

Human Research Ethics Clearance Applications Involving Online Survey Management and Risk – Some Guidance

Importantly, the ethical review body or reviewers are part of the ethical review and monitoring equation. Significantly, in the [National Statement on Ethical Conduct in Human Research \(2007\)](#),

- “the researcher should demonstrate that the research has merit and reflects the values of justice, beneficence, and respect for humans (5.2.5)”.
- The ethical review body member or equivalent “is responsible for deciding in his or her judgement, a proposal submitted ... meets the requirements of the National Statement and is ethically acceptable (5.2.2)”.

Some challenges, problems and issues

Online research, research using the internet or social media, etc, remains an *unfolding* situation for reviewers, institutions and researchers. Recently, some particular matters raised for attention are as follows (not simply meant to be prescriptive or exhaustive):

- Awareness of **terms and conditions** set for accessing or using online facilities or packages, who owns or controls the data, any **restrictions** on use even though material is publicly available.
- **Opinio**: besides a number of researchers stating Opinio has significant limitations as regards functionality and (anecdotally so far) reliability, current security protocols set up for Opinio could be insecure if someone wanted to gain access to information. Can or should Opinio be used for high risk or quite sensitive research?
- **Psychsurveys.org**: currently this has been approved for use but researchers, and those signing off on the research as being adequately resourced, should be aware that, according to the webpages, there is no apparent responsible entity administering or guaranteeing psychsurveys.org which may have consequences for valuable data access/retention.
- Whilst **SurveyMonkey** can be set with the research/researchers not able to access an IP address unless necessary, it seems SurveyMonkey still records or accesses the **IP address** which can permit identifiability with other linking. What does a survey management package collect?
- **Who** else besides the researcher **can access the information** at any time during the research such as system administrators?
- In **some jurisdictions overseas**, there is active monitoring of internet use and it may even be illegal to participate in foreign research without proper permission(s), including internet research. (Beware that requirements can change. See also National Statement Chap 4.8.)
- A number of survey management packages such as psychsurveys.org, SurveyMonkey, Qualtrics, etc, are based overseas and thereby bound by overseas controls or otherwise. These may not sufficiently accord, if at all, with **Australian or Victorian Privacy standards**.
- With **survey management and data management**, it should be known **where** the data are to be securely accessed and retained. If a short-term licence or restricted use of a package/system is involved, will the researcher still be able to access, retain and use the data beyond the **terms of the licence**? If not, what steps are in place to manage this?
- **Dropbox** (for data storage/access): is Dropbox secure enough or reliable, especially for valuable or sensitive information? Also be aware of ITS policy on when Dropbox can be used. (But see next page re info on used of Cloudstor/Cloudstor+.)

In summary, the issues are fitness for purpose: relevance, usability, functionality, reliability, data verifiability/authenticity/integrity, security, confidentiality/privacy and risk.

But a positive – data access/storage for Swinburne researchers:

- ✓ **Cloudstor** run by AARNET can be a good temporary storage or transfer facility during a project.
- ✓ For longer term **Cloudstor+** is available to Swinburne researchers.

See Swinburne's "[Research Data Management: Guidelines and Planning for Researchers](#)".

Survey management and data management: what to consider/detail/justify in research proposals

Re the current Swinburne ethics clearance application form (*but note that a new application form/format is being prepared for use*):

- A3** should identify the survey method and package and show fitness for purpose. Re integrity of online research data: should the questionnaires or other method include or pose some questions that establish bona fides responses (though not necessarily involving deception), say a question on date or place of birth? Or use of a code displayed to the reader to enter to help prove a genuine set of responses versus automated responses? But care needed with methods that may count against confidentiality arrangements.
- A4** should deal with whether the research can lead to or be experienced as being simply inconvenient or as discomfort or stress/distress/other harm in relation also to online research.
- A7:** given the research methods and participant groups, information should deal with the situation of how, in the unlikely event of something that can be anticipated coming about, the situation can be carefully assessed/managed and by whom. One important issue with online research is a participant is likely to be alone if s/he is harmed by or reacts adversely to the research. Care is thus needed as to what back up support is relevant, feasible, accessible, freely available or at cost and if participants are Swinburne students or not, in Australia or overseas.
- A9:** the question is about future use of research data beyond the project and its outcomes. With data held electronically or online, the answer given at A9 should correlate with what is stated or claimed elsewhere, including with regard to future use of participants' de-identified data.
- B:** various items carefully being checked should lead not just to a brief explanation but justification as well (note that the form says at B text box: "explain and justify" – why the need to do what is proposed and how this is to be managed). Asking sensitive questions or recording sensitive information electronically or online need appropriate or particular attention, including:
 - if questions being put are sensitive, can the information lead to someone being identified (even mistakenly)? How best then to protect the data collected/held electronically/online?
 - Beware that sensitive information can be about a health condition, attitudes, practices, behaviour, treatment, legal offences, membership of some types of organisations, etc. The cultural or other context should also be considered.
 - Correlation with information given elsewhere on the form can help address the issues.
- C2:** any email or online recruitment, use of REP for some psychology research, should be clearly disclosed and justified.
- D1:** should deal with the elements of identifiability or potential identifiability and to whom
 - Either or both boxes at D1(b) need to be checked if a participant is to some extent identifiable given the methods being used, including signed consent, 1-to-1 interaction.
 - Care should be taken in situations where inclusion criteria would mean undue disclosure of a condition, behaviour, practice/belief or identity that is sensitive.
- D2:** A common problem is absent or unclear details about the where, who, for how long and what security measures are in place, including for electronic or online storage.

