PRIVACY GUIDELINE: EMAIL COMMUNICATION IN RESEARCH

Required privacy controls

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

The required controls for use of email communication in research are:

- For studies where use of email is optional:
    - o Must provide a secure alternative (e.g. phone or letter)
    - o Consent must be clear that use of email is optional and can stop at any time, without jeopardizing participation

- For studies where use of email with participants is crucial:
    - o Description in the protocol and consent form of why unsecured email communication is needed

- For **all studies** where use of email is proposed:
    - o Plan to limit the PHI/PI in emails (e.g. templates to use, instructions for participants)
    - o Express consent must be obtained before email has been sent to or from participants and must describe:
        - ▪ what kinds of emails are expected/required for participation, and what will be discouraged content
        - ▪ how emails will be handled (e.g. logged, stored, retained, used in research)
        - ▪ who will send/see the emails
        - ▪ the involvement of any actively-engaged third parties (i.e. who, country location, what they will have access to, whether they will retain emails and for how long, any particular limits on privacy based on their involvement)
        - ▪ the standard risks of emailing (*see next page*)

    - o Protocol/study procedures must include detailed descriptions of:
        - ▪ the kinds of emails that are expected/required for participation, and what will be discouraged content
        - ▪ how emails will be handled, tracked & documented
        - ▪ who will send and receive emails
        - ▪ which accounts will be used to send and receive emails (by the research team)
        - ▪ the involvement of any actively-engaged third parties (i.e. who, country location, what they will have access to, whether they will retain emails and for how long, any particular limits on privacy based on their involvement)

Standard Risk Language for an Informed Consent Form:

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

> *There are common risks of using email to communicate:*
> - *Information travels electronically and is not secure in the way a phone call or regular mail would be.*
> - *If someone sees these emails they may know that you are a participant in this study or see the health information included in the email.*
> - *Emails may be read or saved by your internet or phone provider (i.e. Rogers, your workplace, "free internet" providers).*
> - *Copies of an email may continue to exist, even after efforts to delete the email have been made.*
> - *There is always a chance with any unencrypted email, however remote, that it could be intercepted or manipulated.*
>
> *Please note: YOU MUST NOT USE EMAIL FOR MEDICAL EMERGENCIES. If you require immediate help, call your clinic or care provider, or seek emergency services.*

Standard Language for a Poster:

If an email address is given to the participants as a contact for recruitment/registration, participation or questions (and there hasn't previously been an opportunity to obtain full consent for email), the following disclaimer must be added to the poster:

> *Please note that email is not secure. Emails can be intercepted, viewed, changed or saved by others. Only send information to this address that you do not feel is sensitive.*

Note: If email 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 changed to reflect the steps taken to protect the participants/potential participants, such as:

> *Please note that email is not secure. Emails can be intercepted, viewed, changed or saved by others. If interested, please write "Prevention Research" in the subject line and send us your phone number only.*