

AIATSIS HUMAN RESEARCH ETHICS COMMITTEE

INFORMED CONSENT

Introduction to the Informed Consent Menu

The informed consent menu is a table of options for you to choose from according to the type of research you want to do. You should bear in mind that the Ethics Committee will have its own view of what is appropriate in your case and you should not skip any steps that the Ethics Committee might reasonably think are necessary.

The purpose of this Menu, and the *Template for a Plain English Research Statement*, is to ensure that anyone who participates in your research project is *informed* about:

- how you propose to conduct the research,
- what you are asking them to do,
- what the research products will be,
- who will own them and rights to reproduce them,
- how you will protect personal or culturally restricted information,
- what will happen to any raw data (including whether it will be stored with AIATSIS)
- how you will tell the participants the results,

and that they consent to all of these things before participating in the research.

The *Template for a Plain English Research Statement* gives guidance on what you should tell research participants so that they are properly informed about your project. This Menu suggests clauses that you might include in an Informed Consent Form so that it provides an adequate record of research participants' consent to being involved in the research, once they are so informed.

A plain English statement and a record of informed consent are both required for ethical consent practice.

The Menu and the Template are drafted in light of various ethical research standards, including:

- (a) Privacy legislation (the *Privacy Act 1988 (Cth)*);¹ which limits what some researchers or AIATSIS can do with 'personal information' which allows individuals to identify themselves, especially 'sensitive information' (personal information about topics like individuals' religions, ethnic backgrounds, criminal records or health);
- (b) AIATSIS's *Guidelines for Ethical Research in Indigenous Studies*; and
- (c) Other standards which may apply to some types of AIATSIS (-funded) research, eg the NH&MRC's *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*.

¹ This Menu reflects obligations imposed on AIATSIS or researchers under the Commonwealth legislation. Researchers governed by state legislation (eg state university-based researchers) may need to comply with state privacy laws.

INFORMED CONSENT MENU

[NAME OF RESEARCH PROJECT]

[DETAILS OF RESEARCH PROJECT]

[Name of researcher(s)] [Any other appropriate qualifying details, eg place of research, year if this is a revised project requiring new consents, names of participating or supporting indigenous organisations]

1. I understand what this project is about

I have read [or had read to me] the Plain English Research Statement which explains what this research project is about and I understand it.

I have had a chance to ask questions about the project, and I am comfortable with any answers that I have been given. I know that I can ask more questions whenever I like.

2. I have volunteered to participate

I agree to participate in the research. I know that I do not have to participate in it. I made up my own mind to participate – nobody is making me do it or talking me into it.

AND (as appropriate to the research methodology):

I know that I don't have to answer any questions I don't like.

[The researcher(s)] will not write anything down unless I agree that [he/she/they] can.

[The researcher(s)] will turn off the tape/stop filming etc if I ask [him/her/them] to.

3. What will happen if I want to stop participating?

I know that I can pull out at any time without getting into trouble with [the researcher(s)] or anyone else. [There may be a need to specify the other people here, eg if the project is using the records or resources of an indigenous organisation, that organisation or its staff].

AND (choose as appropriate):

If I pull out, none of the information I have given [the researcher(s)] can be used in the research.

OR [if the research data will be corrupted by a person removing themselves retrospectively or without their discontinuation being recorded]:

If I pull out, [the researcher(s)] will be allowed to use any information that I have given them before then, and they will be able to write down that I have stopped participating. But they won't be able to make me keep participating if I don't want to.

4. How the research will happen

[This section should describe what the research participant agrees to do, eg:] I agree that [the researcher(s) – or one of them of an appropriate gender if gender restrictions are appropriate] can interview me for the research [and write down or (video) tape what I say].

OR:

I agree to talk about questions which the researcher gives us in a group of people. This is called a ‘focus group’. I agree that the focus group can be (video) taped. [Or the researcher can sit in and take notes, explain conditions of focus group, etc]

OR:

I agree to visit [X location] with [the researcher(s)] to talk about [eg its dreaming stories and the people who should look after it].

