

Human research ethics guidance note



Online surveys on sensitive topics with non-identifiable (anonymous) populations

Introduction

Online surveys are a popular and convenient way of conducting human research on various issues, some of which may explore sensitive personal, psychological and/or social concerns. Asking people about sensitive issues in an anonymous survey can be a legitimate and appropriate way to conduct a survey. However, it should be recognised that anonymous online surveys can present ethical challenges, particularly around managing risks.

Informed by the [National Statement on Ethical Conduct in Human Research](#) (*National Statement*), this guidance note will help you plan survey research on sensitive topics with non-identifiable ('anonymous') participants.

What is a sensitive topic?

The Victorian Privacy Act defines 'sensitive information' to mean information or an opinion about an individual's:

- racial or ethnic origin;
- political opinions;
- membership of a political association;
- religious beliefs or affiliations;
- philosophical beliefs;
- membership of a professional or trade association;
- membership of a trade union;
- sexual preferences or practices;
- criminal record;
- health (not otherwise defined as 'health information'); and/or
- genetic information (not otherwise defined as 'health information').

While there is no exhaustive list, 'sensitive'

topics in human research can include, for example, issues such as sexuality, anxiety, depression, body image, mental health, relationships, self-harm, experience of violence or abuse, homelessness, substance use, etc.

Risks associated with online surveys exploring sensitive issues

When conducting any human research, it is essential for both researchers and ethics review bodies to assess risks to participants. In some research, these risks may be negligible (no more than an inconvenience), low (no more than discomfort, for example, physical discomfort in completing a research measure or mild anxiety in completing a questionnaire) or more than low (risk of harm which can be physical, psychological, social, economic or legal).

When the topic of the survey is a sensitive issue then the inherent risk to participants is increased, as the research is more likely to generate uncomfortable feelings or more severe responses such as distress, anxiety or relapse in mental illness in participants. The potential impacts of raising sensitive issues with people can be unpredictable as everyone can respond differently and in ways that may not be foreseen or predictable by the researchers, or even by the participants, prior to them undertaking the survey. A survey on sensitive topics may have the potential to cause the participant to discover something about themselves that they were not previously aware of or to recall or reflect on a difficult time or event in their lives. Therefore, it is important that the risks of research involving sensitive issues to participants are:

1. Identified and assessed;

2. Managed and planned for, and;
3. Mitigated.

The online context

In an online setting it is not possible for researchers to observe or see how participants respond to sensitive survey questions. How will the researcher know if participants have become concerned, anxious, or distressed? How are they going to respond to these feelings? How will the researcher know if they are being supported or be sure that they find the right support at the right time? From an ethical point of view the researcher has a responsibility to participants who may find themselves in these situations.

Anonymity

Anonymous or non-identifiable respondents are those who, because of the research design, are not individually identifiable. This can be viewed as a way of protecting participants as, if they cannot be identified by researchers or those interpreting and reading the research, confidentiality is maintained, and their privacy is protected. Often in online surveys anonymity is promoted and may encourage higher rates of participation. An ethical dilemma may arise though if an individual's responses to an anonymous survey raise concerns for their welfare. If a survey is anonymous then the potential actions by a researcher are limited, as there is no direct way to contact the participant without breaking confidentiality. For example, what if a participant's responses to a Depression, Anxiety & Stress Scale (DASS) in a survey indicate concern for that person's mental health and safety? Certainly, in terms of ethics, the researcher still has responsibilities for the welfare of participants in these circumstances. The researcher is required to implement strategies to assist in mitigating these risks, thus providing a step-by-step guide for the participant group in the specific study. For example, a survey may target young people or older people or males or females only. What sort of strategy is adopted may be influenced by factors such as their demographic profile of the group.

Vulnerability

From an ethical perspective, participants may be considered vulnerable because of certain personal characteristics and/or due to the research design. For example, people with a physical and/or mental disability or illness may be regarded as vulnerable where their ability to make competent decisions may be compromised. Further, where potential participants are known to the researcher due to a pre-existing and/or unequal relationship (i.e. participants are students, friends, colleagues or acquaintances for example) these participants might also be regarded as vulnerable due to the impact this pre-existing relationship may have on the voluntariness of consent. A friend or acquaintance can feel obligated to respond to your invitation to participate when their inclination may be to not participate. Therefore, the assessment of vulnerability of participants requires consideration of the individual and/or community circumstances of potential participants, as well as the research context and the potential impacts of the research upon the participants and/or their community. Where research is sensitive or may raise questions that increase the vulnerability of the participants, this raises concerns which need to be managed and mitigated.

Mitigating risks

All research has a certain level of risk, even if the risk is no more than the risk of inconvenience (for example, time spent completing a survey). The *National Statement* identifies three categories of risk for human research:

- **Negligible risk:** Research where there is no foreseeable risk of harm or discomfort and any foreseeable risk is no more than an inconvenience;
- **Low risk:** Research where the only foreseeable risk is one of discomfort; and
- **More than low risk:** Research where the risk to participants is more serious than discomfort and there is a risk of harm.

