SCRRDOH to Address Disparities in Head and Neck Cancer Data Use Policy Overview

The SCRRDOH has as its main goal the elimination of health disparities in early detection, prevention, and survival of head and neck cancer among underserved populations. This document provides an overview of the data use procedures for UFL SCRRDOH.

The objectives of the data use policy are to:
1. Maintain an archive of all raw data associated with SCRRDOH projects and ensure datasets conform to privacy and confidentiality standards.
2. Confirm use adheres to IRB approval (include IRB protocol #).
3. Maximize productive data use so findings receive the widest possible dissemination among appropriate communities in a timely fashion.
4. Involve broad participation of current students, staff, postdoctoral fellows, and faculty in research analysis and writing.
5. Centralize oversight of official SCRRDOH databases to ensure:
   a. investigators know of ongoing research efforts and data-use problems;
   b. duplicating analyses are avoided;
   c. study data integrity is maintained;
   d. SCRRDOH staff has knowledge about all publication or presentation of SCRRDOH data.

Sharing data and encouraging additional or secondary analyses above those initially planned for individual studies enhances the scholarly, public health, and policy impact of SCRRDOH-associated work as well as potentially incorporating into the Center’s repertoire additional approaches, issues, and researchers. Preference will be given to proposals submitted by Center participants.

Procedures for submitting requests to use SCRRDOH data

Submit a brief abstract (outline included below)

1. Abstract will be reviewed to assess appropriateness and non-overlap of work already in progress
2. If the abstract fits criteria below for SCRRDOH’s goals and plans, the user will be asked to complete an application to use the data

General criteria for review and acceptance of an abstract include, but are not restricted to:

1. Scientific appropriateness and lack of overlap with previous or planned work
   a. Scientific worthiness
   b. Overlap with ongoing research
   c. Conflict with prior analyses
2. Resource availability
   a. Extent and nature of collaboration with the project’s research staff
   b. Burden on existing SCRRDOH staff
3. Agreements
   a. Analyses will follow analysis plan and timeline.
   b. Deviations from analysis plan or timeline must be approved by SCRRDOH staff.

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1 This is a modification of a data use policy of the National Latino and Asian American Study (NLAAS) and the Program on Black Americans and the National Survey of American Lives (NSAL), University of Michigan. We thank David Takeuchi, Lisa Colpe, James Jackson and Myriam Torres for permission to modify this document for our purposes. We wish to thank Jane Weintraub for allowing us to modify the data use agreement and policy statement as described above from the UCSF CAN DO Center to reduce disparities in oral health in children. June 23, 2010.
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ABSTRACT/PROSPECTUS OUTLINE
SCRRDOH DATASET ANALYSES

Date: ______________
Request Number (ASSIGNED BY SCRRDOH staff) ____________

IRB protocol # (COMPLETED BY SCRRDOH staff) ____________________________

SCRRDOH Project Number, Title and PI, from which data is requested (if known):

Working Title:

Primary Author/Analyst and contact information:

I. Statement of the problem:
   1. What are the major issues, relevant theory, and concepts?
   2. What is the primary scientific relevance, significance, or motivation for analysis?
   3. What are the specific research objectives, questions, hypotheses, etc?

II. Analysis Plan and Timeline:
   1. What are the specific groups (subgroups) of focus (e.g. adult rural African American men)?
   2. What are the SCRRDOH main project and the dataset(s) to be used?
   3. What is the Timeline for the major tasks?

III. Dissemination Plan:

What are the plans for dissemination? (e.g., journal publication, book chapter, conference presentation, dissertation, master’s thesis, and/or grant proposal)

Note: Do not write a proposal for analyses of these data. All new or subsequent/continuation proposals using SCRRDOH data must first be approved by SCRRDOH.

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UFL SCRRDOH Data Use Confidentiality & Honor Statement

I have read the UFL SCRRDOH Data Use Policy and pledge to strictly comply with that policy. If given access and permission to use UFL SCRRDOH data:

- I will not disseminate, download, make or keep copies of the original or altered dataset in any form (including unrestricted public use or any other unrestricted uses.)
- I will at all times maintain physical and electronic security and maintain confidentiality of all SCRRDOH data entrusted to me.
- I will notify the SCRRDOH staff if I conduct additional analyses other than those proposed in this request.
- I will acknowledge that the original collector of the data and the relevant funding agency bears no responsibility for my use of the data or for interpretations or inferences based upon such uses.
- I will forward to the SCRRDOH staff all documentation of new variables of major study constructs (e.g., combination of more than 2 variables, complex logic statement, or factor analyses) that I create accompanied by the relevant syntax.
- On request by SCRRDOH, I will make available for Executive members to review, any and all documents and accounts of steps in the analytic processes and conduct of analyses (including names and contacts of people who had access to or worked on the data). This information will be kept and be available for a period of at least 24 months after the written approval period expires.
- Just as I expect to receive from SCRRDOH support, encouragement, respect and honest, open, collegial and fair practices, so will I provide SCRRDOH with these same courtesies, for our mutual benefit.

I agree with this pledge and the policy as a condition of collaboration and association with SCRRDOH.

Your Name (type or print): ________________________
Your Signature: _______________________
Date: __________________________

Your contact information (Institution/Department/address/telephone/email)
________________________________________________________
________________________________________________________
________________________________________________________
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SCRRDOH USE ONLY
SCRRDOH Project Number, Title and PI, from which data are requested:

Current CHR Approval # relevant to this request: _____________ Exp date _____________
SCRRDOH Reviewers: ______________________

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