

Minnesota PRAMS Resource Sharing Plan

The Project Coordinator will be responsible for obtaining completed Minnesota PRAMS data request applications and data analysis contracts.

The following documents are used as part of the data sharing process:

- A. Types of Minnesota PRAMS data requests
- B. Minnesota PRAMS Data Request Review Process
- C. Minnesota PRAMS Data Request Guidelines
- D. Minnesota PRAMS Data Request Application Form
- E. State of Minnesota Data Analysis Contract

A. Types of Minnesota PRAMS Data Requests

Methods to obtain Minnesota PRAMS data **Minnesota Department of Health** **Division of Community & Family Health** **Maternal & Child Health Section**

There are three main methods to obtain Minnesota PRAMS data analyses or datasets. If you are interested in obtaining PRAMS data for your project, please read the following descriptions to see which method is most appropriate and contact the PRAMS Coordinator, at HEALTH.MNPRAMS@state.mn.us or call 651-201-3760 for more information.

1. Analysis Requests	Analysis requests are completed by the MN PRAMS Coordinator. To obtain an analysis of MN PRAMS data: <ul style="list-style-type: none">• Contact the MN PRAMS Coordinator HEALTH.MNPRAMS@state.mn.us 651-201-3760• Describe the details of research or program evaluation needs<ul style="list-style-type: none">○ Simple analysis requests (minimum of 3 weeks to complete)○ More detailed/complex analysis may require meetings to discuss analysis plan (minimum of 2 months to complete)
2. Data Requests	Researchers with the capacity to analyze their own data can request a MN PRAMS dataset. To obtain a MN PRAMS dataset for external data analysis: <ul style="list-style-type: none">• Review the <u>MN PRAMS Guidelines for Proposals to Conduct External Analyses</u>• Investigator needs to complete a <u>MN PRAMS Data Request Application, please contact PRAMS Coordinator for a copy.</u> HEALTH.MNPRAMS@state.mn.us

	<ul style="list-style-type: none"> • Investigators are encouraged to contact the PRAMS Coordinator prior to completing the form (a meeting may need to be scheduled to discuss data request). • Submit completed application to the MN PRAMS Coordinator • Complete Data Analysis Contract
3. Interagency agreements	<p>Interagency agreements can be made between state government agencies that have mutual interests in projects that further each agency’s mission.</p> <ul style="list-style-type: none"> • Meet to discuss analysis plan and Data Sharing Agreements • Complete Data Sharing Agreement

B. Minnesota PRAMS Data Request Review Process

**PRAMS Data Request Review Process
Minnesota Department of Health
Division of Community & Family Health**

Requests to obtain a PRAMS dataset with data on individuals (vs. aggregate data) must be reviewed by the Data Request Review Committee. A review is necessary to ensure that MDH data practices will be followed to protect the privacy of the subjects of the data. The steps below outline how a request for MN PRAMS data will be processed and evaluated.

<p>1. Administrative Review:</p> <p>After a completed MN PRAMS Data Request Application is received, the Project Coordinator conducts an administrative review of the application. The goal of this review is to ensure that the application is complete and to identify any administrative or data privacy problems with the proposed methods.</p> <ul style="list-style-type: none"> • The review will be completed within ten business days of receipt of the application.
<p>2. Review Committee Notification:</p> <p>Upon receipt of an application, the PRAMS Project Coordinator will also email the Review Committee to notify them of a forthcoming Data Request Application.</p>
<p>3. Disseminate Application to Review Committee:</p> <p>Approved applications, along with any other relevant correspondence between the PRAMS Project Coordinator and the investigator, will be sent to the Review Committee via email within ten business days after completion of the Administrative Review process. Applications with problems may take longer than one week to send to the committee. The Review Committee members will review the application and complete the Application Evaluation Form and return it to the PRAMS Project Coordinator by the specified deadline.</p> <ul style="list-style-type: none"> • Any deadlines established will provide committee members with 2 working weeks to review the application and provide comment.

4. Evaluation:

The Review Committee will evaluate the application based on:

- Rationale indicating why PRAMS data are useful for the proposed project;
- All co-investigators are qualified to undertake the proposed research, and have experience and/or capacity at using specialized software to analyze complex survey data;
- The aims of the study are feasible and that the hypotheses/research questions are explicit and testable.
- There is a detailed description of how data privacy will be protected, and will include who will have access to the data and how/where the data will be stored.

5. Committee Recommendation:

The PRAMS Project Coordinator will compile responses no later than one workweek after the deadline for completed reviews by Review Committee members.

