

CHILDREN'S HEALTHY LIVING (CHL) PROGRAM GUIDELINES FOR DATA REQUESTS

**Developed by the CHL Data Work Group
for use in the CHL Pacific Region**

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United States Department of Agriculture
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Introduction

The Children's Healthy Living Program for Remote Underserved Minority Populations in the Pacific Region (CHL) is a partnership among remote Pacific states and other jurisdictions of the US: Alaska, American Samoa, the Commonwealth of the Northern Mariana Islands (CNMI), Guam, Federated States of Micronesia (FSM), Hawaii, Republic of Palau, and the Republic of the Marshall Islands (RMI).

The goal of this Food and Agricultural Science Enhancement (FASE) Coordinated Agricultural Program (CAP) among Pacific Region USDA-defined Experimental Program for Stimulating Competitive Research (EPSCoR) states/jurisdictions is to build social/cultural, physical/built, and political/economic environments that will promote active play and intake of healthy food to prevent young child obesity in the Pacific Region. To do this, CHL engages the community, and focuses on capacity building and sustainable environmental change.

An community-randomized intervention was conducted in the 5 jurisdictions of Alaska, Hawai'i, American Samoa, Guam and CNMI (called intervention jurisdictions or INT). Child and community level data were collected at baseline and post-intervention at 24 months. A prevalence survey was conducted in the Freely Associated States (FAS) of Federated States of Micronesia (FSM), Republic of Palau, and the Republic of the Marshall Islands (RMI).

Questionnaires were administered that collected information on lifestyle, particularly in regards to home environment, diet, physical activity, and anthropometry for children aged 2-8 years in each of the jurisdictions. Accelerometry data was also collected. Communities were assessed for readiness for change, food cost, physical activity and food environments. The table below gives a detailed description of the data that was collected. Data will be cleaned and aggregated for data analysis.

Table 1. Summary of types of data collected by Children’s Healthy Living Program (CHL)				
Data Type	Target participant	Respondent participant	Jurisdictions	Goal number of participants
Surveys on Demographics, Family Size, Assistance Programs, Sleep, Screen Time, Culture	Child/Parent	Parent	FAS, INT (Intervention Jurisdictions)	FAS:200 per jurisdiction INT: 150 per community (4-6 communities per jurisdiction) at two time points (baseline and 24 months)
Accelerometry data	Child	Child	FAS, INT	FAS:100 per jurisdiction INT: 100 per community (2-4 communities per jurisdiction) at two time points (baseline and 24 months)
Food, nutrient, and contextual data from two days of dietary records	Child	Child/Parent	FAS, INT	FAS:200 per jurisdiction INT: 100 per community (2-4 communities per jurisdiction) at two time points (baseline and 24 months)
Activities by time from two days of activity logs	Child	Child/Parent	FAS, INT	FAS:100 per jurisdiction INT: 100 per community (2-4 communities per jurisdiction) at baseline
Community readiness assessment data	Key informants for community	Key informants for community	INT	3-5 per community (2-4 communities per jurisdiction) at two time points (baseline and 24 months)
Community evaluation of physical activity and park facilities (component of Community Assessment Tool (CAT))	Community	Community	FAS, INT	FAS: Up to 5 facilities of each type per jurisdiction INT: Up to 5 facilities of each type per community (4-6 communities per jurisdiction) at two time points (baseline and 24 months)
Community evaluation of food venues (component of CAT)	Community	Community	FAS, INT	FAS: Up to 5 facilities of each type per jurisdiction INT: Up to 5 facilities of each type per community (4-6 communities per jurisdiction) at two time points (baseline and 24 months)
Community evaluation of walkability (component of CAT)	Community	Community	FAS, INT	FAS: 1 to 2 walks per jurisdiction INT: 1 to 2 walks per community (2-4 communities per jurisdiction) at two time points (baseline and 24 months)
Food cost survey (component of CAT)	Community	Community	FAS, INT	FAS: 3 to 5 stores per jurisdiction INT: 3 to 5 stores per community (2-4 per jurisdiction) at two time points (baseline and 24 months)

The CHL program wishes to promote use of the data collected to aid researchers and policymakers in the Pacific, in accordance with human subject protection. This document provides guidelines, protocols and procedures for data request and data sharing as established by the CHL Data Center Work Group. The purposes for requesting data as outlined below will determine the types of elements that can be shared:

- 1: Data at the record level (child/family) data for manuscript publication, conference presentations and abstracts, reports, grant applications, dissertation / thesis and program

and policy development. The requested data sets will be generally limited use data sets and dates.

2: Summary statistics for manuscript publication, conference presentations and abstracts, reports, grant applications, and program and policy development.

3. Data for de-identified record level data for children/families or CAT elements. These may be requested for manuscript publication, conference presentations and abstracts, reports, grant applications, dissertation / thesis, program and policy development, and student projects (practicum, class, etc.).

