MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants

REVISED CODE
2017

NAVIGATION CONTROLS

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Human Ethics Code – Introduction

The Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants has been developed to ensure that research, teaching and evaluation activities undertaken by staff and students of Massey University are consistent with Section 161 of the Education Act 1989. This Section guarantees the freedom of academic staff to engage in research and to teach and assess students in the manner which they consider best promotes learning. However, it also requires that institutions maintain the highest ethical standards and permit public scrutiny of the maintenance of those standards.

The following activities must comply with the Code of Ethical Conduct for Research, Teaching and Evaluations involving human participants[1]:

a) All research involving either the participation of humans or where the research impacts on individuals, groups or communities. This includes consultancies, contract research, staff research and supervised student research.

b) Any teaching which involves the participation of students for the demonstration of procedures or phenomena that have a potential for harm[2].

c) Any evaluation of University services, organisational practices or teaching programmes where information of a personal nature may be collected, where participants may be identified, or where the performance of staff may be commented on. This does not include routine organisational quality improvement activities, (e.g. academic programme evaluations or service delivery projects or institutional research assessment exercises, such as that required for the Performance Based Research Fund), but does include activities which have a research component and may be disseminated.

1 Unless specified otherwise 'Code' refers to the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants. A 'human participant' is any person participating in a research, teaching or evaluation situation as:

- an experimental participant
- as an example of some human characteristic or condition
- as a recipient of any physical, psychological, behavioural or social intervention or manipulation, or
- as a provider of information

2 Excluding 'regular' teaching which is covered by the principles of professional conduct as referred to in Massey University's Policies on Staff Conduct and Teaching and Learning, and the Collective Employment Agreement.

The Code is endorsed by the Massey University Council and administered by the Director, Research Ethics through the Massey University Human Ethics Committees at Albany (HEC: Northern) and Palmerston North (HEC: Southern A and B). These Committees receive accreditation from the Health Research Council, which is a benchmark of international best practice. Such accreditation is necessary for any research receiving Health Research Council funding.

The intention of the Code is to provide protection for all participants in research, and certain teaching and evaluation programmes, as well as to protect researchers and institutions.

The Code is an expression of the basic human rights of respect for persons, autonomy, privacy and justice and incorporates the principles implicit in the Treaty of Waitangi and the *Te Ara Tika* Māori ethical framework.

A 'HIGH TRUST' RESEARCH ETHICS SYSTEM

The Characteristics of the Code

The code is characterised by a 'deep consideration – high trust' approach. What this means is that the University expects that researchers will take responsibility to thoughtfully apply the principles to their research (interpreting principles using 'deep consideration' rather than having a set of rules to follow). The 'high trust' factor implies that the institution has the expectation that researchers will as a community (by and large) act on the responsibility to interpret and apply the higher level principles in this Code to their projects. The posing of questions to researchers is an indication of a sharing of responsibility for deep ethical consideration by both the researcher and ethics committee.

Trust might be defined as having four key elements[3], which in the Massey University research, teaching and evaluation context are:

3 Hardin, 1993

1. That the Code promotes a climate of trust and responsibility within the University research community by allowing researchers to interpret and apply the principles thoughtfully to their project, rather than following rules.

2. That the University trusts all researchers to follow the procedures indicated in their application. Researchers are asked in their application for their expertise and experience; committees will therefore have some basis upon which to trust the particular researcher in a specific context.

3. That the University expects that participants should also be able to trust researchers. Committee reviews will also attempt to ensure that researchers will build respect and rapport, and act with reciprocity toward participants; these elements are constituents of 'trust'.

4. That the Ethics Committees aim to earn the trust of researchers by interacting respectfully with researchers.

This trust is verified by procedures which check how researchers apply the code through low risk auditing and committee review. The justification for this checking is two-fold: firstly, to satisfy accreditation bodies and secondly, to build evidence for ongoing 'trust' (trust ought not, in this context, be 'blind faith').

Our system uses both 'ascribed' and 'achieved' trustworthiness. Ascribed trustworthiness is the default trust granted to all members of the University community. This is the basis for not requiring reports on research to the Ethics Office unless there are exceptional circumstances. Achieved trustworthiness is trust given on the basis of demonstrated expertise or capacity to do what the Ethics Office, through its Committees, expects. In requiring that student research is submitted by supervisors, their researcher merit of being 'ethically aware and responsible' is called on. There is, therefore, an element of achieved trustworthiness applied by Human Ethics Committees to researchers who have demonstrated ethical research in the past.

How to use this Code

The Code poses a series of questions designed to identify the key ethical components/issues that researchers need to address to ensure the soundness of their research planning.

These questions are compiled as a summary in Appendix A.

Not all specific questions may be relevant, but a proportion of them would likely need to be considered and addressed.

Section 1 Principles

UNIVERSAL PRINCIPLES

TREATY OF WAITANGI OBLIGATIONS & PRINCIPLES

UNIVERSAL ETHICAL PRINCIPLES

The principles of this Code draw attention to considerations that are typically of ethical significance. These principles are designed to be guides, not rules. Whether and to what extent the considerations matter ethically, and what to do in situations where considerations conflict, are matters of judgement that researchers and Ethics Committee members are charged with making. The principles should inform those judgements, but cannot replace them.

The order of principles in this document does not indicate priority as their relative importance will depend on a specific context.

Autonomy

To what extent will doing/allowing this research enable others to freely decide to participate in light of their own beliefs and values?

