Penn Medicine Guidance for Text Messaging and Research

The purpose of this document is to provide guidance to researchers considering using texting as a form of communication with study participants. Please note texting may raise privacy concerns on behalf of recipients, especially before subjects have signed consent. Please note in all cases:

1. Texting is a common form of communication in many spheres and researchers may wish to use this communication medium to message patients. While it has certain advantages, it also raises privacy risks because messages are unencrypted and can result in message and data charges to the recipient. As a result, consider using the MPM portal, secure/ encrypted email, or telephone for routine study related communications.
2. All plans to use text communication during recruitment must be IRB approved. The plan for any continued texting must with subject consent and also IRB approved.
3. Study subjects should provide consent, in writing or verbally, to communicate via text message, whenever possible, as this is an unencrypted form of communication.
4. All subjects must be informed that message and data rates may apply and have the option to opt out. For Example: “Text stop to opt out of this text messaging program” and “Msg and data rates may apply.”
5. Disclose that texting is not always secure before any protected health information (PHI) is shared. For example, “Texting is not 100% secure.”
6. Limit PHI to the minimum necessary and avoid PHI altogether, if possible. For example, instead of saying “your hysterectomy procedure” say – “your procedure”.
7. Delete any messages that are no longer needed.
8. Responses should be brief. Be mindful of inherent bias. Use language that is equitable and inclusive to all populations of participants including race and preferred gender identification.
9. If a response is received that appears incoherently written, is concerning, or indicates a potential adverse event or reaction, contact the participant immediately via telephone and document the conversation.

Texting Purpose	Additional Requirements and Considerations
Recruitment (texting pre-consent)	This is most commonly pre-consent. Texting a group of patients/ potential subjects for recruitment purposes will be considered equivalent to cold-calling and should not be used as a first option. This type of use should be outlined and approved in the IRB application or standalone protocol. Recruitment methods other than texting first, must be shown to have demonstrably failed before sending out recruitment texts to a group of patients. Whenever possible, use more secure or other forms of communication for recruitment, i.e., phone call, secure portal message (MyPennMedicine).
Communication During the Course of the study • Appointment reminders • Follow up or prep items from or for research visits • Surveys or other Patient Reported Outcomes (ePRO) • Adverse Events	Because subjects are enrolled in the trial at this point, they should have consented to and agreed to texting as a form of communication. This type of use should be outlined and approved in the IRB application or standalone protocol. Consent/HIPAA authorization for this communication should be documented in the consent form. Alternatively, if verbal consent /HIPAA authorization is obtained, a script should be provided to the IRB for approval, and the consent should be documented with a consent process note. Again, limit the degree and sensitivity of PHI in communications. If sensitive information or ePHI is sent from the subject, move to another forum for discussion that is more secure, i.e., phone call, secure portal message (MyPennMedicine). If an adverse event, reaction, or other outcome that indicates a safety related concern is or has occurred, contact the participant via telephone and document the conversation. Ensure all appropriate follow up is done to address and evaluation the concern, including IRB and regulatory reporting as applicable.

Penn IRB approved Texting Providers
At this time the systems below are the only two approved solutions for secure texting. Any additional vendors will need to be evaluated through security risk management **prior** to signing any agreements. Contact a Penn Medicine IS Service Information Officer to initiate this process.

Way to Health
Twilio/ RedCap

FAQ

Q1. What is unencrypted communication and what technology does it include?
A1. Unencrypted communication is a method of communication that does not meet the encryption requirements as outlined in the Transmission of Sensitive Information Standard.

When a communication method is not encrypted, it is possible for anyone inside or outside Penn could read or access the contents of your message while the message is being transmitted from you to the recipient.

Examples of Encrypted and Undecrypted Communication

Encrypted	Unencrypted
E-mails using the "Secure" functionality	E-mails not using the "Secure" functionality
"Messages" through an encrypted/secure platform	Direct SMS messages, e.g. cell phone to cell phone

Q2 Can I use my personal cell phone to text message subjects?

No, you must use a Penn Medicine issued device to text message subjects in the context of a research study. If that device is lost or stolen, immediately contact your local support provider (IS Service Desk or PMACS/ DART Support.

Q3 What Should the Informed Consent Say about Texting?

Subjects should be made aware that texting is not completely secure and that message and data rates may apply. Text messages should only be used for non-sensitive and non-urgent study related issues.

Depending upon the specifics of the study you may wish to instruct patients to "delete" text messages after receiving and reading. Participants should also notify the study team if they lose or have their phone stolen so text messages can be discontinued, or a consent addendum for unencrypted communication can be signed to receive messages at an alternate number.