AND (if appropriate):

We won’t talk about [a particular kind of topic]. I won’t pass on any [particular kind of] information. If I accidentally tell [the researcher(s)] these kinds of things, they will not record them.²

5. Having my picture taken or being filmed (including when performing)

(If previous clauses don’t already provide for photography or cinematography):

I agree to be photographed/videoed for the research project.

AND EITHER:

Those tapes/photos/videos/DVD’s are just for the researcher to use for this research. I don’t want other people looking at them (unless I say they can). [Refer to the section on storage of information.]

OR

I agree that those tapes/photos/videos/DVDs can be shown to other people.³

AND (if appropriate):

I agree that those pictures can be put into a book or magazine or shown on TV or the internet⁴

² A clause like this could be particularly important not just to protect personal or culturally sensitive information, but to ensure that researchers do not receive information (eg about undetected criminal offending) which they could by law be forced to divulge in court.

³ There may be a need to limit this for cultural reasons, eg ‘while I am still alive – after that, if someone wants to look at them they have to ask my family’ or ‘except not straight after I die’.

⁴ There may be a need to extend this to other media or to limit it to particular contexts or uses.

OR (If a performance is to be recorded for public display :)⁵

I agree that [the researcher(s)] may record my performance [provide identifying details, eg of ABC ceremony at DEF next week] and that they can use that recording for [eg to make a documentary for SBS, to show their students at X University, to show at the AIATSIS conference etc. Be clear about whether other copies of the recording can be made, by whom and for what purposes].

6. Getting paid for participating in the research

I know that I won't get paid for participating in the research project.

OR (if appropriate):

I will get paid [insert amount] for participating in this research project. This is a payment for my time [or for some other reason, eg because of the valuable knowledge that I will contribute to the research].

AND (if appropriate, eg in social or public health research):

Just because I get paid does not mean that I have to give answers which [the researcher(s)] want(s) me to give.

7. Risks and benefits of the research

I understand that the research may have the following benefits [set out any listed in the Plain English Research Statement].

AND (if appropriate):

But I understand that the research is not guaranteed to achieve these benefits [and possibly some more information, eg 'it depends on what [the researcher(s)] find out' or 'it depends on whether the government listens to what [the researcher(s)] say'].

I know that the risks of the research are [set out any risks, eg]:

- for a project which requires participants to discuss trauma or depression, 'that talking about those things with [the researcher(s)] might make me feel worse';
- for a project which aims to assess levels of undetected criminality 'that if I tell [the researcher(s)] what drugs I took, the police might be able to force [the researcher(s)] to do on me'
- for a project which uses focus groups 'that, while the researchers will ask other people in the group not to discuss focus group business outside the group, they may not be able to stop them doing that'.

8. Who will be the authors of the research?

⁵ Under Part XIA of the *Copyright Act 1968* (Cth), recording such performances without the performer's authority is an unauthorized use of the performances. A performer can sue someone who makes such an unauthorized use for damages.

I understand that [the researcher(s)] want(s) to write about the research in a [book, article in a university journal, report for X organisation etc – adjust to suit the medium, eg video, DVD].

AND (choose whichever is relevant):

I understand that the researcher will [write the book, produce the video etc] by him/herself/themselves. I won't write [etc] it with him/her/them. [Add other relevant information, eg 'but my story and photo might be in that book' .]

OR

I understand that [researcher(s)] want to [write the book, make the video etc] with me [and any other co-authors, producers]. I agree to become an [authors, producer etc].⁶ My name will be mentioned on the [front cover, titles etc] as an [author, producer etc].

9. Will people find out personal things about me from the research?

I agree that my name and other [the following] personal information:

[where possible, specify exactly what information, eg 'where I live, what my country is, how old I am, but not my kids' names or that I have been in jail or have hepatitis']

can be mentioned in any [books/videos etc] that come out of this research. I don't mind if people find out these things about me from [reading the book etc].

