

EVALUATION BRIEF

Program Evaluation and Research Ethics

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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."

Source: Adapted from Hafford, C. & Lyon, K. (2007). The Challenges of Conducting Evaluation in Tribal Communities. Office of Family Assistance Grantees Meeting. November 2007. Washington, D.C.

¹ Berg, B. (2001). *Qualitative Research Methods for the Social Sciences*. Boston: Allyn & Bacon. P 45-46.

² Esbensen, F., E. Deschenes, R. Vogel, J. West, K. Arboit, and L. Harris. (1996). Active parental consent in school-based research: an examination of ethical and methodological issues. *Evaluation Review* 20: 737-753.