- A recommendation for approval will be automatic if all members approve the proposal;
- Committee interaction will be needed if members disagree about the application. Interaction can take place by conference call, e-mail, or in-person meetings. The goal of these exchanges is to reach a unanimous decision regarding the application.
- Note: If Review Committee member(s) are out of the office during this time period; the time frame will be extended to allow each Review Committee member to review the application.

6. Notification of Decision:

The Project Coordinator will notify the applicant of the Review Committee's decision.

- If approved, investigators will complete a Data Analysis Contract and return the form to the Project Coordinator.
- Approval to analyze PRAMS data applies only to the topic described in the proposal. If a researcher wishes to conduct additional analyses, a separate proposal will need to be completed and reviewed.
- The Review Committee may ask for changes that need to be made to the application before the application is approved (which will extend the time period for the review process.)

7. Receipt of PRAMS Data:

If the application is approved and data sharing agreement completed, the Project Coordinator will create a dataset in consultation with the researcher. The variables included in the dataset will be those specified by the researcher in the application. The construction of the dataset will be completed within 1-2 months based on the complexity of the data request.

C. Minnesota PRAMS Data Request Guidelines

Minnesota PRAMS Guidelines for Data Analysis Proposals for External Researchers

Overview of PRAMS

The Pregnancy Risk Assessment Monitoring System (PRAMS) is an ongoing, population-based surveillance system that collects information on maternal characteristics, behaviors, and experiences that occur several months prior to conception, during pregnancy, and immediately following delivery. The PRAMS survey supplements birth certificate information, and can be used to plan and evaluate maternal and child health programs and inform health policy decisions.

Methods

Minnesota PRAMS began collecting information for mothers who gave birth in May 2002. Each month, mothers who are state residents and have recently delivered a live-born infant during the preceding 2–4 months are randomly selected from a file of birth certificate records using stratified systematic sampling. Mothers who gave birth outside their state of residence and mothers who had a multiple birth greater than three gestations are excluded from the sampling frame.

PRAMS states oversample mothers who are at increased risk for adverse pregnancy outcomes. Some small populations are at higher risk of poor birth outcomes. Minnesota PRAMS asks a larger share of these mothers to participate in PRAMS so that there are enough participants to obtain more precise estimates for these groups. State estimates are “weighted” to account for oversampling. Because of this complex sampling method, analyses must use weighted data, which re-adjusts input from oversampled groups back to their true share of the Minnesota population. Because of disparities in infant mortality, low birth weight and premature births, Minnesota PRAMS currently oversamples US-born African American mothers and American Indian mothers.

Sampled mothers are mailed a letter that introduces them to the project, followed by a self-administered standardized questionnaire several days later. If the questionnaire is not returned, a reminder letter and two additional questionnaire mailings are sent. All states conduct telephone interview follow-up for non-responding mothers. The PRAMS questionnaire consists of about 60 core questions that are asked by all projects. In addition, each project inserts 10–30 questions they develop themselves or modules of questions developed by CDC standard questions. The Minnesota PRAMS questionnaire has been translated into Spanish for Spanish-speaking populations.

Available years for Minnesota PRAMS analysis*:

- Minnesota PRAMS Survey 2004-2008 (Phase 5)
- Minnesota PRAMS Survey 2009-2011 (Phase 6)
- Minnesota PRAMS Survey 2012-2015 (Phase 7) (Note: 2012 is a partial year containing 8 months data. Response rate for 2014 and 2015 did not meet the 60% and 55% threshold, respectively, set by CDC, so results should be interpreted with caution.)
- Minnesota PRAMS Survey 2016 (Phase 8) (Note: Response rate for 2016 did not meet the 55% threshold set by CDC, so results should be interpreted with caution.)

**Minnesota receives weighted final PRAMS data approximately 18 months later from CDC that is available for analysis purposes*

For detailed descriptions of core and standard PRAMS questionnaire topics, refer to national PRAMS web page at the website:

<http://www.cdc.gov/prams/Questionnaire.htm>

For more information on PRAMS methodology, please go to:

<http://www.cdc.gov/prams/methodology.htm>

Data Sets

States collect and submit data to CDC from three different sources: the PRAMS questionnaire, the birth certificate, and survey operational data. The data are weighted annually for each state to adjust for nonresponsive, non-coverage, and sampling fractions. The annual weighted data sets contain data from all three sources. The questionnaire data contain mothers' responses to the questionnaire. The birth certificate data contain information on selected maternal characteristics and pregnancy outcomes. The operations data are generated by the PRAMS operational software and are used primarily for operational evaluations and analyses of survey methods and are submitted to CDC. In addition, a comment data set is maintained separately from the weighted project area data sets. The comment data set consists of mother's comments to the questions or their comments about answering questions related to their pregnancies (either directly written on a mailed questionnaire or spoken during a telephone interview). Analysts use the comment file to re-code maternal responses or to obtain qualitative data from written or verbatim comments.

