Information for research projects:
Confidentiality, informed consent and secure data collection and storage

The Foundation has developed the following information for grant recipients undertaking research projects. It covers key areas to consider when collecting data and information from participants, and what to do with this data.

Because the nature of research and data collection conducted for Foundation grant projects varies, ethical considerations and requirements for specific projects also vary. For example, some projects may draw upon existing service data, while others will collect additional data and information from participants. As a rule of thumb, the greater the potential for and risk of detrimental impacts on participants, the greater the efforts to try to mitigate that risk that are likely to be required.

Before starting your research, we strongly recommend that you review the documents in the Resources list below, in particular the National Health and Medical Research Council (NHMRC) Ethics in Human Research Guidelines, which are considered best practice. The Foundation is not an ethics body, but we can offer support to review documents and policies.

We recommend that your Board or management team develop specific guidelines, processes and/or policies before any research project to ensure that your organisation complies with best-practice ethics standards in the collection, use, storage and disposal of data and information. The NHMRC Ethics Guidelines can inform this process.

Understanding and mitigating risk to participants
All research involving people and their personal information has a level of risk. This could involve harm to participants, either by being identified, their personal information shared, or that the research process itself could be harmful or detrimental, for example in raising painful issues or experiences. The following questions will help you to consider the potential risks for participants and how you might minimise them to the greatest extent possible.

Some of the key areas to consider when approaching your research project are:

- understanding the risk to participants
    - does the research directly involve potentially vulnerable groups (for example, children and young people, people experiencing disadvantage, victims of family violence)?
    - does the research involve discussion of sensitive topics (for example, family violence, assault, mental health), including those that risk causing psychological stress, anxiety, harm or negative consequences beyond what would be normally encountered by the participants in their life outside research (for example, are you requiring participants to recount traumatic past experiences)?
    - does the research involve data that could identify participants (for example, interview materials that contain participant's names, date of birth, other personal circumstances, place of residence)?
    - how will you minimise harm to participants (for example, using researchers trained in trauma-informed interview techniques, having clear guidelines if people require professional help, reassuring participants that they do not have to answer any questions they do not want to)?

- informed consent
    - how will you seek informed consent from participants (what materials are provided to participants and in what formats, how will you check whether participants understand what it is they are consenting to, how will you manage ongoing consent[1])?
    - does the research involve participants who are unable to provide informed consent themselves (for example children, who will require consent from a parent or guardian)?
    - will you provide a participant information sheet explaining the research (or another form of contact, for example, a dedicated phone line that is staffed regularly, so that participants can contact you to ask questions or withdraw consent)?
    - what rights do participants have regarding use of their data? And how will you communicate this to them?
- secure storage of data
    - how will you store your data and for how long (who will have access to the data, how will keep physical and electronic documents secure)?
    - how and when will you dispose of the data (what protocols do you have in place for the destruction of data)?
    - will you be collecting information through a third party (for example, a survey company)? What might the risks be (what secure data storage protocols does the third party have in place)?
- confidentiality
    - where data can identify participants, how will you ensure their participation remains confidential? Will data be de-identified?

The approach you plan to take to both storage and confidentiality should be made clear to participants as part of their consent. All participants should be provided with a plain language statement with relevant information about the project, including how they can withdraw their consent and contact details for the lead researcher. The statement should clearly explain how their data will be used in any research or publications and how confidentiality and anonymity will be maintained.

Examples of informed consent forms have been provided. These consent forms reflect data collection using an interview methodology. Consent forms should be adapted for the particular research methods (e.g. administrative service data, observation, etc.).

Resources
The following resources may assist in the development of your research activities:

The NHMRC Ethics in Human Research Guidelines (2018)
https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018

If you are working with Aboriginal or Torres Strait Islander Peoples and communities, there is a specific set of guidelines

[1] Informed consent is ongoing. This means that participants can withdraw their consent to participate in the project at any time. This also means that you need to get consent for different stages of your research project, for example, the first consent will be to participate in the project, such as giving an interview.

https://www.nhmrc.gov.au/about-us/resources/ethical-conduct-research-aboriginal-and-torres-strait-islander-peoples-and-communities

Trauma-informed practice
If you are working with people who are likely to have, or are continuing to experience trauma, it is vital to undertake research using trauma-informed principles. This is critical both for participants and for researchers.

If you have identified that participants are likely to have experienced trauma, trauma-informed practice is one that understands the particular type of trauma
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4276126/

Researchers working with victim/survivors are also at risk of vicarious trauma. Research methodology and design should also consider the safety of the researchers.
https://vtt.ovc.ojp.gov/ojpasset/Documents/IMP_VT_In_Sex_Violence_Research-508.pdf

CASA House Melbourne provide training (for a fee) for people working with victims/survivors of sexual assault.

Other useful resources:
Privacy and Data Protection Act 2014 (Vic)

Privacy Act 1988 (Cth)

Stanford Center on Philanthropy and Civil Society have developed a toolkit for not-for-profit organisations on digital data governance
https://digitalimpact.io/toolkit/

Need help?
Please contact the Foundation if you have any questions. Some of the things we might be able to help with include review of documents such as a risk analysis, consent and participant information forms or data security and storage protocols.

Contact us
For more information please contact the Foundation on 9604 8100 or email
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