Privacy (HRPP 3.3)

Description:

This policy describes UNMC's requirements for the protection of privacy interests of research subjects.

Definitions:

Privacy: an individual's right to control the extent, timing, and circumstances under which they share information about themselves.

Private Information: information provided for specific purposes by an individual *(e.g. for healthcare or research);* and is reasonably expected by the individual not to be made public.

Protected Health Information (PHI): individually identifiable health information that:

1) Is created or received by the organization, and
2) Relates to:
    a. The past, present, or future physical or mental health condition of an individual,
    b. The provision of health care to an individual, or
    c. Payment for the provision of health care to an individual

Identifiable Sensitive Information: information about an individual that is collected or used during the course of research and:

1) Directly identifies an individual, or
2) Presents at least a very small risk that the combination of the information, a request for the information, and other available data sources could be used to deduce the identity of the individual

Protecting Privacy (protecting subjects):

In its review, the **IRB will consider both:**

- The nature and degree of risk to participants' privacy interests, and
- The participants' reasonable expectations of privacy based on the context of the study

The **IRB will make the following determinations**, as appropriate:

- The PI and other study personnel have ethical access to the participant's private, identifiable information, in accordance with HRPP Policy 3.12
- The methods used to identify, recruit, and contact potential participants minimize risk to privacy
- The location where informed consent is obtained is conducive to protecting participants' privacy
- The persons present during the informed consent process or during research activities will be limited to:
    - Those listed on the IRB application,
    - Those involved in the clinical care of the participant, or
    - Others present with the participant's explicit consent
- Research activities will be conducted in as private of a setting as possible, consistent with the nature of the research and the context of participant interactions