HAWAII PREGNANCY RISK
ASSESSMENT MONITORING SYSTEM (PRAMS)
ADDITIONAL GUIDELINES FOR RESEARCHERS

Additional guidelines for researchers are as follows:

- The confidential information obtained from vital records and PRAMS data is not to be used to deny current and/or future benefits or eligibility for services or care.
- Follow-up studies involving contact with individuals or next-of-kin of individuals in the Hawaii PRAMS sample are prohibited without the specific written approval of the CDC PRAMS Program, the Hawaii State Registrar, and the Hawaii PRAMS Principal Investigator.
- Estimates based on unweighted cell sizes of less than 10 or unweighted marginal values of less than 30 will not be published.
- Once research findings are available for distribution, the Hawaii PRAMS Program Coordinator will relay findings to interested audiences in partnership with the Hawaii State Department of Health, Family Health Services Division (FHSD) and the Hawaii PRAMS Steering Committee.

Policy on Authorship:

Several guiding principles should be considered in the process of deciding who the authors are and in what order they should appear on the authorship line. Certain criteria must be met in order for an individual to claim authorship:

1. An author should be an active participant in the planning, design, analysis, and interpretation of the study.
2. An author should have an active part in writing and reviewing the paper.
3. An author must be able to publicly defend the study if the need arises.

All three criteria must be met to justify authorship. The order of listing of the secondary authors will be based on the magnitude of their contribution to the project. Individuals who have made substantive contributions to the project but do not meet the criteria for authorship will be included in an acknowledgment.

It is suggested that at least one Hawaii PRAMS team member be an author on all publications written in the course of a collaborative research project using Hawaii PRAMS data. This ensures an opportunity to participate in the development of the document and provide review and comment from the Hawaii Department of Health PRAMS program perspectives.

For research studies conducted by researchers using the Hawaii PRAMS dataset, which are not part of a CDC-approved multi-state research project, a representative of the Hawaii PRAMS Program will be listed as co-author unless other arrangements have been made and approved by the Hawaii PRAMS Principal Investigator.

As described in the Hawaii PRAMS Data Sharing Agreement, all oral or written presentations of the results of Hawaii PRAMS Data Sharing Agreements will include an acknowledgment of the Hawaii PRAMS Program and the Centers for Disease Control and Prevention (CDC). If possible, presentations of Hawaii PRAMS data analysis projects will also include the contact information of the Hawaii PRAMS Program.

Policy for Review of Reports, Manuscripts, and Presentations:

State and CDC review of abstracts and manuscripts is suggested to enhance collaboration, to share expertise, and to improve the quality of publications and presentations. The CDC PRAMS team may be more familiar with the validity and reliability of particular core data items; states may be more aware of the implications concerning uses of certain data in the state. Mutual review of publications and presentations also serves to ensure that everyone (state and CDC) is informed of analyses being conducted, their findings, and where presentations of PRAMS data will occur.

Researchers are required to submit their publication and presentation materials to the Hawaii PRAMS Program and Hawaii State Department of Health, Family Health Services Division (FHSD) for review and approval at least four weeks prior to presentation, distribution, or submitting for publication. If review and approval cannot be completed within the suggested time frame, the need for more time will be communicated to the authors as quickly as possible.

The purpose of the review process is to improve and strengthen the manuscript or abstract. Authors are encouraged to consider carefully any comments or recommendations that are offered, but all comments may not be incorporated into the final paper in every case. If Hawaii PRAMS or FHSD disagrees with stated conclusions and agreement cannot be reached, the researcher or organization must allow Hawaii PRAMS and/or FHSD to provide comments or a disclaimer that will be distributed with the findings.

Limitations of PRAMS Data:

PRAMS provides valuable population-based data on an ongoing basis for numerous state uses. As with any study design, PRAMS data has some limitations and these limitations must be considered when planning analyses and presenting results.

i. **Limitations in Generalizing to the Study Population (Selection Bias).** These are limitations in the ability to apply findings from PRAMS to the population of women who have had a recent live birth. They arise if women who participate in PRAMS are different from all women who had a live birth, and those differences are not completely corrected for by the weighting process. Many of these differences are identified and corrected during the weighting process using the birth certificate information on all women in the population. Uncorrected differences result in estimates that are inaccurate for the population or underrepresented subgroups.

