



Assessing the Impact of Proposition 54 on Health Care Policy Research: Preliminary Findings

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A broad array of publicly funded health programs, ranging from prenatal genetic screening and birth-defects monitoring to services for AIDS and Alzheimer patients and prevention of occupational injuries, seek to protect Californians' health. Associated data-gathering activities enable evaluations of their effectiveness in serving the state's diverse population. Improving the effectiveness of these programs is important, as health policy experts agree that racial and ethnic minorities have less access to care and poorer health status, and that overcoming these health disparities is necessary for improving health for all.

Proposition 54, the ballot initiative officially titled Classification by Race, Ethnicity, Color, and National Origin, would amend the state constitution to prohibit state, county, and local authorities (including public schools and universities) from collecting and using data with regard to race, ethnicity, national origin, or color (RENOC). A few exemptions are written into the measure, notably for data gathered from "medical research subjects and patients" or those needed to "comply with federal law, or establish or maintain eligibility for federal programs, where ineligibility would result in a loss of federal funds to the state."

In this paper we report the preliminary results of our study to explore (1) the initiative's implications for the collection, maintenance, and use of "health-related datasets" by state and county agencies as well as researchers at public universities, and (2) its possible consequences for California's health programs and policies. We find that virtually all state and county datasets include information on one or more of the RENOC variables, and that many of the purposes of these datasets could not be met adequately if these variables were excluded. Only a few of the datasets are likely to qualify for the initiative's exemptions.

Research Methods

We surveyed key informants in four health-related state agencies and in the health departments of five representative counties (Los Angeles, Riverside, San Francisco, Solano, and Stanislaus) to generate an inventory of health-related datasets collected or maintained by the state and the sample counties. We identified 69 unique datasets collected or maintained by the state, and 40 unique datasets by the sample counties. We also asked 970 health policy researchers in California to answer a web-based survey about their collection and uses of health-related data. We received responses from 224 researchers, of whom 173 had used at least one California health-related dataset in the past five years; the majority of them (124) work in the University of California or California State University systems and collected health-related data during those five years.

The respondents were asked about their regular uses of the datasets, whether RENOC variables

were included, the particular uses of these variables, whether and how a prohibition on their collection and use might affect the utility of the datasets, and whether other variables in these or other datasets could serve the same purposes as the RENOC variables.

Findings

- ▶ ***The vast majority of state and county datasets include some information about race, ethnicity, national origin, or color.***

Of the 69 state datasets identified, 67 include one or more RENOC variables; among the 40 county datasets identified, 36 include at least one RENOC variable. Among the datasets with RENOC variables, all collect data on race and ethnicity data, and one-third collect data on national origin. The state datasets are used most frequently for reports (87%), program development and administration (70%), program evaluation (57%), monitoring and targeting special populations (55%), epidemiological surveillance (25%), and research (25%). The county datasets are used most frequently for reports (82%), monitoring and targeting special populations (80%), program development and administration (68%), program evaluation (48%), research (32%), and epidemiological surveillance (28%).

- ▶ ***Our research suggests that the Proposition 54 exemptions relating to federal mandates and funding or to medical research subjects and patients would not apply to many of these datasets, unless those exemptions are interpreted very broadly by the courts. Moreover, even if all health-related datasets were exempted, their value would be limited by the proposition because public-sector researchers could not combine health-related data with information from non-health-related population data in order to calculate group-specific rates of health problems.***

The initiative exempts data that include the “otherwise lawful classification of medical research subjects and patients.” None of the state or county datasets identified in our study use data from medical research subjects, although some do describe patients. Advocates for Proposition 54 claim that this exemption would apply to *any* RENOC data used for health-related purposes, in which case all the datasets we reviewed in this report would presumably be exempted.

Even under this generous interpretation, however, there would be a significant impact on the use of these data in public-health research because non-health-related datasets could not include RENOC data. So, for example, if an exempted health-related dataset revealed the number of specific cases of cancer diagnosed in a particular racial, ethnic, or other group by national origin, researchers working for the state could not calculate associated cancer *rates* without also knowing the composition of the relevant population. Relevant populations could be defined as the population of the entire state, or as a specific group such as “agricultural workers,” “women with no children,” or “residents near power plants.” The state presumably would be prohibited from gathering data on the ethnicities of these subgroups and so could not generate RENOC-specific epidemiological knowledge.

Also exempt from the initiative is any “action which must be taken to comply with federal law, or establish or maintain eligibility for any federal program, where ineligibility would result in a loss of federal funds to the state.” Some of the datasets might qualify for this exemption because the data are reported to the federal government (see Group A of Table 1). Of this group, a few collect federally *mandated* RENOC variables, while the rest are federally *funded* for data collection that is not mandatory.

- ***The loss of information about race, ethnicity, national origin, and color will have a significant impact on most of the state and county datasets that include this information. Although a large majority of respondents (87 out of 109) thought that the datasets they described would continue to be useful to some degree without RENOC variables, they emphasized that important goals of data collection would suffer.***

The exclusion of RENOC variables would render many datasets virtually useless, would substantially degrade the usefulness of many others, and would have little or no impact on a few. If any of the datasets in the potentially exempt category (Group A in Table 1) do not qualify for exemption and consequently cannot include RENOC variables, they would lose most of their utility for policy, planning, and research.