Requestors will include:

- (1) CHL researchers
- (2) CHL trainees
- (3) Community stakeholders in the CHL jurisdictions
- (4) Other interested parties

The Data Center of the CHL Coordinating Center (CCC) will serve as a repository for all CHL data, including community readiness assessments, and CAT and child data from all jurisdictions. Additionally, each jurisdiction with sufficient resources will maintain a copy of CHL data collected at their location. To receive back the cleaned jurisdiction specific data from the CCC, the jurisdiction needs to identify an entity, such as the land grant extension or public health office that is willing to house the data securely and be responsible for learning of its use. All requests for data will be made to the CCC, except requests for summary statistics for a specific jurisdiction, which can be requested directly from the jurisdiction office holding the data.

Protocol for dataset requests

At the first stages of inquiry about using the CHL data, the CHL Publication Guidelines, CHL Data Dictionary, and these CHL Data Request Guidelines will be provided for the purpose of preparing a data request.

Data requests will be considered for approval by the CHL Program Steering Committee (PSC) and approved requests will be managed at the CHL Data Center by the Data Coordinator. Dataset requests for Purposes 1 and 3 will be submitted to the CHL Data Center, after approval is obtained from the CHL Program Steering Committee (PSC) using Form 1. For Purposes 2 and 3, no Protected Health Information (PHI) will be provided.

Eligibility

Eligible individuals who make a data request will be hereinafter called investigator of this data request.

Students should make data requests through their Academic Advisors. For CHL trainees, data requests may be made through their CHL Advisors. Documentation of approval should be attached.

For Purposes 1 and 3, Investigators must complete and present documentation of IRB and HIPAA training prior to receiving datasets. IRB training and HIPAA training is available via CITI (available at <http://www6.miami.edu/citireq/>).

For requestors outside of the CHL research team, a data use agreement will be set up between University of Hawai'i and the requestor's institution. The costs of data preparation and consultation can be recoverable.

Dataset format

Datasets will usually be distributed in a SAS compatible format. For those who are more familiar with SPSS, please note that SPSS can open a SAS data set directly. Other formats of datasets that can be requested include .csv file, .xlsx or other versions of Excel files. Please indicate in the data request the preferred data format, e.g., SAS or .CSV.

Dataset Delivery

For sharing data with the CHL research team, the CHL server will be used for data distribution whenever possible. The requested data set will be uploaded to the CHL server to the specific jurisdiction folder that the Investigator is associated with.

For non-CHL personnel who do not have access to the server, datasets will be distributed via a web download portal (University of Hawai'i file drop). Investigators will receive a time-limited link to retrieve the data set. The data set will be a limited data set with minimum or no Protected Health Information, depends on the types of data requested. The data set will be encrypted using TrueCrypt or other software with password protection. The password will be sent to the Investigator in a separate email. Large datasets or multiple datasets will be distributed in one compressed .zip package which contains the data files. You can open .zip packages with MS Windows' built-in extraction by double-clicking the .zip package and choosing File > Extract All. You can also use a free utility called 7Zip, or other zip package software.

Timeline: The goal will be to provide data within 6 weeks after PSC approval. In cases where there are deadlines, such as for abstract and student projects, we will make every effort to meet the deadlines. It would be helpful to let the Data Center know in advance of your PSC approval when data will be needed on a short timeline. The 6 week timeline is to account for workforce and workload issues.

Requests for Summary Statistics

Reports will be created that provide many summary statistics by community and jurisdiction. These reports will be available publicly online.

For requests for summary statistics requiring data analysis for the CHL research team, fulfillment of and timeline for requests for the CHL Data Center to run analyses will be handled on a case-by-case basis. In these cases, the CHL data analyst will usually become an author (member of the writing team). Requests will be considered in light of the integrity of the overall program objectives.

Requests for summary statistics requiring data analysis for the outside researchers will be entertained when possible and may require cost recovery.

TERMS OF USE AGREEMENT

The CHL program has collected data on young children and their families in the Pacific region. The CHL Data Center is designated to provide data from this study to qualified individuals for the purpose of statistical analysis and reporting.

The Investigator agrees to the following terms and conditions:

I. OWNERSHIP OF DATA

- a. Ownership of the Data will be retained by CHL. Permission to use the Data by the Investigator may be revoked by CHL at any time, at their discretion. The Investigator must return or destroy all originals and copies of the Restricted Data, on whatever media it may exist, within 5 days of written request to do so.
- b. The Investigator will not make any claim to copyright ownership of the data or any accompanying documentation. The Investigator will not distribute copies of the data and accompanying documentation to others or make copies for reasons other than research in accordance with the conditions outlined in this data request.

II. ACCESS TO THE DATA

- a. Access to the Data will be limited to investigators (the individual who makes this data request and signs this request). The data must not be "loaned" or otherwise conveyed to anyone other than the signatories to the data request. Other people, e.g., students, or coauthors who will use the data should be identified in the data request and must submit their certificate of IRB training documents during data request.
- b. Copies of the Restricted Data or any subsequent variables or data files derived from the Restricted Data will not be provided to any other individual or organization, except in summarized (eg. table) form where cells contain 5 or more individuals.