Autonomy is about making decisions on the basis of one's own values and beliefs. There are four main components to autonomous decision-making:

a) Agency (the capacity to make decisions in light of one's values and beliefs);
b) Information (on which to base the decision);
c) Comprehension (so that the decision is based on full understanding); and
d) Absence of pressure, coercion or manipulation (so that the decision can be said to belong to the agent).

Providing conditions a) through d) are appropriately met, research typically promotes autonomy by providing others with the opportunity to participate. The corollary of this is that preventing research from proceeding can often be disrespectful to the autonomy of others by depriving them of the opportunity to make their own decision about whether or not to participate.

Note that it is important not to confuse vulnerability with lack of autonomy. Those who lack autonomy are vulnerable, but those who are vulnerable do not necessarily lack autonomy. When it comes to vulnerable individuals and groups, special care may need to be taken to ensure that component 'd' is adequately satisfied; and it is important not to deprive the vulnerable from the opportunity of exercising their autonomy and having their voice heard.

This principle incorporates elements of the following principles from the previous code: respect for persons, informed and voluntary consent, respect for privacy and confidentiality, the avoidance of unnecessary deception and the avoidance of conflict of interest.

Avoidance of Harm (non-maleficence)

To what extent will doing/allowing this research risk or cause harm?

Harm should be understood broadly to cover physical and psychological harm as well as damage to one's reputation, dignity and relationships with others. Note that harms of this broad kind can accrue to individual participants, communities and institutions, as well as researchers.

Typically harm operates as a negative ethical consideration. However, this may not always be the case and, as with all the considerations mentioned in this code, judgement needs to be exercised. For instance, the fact that a particular harm or risk of harm would have occurred anyway may sometimes operate to make the harm in question ethically insignificant, or less significant than it otherwise would have been. There may also be cases where it will be unethical for a researcher to be the agent of a harm that would otherwise have occurred. Cases are different and it is for the researcher and relevant Ethics Committee to judge, on an individual basis, whether the fact a harm would have occurred anyway operates, in a particular case, to make it ethically permissible to cause it, or not.

Sometimes it may be ethically relevant whether a harm was actively caused, or merely allowed. Sometimes it may be ethically relevant whether a harm was intended or merely foreseen. But again, the ethical relevance of this distinction can vary from case to case and so judgement is needed. The point here is that the purpose of the research can affect the ethicality of any harm or risk of harm that it may cause.

Normally, the greater the autonomy of prospective participants, the less ethically justified paternalism becomes; conversely, the less autonomy prospective participants will be capable of exercising, the greater the degree of paternalism that may be justified.

Benefit (beneficence)

To what extent will doing/allowing this research create, support or make likely benefits?

Benefit should be understood as broadly as harm has been above.

Other things being equal, the promotion of benefit is an ethical positive. As such it can sometimes operate to countervail ethical negatives and make ethically permissible what might otherwise be unethical. The word 'sometimes' is important; it should not be assumed that benefits can always be used to offset harms or other ethical negatives.

The same distinctions that apply to harm can also be applied to benefit. That is, it is typically better to have caused a benefit than to have allowed one (though this is not always the case). And it is sometimes ethically relevant whether one intended the benefit, or merely foresaw it.

Justice

To what extent will the benefits and burdens of this research be fairly distributed?

Justice typically involves the fair distribution of harms and benefits. For example, if all the benefits of a research proposal accrue to one group, and all the harms to another, then this typically counts as an ethical negative due to it being unjust.

Achieving a fairer distribution of harms and benefits by increasing the harms or decreasing the benefits will probably not operate to make a proposal more just (this is why justice only 'typically' involves fairly distributing harms and benefits). By contrast, if a fairer distribution can be achieved by increasing benefits or reducing harms, then normally this will operate to make a proposal more just.

Discrimination in the selection and recruitment of participants, except where necessary logistically or for the purpose of the research, will typically be unjust. However, even when necessary for logistical reasons, some kinds of discrimination may still be ethically problematic.

Special relationships

To what extent would doing/allowing this research honour the ethical norms generated by the special relationships that the researcher has?

Relationships can take many different forms, including between persons and other persons, institutions, communities, activities, objects, and places. These relationships can generate ethical obligations and permissions that would not exist otherwise. For example, researchers come to be in a special relationship to their participants and thereby acquire a special obligation to respect their autonomy, welfare, values and beliefs that would not be owed to the same degree to perfect strangers. Similarly, researchers at Massey University have a special relationship to the institution of Massey University, to colleagues, to students, and to the wider research community. In each case the existence of these relationships can generate obligations that would not otherwise exist, or make more stringent those that do.

Special relationships can sometimes operate to make ethically permissible what might otherwise be unethical. That is, they can generate permissions as well as obligations. For instance, some methods of recruitment may be unethical in the context of strangers, yet ethical in the context of family members, friends, fellow community members or colleagues.

Special relationships can sometimes render impermissible what would otherwise be permissible. For instance, it may be ethically inappropriate for an Ethics Committee member to pass judgement on the proposal of, say, his/her partner, even if no bias would be shown. In this sort of case it is the brute existence of the relationship that is making the ethical difference. In other cases, relationships can generate conflicting requirements. Being a good researcher may not always be compatible with being a good friend, parent, community member or colleague. In cases where a researcher's relationships are generating conflicting requirements, judgement has to be exercised to determine which requirements are ethically more binding.

TREATY OF WAITANGI OBLIGATIONS & PRINCIPLES

Massey University as an institution has agreed, as have Massey University researchers as individuals, that all research conducted under the auspices of the University will comply with the principles (implicit in the Treaty of Waitangi) of partnership, participation and protection. The Treaty principles, while not specific to research, nonetheless provide general obligations and considerations to all staff and students. Ethical principles and the interpretation of them draw from cultural understandings; it follows then that, as good Treaty partners, New Zealand researchers need to be cognisant of Māori ethical principles.