Research that is conducted with vulnerable participants and/or that involves a sensitive topic has a higher level of risk and would arguably be regarded under the *National Statement* guidelines as being 'more than low risk'. Careful consideration should be given to the research participants, design, context, and foreseeable risks, to inform the classification of the risk level.

No matter what the level of risk, the researcher is responsible for managing and mitigating those risks. The first stage of is ensuring that foreseeable risks are identified, and a plan or protocol put in place to manage these. It is critical to ensure that the participants are fully informed and understand the nature of the research and any risks (*National Statement* 2.2.2).

Research activities should be designed so that informed consent is obtained from participants *before* data is created and collected. This includes data used in L&T projects, such as students' work from previous semesters, their grades, their comments on Canvas posts, etc.

What are the ethics review bodies' expectations?

Every application reviewed by an ethics review body is considered on its merits, using the *National Statement* guidelines as a basis for its decision. It is a key responsibility of the ethics review body in granting ethics approval to establish that the potential benefits of a project outweigh the likely risks. Further, the greater the risks to participants, the more certain ethics reviewers must be that the risks identified will be well managed and that the participants clearly understand these risks (*National Statement* 2.1.8). It is important that all participants are fully aware of any risks in a project. While risks and the management of them are reviewed by the ethics review body their expectation is that the researcher will adequately address these matters. Risks need to be managed and addressed. If your project involves a sensitive topic area, obesity for example, then part of your risk mitigation strategy might be to provide information about relevant support groups or

help lines.

What are the researcher's responsibilities after formal approval of an application?

Once an application is approved the researcher has a responsibility to monitor the research and the individual responses of participants. Should participants contact researchers then a timely and appropriate response is important. It is important to monitor the activity related to the research and ensure that ethical standards are maintained. As much research in this category involves the use of social media it is recommended that related social media traffic is monitored. In the past participants have 'outed' themselves as a participant on social media, perhaps not realising the implications of doing so. In this case what is the appropriate response by a researcher? Maybe a discreet private message to the participant is appropriate. In other cases, people have used social media to cajole friends, relatives, and colleagues to participate, or have utilised websites without appropriate permissions. Researchers need to be careful that such efforts do not contradict the conditions of approval of an ethics application and ensure that all research protocols are followed. Remember that researchers must report immediately any serious or unanticipated adverse effects of their research on participants, and/or any unforeseen events that might affect continued ethical acceptability of the project, to the relevant Research Governance and Ethics Coordinator. If in doubt about any of the ethical aspects, then please contact the ethical review body that approved your application.

Suggestions for your application

In projects such as those that fall into this category of sensitive research with vulnerable populations it is common to utilise a variety of research instruments like the DASS 21 or 42. Make sure that the use of such instruments is explained and contextualised. For example, the

DASS is a self-report questionnaire designed to measure the severity of a range of symptoms common to both depression and anxiety and can be confronting for participants as it provides information about a person's mental health symptoms. The severity rating of this survey ranges from "Normal" to "Extremely Severe". Be sure to explain the purposes and limitations of such tools and include ways to encourage the respondents to seek further advice where they are concerned about their responses or self-scoring.

- The Participant Information Statement (PIS) template includes specific reference to online surveys. You should provide advice to participants about how to print a hard copy or download or screenshot a digital copy of the PIS on their own device. They may wish to take this to their preferred health practitioner should they feel they need to seek assessment or advice.
- Management of risks is an important responsibility of the researcher. It is important that researchers carefully consider how they provide participants with information about support services or other ways to self-manage potential distress or other outcomes of participation.
 - o If there are support groups or services available for specific topics or participant groups, communities, issues, or other groups reference these in the step-by-step information for participants.
 - o It is important to provide this information at the beginning of a survey and near the end in a way that is easy for participants to access (e.g. alerting them to download or screen shot the PIS and a support service info sheet/numbers/websites, providing clear hyperlinks).
 - o Including services that specifically address the issues you're researching may be more effective than general services e.g. LGBTIQ mental health services as well as Lifeline; a variety of substance use services including those in regional areas if your inclusion criteria is Victoria-wide.
 - o Depending upon the recruitment strategy of the project it is possible that overseas-

- based participants may be recruited, which may mean that their needs will have to be addressed in the application as well.
- Often social media will be used for recruitment in this type of research. This is usually appropriate, if managed correctly, but this must be fully explained in the human research ethics application form. Do not use your own social media accounts to recruit but create new dedicated accounts for the purpose of the research.
- Remember that if participants are assured their participation will be anonymous then the identity of anyone who has or has not participated must not be divulged before, during or after the research. Absolute discretion is required if anonymity has been promised to participants. It is inappropriate to name or identify participants in any context, especially on those social media sites that you may have used for the purpose of recruitment. If, as part of the research, raffle prizes or incentives are used then do in a way that ensures the anonymity of participants. Do not announce winners.
- When submitting copies of documentation to the ethical review body ensure that it is presented in the way that it is presented to the respondent, this may require you to develop a trial survey on a survey platform. Remove any irrelevant or redundant content.

Further information

For further advice on this topic or other human research ethics matters, please email humanethics@rmit.edu.au. A Research Governance and Ethics Coordinator will assist you and may connect you to one of the CHEAN or HREC members in your discipline who can offer expert ethics advice.