

## PRIVACY GUIDELINE: TEXTING IN RESEARCH

### Required privacy controls

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The following controls mirror those used for email, and are required by the IPC, CMPA and CPSO for unsecured communications.

The required controls for texting in research are:

- For studies where texting is optional:
  - o Must provide a secure alternative (e.g. phone or letter)
  - o Consent must be clear that texting is optional and can stop at any time, without jeopardizing participation
- For studies where texting is crucial:
  - o Description in the protocol and consent form of why unsecured texting is needed
- For all studies where texting is proposed:
  - o Appropriate agreements with actively-engaged third parties (e.g. companies managing texts, not telecom providers)
  - o Plan to limit the PHI/PI in texts (e.g. templates to use, instructions for participants)
  - o Express consent must be obtained and must describe:
    - what kinds of texts are expected/required for participation, and what will be discouraged content
    - how texts will be handled (e.g. logged, stored, retained, used in research)
    - who will send/see the texts
    - the involvement of any actively-engaged third parties (i.e. who, country location, what they will have access to, whether they will retain texts and for how long, any particular limits on privacy based on their involvement)
    - the standard risks of texting (*see next page*)
  - o Protocol/study procedures must include detailed descriptions of:
    - the kinds of texts that are expected/required for participation, and what will be discouraged content
    - the dataflow
    - how texts will be handled, tracked and documented
    - who will send and receive texts
    - what devices will be used to send and receive texts (by the research team) & how these devices will be protected
    - the involvement of any actively-engaged third parties (i.e. who, country location, what they will have access to, whether they will retain texts and for how long, any particular limits on privacy based on their involvement )

### Standard Risk Language for an Informed Consent Form:

Whenever texting will be part of a study, whether optional or required, one or two way, the following language regarding texting must be added to the ICF, either in a section that describes how texts will be used, sent and handled, or in the risk section of the ICF:

*There are common risks of using texting to communicate:*

- *Information travels electronically and is not secure in the way a phone call or mail would be.*
- *If someone sees these texts they may know that you are a participant in this study or see the health information included in the text.*
- *Texts may be read or saved by your phone provider (i.e. Rogers, your workplace, "free internet" providers).*
- *Copies of a text may continue to exist, even after efforts to delete the email have been made.*
- *There is always a chance with any unencrypted text, however remote, that it could be intercepted or manipulated.*

*Please note: YOU MUST NOT USE TEXT FOR MEDICAL EMERGENCIES. If you require immediate help, call your clinic or care provider, or seek emergency services.*

### Standard Language for a Poster:

If a phone number is given, with an encouragement to text for recruitment/registration, participation or questions (and there hasn't previously been an opportunity to obtain full consent for texting), the following disclaimer must be added to the poster:

*Please note that texts are not secure. Texts can be intercepted, viewed, changed or saved by others. Only send information to this number that you do not feel is sensitive.*

**Note:** If texting is required to adequately recruit and/or engage the study population, but the study subject is sensitive (e.g. stigmatizing, involves illegal activity), the wording should be tailored to reflect the steps taken to protect the participants/potential participants, such as:

*Please note that texts are not secure. Texts can be intercepted, viewed, changed or saved by others. If interested, please text "Prevention Research" to [phone number] and tell us when to call you back.*