researchers. The implications of most of these principles are self-evident, but we have added some emphases and comments:

1. Personal information can only be collected for a lawful purpose. [That would include research purposes.]

2. It shall be collected from the individual unless it is publicly available, or authority has been given for it to be collected from someone else, or it would not prejudice the interests of the person, or non-compliance is necessary for law enforcement and the like, or compliance would prejudice the purposes of the collection, or compliance is not reasonably practicable, or the information will not allow the individual to be identified, or will be used for statistical or research purposes and will not be published so as to identify the
individual. [Note that the various exemptions are relevant only to the question of whether it is possible to collect personal information other than directly from the individual: see 10 and 11 below for the principles relating to the use of information.]

3. Where information is collected from individuals, they have to know the purpose and the intended recipients etc. However, this is subject to exceptions that are similar to those under principle 2. [Again, this is relevant only to the question of the collection of the information: see 10 and 11 below for the principles relating to the use of information.]

4. Only lawful and fair means shall be used to collect information. [This may have an impact on the methods used in research.]

5. Information has to be stored securely. [This explains the requirements the UAHPEC has about the storage of information collected.]

6. People have a basic right of access to information held about them where it can be retrieved readily.

7. People are entitled to seek correction of any inaccuracies.

8. The holder of information shall not use it without taking reasonable steps to ensure that it is accurate, up to date, complete, relevant and not misleading.

9. Information may not be kept for any longer than is required for the purposes for which it may lawfully be used.

10. Information obtained for one purpose shall not be used for another purpose unless it is publicly available, or authority has been given by the person, or it is necessary for law enforcement and the like, or to prevent or lessen a serious or imminent threat to public health or safety or the life or health of the individual or another, or the purpose is directly related to that for which the information was collected, or the information is used in a form that will not allow the individual to be identified, or will be used for statistical or research purposes and will not be published so as to identify the individual. [Note that there are some differences between the exceptions applicable under principles 2 and 3: in particular, the exceptions for not prejudicing the interests of the person or compliance not being reasonably practicable are missing. This principle and principle 11 below are of clear importance when a researcher is reviewing material stored by another organization. UAHPEC will look at what consent was given to the organisation at the time it collected the data as to the circumstances in which the information might be used further for the purposes of research, and if no express consent has been given for that further
purpose, the committee will look to whether or not any identifying material might be released, including to those involved in carrying out the research. It should be noted that the basic principle is that people have the right to control access to their private data and so express consent to the use of data is the most obviously suitable scenario: reliance on other circumstances may nevertheless be ethical on the facts of a particular case.]

11. The body holding information cannot disclose it unless it is for a purpose for which it was obtained (or a directly related purpose), or it is publicly available, or has been authorised by the individual, or non-compliance with this requirement is necessary for law enforcement and the like or to prevent or lessen a serious or imminent threat to public health or safety or the life or health of the individual or another, or the purpose is directly related to that for which the information was collected, or the information is used in a form that will not allow the individual to be identified, or will be used for statistical or research purposes and will not be published so as to identify the individual.

12. Unique identifiers are to be used only when necessary.
Appendix 2: Complaints procedure

a) A person 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 Chair of UAHPEC.

b) A complaint, or expression of concern, should be set out in sufficient detail to enable the Chair to identify both the research and the issues of concern.

c) In consultation with the Chair, the Manager, Research Integrity will determine if the complaint will be investigated and, if so, the process to be followed.

d) The Manager, Research Integrity will co-ordinate, or lead, the investigation in consultation with the Chair.

e) UAHPEC will be informed that a complaint has been received. The complaint will be recorded and the documentation held confidentially in the office of the Research Integrity Unit.

f) To protect the privacy of the complainant, the researchers, and research participants, all complaints will initially be treated as confidential to the Chair and the Research Integrity Unit. The Manager, Research Integrity, in consultation with Chair, will determine the appropriate levels of confidentiality throughout the proceedings.

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

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

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

j) The Manager, Research Integrity will ask the subject of the complaint for a written response.

k) After considering the response and in consultation with the Chair, the Manager, Research Integrity may seek such further information, as may be necessary to pursue the resolution of the complaint.

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

m) Complainants should be kept informed about the progress of their complaint.

n) At any stage of the investigation 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.

o) 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.

p) Where the Manager, Research Integrity’s investigation determines that there may be a breach of the University’s Code of Conduct for Research, the Manager, Research Integrity will inform the Chair and refer the matter to the Deputy Vice-Chancellor (Research) (DVC(R)). In such circumstances the Chair will inform the complainant and the subject of the complaint accordingly.

q) UAHPEC will be informed of the outcome of the investigation. Normally UAHPEC will only be informed of the identity of the researcher and the research project where the complaint (or parts thereof) is upheld.

r) Where the matter is not resolved through the investigation carried out by the Manager, Research Integrity the Manager, Research Integrity will inform the DVC(R) and advise the complainant and the subject of the complaint accordingly.

s) The DVC(R) shall determine if further steps be taken within the University to address the matters raised by the complainant.

t) Where the complaint remains unresolved at the University level the complainant may refer it to the Health Research Council Ethics Committee for an independent opinion.

u) If the complaint is about the Chair, or if the complainant is dissatisfied with the Chair’s response, the complainant should, in the first instance, write to the Manager, Research Integrity who will then direct the complaint to the DVC(R).

v) Complaints concerning another ethics committee must be made to that committee.