Analysis Limitations

CDC strongly recommends that PRAMS data not be reported unless the weighted response rate is at least 65%, for years prior to 2012, 60% for 2012 – 2014, 55% thereafter. Minnesota's overall weighted response rate has been sufficient up until 2014 when response rates fell below the 60% threshold. Therefore data from 2014 through 2016 should be interpreted with caution, as the response rates did not reach the CDC threshold. Additionally, we request that you **do not run subpopulation analysis for either of these two groups (US-born African Americans and American Indian mothers)**, as the data are unlikely to be completely representative of the population. In addition, the PRAMS data are not currently available for regional analyses other than the 7 county metro or non-metro areas. Please note, analyses that represent denominators of less than 30 respondents will not be reported. And, analyses that represent denominators of less than 60 respondents, but, greater than 30 respondents need to indicate that the data might not be reliable.

Analysis Software

Due to the complex survey design used by PRAMS, CDC recommends that analysts use SUDAAN (Survey Data Analysis, Research Triangle Institute, NC) software, SAS (using Survey procedures) or another software product that allows for complex sampling designs to compute the appropriate variance estimates and perform significance testing.

Application process

For each project, we request the following be submitted:

1. Application Form

- a. Author name, credentials, and contact information.
- b. Content of abstract/project summary.
- c. Years of data requested.
- d. Data security for PRAMS analysis dataset

2. Abstract: Include an abstract that briefly explains the following:

- a. Research question(s).
- b. Methods & software.
- c. Discussion of intended outcomes.
- d. Rationale for using PRAMS data.
- e. Justification for questionnaire variable request.
- f. Type of publication.

Contract process

For each project an approved and signed State of Minnesota Data Analysis Contract

Authorship

Because PRAMS is a collaborative effort among state health departments and CDC's Division of Reproductive Health acknowledgement should appear on all materials published.

Minnesota will recognize external researchers by placing the individual on the authorship line. Minnesota will also have at least one PRAMS team member as an author on all publications written by external researchers. This will ensure an opportunity to participate in the development of the document and provide review and comment from an MDH perspective.

The following example illustrates how the acknowledgement should appear:

Sample Acknowledgements:

Minnesota Pregnancy Risk Assessment Monitoring System (PRAMS), Minnesota Department of Health, Division of Community and Family Health, Maternal and Child Health

This manuscript was made possible by grant number: IU01DP006217-01 from the Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion.

Submission Steps

Send research proposals to Minnesota PRAMS Coordinator at HEALTH.MNPRAMS@state.mn.us.

Proposals will be reviewed by Minnesota PRAMS Review Committee regarding the suitability of PRAMS data for the proposed analysis and the appropriateness of the analysis plan considering the PRAMS survey design.

There should be one application for each proposed project.

Approval to analyze PRAMS data applies only to the topic described in the research proposal. If a researcher desires to conduct additional analyses, a separate application is required.

All researchers who are listed on the proposal will sign a State of Minnesota Data Analysis Contract and submit the form to Minnesota PRAMS once the application is approved.

Minnesota PRAMS will respond to the primary researcher within eight-ten weeks. This response will include a summary of comments/questions of Minnesota PRAMS Review Committee members and notification of an approval/disapproval or needed changes for approval to conduct the analysis.

Minnesota PRAMS will create an analysis data set for the primary researcher.

Once the analysis described in the research proposal has been completed, researchers are to destroy their copy of the data and confirm in writing the data has been destroyed.

Publication or presentation

As a condition of the data analysis contract, researchers must submit to the Minnesota PRAMS team a copy of the abstract or manuscript using Minnesota PRAMS data for comment at least two weeks prior to submission to a conference or to a peer-reviewed journal. A courtesy copy of slides for oral presentations is also requested prior to a presentation. And, a final copy of the abstract, manuscript, or presentation will be sent to the Minnesota PRAMS team.