   - **Noncoverage Bias.** This bias occurs when certain groups are underrepresented in a study sample. Noncoverage bias could arise in PRAMS if birth certificate records from one area of the state or one hospital are systematically excluded from the sample because there is a regular and substantial delay in submitting records to the state health department. If noncoverage is small, bias from this source should be minimal. The percent coverage and any comments on substantial noncoverage for a given year of data can be found in the Hawaii Weights and Comments report for that year.

   - **Nonresponse Bias.** Nonresponse bias occurs when some subgroups of the sample do not respond to the survey or are less likely to respond than other groups. In PRAMS, nonresponse bias among some subgroups can be assessed using data from the birth certificate, and weights are used to adjust for identified differences in response. These weights assume that the women in a particular subgroup who responded have the same response as those who did not respond. If response rates are 65% or higher, this is a reasonable assumption. However, as response rates drop below 65%, the potential for bias increases.

ii. **Inability to Generalize to Related Populations.** It is important to remember that PRAMS only includes in-state residents who had a live, in-state (for most states) birth. Findings from PRAMS cannot be generalized to other populations. Some specific examples are:

   - If a substantial proportion of residents give birth outside of Hawaii, and these residents differ from those who give birth within Hawaii, findings from PRAMS may not be applicable to questions concerning all state residents, or to those areas of the states where many women deliver out of state.

   - PRAMS findings do not represent all pregnant women. They are not applicable to women who had abortions, stillbirths, or fetal deaths.

iii. Limitations of PRAMS Information (Information Bias). The PRAMS analytic data file includes questionnaire data, birth certificate data, and operations data. Each of these can have problems with missing or inaccurate data, but the causes and result of the problems may be different for each data source. When data are equally likely to be missing or inaccurate among all groups of interest, the bias is referred to as nondifferential. If some groups of interest are more likely to have missing or inaccurate data than others, the bias is referred to as differential. When interpreting your PRAMS results, you should consider whether your data may be subject to any of these biases, and if so, how the bias may have affected your results. Any problems with questionnaire data should be reported to the Hawaii PRAMS coordinator so the issue can be addressed in the next questionnaire revision.

1. **Questionnaire Data.** PRAMS questionnaire data are self reported and may be subject to inaccurate reporting. These inaccuracies may occur for a variety of reasons and have differing effects on estimates.

   a. **Recall Bias.** Recall bias occurs because respondents asked about events in the past may not remember them accurately. The bias can be differential if a subgroup of respondents is more or less likely to recall events accurately.

   b. **Reporting Bias.** Women may be unwilling to report some behaviors or events, leading to an underestimate of the prevalence of these events, or they may overreport socially desirable behaviors such as car seat use.

   c. **Mode Bias.** Women who complete a telephone interview may answer differently than they would have if they had completed a self-administered questionnaire. These differences may be caused by differences in trust or concerns about confidentiality, or differences in the way the question is understood when it is read by the interviewer than when it is read by the woman herself.

   d. **Misunderstanding the Question.** Generally, the interpretation of PRAMS questions is left up to the respondents. The questionnaire does not instruct women in the meaning of the questions. If women interpret the question differently than expected, or some subgroups interpret the question differently than others, inaccurate information may result.

2. **Birth Certificate Data.** The medical and public health literature includes several reports on the reliability of birth certificate data. In general, infant information for current birth is usually reliable, but information on previous births may not be. Some maternal information is also questionable, e.g., cigarette and alcohol use is known to be underreported on birth certificates. Information on birth certificates can be from maternal self-report or from medical records and the source of the data may affect the results. The information may be collected differently at different hospitals within Hawaii. Some variables are missing for a large percentage of women (>10%), and some groups of women may be more likely to have missing data than others.

3. Operations Data. Operations data are used most often in methodological analyses.

These data are derived from PRAMS Integrated Data System (PIDS), the tracking system. Inaccurate information may result from data entry errors or miscoding. Data entry errors are most likely to be random and so would not bias results. Biased results could occur if a variable is systematically entered or coded incorrectly.

iv. Confounding. Many factors can affect an observed association between two variables. PRAMS includes information on many of these factors, but may not include all of them. For example, core PRAMS data does not include information on drug abuse. The interpretation of an association may be incorrect if it is affected by an unmeasured confounding variable.

v. Power. Standard errors for PRAMS estimates are frequently larger than they would be from a simple random survey. This increase in error may lead to a lack of power for some analyses, even if the total sample is large. Lack of power is a particular concern when an event or behavior is very rare.

My signature indicates that I have reviewed the additional guidelines for researchers and agree to the terms dictated therein.

Name:

Title:

Organization:

Signature:

Date: