PROTECTING THE PRIVACY OF RESEARCH PARTICIPANTS

DESCRIPTION

Some research projects pose risk to participants simply because they are involved in the study. In such cases the IRB will ensure that the study design and data collection protect the privacy of participants.

RESPONSIBILITY

The IRB Chairperson and IRB members will review the written protocol to evaluate the adequacy of privacy protections. If the investigator’s plan is insufficient, the IRB Chair and/or IRB members will recommend revisions to make participation more private for the participant.

PROCESS

At the time of initial protocol review, the IRB Chair and/or IRB members will consider the potential for harm to participants if their participation in the study should become known. If the potential for harm is greater than minimal, the IRB Chair and/or IRB members will assess the protections written into the protocol to ensure their adequacy. If the protections are inadequate, the IRB Chair and/or IRB members will recommend revisions to increase protection of participants’ privacy.

Methods of protecting the privacy of participants may include any of the following:

- Recruiting by allowing the participant to contact the investigator (for example, by telephone) when the participant feels there is sufficient privacy to make the contact.
- Arranging the study site so arriving and departing participants cannot see each other.
• Spacing the arrival and departure of participants so they will not meet when coming or going.

• Conducting study activities at the participant’s chosen site and time.

• A summary of the discussion when real Social Security Numbers (SSNs), scrambled SSNs, or the last four digits of SSNs will be used in the study is provided. The summary needs to include the security measures that are in place to protect the SSN instances embedded in the study.
  
  o NOTE: This does not apply if the only use of SSNs is on the informed consent form or the HIPAA authorization as required by VHA Handbook 1907.01.

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<thead>
<tr>
<th>Adoption Date:</th>
<th>Created by:</th>
<th>Date of Revision:</th>
<th>Revised By:</th>
<th>Summary of Revision:</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>11/2011</td>
<td>J. Osborne</td>
<td>Added text regarding use of social security numbers.</td>
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<td></td>
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<td>06/2014</td>
<td>A. Braggs-Brown</td>
<td>Revised to clarify language</td>
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Date Adopted  June 2014  
Signature  signed copy on file