AND (as appropriate and required by National Privacy Principle 3):

[The researcher(s)] will check with me before they put the [book/video etc] out that it only contains the right kinds of personal information.

OR:

I understand that my name will NOT be mentioned in any [books/videos etc] that come out of this research, and that people won't know who I am from [reading/watching etc] the [books/videos etc]. [It may be appropriate to mention here any blinding strategies, eg 'when I am talking into the camera, my face will be blacked out so the police won't recognise me' or [the researcher(s)] will just call me a number or gammon name, like everyone else who participates in the research'].

AND (as appropriate):

If [the researcher(s)] keep(s) a record of what I said [or did] during the research with my name on it [or which could be used to identify me], [she/he/they] will keep it in a locked filing cabinet in their offices in [location]. After two years [or other appropriate period, keeping in mind National Privacy Principle 4.2 and what you have said in your Plain English Research Statement], [the researcher(s)] will either destroy this record or give it back to me. [With the participants' advance consent, it may also be possible to transfer such records to an organisation which will use them for purposes directly related to the research – if this is an option, address it now.]

OR:

⁶ Note that, if the participant becomes a research author, his or her name may need to be added to the list of researchers.

If [the researcher(s)] keep a record of what I said [or did] with my name on it [or which could be used to identify me], I want them to give it to AIATSIS for safekeeping. I want AIATSIS to let my family [there may be a need for specificity about individuals here] or [eg other language group or Aboriginal] people to have access to it, but I don't want other people to read it without my permission of my wife, children or grandchildren after I die.

OR:

If [the researcher(s)] keep a record of what I said [or did] with my name on it [or which could be used to identify me], I want them to give it to AIATSIS for safekeeping. I don't mind if AIATSIS lets other researchers read this record.

10. What about culturally restricted information or things?

[Only insert a clause on this if you propose to collect culturally restricted information etc – otherwise, rule it out under 4. 'How the research will happen' above].

I understand that, if [researcher(s)] find out secret or sacred information, or are given secret or sacred things, they won't tell or show them to the wrong people.

I understand that, if [the researcher(s)] collect any secret or sacred information or things, they will put them into [the keeping place at X location; AIATSIS for safekeeping]. Other people should not be allowed to access this information or these things without [my and/or someone else's] permission.

OR:

I agree that, when [the researcher(s)] have collected all the information or things they need, they will talk to me [and/or whoever else has the authority to discuss them] about what to do with any secret or sacred information or things.

11. Who will have access to the research results?

I understand that this research will produce a report for [ABC indigenous organisation]. Members of the organisation will be able to read it, and so will other Aboriginal people who participated in the research. [The researcher(s)] won't give a copy of the report to anyone else without [ABC's] permission. [There may be a need for further restrictions, eg on who can view it and for what purpose.]

OR:

I understand that anyone can read the book/article/report [watch the video, DVD etc] that comes out of this research, and that even people on the other side of the world might see it, maybe on the internet. That's OK with me.

AND (if appropriate):

I agree that [the researcher(s)] can present information from the research at conferences even if I'm not there. [If there's no co-authorship, add 'I understand that [the researcher(s)] can do this without asking me first'].

AND:

[The researcher(s)] will give me [or someone else, eg an indigenous organisation] a copy of any books, articles, databases, CDs, videos or DVDs that s/he writes or produces out of the research.

12. Intellectual property

I understand that [the researcher(s)] will hold copyright in any books, articles, databases or conference papers [or tapes, CDs, videos, DVDs etc – add or delete research products as appropriate] produced as a result of this research.

