

How to meet ethical standards when you gather outcomes information

Evaluation has many of the same ethical rules applied to it as are applied to research.

There are standards or procedures that guide how we gather information from people for evaluation or reporting purposes.

What is the difference between research and evaluation?

Traditionally evaluation has been seen as a sub-species of research. They're actually different activities. The theories behind them are different, the roles of researchers and evaluators are different, and evaluation looks at only single programs where research tries to learn something that might be true of the whole population.

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It's well worth making the effort to meet these ethical standards. You will have certain goals when you collect information for research or reporting – to get to the truth, to avoid mistakes, to avoid doing any harm to your clients when you collect the information, and to be accountable to the people who have an interest in your service including clients, Board, staff and volunteers, and funders. The agreed standards help you to achieve these goals.

The standards are found in the <u>National Statement on Ethical Conduct in Human Research</u>. If you are doing research, you might put your research proposal to an independent Ethics Review committee, but even just for data collection purposes you need to consider meeting the key ethical guidelines.

This is a step-by-step guide on how to meet them.

Think about the values you are using to guide your information collection.

Base your approach on respect for the people you are asking for information from and make a commitment to integrity, justice (fairness in the process) and 'beneficence'. Beneficence is making sure the likely benefit of collecting the information justifies any risks of harm or discomfort to the participants. The benefit could be directly to the participants or longer term to the wider community, or both. If you make this commitment, you'll have a sound framework for decision making about what information you'll collect, how you will collect it and how you will treat the people you are collecting the information from.

Get informed consent

In most situations it's essential to get someone's informed consent to collect information from them. Informed consent is given voluntarily and based on having enough information to make the decision. Depending on how much information you are collecting and how sensitive the information is, consent can be given verbally, or you might need to get someone to sign a consent form. Part of getting informed includes ensuring it is clear that people can change their minds about participating in your information gathering process at any time, and that changing their minds won't cause them any problems. For a guide on how make sure consent is genuinely understood and

communicated see How to get informed consent to gather information from clients.

You don't have to get informed consent if you are producing a report using a body of information which has already been collected, the information is non-identifiable and it's not practical to get consent. Collated service data would fall into this category.

Ensure client confidentiality

Take proper steps to protect the confidentiality of the people whose information you have collected. This might include using pseudonyms instead of names, excluding identifying details from case studies or stories. Quantitative data can also reveal people's identities if the number of people being counted (the data set) is so small that the individuals included can be identified. If this is the case you will need to remove these data sets from any publications.

How you are going to store the information

You might be collecting information from interviews, focus groups, or surveys – you might have electronic files, sheets of paper, online surveys or videos. Whatever the data (or pieces of information), you need to follow the following steps.

Make sure the data is kept in a safe place – a locked filing cabinet, a secure part of your computer. Store instructions on how the information can be used; make sure the data is only available for the uses which the participants gave consent for. You'll need to be particularly careful if the information can identify people. There is usually a set time that data has to be stored for – normally five years. Make sure you leave clear instructions with it about when (and how) the data is to be destroyed.

Are there special considerations to be taken into account?

There are some groups in the community who should be given special consideration when you are planning to collect data from them.

For example, the National Health and Medical Research Council – <u>Ethical guidelines for research with Aboriginal and Torres Strait Islander peoples.</u>

How are you going to deal with complaints about your information collection?

You may receive complaints about the people gathering the data for you, or about the questions you are asking. Make sure that people know who they can take their complaint to and what the procedure will be for dealing with it. The procedure should be simple and direct.

Referenced links

- National Statement on Ethical Conduct in Human Research
- · How to get informed consent to gather information from clients
- Ethical Guidelines for research with Aboriginal and Torres Strait Islander peoples