

Standard Operating Procedures

Subject: Maintaining Confidentiality

Date: 15Jun2006

Purpose: The purpose of this Standard Operating Procedure (SOP) is to define the minimum standards of confidentiality. Researchers at the Frank Porter Graham Child Development Center (FPG) are firmly committed to the principle that the confidentiality of each individual's data obtained through research projects must be protected. This principle applies whether or not any specific guarantee of confidentiality was given at the time of the data collection. Furthermore, the research databases and analysis outcomes produced at the FPG Data Management and Analysis Center (DMAC) are themselves confidential information under the control of the principal investigator(s) for each project.

Scope: This procedure applies to all projects managed and maintained at the FPG Data Management and Analysis Center.

Responsibility: Through consent procedures, researchers make a commitment to protect the privacy of participants. Maintaining this commitment becomes the responsibility of each staff member of the research projects. The following guidelines delineate the responsibilities of staff members in maintaining confidentiality. These guidelines are broad based but may not address all confidentiality issues that arise in your work. When issues arise that are not covered by this policy, you **must** contact your supervisor, who will decide how the issue should be handled.

Types of Confidential Information:

- The privacy of participating individuals and/or organizations is to be protected at all times. Personal information is always "owned" by the subject/research participant. In particular, the following must be kept confidential:
 - Names of all respondents, interviewees, and other participants
 - All information or opinions collected during surveys, interviews, and/or observations linked to a particular participant
 - Any information learned incidentally about any participants.
- The projects using the FPG Data Management and Analysis Center maintain "ownership" of their data. The following can be released only at the direction of the unit director, the principal investigator or the project director:
 - Data sets created for a particular project
 - Results of analysis using data for a particular project.

Procedures:

- Confidentiality Pledge:
 - Unit personnel are expected to sign the confidentiality agreement attached to this document

- Raw Data:
 - It is expected that personal identifying information will be removed from raw data and replaced with coded ids before the raw data is received in the unit for processing
 - Any materials received with personal identifying information will be kept in locking cabinets, offices or suites when not being used in project activities
 - After data entry, any materials received with personal identifying information will be stored or returned to the project in a manner approved by the unit director, principal investigator or project director
 - Any materials with personal identifying information on them that are to be discarded will first be shredded.

- Computer Files:
 - Computer data files should contain only coded id information, not personal identifiers
 - When computerized names and addresses are needed, they will be kept separately from other project data
 - All computer files will be password protected
 - Any computer disks with personal identifying information that are to be discarded will first be destroyed
 - Personal identifying information will not be sent via email.

- Release of Data Sets and Analysis Results:
 - Authorization from the unit director, the project director or the principal investigator is needed prior to giving data sets to anyone outside the project and outside our unit
 - The principal investigator(s) or project director must authorize any release of information about the analysis results of their project.

Attachment:

- Confidentiality agreement

Based in part on the Statement of Policy and Procedures for Maintaining Confidentiality created for the Smart Start Evaluation Project by Kelly Maxwell.

CONFIDENTIALITY PLEDGE

- I hereby certify that I have carefully read and will cooperate fully with the FPG Data Management and Analysis Center's Standard Operating Procedure for Maintaining Confidentiality.
- I will keep completely confidential all information, except that pertaining to abuse and neglect, arising from the projects concerning individual respondents to which I gain access.
- I will not discuss, disclose, disseminate, or provide access to data and identifying information except as authorized by the unit director, the project director or the principal investigator.
- I will comply with any additional procedures established.
- I will devote my best efforts to ensure that there is compliance with the required procedures by personnel whom I supervise.
- I understand that violation of this pledge is sufficient grounds for disciplinary action, up to and including dismissal.
- I also understand that violation of the privacy rights of individuals through such unauthorized discussion, disclosure, dissemination, or access may make me subject to criminal or civil penalties.

- I give my personal pledge that I shall abide by this assurance of confidentiality.

Print Name: _____

Signature: _____ / ____ / ____
Date

Witness Print Name: _____

Witness Signature: _____ / ____ / ____
Date