While the academic literature on Māori research contains a number of ethics relationship-based models, Massey University looks to the comprehensive review of mātauranga Māori (Māori knowledge) on research ethics undertaken for the Health Research Council by the Putaiora writing group in *Te Ara Tika*[4]. The writers produced a Māori ethics framework which extrapolates the Treaty principles, and applies tikanga (cultural) concepts into research contexts. The framework helps researchers to identify ethical issues in terms of 'the rights, roles and responsibilities of researchers and Māori communities: the contribution that research makes towards providing useful and relevant outcomes; and addressing inequalities' (*Te Ara Tika*, p.1).

The Māori ethics framework proposed in *Te Ara Tika* has four principles: whakapapa (purpose and relationships), tika (research design), manākitanga (cultural and social responsibility) and mana (justice and equity). Below are summary questions for mainstream research; for fuller explanations and for applying these principles in Māori-centred research, see the full *document*.

Whakapapa (relationships)

In what ways are relationships being established, developed and maintained with iwi, hapū, whānau and Māori communities?

Consulting meaningfully and developing authentic relationships contributes to the ethical tenor of the research. This ethical principle links to the Treaty principle of partnership, being concerned with consultation and engagement with communities, and demonstrating reciprocity to them.

Tika (purposefulness)

Can the research achieve its aims? In what ways will it impact on Māori?

Will the research protect the rights and interests of Māori and contribute to building Māori capacity and welfare across the research stages and roles?

This principle links to the Treaty principles of participation and active protection of the rights and interests of Māori.

Manākitanga (cultural and social responsibility)

Does the research treat people with cultural sensitivity? In what ways will the research ensure that the dignity and respect of all parties is upheld?

This principle links to the Treaty principle of partnership.

Mana (justice and equity)

Who will benefit from the research and how will this benefit be manifested? In what ways will the research strengthen and protect Māori culture, values, practices and language?

In the context of this framework mana relates to equity and distributive justice and therefore to the Treaty principle of protection.

All research in New Zealand is of interest to Māori and this ethical framework provides the context within which Massey University researchers can enact the Western principles in the previous 'Universal' sub-section. When undertaking research in New Zealand there are core values which can guide how research is designed and undertaken by researchers to be biculturally appropriate, regardless of whether the participant focus is Māori or not. See 'Researcher values in the New Zealand context' in Section 2 of this Code for explanation of the core values.

4 Hudson, M., Milne, M., Reynolds, P., Russell, K. & Smith, B.

Section 2 Applying the Principles

RESEARCHER VALUES IN THE NEW ZEALAND CONTEXT

RESEARCH ON TEACHING AND LEARNING

RESEARCH INVOLVING CHILDREN

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RESEARCH VALUES IN THE NEW ZEALAND CONTEXT

When conducting research in New Zealand there are core values which guide how research is designed and undertaken by all researchers to fulfil the Treaty principles (for communities as well as for individuals), regardless of whether or not the participant focus is Māori. For guidelines on consultation, see *Te Ara Tika*, Table 1 (p17).

Values such as those in the table below assist researchers in New Zealand to be aware of our bicultural context and to acknowledge the ethical implications of bicultural engagement whether working specifically with Māori or not. The values are demonstrated using explicit behaviours of appropriate conduct.

Researcher values [5]

Cultural Value	Researcher Guideline
Aroha ki te tangata	A respect for people – allow people to define their own space and meet on their own terms.
He kanohi kitea	It is important to meet people face to face, especially when introducing the idea of research, "fronting up" to the community before sending out long, complicated letters and materials.
Titiro, whakarongo … korero	Looking and listening (and then maybe speaking). This value emphasizes the importance of looking/observing and listening in order to develop understandings and find a place from which to speak.
Manaaki ki te tangata	Sharing, hosting, and being generous. This is a value that underpins a collaborative approach to research, one that enables knowledge to flow both ways and that acknowledges the researcher as a learner and not just a data-gatherer or observer. It also facilitates the process of "giving back," of sharing results and of bringing closure if that is required for a project, but not to a relationship.
Kia tupato	Be cautious. This suggests that researchers need to be politically astute, culturally safe, and reflective about their insider/outsider status. It is also a caution to insiders and outsiders that in community research, things can come undone without the researcher being aware or being told directly.
Kaua e takahia te mana o te tangata	Do not trample on the "mana" or dignity of a person. This is about informing people and guarding against being paternalistic or impatient because people do not know what the researcher may know. It is also about simple things like the way Westerners use wit, sarcasm and irony as discursive strategies or where one sits down. For example, Māori people are offended when someone sits on a table designed and used for food.
Kaua e mahaki	Do not flaunt your knowledge. This is about finding ways to share knowledge, to be generous with knowledge without being a "show-off" or being arrogant. Sharing knowledge is about empowering a process, but the community has to empower itself.

[5] Adapted from Smith, L.T. (2005).

Further implications of Māori ethical framework and researcher values

In New Zealand, Māori generally consider *collective welfare* is paramount. Consideration for collective welfare requires additional ethical consideration when gaining consent from and acknowledging ownership of information by whānau, hapū and iwi. Given this paramount importance of collective welfare, the results of any research should be appropriately disseminated.

Research, teaching and evaluations covered by this Code should therefore be undertaken in a culturally sensitive and appropriate manner in full discussion and partnership with participants. Considering the inclusion and facilitation of whānau support for participants is one example of sensitivity to cultural well-being. The rights of participants with regard to personal data must be respected.

