

Requests for PRAMS Data Sets

To facilitate the planning and implementation of analyses, ensure scientific quality and appropriate use of the data, and avoid duplication of efforts, any researcher intending to analyze Florida (FL) PRAMS data **must** submit a brief proposal:

Florida PRAMS Coordinator Florida Department of Health 4052 Bald Cypress Way, Bin A-24 Tallahassee, FL 32399

Please see the Format for Proposal document for proposed guidelines.

Researchers should consult with the Ethics and Human Research Protection Program to determine whether their proposed research warrants review by the FL Department of Health (DOH) Institutional Review Board (IRB). A request for consultation can be submitted online at <u>Distinguishing Public Health Practice and Quality Improvement from Research</u>.

Upon receipt of approval by the FL PRAMS team (and the DOH IRB, if necessary), all researchers who are listed on the proposal will complete a Data Sharing Agreement [link to AGREEMENT FOR SHARING DATA] and return the form to the FL PRAMS Coordinator.

Review and Approval Process

- 1. Proposals will be circulated among the FL PRAMS team to solicit input regarding the suitability of FL PRAMS data for the proposed analysis and the appropriateness of the analysis plan considering the FL PRAMS survey design. A select set of variables will be released to the researcher upon approval by the FL PRAMS team. The variables are limited to non-identifiable variables. Examples of variables that will not be included in the dataset include: mother's date of birth, infant's day of birth, hospital of birth, maternal zip code, maternal and paternal places of birth, birth certificate number, and FL PRAMS interviewer identification number. Researchers who request variables that are not included in the public use dataset might have to seek approval from other DOH offices. The FL PRAMS team will contact these other DOH offices, as necessary.
- 2. The FL PRAMS team will respond to the primary researcher within three weeks. This response will include a summary of comments received from the FL PRAMS team and notification of approval or disapproval to conduct the analysis.

- 3. Upon receipt of FL PRAMS team approval, all researchers who are listed on the proposal will complete a <u>Data Sharing Agreement</u> and return the form to the FL PRAMS Project Coordinator. Approval to analyze FL PRAMS data applies only to the topic described in the research proposal. If a researcher desires to conduct additional analyses, a separate research proposal is required. The Data Sharing Agreement will require final approval from the FL PRAMS Project Director/Principal Investigator.
- 4. FL PRAMS will create a SAS analysis data set with de-identified information for the primary researcher on a password-protected CD-ROM. A codebook, describing the variable name, variable label, associated SAS format, and response codes will accompany the SAS dataset. The source of the variable (questionnaire, birth certificate, operations, weights) will be included as well. A letter describing the contents of the CD-ROM will accompany the data. The data will be zipped using WinZip software, and password protected, so that only the intended recipient will be able to unzip the files.
- 5. Once the analysis described in the research proposal has been completed, researchers must destroy their copy of the data (confirmed in writing to FL PRAMS) and/or return the data to FL PRAMS.

Authorship

Because PRAMS is a collaborative effort between the FL DOH and the Centers for Disease Control and Prevention (CDC) Division of Reproductive Health, both FL DOH and CDC representatives should be acknowledged as follows:

Acknowledgments

Florida Department of Health PRAMS Team and Bureau of Vital Statistics. The CDC PRAMS Team, Program Services and Development Branch, Division of Reproductive Health.

In addition, authorship of all articles and journal submissions shall be negotiated based on the amount of time, consultation, collaboration, and technical support provided by FL PRAMS staff and the primary investigator(s).

Publication or presentation

Before giving an oral presentation using FL PRAMS data, researchers must submit their slides and abstract to the FL PRAMS team two weeks prior to the presentation.

Before submitting a manuscript for publication, researchers are required to submit copies of their work to the FL PRAMS team four weeks prior to submitting the manuscript to a peer-reviewed journal.