In addition, four datasets that monitor health among specific racial and ethnic groups (Group B) would no longer exist because the target population could no longer be identified. Another two datasets used in planning and research (Group C) are structured to oversample certain racial or ethnic groups, and could not be reweighted to provide reliable or representative information about the California population as a whole. Among respondents for the 84 remaining datasets, three-fourths (65) said that if RENOC data

Table 1. State and county datasets that would become useless or virtually so under Proposition 54	
Group A (possibly exempt)	<u>State data:</u> AIDS Case Management Program, AIDS Drug Assistance Program, California WIC Program, California Behavioral Risk Factor Survey, Medi-Cal Case Management Information System, Refugee Health Electronic Information System, the Infant Botulism Program, Housing Opportunities for Persons with AIDS. <u>County data:</u> Response and Surveillance System for Childhood Exposures; TB Registry Information Management Information System; Family Planning; HIV/AIDS Case Surveillance; Fetal Infant Mortality Database; WIC (LA); Supplement to HIV/AIDS Surveillance; Adult/Adolescent Spectrum of HIV-Related Diseases; Project 1; Context of HIV Infection; Asian-Pacific Islander Immunization Survey
Group B	Bone Health (targeted at Latinas), American Indian Infant Health Initiative, Black Infant Health, Indian Health Monthly Progress Report
Group C	California Adult Tobacco Survey, California Youth Tobacco Survey
<i>Group A:</i> Might qualify for a RENOC exemption because data are reported to federal government.	
<i>Group B:</i> Datasets would not exist if RENOC variables were prohibited.	
<i>Group C:</i> Datasets would not be usable because RENOC variables are used to make the data representative of California.	

were eliminated, monitoring at-risk populations, program targeting, needs assessment, or epidemiological surveillance would be undermined; nearly half (39) reported that outreach and program planning would suffer; and almost one-third (26) reported that public health or medical research would suffer. (Many respondents reported that their datasets are used for more than one purpose.) Only five reported that the utility of their datasets would not be degraded at all.

- ▶ ***Respondents explained that RENOC variables illuminate the biology and genetics of disease as well as culturally influenced health behaviors, and thus are crucial for the accurate interpretation of other pieces of information.***

Some illustrative comments about particular programs emphasize both aspects of RENOC variables.

—Regarding the Breast and Cervical Cancer Tracking program: *“Should racial/ethnic data no longer be available, [we] may not be able to accurately assess how effectively the BCCT [Breast and Cervical Cancer Treatment] program is serving racial/ethnic populations known to have a high incidence of breast and/or cervical cancer or to assess any new potential trends in terms of ethnicity . . . ”*

—Regarding the WIC program, which provides nutritional supplements to pregnant women, infants, and children: *“[We would not be able to] investigate race/ethnic uses of various foods. The program would be less able to adapt appropriately, including classes on incorporating foods into a diet lacking in those items.”*

—Regarding the Newborn Screening Program: *“[If test results cannot be interpreted in light of known race-specific rates of genetic conditions], it is possible that genetic defects would be missed, resulting in severe consequences, such as a child with a correctable disease suffering mental retardation or physical impairment. Education and outreach would not be linguistically or culturally appropriate with lower rates of detection of disease as a result.”*

Only 10 respondents could identify possible replacements for RENOC variables, such as primary language, economic status, geographic location, or age.

- ▶ ***An overwhelming majority of researchers stated that prohibition of RENOC variables would undermine their work.***

Were Proposition 54 to become law, 93% of the 173 researchers who use California data said their current research would be compromised, and 82% said that federal research funds would be harder to obtain. Nearly three-fourths thought that the ban would change the direction of their future research. Their three most frequent uses of the RENOC variables were in research/publication (95%), reports (52%), and evaluation (45%). Seventy-two of the 124 UC and CSU researchers (58%) reported receiving federal funds for data collection, and an overwhelming majority of them reported that if they could no longer collect RENOC variables, their datasets would no longer be useful. Nearly half of these university-collected data sets were used by state, county, and local governments. If prohibited from collecting RENOC data, it is very likely that these data-collection efforts would no longer be seen as sufficiently useful to warrant receipt of federal funding.

Conclusion

Well-documented racial and ethnic variations in health—specifically, in disease prevalence, health status, health behaviors, and health care utilization—are of particular importance in California because of the state’s remarkable diversity. Health problems that may initially be concentrated in a specific group can have far-reaching consequences for the well-being of the entire population. Therefore, it is no surprise that in the inventory of state and county health-related datasets that we examined, virtually all include one or more RENOC variables and use them in many different ways—for disease surveillance,

program planning and evaluation, prioritizing public health interventions, and designing outreach programs.

Without the RENOC variables, many of these datasets would lose much of their value. Despite the inherent ambiguity of categories of ethnicity and race, these variables carry unique information that cannot be replicated by alternate measures such as poverty status, location of residence, or primary language spoken. The unique contribution of RENOC information is due in part to cultural practices associated with different races, ethnicities, and nationalities, in part to shared biological traits, and in part to a mixture of the two. This study provides strong evidence that prohibiting the collection and use of RENOC information in health-related datasets could undermine programs that protect the health of all Californians, particularly by hampering government's ability to respond to emerging public-health threats and to address health disparities.

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