

PRIVACY & SECURITY GUIDELINE: SURVEY TOOLS IN RESEARCH

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As with any other electronic system, the use of online survey tools must comply with privacy & security requirements. From time to time, Unity Health reviews survey tools for compliance with privacy & security requirements. While many tools advertise that they have some form of privacy or security protection (e.g. storage of the main database in Canada), they may not meet all other privacy & security requirements (e.g. storing backups or login credentials in Canada, agreeing to notify us if there is a breach).

For example, the following tools have been reviewed and have **not** been approved for the storage or collection of **identifiable information**:

- FluidSurveys & Survey Monkey
- CheckMarket
- Qualtrics
- SimpleSurvey
- JotForms

Using Unapproved Survey Tools for De-Identified Data

- Survey tools that have not been approved by Unity Health Toronto can be used in research, as long as no identifiable information is stored or gathered in the tool (or unless the sole exception, described below, applies).
- **Direct identifiers** must not be asked for or entered into the survey tool by a participant, researcher, sponsor or other third party. Any of the following is a direct identifier on its own and, if captured with other survey data, would identify the individual to whom the survey responses apply:
 - Name
 - OHIP or other insurance number
 - Medical Record Number (MRN)
 - Any other unique number used in the community
 - Street address
 - Phone number
 - Email address
 - Device identifier (e.g. MAC address, IMEI, ISEI)¹
 - IP address of a computer
- **Indirect identifiers** must not be asked for or entered into the survey tool by a participant, researcher, sponsor or other third party. Indirect identifiers can be used to re-identify a survey participant. Indirect identifiers include:
 - Combination of (a) full date of birth, (b) gender & (c) full postal code or city/town
 - Any other piece of information that could identify the individual (e.g. job title)
- The REB may verify the survey questions to ensure that no direct or indirect identifiers will be collected via the survey tool.

¹ <https://www.priv.gc.ca/en/blog/20161208/>

- You must turn off features that track individuals and collect identifiers from individuals outside of your survey and/or turn on ‘anonymization’ features, if they are available. (For example, Jot Forms² and Survey Monkey allows users to turn off IP address tracking and otherwise make the survey anonymous³.)
- At the beginning of the survey, in the consent section or instructions section, researchers should include a statement that matches the following or has the same meaning:

We do not want to identify your answers as belonging to you. We have not asked for your name or any other piece of information that identifies you. If you do not want your answers to be linked to you, please do not enter your name or any other piece of information that identifies you into any of your answers below.

- **EXCEPTION:** Unapproved survey tools can be used to collect contact information from participants for the purposes of (a) providing compensation, or (b) providing consent for future studies, if the following requirements are met:
 - A separate survey is used to collect the identifiers (e.g. name & email address).
 - The separate survey does not reference the title or content of the main research study. (A “Thank you for participating in our research study” or similar introduction may be used.)
 - Any description of future research (provided for participants to consent to be contacted in future) does not reference any sensitive or illegal activity/status.

² <https://www.jotform.com/privacy/>

³ https://help.surveymonkey.com/articles/en_US/kb/How-do-I-make-surveys-anonymous