

Appendix W

Data Sharing Agreement with CDC for PIDS (Optional)

CDC does not require states to complete a data sharing agreement to house birth certificate data on the CDC servers for PRAMS Integrated Data Collection System (PIDS). States may complete a data sharing agreement with CDC if required by the state Vital Statistics/Health Statistics office.

A prototype agreement developed by CDC is included below. States may use this agreement, modify it, or create their own agreement. Any changes to the prototype must be reviewed and agreed upon by both parties prior to approval. Once signed, the data sharing agreement will remain in effect as long as the PIDS system is in use.

Protocol Development Task

Place your state data sharing agreement with CDC here if needed. If not required by your state, indicate as such.

Sample Data Sharing Agreement

Information obtained during research is confidential and is collected with the intent that it be used only for research purposes. This agreement to share research data is between the _____ (“State PRAMS Department”), who collected the data, and the Centers for Disease Control and Prevention (“CDC”), who is receiving the data. Before research data are shared, _____ and CDC agree to the following terms and conditions:

Terms:

1. This agreement covers only data from the Pregnancy Risk Assessment and Monitoring System (PRAMS) that is administered by the State PRAMS Department.
2. CDC developed and houses the PRAMS Integrated Data Collection System (PIDS)
3. The State PRAMS Department staff will perform the following using the PIDS system:
 - a. Upload the necessary vital records data which might include identifying information for conducting PRAMS data collection activities.
 - b. Collect the PRAMS survey and operations data.
 - c. Transfer de-identified data from the system to CDC for processing and weighting.
 - d. Delete contact information, survey responses, and operational data as desired when data collection is completed.
4. CDC will perform the following:
 - a. Maintain and support the PIDS system which might require access to the identifying data to resolve issues with the system, if any.
 - b. Perform data management activities and compile data.
 - c. Provide a secure environment for PRAMS data and limit access to authorized [STATE] users.

Conditions:

1. CDC will use the data only to perform data management, compilations of data, and support data collection activities, if needed.
2. CDC will not use or permit others to use these data for purposes other than described in Condition 1 unless written approval of the State PRAMS Department is granted.

3. CDC will establish and maintain appropriate procedures to protect the confidentiality of the data.
4. CDC will not attempt to link the data with individually identifiable records in any other database except for that required to weight the data.
5. CDC will not attempt to learn the identity of any of the study respondents nor attempt to contact any of the respondents.
6. CDC staff with access to the PRAMS data will sign Confidentiality Agreements
7. CDC will report to the State PRAMS Department immediately any unauthorized use or disclosure of data.
8. CDC will destroy all copies of the data or return all copies to the State PRAMS Department after data collection has ended and the weighting is complete.
9. This agreement will remain in effect as long as the PIDS system is in use.

IN WITNESS WHEREOF, the parties have executed this Agreement:

_____ Date_____

Signature of State PRAMS Department Representative

Title of State PRAMS Department Representative

_____ Date_____

Signature of CDC PRAMS Official

Leslie Harrison
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