Te Reo Māori is an official language of New Zealand and is highly valued by many research respondents. Research respondents should be offered the choice of responding in either Māori or English (or, alternatively, if participants volunteer to respond in Māori, they should not be excluded for wanting to do so). If researchers are not fluent, appropriate alternative arrangements should be made to enable respondents to communicate in Māori.

Māori ethical perspectives will be important when the situation in question would normally require observance of tikanga. Observing tikanga can be as simple as removing one's shoes when entering a home, or as complex as working with whānau of Māori who have recently died, where appropriate expert consultation and support is required to uphold the mana of all involved. Another example is when a research project seeks knowledge which may be considered tapu by the respondents and therefore not usually available to outsiders, such as the encountering of whakapapa or research projects that relate to historical artefacts. Such knowledge can be held by living respondents or contained in personal documentation that has not been made public.

Historically, researchers in New Zealand working with human participants have tended to fail to recognise our bicultural history and Treaty obligations and so have undertaken research which has caused harm and provided few benefits. Smith (1999) speaks to the credibility problem the research community has created for itself:

> *Some scholarly communities of scientists may have well established ethical guidelines, many have not. Even if such communities have guidelines, the problem to be reiterated again is that it has been taken for granted that indigenous peoples are the 'natural objects' of research. It is difficult to convey to the non-indigenous world how deeply this perception of research is held by indigenous peoples. (p.118)*

Applicants are here referred to the Guidelines for Māori Research Ethics, Te Ara Tika

RESEARCH ON TEACHING AND LEARNING

As the introduction indicates, this Code applies to research on teaching and learning, but not to evaluation of teaching. Ethical issues to be addressed in the context of conducting research on teaching and learning may include: conflicts of interest and the power relationships involved in teaching and research, the use of existing data for a new purpose, the privacy of information and where dissemination may involve confidentiality issues. While research on teaching and learning may or may not involve research within one's organisation on one's own students, this section focuses on the key considerations involved in undertaking research on and with one's own students. Comments on the broader ethical issues are included elsewhere in the Code.

RESEARCH ON YOUR OWN STUDENTS/PUPILS

The definition of 'own students' includes persons who are current students, potential students in the future and those with whom a prospective relationship of power/influence is likely.

The conventional view of the distinction between teaching evaluation and research would imply that reflective teaching and research (or scholarship) on one's teaching are based on quite different sets of requirements depending on whether one is referring to the rights of learners or of research participants. In this view, research on one's own teaching and student's learning may only occur where students exercise their rights as individuals to participate[6] .

So while evaluation of teaching and research into the teaching and learning can involve the same kind of teacher/researcher behaviour, the permissions required of the students are different because their rights as learners are different from those of research participants.

> *Students have the right that (a) their explicit consent will be sought by researchers whenever this is practicable; but that in any proposed study where their explicit consent is not sought, (b) the proposed research will be reviewed and approved by an institutional ethics committee; and (c) any research report may not identify or permit inference of the identity of individuals.* [7]

Further, anonymity of data is not sufficient if data is provided to a teacher without expectation that it might be used for research purposes, ie some material that students provide is personal and is not given by them as 'learning data'. A decision-making chart is included here to guide thinking in this area. In summary, the key criteria included are:

- Whether consent for research has already been given
- The student's purpose in providing data
- The student's expectations for use of the data
- The anonymity and identifiability of the data
- Whether the findings will be disseminated within or beyond the institution

The decision chart captures the following scenarios:

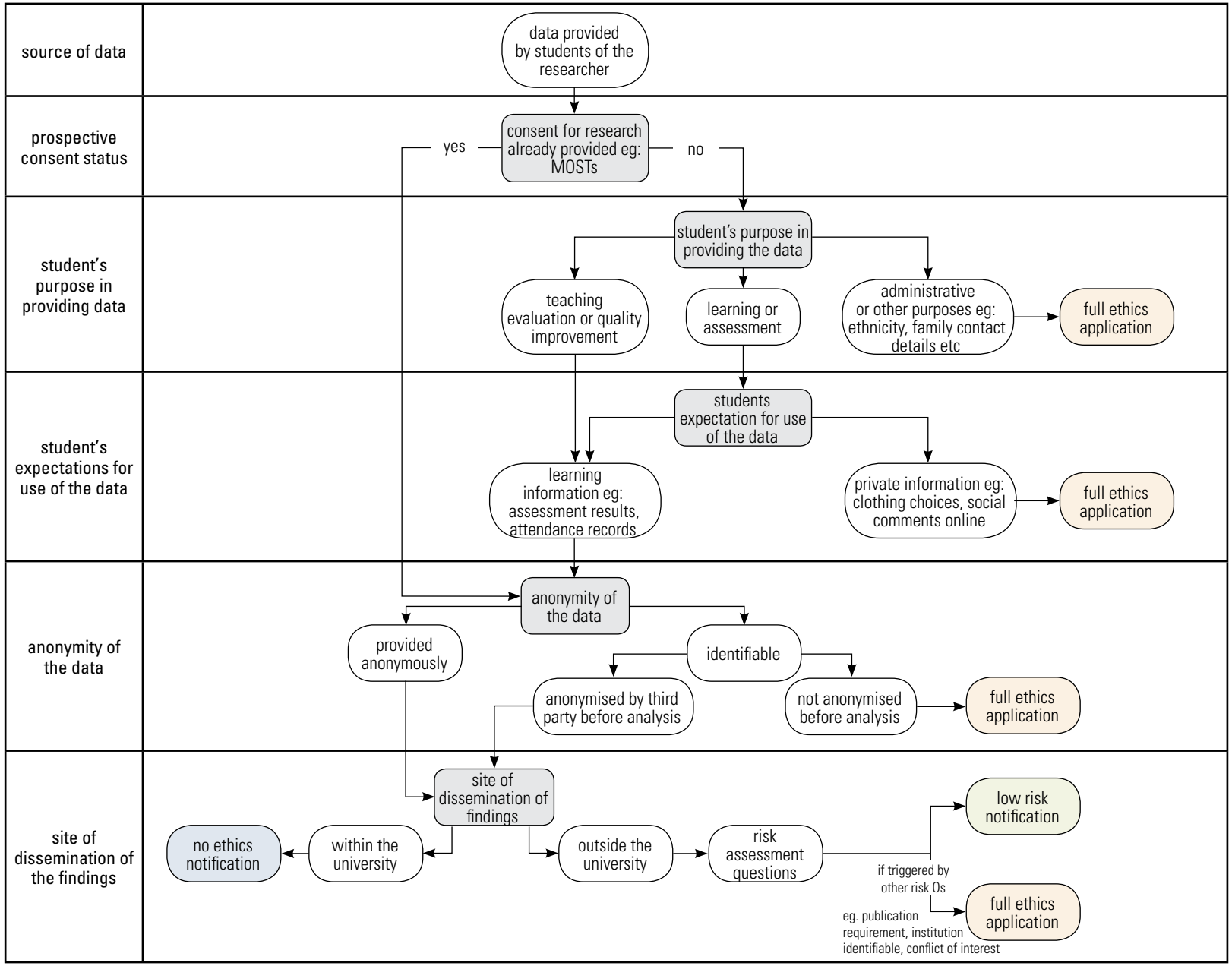
1. Dissemination of anonymous student data within the university, for which the student has already given consent for use, or could reasonably be expected to think would be used in teaching evaluation, can proceed without any ethics notification.
2. Dissemination of such data outside the university would require low risk ethics notification (assuming no other ethical issues).
3. In situations where the student might not expect that their data would be used for evaluation or research, full ethics applications are required.
4. In situations where data is disseminated in identifiable form, a full ethics application is required

6 O'Neill, J. (2010).

7 ibid

Decision Chart

Decision chart for use of Massey student data where specific consent has not been sought prospectively and the students are not currently being taught by the researcher.



RESEARCH INVOLVING CHILDREN

The Code considers research participants under the age of sixteen to be children. A prime consideration in any research involving children is that the research is not against the interest of any individual child participant.

In undertaking research involving children the following considerations arise:

a) Do the Information Sheet and Consent form use appropriate language for the reading levels of the participants?

b) How autonomous will the children's own consent be? Child participants can provide consent if the researcher believes that they are competent to understand the nature of the project. This usually applies from around the age of seven, but it can be younger.

c) Is there a separate appropriate Information Sheet for parents/guardians? If the participation of children is being sought, their parent/guardian/carer's consent is normally obtained because their judgement about what is in the child's best interest is normally more reliable than anyone else's. Where the researcher believes that the gaining of parental consent is unnecessary or would be of potential harm to the child, a case should be made in the ethics application for not gaining parental consent.

d) In what ways will the anonymity of non-participants be protected? If children in a classroom or other group setting are being asked to participate in a research project, procedures are needed to protect the anonymity of those children who do not wish to participate, or whose parent/guardian/carers do not wish them to do so. The Information Sheet should indicate what disruption, if any, will happen to the child's education programme; disruption should be avoided if at all possible.

e) Will the research be undertaken in a Pre-School/School setting? Such institutions usually require researchers to submit a Police Security Clearance.

f) Are the researcher's own children or family members involved? How will conflicts of interest be addressed?

MASSEY UNIVERSITY STAFF AND STUDENTS AS PARTICIPANTS

Particular care must be taken to preserve the rights of staff and students who are participants in research projects. In such cases, confidentiality is particularly important. Where possible, avoid recruiting students from teaching and learning spaces (physical and online). Once the research design and project scope have been established, time spent informing students about the research in a teaching and learning context should be kept to a minimum, normally no more than five minutes.

COMPENSATION OF PARTICIPANTS

a) If participants suffer physical injury as a result of participation in Massey University research, and should ACC decline cover, participants are directed through a statement on the Information Sheet to contact the researcher who will then notify the Research Ethics Office to initiate discussions concerning cover under the relevant Massey University insurance policy.

b) At the onset of the project, researcher(s) should make clear to participants their absolute right to withdraw from research, irrespective of whether or not payment is involved. Payments to participants must not be used:

   i. either as an inducement to participate in research

   ii. or to encourage participants to undertake dangerous or harmful acts which they would not perform in their normal lifestyle.

c) Researchers may wish to reimburse participants for expenses incurred as a result of participation. These expenses may include opportunity costs (e.g. for time) or other costs (e.g. for travel). Reimbursement of reasonable travel costs is accepted as a legitimate practice. The case for payment of opportunity costs for participation in the research is less clear and some guidelines are detailed below.

   i. the payment must in general apply to all participants and all participants must be fully informed of the terms and conditions of the payment;

   ii. the level of, and reason for, the payments should be clearly explained in the application and the Information Sheet;

   iii. the opportunity must be given for the participant to decline payment or seek recompense in an equivalent or alternative manner (eg koha payment);

d) Payments to children must not be made without prior approval by their parents or guardians.

e) Traditionally, koha is an acknowledgement of the knowledge and/or hospitality extended by tangata whenua to manuhiri and is often presented as part of a pōwhiri or mihi whakatau. Koha may also be offered in line with the cultural norms of the researchers and/or participants in research.

f) In some contexts, it is inappropriate to require participants to sign for compensation. There are specific guidelines for such situations in the Additional Information document.

g) Researchers undertaking clinical trials (through HDEC) must complete the relevant forms included in the National Application Form concerning coverage of research participants for injury in a research study.

