

ASU IRB Guidance Document – Practices Regarding Types of Internet Research

Arizona State University (ASU) requires that all research involving human subjects conducted by faculty, students, or staff affiliated with the university, be reviewed and approved by the IRB prior to initiation, regardless of the source of funding or its Federal status as an exempt, an expedited, or a full review project. Investigators may not solicit subject participation or begin data collection until they have received written approval from the IRB.

The following options are applicable to Internet Research conducted at Arizona State University.

Surveys

- **Minimal risk (anonymous and/or on benign topics) surveys targeting adult participants:**
 - Investigators develop a standard cover letter that includes the required standard elements and provides assurance at the end: “By clicking the Continue Button I acknowledge that I am at least 18 years old and that I voluntarily agree to participate in this study.”
 - If using a vendor to conduct the study, PI is responsible for reporting to the IRB the policies of the vendor regarding ownership of the data and whether the vendor will keep a copy of the data as part of the IRB application. Similarly, the PI would be responsible for confirming that the vendor does not retain a copy of any mailing or master list.

- **Surveys of non-sensitive populations that are not anonymous (e.g., longitudinal studies or studies that will link survey data with other data) and include potentially compromising content:**
 - Use of data encryption technology is required.
 - If using a vendor to conduct the study, PI is responsible for reporting to the IRB the policies of the vendor regarding ownership of the data and whether the vendor will keep a copy of the data as part of the application.
 - Vendor copies cannot include identifiers/master list.
 - Master list should not be kept by vendor.
 - Consent or cover letter must disclose if vendor retains a copy and explain steps taken to protect identity of participants and privacy of their data in terms that are as non-technical as possible.

Surveys

- **Surveys of sensitive populations** (e.g., if membership became known to others, this alone could compromise participants' welfare in some way such as reputation, employability, ability to obtain/sustain insurance coverage, threaten personal relationships) **that cannot be anonymous** (e.g., longitudinal studies):
 - Use of data encryption technology is required.
 - If using a vendor to conduct the study, PI is responsible for reporting to the IRB the policies of the vendor regarding ownership of the data and whether the vendor will keep a copy of the data as part of the application.
 - Vendor copies cannot include identifiers/master list.
 - Master list should not be kept by vendor.
 - Consent or cover letter must mention if vendor keeps a copy and steps taken to protect identity of participants and privacy of their data in terms that are as non-technical as possible.
 - Investigator must explain to the IRB and to participants (in consent forms) the steps they will take to delete (or not collect) inadvertent identifiers (IP addresses perhaps educating participants in steps to take to avoid inadvertently identifying themselves).

Data mining (searching Internet sites for particular types of data):

- Do not collect data that includes identifiers when possible.
- Do not present/publish data in a form that makes sources of data (individuals) readily identifiable (an absolute guarantee is not likely possible).
- PI must describe the "terms of service" of internet sites to be targeted.
 - Those open to anyone are fair game for most purposes.
 - Those that require membership in some meaningful way may require the PI to obtain permission from a site manager and/or to disclose his/her "presence" to other users and acknowledge their role as data gatherer.
 - "Acknowledging their role as researchers" would be similar to a recruitment script and any statement used for this purpose would need to be reviewed by the IRB.