

Policy for the Release of Data Collected through the National Profile of Local Health Departments and Forces of Change Studies

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Purpose

This document serves as a policy to respond to requests for data from the National Profile of Local Health Departments (Profile) and Forces of Change studies, and to govern all other uses of the study data.

Background

NACCHO has completed nine Profile studies to date: in 1989, 1993, 1996, 2005, 2008, 2010, 2013, 2016 and 2019. NACCHO has completed four Forces of Change surveys: 2014, 2015, 2017 and 2018. The Centers for Disease Control and Prevention (CDC) sponsored each of these studies, and the Robert Wood Johnson Foundation (RWJF) co-sponsored the 2008, 2010, 2013, 2016 and 2019 Profile studies and the 2014, 2015, 2017 and 2018 Forces of Change surveys.

Participants in the 1989 Profile study were informed that individually identified data would not be distributed outside of NACCHO. For all subsequent studies, local health departments (LHDs) were informed that individually identified data would be shared under the provisions of a data use agreement. A small number of fields may be made publicly available, while the rest of the data must be obtained by executing a data use agreement (detailed in section II below) with NACCHO.

The grant provided by RWJF to support the 2008, 2010, 2013, 2016 and 2019 Profile studies and the 2014, 2015, 2017 and 2018 Forces of Change surveys required that the data collected be made available to researchers at no charge through the Inter-university Consortium on Political and Social Research (ICPSR), housed at the Institute for Social Research, University of Michigan.

Goals

NACCHO recognizes the importance of disseminating public health information to policy makers, researchers, and practitioners effectively. Goals of the data use policy are threefold:

- To facilitate public health systems and services research and to contribute to the evidence-base for practice and policy by maximizing the availability of Profile and Forces of Change data to public health practitioners, researchers, and policy-makers.
- To document the nature of research supported by the Profile and Forces of Change surveys and to demonstrate the studies' value by tracking use of the Profile and Forces of Change data by researchers and publications resulting from their research.
- To assure that the confidentiality of respondents is respected.

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I. Basic Information about LHDs

NACCHO may provide basic information about LHDs in a database that is publicly available. NACCHO hopes that making this basic data available to all researchers will prevent them from requesting the same information from LHDs in their own survey research.

The data elements to be included in this resource are: LHD name, city, and state and Type of jurisdiction (city, county, district, etc.) Population estimate (and year) Expenditures and revenues (and year) (Profile only) Presence of local board of health (Profile only) Number of FTEs (Profile Only) Services provided by LHD Geographic identifier (such as zip code or FIPS code)

II. Other Information about LHDs

In addition to the basic information about LHDs listed above, the Profile and Forces of Change studies collect information about governance, funding, partnerships, performance improvement, workforce, and information technology. The Profile and Forces of Change data are available to researchers, public health practitioners, and other individuals at no charge through ICPSR, using the following process:

- a. Requests for access to any Profile or Forces of Change data (identified or de-identified) require completion of a request form, identifying who requests the data, what the study is about, what questions are being investigated, and how the resulting findings will be published or disseminated. Copies of these request forms are provided to NACCHO.
- b. Requests for access to any Profile or Forces of Change data (identified or de-identified) require adherence to a data use agreement, which includes the following stipulations:
 1. Data will be used for statistical analysis and reporting of aggregated information, and not for investigation of specific LHDs, except when identification is authorized in writing by the LHD.
 2. Data will not be redistributed to others without written agreement by ICPSR. Any publication using the data must acknowledge NACCHO and the Profile and/or Forces of Change study funders, CDC and RWJF.
 3. Requests for identified data are subject to additional requirements under ICPSR's restricted data use agreement. These provisions are available at <http://www.icpsr.umich.edu/icpsrweb/content/ICPSR/access/restricted/index.html>.

Data from previous Profile (1989, 1992-3, 1996-7, 2005, 2008, 2010, 2013, 2016 and 2019) and Forces of Change (2014, 2015, 2017, and 2018) surveys will be made available to researchers, public health practitioners, and other individuals at a nominal charge (\$200 per dataset for Profile, \$100 per dataset for Forces of Change) through NACCHO, using the following process:

- a. Requests for access to Profile or Forces of Change data must be received by NACCHO in writing. The request must identify who requests the data, the purpose of the study, a description of research questions and/or hypotheses. Additionally, requests must describe

how the study advances the goal of strengthening the public's health, whether and why identifiers are needed, when the information will be used, and how the resulting findings will be published or disseminated. Requests may be made using the Data Request Form available on NACCHO's website.

- b. Requests will be considered by NACCHO's Senior Director for Research and Evaluation, in consultation with the NACCHO staff designee. In order to be approved, any request for use of these data must be in the interest of the public's health. If the purpose of the study is unclear, further information will be requested.
- c. NACCHO may choose to waive the fee for obtaining data for researchers without funds to purchase the data and where the proposed research benefits LHDs.
- d. If identifiers are to be released, some requests for data may be met without releasing the entire dataset, e.g., only those data fields that are pertinent to the request will be released.
- e. If inquiries are made concerning information for a particular health department or departments, the requestor must obtain authorization from the appropriate local health officials(s) and provide an original copy of that authorization to NACCHO in order for NACCHO to release the information.
- f. The requesting party must agree to and abide by the Profile and Forces of Change Data Use Agreement, which includes the following provisions:
 1. The National Profile of Local Health Departments and/or Forces of Change survey, NACCHO, LHDs and the study sponsors will be acknowledged in the publication of the results using language provided by NACCHO.
 2. The data will be used for the specified purpose only. Researchers wishing to use the data already obtained for any additional specific study must submit separate permissions requests for the additional study.
 3. No portion of the data will be released to another party.
 4. NACCHO will be provided with an electronic copy of any publication that uses the Profile data.
 5. If planned analysis, reports, or publications include the possibility that identifiable data on individual LHDs will be disclosed, authorization from the appropriate health officials must be obtained *in advance of release of the data to the researcher* and an original copy of the authorization must be provided to *NACCHO in advance of the release of the data*.
 6. Data files will be deleted upon conclusion of the research.