This means that:

- [The researcher(s)] will be able to reproduce the information that is in these books, articles, databases or conference papers (or tapes, CDs, videos, DVDs etc) in other places or for other purposes (eg on the internet) without asking for anyone else's permission,
- [The researcher(s)] will be able to let other people reproduce that information without asking for anyone else's permission,
- If the books, articles, databases or conference papers (or tapes, CDs, videos, DVDs etc) make any money; [the researcher(s)] will keep it,
- [The researcher(s)] can pass copyright onto people I don't know (eg their own children), who also won't have to ask anyone's permission before they reproduce the information in the books, articles, databases or conference papers (or tapes, CDs, videos, DVDs etc), let other people reproduce it or keep any money that these research products make.

AND (as is usually appropriate):

[The researcher(s)] will grant [ABC indigenous organisation, nominated individuals or some other choice that represents the research participants] an irrevocable perpetual⁷ license to use this copyright material for any purpose whatsoever.⁸

OR:

[The researcher(s)] will **SHARE COPYRIGHT** in any books, articles, databases or conference papers (or tapes, CDs, videos, DVDs etc) produced as a result of this research with [ABC indigenous organisation or, where none is available, a small number of indigenous people, eg research participants].⁹ This means that:

- [The researcher(s)] **CANNOT** reproduce the information in those books, articles, databases or conference papers (or tapes, CDs, videos, DVDs etc) in other places or for other purposes without asking [ABC or other nominated individuals] first;
- [The researcher(s)] will not be able to let other people reproduce that information without asking for [ABC's or other nominated individuals'] permission first;
- If the books, articles, databases or conference papers (or tapes, CDs, videos,

⁷ The legal jargon is necessary here. You could grant a license for a limited period of time or revoke it later, but an irrevocable perpetual license is more appropriate where you want to allow research subjects or informants to use research products freely and indefinitely for their own purposes.

⁸ You could let ABC use the information only in particular contexts or for particular purposes (eg 'on its web page for school publicity'). But these kinds of restrictions may be difficult to police and are inappropriate where copyright relates to personal or traditional information.

⁹ AIATSIS does not encourage sharing copyright with a larger groups of individuals because this will make it difficult to make decisions about how the copyright should be used.

- DVDs etc) make any money, [the researcher(s)] will share it with [ABC or other nominated individuals];
- [The researcher(s)] will share any money that the books, articles, databases or conference papers (or tapes, CDs, videos, DVDs etc) make with [ABC or other nominated individuals].
- If [one of] [the researcher(s)] passes on their copyright share to another person, that person will NOT be able to reproduce the information or let other people reproduce it without [ABC's or other nominated individual's] permission.

OR (for scientific research, eg into applications of traditional medicines):

Where a patent application is going to be made from the research results, [the researcher(s)] will include the names [ABC indigenous organisation, a small number of indigenous individuals] on any patent application.

Where a patent application is envisaged or likely to arise out of the research, indigenous participants must get independent legal advice about intellectual property issues.

[PLEASE do not include in your Informed Consent Form a clause stating that indigenous people 'retain' 'intellectual property rights' in 'indigenous knowledge'. This is *misinformation*: the law recognises no such rights in knowledge which has not been converted into a material form, scientific discovery etc.]

13. Complaints

I know that, if I am worried about the research project, I can ring up [the researcher(s)] on (phone number) and talk to him/her/them about it.

I know that I can also complain to:

- the AIATSIS Director of Research, phone [phone number],
or
- Ms Chrissy Grant, Chair of the AIATSIS Human Research Ethics Committee, phone [AIATSIS grants administrator phone number]. This is an independent committee – its members do not work for AIATSIS.
I can also write to the Ethics Committee at AIATSIS, GPO Box 553, Canberra, ACT 2601.
Or
If I think there has been a breach of my privacy I can write to the Privacy Commissioner.

I have read this Informed Consent Form and I agree with it.

Signed by the research participant.....

Date.....

OR

I read this Informed Consent Form aloud to [name of research participant] and I believe that s/he understood and agreed to it:

Signed by a witness.....

AND:

Signed by or on behalf of the researcher(s)¹⁰

.....
Name

Date.....

¹⁰ The researchers need to sign if they propose to transfer intellectual property rights to anyone else.