- c. The Investigator will protect the Data and any data derived from the Data from access by unauthorized individuals.
- d. The Investigator will not store the data on a networked computer or other electronic storage device without taking steps to prevent unauthorized access. Such steps include password protection of shared devices, data encryption, and the use of firewall technology. Data sets should not be stored or transferred on flash drives, which are easily lost.

III. USES OF THE DATA

- a. The Data will be used solely for the purpose of scientific and public policy research and program planning, as stated in the request, and not for proprietary or law enforcement purpose.
- b. The Data will be used to generate only statistical summary information that does not allow any individual, family, household, business, or organization to be identified.
- c. No attempt will be made to identify any individual, family, household, business, or organizations. If an individual, family, household, business, or organization is inadvertently identified, or if a technique for doing so is discovered, the identification or discovery will be immediately reported to CHL, and the identification or discovery will not be revealed to any other person who is not a signatory to this data request.
- d. No attempt will be made to link this Data with any other dataset without written authorization from the CHL Principal Investigator, Rachel Novotny.
- e. Use of the Data will be consistent with the CHL policy regarding scientific integrity and human participant research.
- f. This data sharing document may be modified at any time when new experiences or insights necessitate it. In general, the requestor should follow the version of this document in force at the time of the data request, unless otherwise instructed.

IV. LIMITS ON DISCLOSURE OF INFORMATION

- a. Identifying information concerning research participants from the Restricted Data will not be revealed to unauthorized individuals through personal communication, publication, or other data release.

- b. CHL will be notified immediately if the Investigator receives any legal, investigatory, or other demand for disclosure of the Data, including any request or requirement to provide data to any State agency or State contractor under conditions that are inconsistent with any requirement of this data request. CHL is authorized to revoke this agreement and take possession of the Data, or take any other action necessary to protect the confidentiality of the data.

V. DATA CONFIDENTIALITY PROCEDURES

- a. CHL will be notified immediately if the Investigator discovers a suspected breach of security or any actual disclosure of subject data to unauthorized individuals.

VI. REPORTING AND PUBLICATION REQUIREMENTS

- a. The Investigator will provide CHL with a copy of published works or reports based wholly or in part on the CHL Data, and a listing of presentations at professional meetings based upon the CHL Data. In the case of publications, specifically, the copy will be sent concurrently with submission of the manuscript. Publications are considered to be any work that is made available to the public in a distributed fashion, including but not limited to journal articles, book chapters, and articles distributed through a Web site.
- b. The Investigator will acknowledge CHL in any publication or presentation based wholly or in part on the CHL Data. The following acknowledgement should be used:

This document includes data from the Children's Healthy Living Program for remote Underserved Minority Populations in the Pacific Region (CHL). CHL is a project funded by the Agricultural and Food Research Initiative Grant no. 2011-68001-30335 from the USDA National Institutional of Food and Agricultural Science Enhancement Coordinated Agricultural Program. The information and opinions expressed herein reflect solely the position of the author(s). Nothing herein should be construed to indicate the support or endorsement of its content by USDA or by CHL.

- c. When returning the dataset, the author will share SAS/or any other statistical package commands used for the analyses and calculations of new variables created so that we can be cognizant and consistent with the use of variables, which will be added to the Data Dictionary. Description of newly derived variables should be included.

VII. DESTRUCTION OF DATA UPON COMPLETION OF RESEARCH PROJECT

The Investigator will certify to CHL that all originals and copies of the restricted data, on whatever media, will be destroyed 1 year after the completion of the research project (eg. Publication of manuscript) or within 5 days of written request

from CHL.

VIII. LIABILITY

The receiving Investigator agrees that CHL and the University of Hawaii are not responsible or liable for the Receiving Investigator's acts, errors, or omissions.

IX. VIOLATION OF THIS AGREEMENT

If CHL determines that the Agreement may have been violated, CHL will inform the Investigator of the allegations in writing and will provide an opportunity to respond in writing within 10 days. CHL may also, at that time, require immediate return or destruction of all copies of the Data in possession of the Investigator. If CHL determines that any aspect of this Agreement has been violated, the Investigator will be subject to Revocation of the existing agreement and denial of access to CHL data.

Fill out the form below **or** complete and e-sign the online form with request submission at <http://www.chl-pacific.org/chl-data-request-form>

I certify that I have read the CHL Data Use Guidelines and agree to all the terms specified. I certify that all materials submitted with this request for the data are truthful.

Investigator

Signature: _____ Date: _____

Typed name: _____

Title: _____

Institution: _____

Building/Room Number: _____

Street address: _____

City/State/Zip: _____

Telephone: _____

E-mail: _____