RESEARCH ADEQUACY

Research should meet appropriate standards of adequacy to be considered ethical. While different research paradigms may inform the conception and design of projects, the following questions should be able to be answered in the affirmative.

a) Does the project have clear research goals?

b) Does the design make it possible to meet these goals?

c) Does the project potentially contribute to the advancement of knowledge to an extent that warrants the cost, in time and effort, from the participants? In the case of student research, it is recognised that research is undertaken for training purposes and may not always advance knowledge.

d) Does the researcher/supervisor have appropriate qualifications and/or experience to conduct or guide the research?

e) Has there been discussion with colleagues, preferably independent of the research/teaching about the ethical issues associated with the research? In the case of student research, has the student discussed the ethical issues associated with the research with their supervisor(s)?

f) Have innovative methodologies demonstrated adherence to a set of standards set by professional peers?

Researchers need to demonstrate to an Ethics Committee that they have consulted with appropriately skilled experts to establish the validity of innovative approaches. Where methodological development is a component of the research, such development needs to be accompanied by mechanisms for participant protection.

ACCESSING, USING AND SHARING DATA

When research involves obtaining data from people, researchers are expected to maintain the high ethical standards set out in the Code both during research and when sharing data.

Research data, even sensitive and confidential data, can be shared ethically and legally if researchers pay attention, from the beginning of research, to five important aspects: [8]

- Consent
- Privacy and confidentiality
- Ownership and authorship
- Governance and custodianship
- Data sharing: assessing the social benefits of research

These measures should be considered jointly between students, supervisors, staff and Ethics Committees. The same measures form part of good research practice and data management, even if data sharing is not envisioned. Data collected from and about people may hold personal, sensitive or confidential information.

There can be a perceived tension between data sharing and data protection where research data contain personal, sensitive or confidential information. However, in many cases, data obtained from people can be shared while upholding both the letter and the spirit of data protection and research ethics principles.

See *Appendix B* for further material on the following aspects of data:

- *Consent*
- *Privacy and confidentiality*
- *Authorship & ownership of digital data*
- *Data governance & custodianship*
- *Disposal of data*
- *Data sharing: assessing the social benefits of research*
- *Open data*
- *Big data*

8 Adapted with permission from Clark, K. et al (2015).

RESPECT FOR PROPERTY RIGHTS

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

Applicants are referred to the Massey University Policy on Intellectual Property from the Massey University Policy Guide website: *http://policyguide.massey.ac.nz/*

RE-USE OF SAMPLES/DATA

Samples and/or data cannot be re-used in a new research project without going back to the participants for their informed consent.

Where it is impossible to do this, approval for the use of de-identified samples or data can be applied for from a Massey University Human Ethics Committee on a case-by-case basis.

THE TREATMENT OF HUMAN TISSUES, BODY FLUIDS AND REMAINS

All human remains must be treated with respect, irrespective of age, condition, origin, ethnicity, religion, sex or nationality.

Research, teaching and evaluations involving human remains, tissues and body fluids should only take place if there are demonstrated legitimate, scientific or educational reasons. In addition, the wishes of the local community, ethnic groups, relatives, guardians and the dead persons, with respect to investigation, storage, and/or disposal should be complied with when they are known or can reasonably be inferred.

FORMULATION AND PUBLICATION OF RESULTS

There is an ethical dimension to the formulation and publication of results, an obligation to share research findings with participants in an appropriate form and to inform participants how the findings will be disseminated. Researchers are advised to be aware of the uses to which less scrupulous people might put the research findings (see the 'Additional Information' document on the Ethics website, section 'Media Communications').

Applicants are referred to the policy on Grounds for Embargoing of Theses.

FURTHER INFORMATION

GLOSSARY

REFERENCES

APPENDIX A: KEY QUESTIONS

APPENDIX B: DATA

RESOURCES

GLOSSARY

Hapū	extended family, subtribe
Iwi	tribal group
Koha	gift
Mana	authority
Mātauranga	knowledge
Mihi whakatau	welcome or greeting between groups, less formal
Pōwhiri	formal greetings between groups
Tangata whenua	indigenous people, in Aotearoa New Zealand, Māori
Tapu	requiring respect and observance of related tikanga
Tikanga	Māori customs, protocols and social values
Whānau	family
Whakapapa	lines of descent, connections, genealogy

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Appendix A

ETHICAL PRINCIPLES: KEY QUESTIONS

Autonomy	To what extent will doing/allowing this research enable others to freely decide to participate in the light of their own beliefs and values?
Avoidance of harm	To what extent will doing/allowing this research risk or cause harm?
Benefit	To what extent will doing/allowing this research create, support or make likely benefits?
Justice	To what extent will the benefits and burdens of this research be fairly distributed?
Special relationships	To what extent would doing/allowing this research honour the ethical norms generated by the special relationships that the researcher has?
Whakapapa (relationships)	In what ways are relationships being established, developed and maintained with iwi, hapū, whānau and Māori communities?
Tika (purposefulness)	Can the research achieve its aims? In what ways will it impact on Māori?
Manākitanga (cultural and social responsibility)	Does the research treat people with cultural sensitivity? In what ways will the research ensure that the dignity and respect of all parties is upheld?
Mana (justice and equity)	Who will benefit from the research and how will this benefit be manifested? In what ways will the research strengthen and protect Māori culture, values, practices and language?

Appendix B

DATA

Consent

Although the conditions for consent are well established in research practice, there are issues regarding consent that are specific to using data.

Questions for Consideration

- Is an ongoing process of informed consent (rather than a one-off consent) more appropriate for this research?
- Who is most appropriate to give approval for the research to be undertaken in an organisation or for the organisation to be named?
- Have all avenues for gaining informed consent from individuals to use potentially identifiable data been explored?
- Are participants aware that data collected for one research project may be reanalysed in future research projects?
- Is there a need for renegotiating consent if the data are used by someone other than the researcher who collected it?
- Has consent been provided to link these data to other data (including personal data)?
- Does the consent process make clear the uses to which the population data (ie the individual data) may be put?
- When information is generated in one context, in what instances should consent be obtained to use this material for research purposes in another context?

Ensuring that participants are enabled to make informed decisions about their research participation is fundamental to consent in research. In consenting to participate in research, the process must be voluntary, and based on provision of sufficient information and adequate understanding of the purpose, aims and risks of the research, as well as what is required from participants.

Privacy and confidentiality

Privacy and confidentiality are both key to ethical research practices. Privacy can be defined as the control that individuals have over who can access and manage their personal information. There are a number of kinds of privacy including location privacy and information privacy, both of which are substantially affected by the widespread use of digital devices and the production of digital data.

By contrast, confidentiality is the principle that only authorized persons should have access to information. In research, confidentiality refers to the process of keeping information gathered in research secure, and ensuring that access will be restricted to authorised users (data governance).

Questions for Consideration

- Do the data in question constitute personal information in the sense of the Privacy Act? [Personal Information includes contact details and information about an identifiable individual that is maintained by the Registrar-General pursuant to the Births, Deaths, Marriages, and Relationships Registration Act 1995. See Massey Human Ethics webpage, 'Ethics Notes: Privacy']
- Is there any mechanism, regulatory framework, or administrative structure that is designed to protect the individual's privacy in relation to this project?
- Does the creation of data in this project challenge individual or community expectations about privacy?
- If explicit consent has not been obtained for this usage of data, does the public interest support its use without consent?
- To what extent are the data gathered in this context considered personal and private, or public and available for research purposes?

It is important to differentiate between the ethical value of confidentiality, which is a central aspect of the relationship between the researcher and research participants, and the legal definition of privacy.

Authorship and ownership of digital data

Questions for Consideration

- What are the risks associated with the use of a data repository?
- Who has authority to access, release and manage this data?
- What processes have been used to anonymise this data?
- What potential harms may result from stripping data of identifiable information?
- Who is accountable for data quality, protection and access to data?
- Who is responsible for providing documentation and metadata?
- Who is responsible for long-term maintenance of this data?
- Is data destruction (as a requirement of ethics applications) a relevant approach to digital data?
- Has the relevant University policy pertaining to data ownership been accessed, read and considered?

The subject of authorship and ownership of digital data is one where there is little consensus about who has responsibility for the data and at what point the individual has given up their right to control their personal data. This becomes an issue, particularly in relation to data sharing and data management, in projects where data are being re-used or shared.

Data governance and custodianship

Questions for Consideration

- Are there processes in place to track the use of the data?
- Who is responsible for archiving data and/or deleting data if that is appropriate?
- Are processes in place to enable adequate data archiving and deletion as needed?
- How is access to data managed?
- What are the principles of data system management?
- How well informed and trained are the data gatekeepers?
- Is there a means of knowing when data has moved from one storage place to another or been copied/replicated in many places?
- Is there a way of retrieving data that has previously been shared?
- Who assumes responsibility once data is in the cloud or is managed/ stored by third parties?
- Who has ultimate responsibility for the data (and succession, should that person leave Massey)?

The management, organisation, access to and preservation of digital data are all vital to research integrity and represent great challenges. There is increasing emphasis on data access and preservation worldwide as digital data storage becomes more available and has become increasingly commercialised.

Data governance can be distinguished from authorship in that it deals with data storage and access to data and its possible reuse after the research has taken place.

See Massey University Library's research support webpage on research data management.

Disposal of data

Clear procedures must be established for the destruction of any identifiable data at the end of the storage period, including determining who will be responsible for the destruction. Nonidentifiable data does not have to be destroyed at the end of a set period, but the researchers should specify a clear plan for ongoing storage, and how data will eventually be deleted (if it is to be deleted).

Data provided by participants is not owned as such by the researcher but rather is in the safe-keeping of the researcher (or supervisor where the project is conducted by a student). Where sound and image recordings are involved, the option of the participant retaining the recordings or agreeing to storage in a research archive can be considered. In the case of the latter option a suitable release form should be negotiated with the interviewee, clarifying the conditions of access. Advice on the nature of the release form can be found in the Code of Ethics devised by the National Oral History Association of New Zealand.

The Massey University Code of Responsible Research Conduct recommends that data generated by researchers be recorded in an appropriately referenced and durable form having regard to the research or ethical protocols under which the data have been obtained, the time such data may be held and the extent to which the data will be accessible. See Part 2, section 2 of the *Code of Responsible Research Conduct:* http://policyguide.massey.ac.nz/ All researchers must be aware of the need for care with respect to computer-stored data when the ownership of a device changes.

