

Institutional Review Board

Investigator Guidance Series

Privacy (HRPP 3.3)

Description:

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

Definitions:

<u>Privacy:</u> having control over the extent, timing, and circumstances of sharing oneself.

<u>Private Information:</u> information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public (ex. Medical record).

<u>Protected Health Information (PHI):</u> individually identifiable health information that:

- 1) Is created or received by the organization, and
- 2) Relates to the past, present, or future physical or mental health or condition of an individual, the provisions of health care to an individual, or the past, present, or future payment for the provision of health care to an individual.

<u>Identifiable Sensitive Information:</u> information that is about an individual and that is gathered or used during the course of research where the following may occur (1) through which an individual is identified; or (2) for which there is at least a very small risk, that some combination of the information, a request for the information, and other available data sources could be used to deduce the identity of an individual.

Protecting Privacy (protecting subjects):

The IRB look for the following in an application:

- The PI and other research personnel have ethical access (HRPP Policy 3.12).
- The methods used to identify, recruit, and contact potential subjects minimize the risk to privacy.
- The location where informed consent is obtained is conducive to the privacy of subjects.
- Persons involved with the informed consent process or research activities are listed on the IRB application or are involved in the clinical care of the subject.
- The research activities are performed in as private a place as possible.

