## Use of 3<sup>rd</sup> party vendors for recruitment and screening purposes

In an effort to increase recruitment to clinical protocols, study teams may wish to engage with 3<sup>rd</sup> party vendors (e.g., Buildclinical, Qualtrics) to recruit and screen prospective research participants. In many cases, those vendors are collecting personally identifiable information (PII) from the individual and subsequently providing that information back to the NIH study team. The vendors may also be storing and using the PII for their own commercial purposes.

There are several important issues that study teams need to take into consideration when using such services. When PII is entered into a 3<sup>rd</sup> party system, the NIH has no control over how that information may subsequently be used. This is particularly important if sensitive information is being collected that may put the individual at legal risk or risk of social stigmatization. In addition, if the vendor's webpage has the appearance of being an NIH site because, for example, the webpage displays the NIH logo, the prospective participant may reasonably believe that they are providing their information directly to the NIH.

NIH Investigators who seek to use (or are currently using) a 3<sup>rd</sup> party vendor to recruit and screen research participants and PII will be provided to the vendor by participants, must ensure that the following steps are taken:

- 1. Contact your IC Information Security Office and provide them with the relevant information so that they may determine that all NIH information security requirements are met.
- 2. Review the vendor's terms of service and privacy policy to ensure they are consistent with NIH policy, and do not include terms that might place potential research participants at risk (such as disclosure of sensitive information to law enforcement).
- 3. Contact your IC Privacy Officer to determine whether a Privacy Impact Analysis is needed.
- 4. Provide a Privacy Act notification approved by your IC privacy office to the vendor to list on the webpage collecting participant information.
  - a. Additional information that the participant may need to know with regard to the collection and storage of the data by a 3<sup>rd</sup> party may also need to be included in this disclosure.
- 5. Ensure that any use of the NIH logo is permissible and consistent with NIH policies.
- 6. You must describe any plan to use a 3rd party vendor for recruiting in your protocol.
- 7. If an incident or breach occurs or is suspected, the IC ISSO must be immediately notified per NIH policies and procedures regarding the reporting of breaches. Further information is available at https://policymanual.nih.gov/1745-2.

If you are already using the vendor and these steps have not been taken, you must stop using the vendor and complete the assessments listed above.

Please review the following links for additional information:

- Information on the use of NIH names and logos can be found <u>here</u>.
- Information about the use of 3<sup>rd</sup> party websites can be found <u>here</u>.
- Information about the use of social media to recruit study participants can be found <u>here</u>.
- Information on the Privacy Impact Assessment process can be found here.
- Your IC privacy coordinator can be found <u>here</u>
- Your IC Information Security Office point of contact can be found <u>here</u>.