Data sharing: assessing the social benefits of research

Questions for Consideration

- Does the approval/permission regime for the original data include or preclude the new use of the data?
- Do researchers accessing data gathered in another context have a responsibility to understand the conditions of its original collection?
- Do researchers have a responsibility to assess whether the secondary use of the data is aligned with the original intent for which it was collected?
- Do researchers using data gathered by another research project have a responsibility to ensure that access to, and use of, the data does not pose a risk to individuals from whom it was originally collected?
- Is there a risk that, in accessing the data collected by others, research participants will be adversely affected? How can this risk be evaluated?
- Do the benefits outweigh the potential risks and/or unintended consequences of repurposing data?
- What are the researchers' ethical and legal responsibilities in the use of re-purposed data?
- Is it possible to withdraw data from a project which may be secondary to the original research? (Is it ever possible to withdraw digital data?).

Data re-use and data matching are techniques that have been enabled by the widespread creation and use of digital data and by increased computing capacities. The use of data from one research project by another research project is one form of repurposing of digital data.

Ethical challenges can arise when digital data produced by one project are used in another project or combined with data from another source, where such reuse must be approved or justified under the same framework as the original use of the data.

Open data

Research data should be made available to peers who wish to repeat or elaborate on the study, subject to requirements for privacy, confidentiality and intellectual property; in many cases however, it may be appropriate to keep identifiable information confidential, but share de-identified data openly.

Research data may be made available either by providing it on request or by posting it in an openly accessible online repository. Data thus shared should usually be anonymous or de-identified, unless the participants have consented to the sharing of identifiable information.

Metadata

Metadata means "data about data". It is information about an object or resource that describes characteristics such as content, quality, format, location and contact information. It can be used to describe physical items as well as digital items (documents, audio-visual files, images, datasets, etc). Metadata can take many different forms, from free text (such as read-me files) to standardised, structured, machine-readable content. Key ethical issues are comparable to "big data".

Big data

The term 'big data' is frequently used. There is no agreed definition, but in public discourse it tends to refer to the increasing ubiquity of data, the vastness of datasets, the growth of digital data and other new or alternative data sources. Key ethical issues in relation to "big data" are privacy, confidentiality, transparency and identity.

RESOURCES

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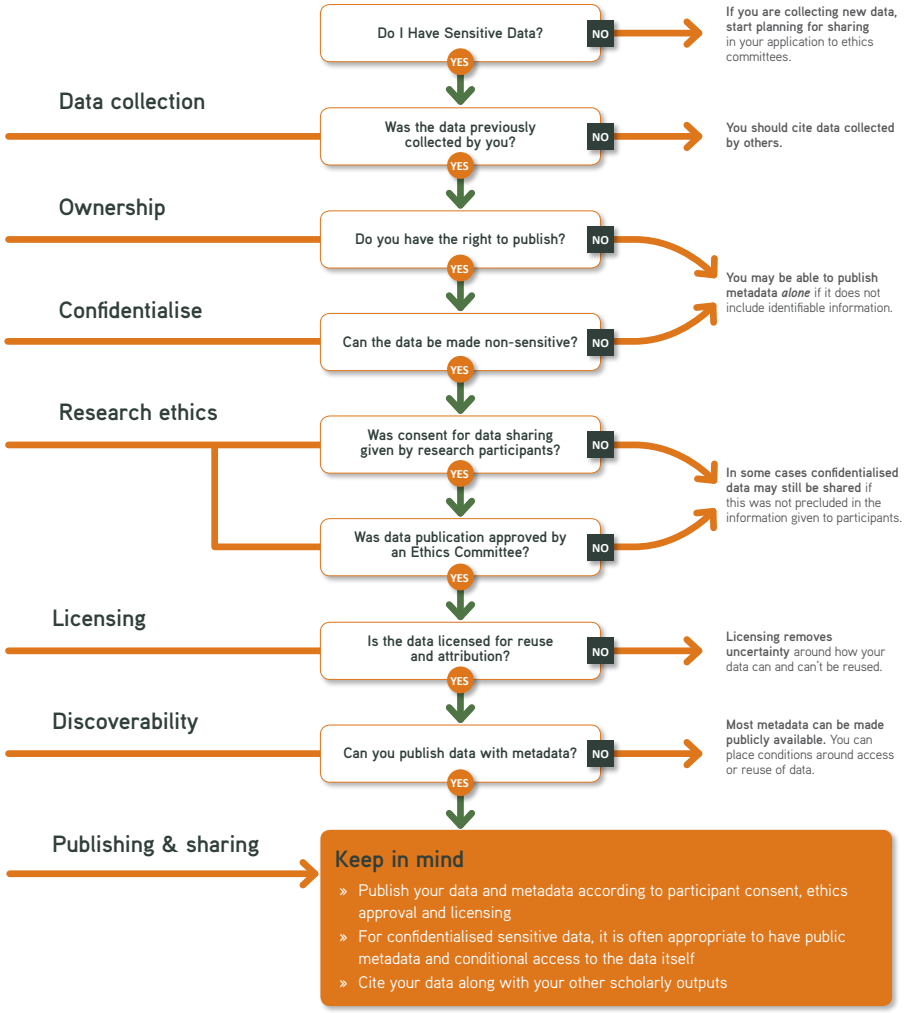
PUBLISHING AND SHARING SENSITIVE DATA

When and how to publish sensitive data as openly and ethically as possible
For more information see: ands.org.au/sensitivedata

ands
AUSTRALIAN NATIONAL DATA SERVICE

Sensitive data identifies individuals, species, objects or locations, and carries a risk of causing discrimination, harm or unwanted attention



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