**Informed Consent**

Consent to participate in a study or to have one’s child participate in a study is a foundation of ethical conduct of research on human subjects.\(^1\)

*Obtaining informed consent for institutionally sponsored research:*

- Consent must be ensured in writing;
- The form must contain a written statement of potential risks and benefit and a phrase that indicates that these risks and benefits have been explained; and
- The form must be signed and dated by both the potential subject and the researchers or designated representatives.

*Active vs. passive consent by parents of children involved in research:*

- Active consent is formal written permission to by an informed parent or legal guardian that allows a child to participate in a research project.
- Passive consent is based on the assumption that parental permission is granted if parents do not return a refusal form after being informed about the study’s purpose.\(^2\)
- Assent is a child’s affirmative agreement to participate in research.

**Confidentiality and Anonymity**

*Definitions:*

- Confidentiality is the active attempt to remove from the research records any elements that might indicate the subject’s identities. This is very important to consider in qualitative research.
- Anonymity means that the subjects remain nameless (e.g., self-administered survey questionnaires).
Maintaining confidentiality when collecting or accessing data:

- Redacting text: If using case files, black out all personally identifiable information on a copy of the forms or report. Then photocopy the form and discard the original blacked-out version. This will ensure that the names are truly redacted.

- In qualitative data-gathering strategies: The relationship between the researcher and the subject is frequently ongoing and evolving, involving observation and participation in activities.

Maintaining confidentiality when storing survey data:

- To ensure confidentiality, keep written consent forms separate from survey response sheets. Assign a unique identifier to survey form/responses. Maintain consent forms and data in separate and secure locations.

Maintaining confidentiality when reporting findings:

- Names: Researchers must systematically change each subject’s real name to a pseudonym or a case number when reporting data.

- Places: The names of places, along with description of a person’s characteristics, may make it possible to discover a subject’s identity. Researchers should take care about how subjects and settings are discussed.

- Communities: Researchers may need to protect the identity of the community altogether. Sometimes, particularly sensitive research is published using general descriptors such as “a small town in the Southwest.”