- **Data retention** periods need to be appropriate to the type of data or research outcome:
 - Professional codes may set a minimum standard, eg, APS code of ethics suggests psychologists keep records for **7 years**;
 - the [Australian Code for the Responsible Conduct of Research \(2007\)](#) has a minimum of **5 years post-publication** for most research;
 - if the research data can be deemed “health information” within the context of health service provision, then a minimum of 7 years after last health-related service or interaction would apply; in the case of minors – until the particular **minor attains 25 years of age**. (See [Health Privacy Principles, Health Records Act \(Vic\)](#))
 - If a number of durations could apply, the **longer period** may be needed.
 - If the human research is a limited research training exercise and accordingly justifiable, the period can be that applicable or appropriate to student assessment and appeals timeframes (but “health information” should not then be collected.)

- If the research invites **participant contact info** in relation to research outcomes or a prize draw entry (if justifiable), it needs to be clear as to careful and proper (non-matching/-matchable) separation of this information from research data/questionnaire returns. The consent and other info should then not state that “participation is completely anonymous”.

- **Overseas Participants.** If the online research is targeting overseas participants or likely to include them (not merely incidentally), the consent or plain language statement could or should include an alert such as: “If you are interested in participating in this Australian project from outside of Australia, you should be alert to any local or government restrictions on involvement in on-line or foreign research activity.” What about risk management or back up support for overseas participants?

- The **consent info or plain language statement** should disclose the survey management package being used and provide the link (url) to the privacy/security settings of the package. Also clearly outline the method for establishing anonymous, implied or identifiable consent.

- **Closing off statements** should be devised and used with online surveys more so for lengthy questionnaires or the set up will not permit a return to the first or info page. This statement should again summarise what the research is about, repeat necessary assurances, state who to contact about the research/participation, refer to concerns raised that may need backup support (eg, counselling) which should be outlined, and contain the complaints clause. If participants are being asked to show interest in further participation, research outcomes, then adjust accordingly. **Or**, in some projects, more of a **Debriefing Statement**, is needed.

- Sometimes there needs to be quite close **correlation between the various parts** of the application; use consecutive page numbering, correctly label or distinguish between documents, preferably use version control, use good cross-referencing – more so for large submissions.

- In a number of submissions for online research there will be special need for researchers to demonstrate risk assessment and management and to **show that the “potential benefits justify any risks involved in the research”**. It is not a case of benefits outweighing the risks on some sort of proportional basis (5 benefits to 2 risks) but the potential benefits justifying *any* risks.

Some additional points:

- Avoid simple or incorrect **cutting and pasting** from previous or other submissions

- Avoid using **absolute or simplistic language or making unrealistic or incorrect claims** such as:
 - X “Only the researchers will be able to access the online data.” when system administrators can access the same info or, for that matter, some can easily hack into the system.
 - X “The research data is completely confidential and no one other than the researchers can or will access the data” when this cannot be guaranteed.
 - X “The research is completely anonymous” yet participants are asked to supply contact information for research outcomes or enter into (a justifiable/approved) prize draw.
 - X “The research is low risk because it is anonymous/conducted online” or “... because it is a validated questionnaire”.

- Avoid **shifting or varying language** about “stress/discomfort/distress/etc” given the National Statement language/guidance in relation to what is or is not negligible or low risk (Chap 2.1).

- Care also needed with **language re identifiability/deidentified/non-identifiability/confidentiality/anonymity**. “Deidentified/deidentification” can mean replacement of names with a code that still permits data matching or (re)identifiability versus rendering data fully non-identifiable. Anonymity (= no name) may still permit identifiability given the circumstances.

- Don’t underplay or overplay **risk**
 - A realistic appraisal needs to be shown about the possibility or probability of someone targeted being affected by the questions or line of questioning being put.
 - Research could uncover or reawaken stressful or distressing situations or cause distress.
 - Even if there is no intentional targeting of participants with a diagnosable mental illness or cognitive impairment or intellectual impairment, it can nonetheless be reasonably assessed that such people would be included *and* significantly impacted by the research.

- Appreciating and showing **what is or is not “low risk”** and **justifying** the risks involved including for online research:
 - administering a validated anonymous questionnaire online which asks about or uncovers illegal activity would not be considered low risk particularly if a third party can access or ‘hack’ the on-line site or system.
 - Administering a validated anonymous questionnaire that reawakens distress or can give rise to a serious negative self-image or be suggestive of a diagnosable illness is not low risk.
 - Asking someone who has experienced trauma or distress to answer research question(s) that simply leads to an academic outcome is unlikely to provide sufficient justification for conducting the research; similarly with involving a vulnerable human being even if the questions are not that sensitive.
 - Over-researching or overtaxing participants would go beyond just inconvenience or discomfort and may significantly raise stress levels.

Swinburne Human Research Ethics pages on the [Research Intranet](#) (needing SIMS log-in) including:

<http://www.research.swinburne.edu.au/ethics/human/>

<http://www.research.swinburne.edu.au//ethics/human/levels-of-review/>

<http://www.research.swinburne.edu.au/ethics/human/apply/>

<http://www.research.swinburne.edu.au/ethics/human/faqs-issues-helpnotes/index.html>