D. Minnesota PRAMS Data Request Application Form

**MN Pregnancy Risk Assessment Monitoring System (PRAMS)
Proposal Application Form**

Please complete one form per proposal

Principal Researcher Name and Title:	
Principal Researcher's Affiliation:	
Address (include mailing and physical address):	
Phone number:	
E-mail:	
Names and affiliations of other researchers:	
Proposal Title:	
Data Security:	
Abstract: Please attach an abstract describing your project. Include items listed to the right.	Research question(s) Methods and software Discussion of intended outcome of analysis Rationale for using PRAMS as the data source Justification for questionnaire indicators Type of publication (journal article, thesis, dissertation, report, etc.)

<p>Years of PRAMS data requested: Phase 8 (2016) Phase 7 (2012-2015) (Note: 2012 is a partial year containing 8 months data) Phase 6 (2009-2011) Phase 5 (2004–2008)</p>	<p>Timeline for the research</p> <p>Check all that apply</p> <p><input type="checkbox"/> Most recent year of data available</p> <p><input type="checkbox"/> List of specific years:</p> <p>_____</p> <p>_____</p> <p>_____</p>
<p>Indicator List: Please attach list</p>	<p>Please review the variables included in the PRAMS Analytic Research File.</p> <p>A justification should also be included in your abstract.</p> <p>We recommend you describe the indicators (e.g., hospital breastfeeding practices), and provide the survey question number (e.g., Standard Question B3)</p>

Proposal Form Instructions

FORM INSTRUCTIONS

Please provide the following information on the form. Please submit a separate form for each study.

Principal Researcher & Title:

Write the name of the principal researcher, and include their credentials and title (e.g., Jane Doe, Ph.D, Associate Professor). This person will be the primary point of contact regarding the proposal.

Principal Researcher Affiliation:

Write the affiliation of the principal researcher (e.g. Emory University, Rollins School of Public Health).

Address: Write the address for mail correspondence. This address will be used when mailing out the dataset. A physical address must be provided for delivery. Also include P.O. Box if used for receiving mail.

Phone Number:

Write the phone number of principal researcher; this phone number will also be used for the delivery form.

Email:

Write e-mail address of principal researcher; this will be used as the primary means of communication regarding the proposal.

Names and Affiliations of other researchers:

List the names, credentials and affiliations of any additional researchers.

Title:

Provide the proposed or working title of the project

Data Security:

Describe the data security procedures that will be used for the PRAMS analysis dataset

Abstract:

Attach an abstract describing the study. Include the following:

- 1) **Research question or questions:** Clearly state the research questions you plan to address with your study.
- 2) **Methods and software:** Briefly describe the methods you intend to use (descriptive/bivariate analysis; multivariable analysis; survival analysis, etc.); PRAMS has a complex sampling scheme necessitating the use of appropriate analytic software (SUDAAN, STATA, complex survey modules of SAS or SPSS, etc.); please indicate the software package you plan to use. Describe your experience with SAS, SUDAAN, or other statistical packages that you plan to use for your analysis.
- 3) **Discussion of the intended outcome of the analysis:** Describe the importance of your analysis in terms of contribution to gaps in the literature or public health impact.
- 4) **Rationale for using PRAMS data:** PRAMS is a rich data source, but may not be appropriate for addressing all research questions; please indicate why PRAMS would be a good source of data for your study.
- 5) **Justification for questionnaire indicators:** Please justify the inclusion of questionnaire variables. A list of these indicators should be provided separately.
- 6) **Type of Publication:** Describe the plans for interpretation and dissemination of findings. Please specify type of intended publication (e.g. journal article, presentation, report, fact sheet, thesis, dissertation)
- 7) **Timeline:** Provide a timeline for the proposed research and completion of the manuscript.

Years of PRAMS data requested:

Indicate the years of data that you would like to request. The PRAMS data has undergone a series of revisions over the years. With each revision, some of the questions change. While most indicators can be compared across phases, it is often easiest to analyze data within a single phase. The years covered by the different phases are listed on the application form. For information on the questions from each phase please refer to the PRAMS Topic Reference Documents. PRAMS Core and Standard Question Lists by phase may also be helpful. These documents can be found at <http://www.cdc.gov/PRAMS/Questionnaire.htm>.

PRAMS data for any given calendar year are usually available about 18 months later (e.g., 2008 data is available in summer of 2010). This is because of the data collection methodology and weighting process. You may request the most recent year of data available at the time of your request. You may also request specific years of data (with or without the most recent year).

Indicator list:

Please attach a list of questionnaire variables that you would like included in the dataset. Please refer to the PRAMS Research File codebook to determine what is included. The optional or standard questions that states may elect to add to their surveys are found in the Topics Reference Document and the PRAMS Standard question lists at <http://www.cdc.gov/PRAMS/Questionnaire.htm>. We recommend that you describe the indicators (e.g., hospital breastfeeding practices), and provide the survey question number (e.g., Standard Question B3).

E-mail this form to the PRAMS Project Coordinator at HEALTH.MNPRAMS@state.mn.us. If you have any questions, please e-mail or call 651-201-3760.

E. State of Minnesota Data Sharing User Agreement



**STATE OF MINNESOTA
MINNESOTA PRAMS EXTERNAL RESEARCHER
DATA SHARING USER AGREEMENT**

I, _____, as principal investigator/co-investigator on this proposed analysis of Minnesota Pregnancy Risk Assessment Monitoring System (MN PRAMS) data, agree to the following requirements for the use of Minnesota PRAMS data, and assure compliance with the requirements by all staff and collaborators approved as part of this agreement.

1. I will not use these data except for statistical analysis and reporting as described in the attached proposal titled _____.
2. I will not use nor permit others to use these data to conduct analyses other than those described in the proposal, titled _____, which accompanies this statement.
3. I will not release the dataset or any part of it to any person other than those listed as collaborators in the attached proposal. I will assure that all approved collaborators understand that they may not share the dataset or any part of it.
4. I will not attempt to link nor permit others to link the dataset with individually identifiable records from other Minnesota Department of Health (MDH) or non-MDH datasets.
5. I will not attempt nor permit others to use the dataset to attempt to learn the identity of any participant. If the identity of a respondent should be inadvertently discovered, I will make no use of this knowledge, nor will I permit others to use the knowledge. I will inform the Minnesota PRAMS staff of the discovery, so they can prevent future discoveries. I pledge that neither I nor other members of my team will inform anyone else of this knowledge.
6. I agree that the data will be kept in a secure environment and will be password-protected in that environment and encrypted when transported to another environment. Only authorized users named in this signed agreement will have access to the dataset and password.
7. I will adhere to the authorship agreement discussed with the Minnesota PRAMS Team. Additionally, all oral or written presentations of the results of the analyses will include an acknowledgement of the Minnesota PRAMS Team and the Centers for Disease Control and Prevention's PRAMS Team.
8. All oral or written presentations of the results of the analyses will include an acknowledgment of Minnesota PRAMS and the Centers for Disease Control and Prevention.

9. All abstracts, oral presentations and poster presentations based on analysis of Minnesota PRAMS data must be submitted to the Minnesota PRAMS Coordinator for review at least two weeks before submission/presentation.
10. All manuscripts based entirely or in part on analysis of Minnesota PRAMS data must be submitted to the Minnesota PRAMS Coordinator for review at least 28 days before submission.
11. If Minnesota PRAMS determines that Data User has breached or violated a material term of this Agreement, Minnesota PRAMS may, at its option, pursue either or both of the following remedies:
 - (1) Take any other reasonable steps that Minnesota PRAMS, in its sole discretion, shall deem necessary to cure such breach or end such violation; and/or
 - (2) Terminate this Agreement immediately.
12. All copies of data for the proposed analyses will be destroyed or returned to the Minnesota Department of Health (to the attention of Minnesota PRAMS Coordinator) within 30 days of completion of the work described in the data request. If destroyed, I will provide the Minnesota PRAMS Coordinator with a written description of the method I plan to use - prior to destroying the data to ensure that the proposed method is acceptable. Written confirmation that the data has been destroyed will also be provided to the Minnesota PRAMS Coordinator.
13. I understand that sharing of this data does not imply, in whole or in part, that the proposed topic has been investigated before, or will be investigated now or in the future, by other investigators interested in this topic.
14. I agree to allow Minnesota PRAMS staff to disseminate any materials or products developed as a result of this research for the purpose of promoting the health and well-being of all Minnesota residents.

My signature and the signatures of all investigators indicate our agreement to comply with these requirements and the requirements outlined in the Minnesota PRAMS guidelines for sharing data with external researchers.

Name of principal investigator: _____

Title: _____

Organization: _____

Signature: _____

Date: _____

Signatures of other investigators/collaborators:

Name: _____

Role: _____

Name: _____

Role: _____

(Additional names and signatures can be included on a separate page.)

Distribution:

Agency – original

External Researcher– copy

State’s Authorized Representative - copy