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Racial and Ethnic Data Collection and Use in Health Care: Examples of Projects that Might Be Affected by Proposition 54

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The California HealthCare Foundation is an independent philanthropy committed to improving California's health care delivery and financing systems. Our mission is to expand access to affordable, quality health care for underserved individuals and communities and to promote fundamental improvements in the health status of the people of California.

Introduction

Proposition 54 will appear before California voters on the ballot on October 7, 2003. The ballot initiative is known formally as "Classification by Race, Ethnicity, Color or National Origin" (CRECNO) and informally as the "Racial Privacy Initiative." This initiative would broadly affect many aspects of state and local government by restricting collection of data or classification of individuals by race or ethnicity. This issue brief focuses specifically on the potential impact of Proposition 54 on *health-related research and projects* that use ethnic and racial data. It does not attempt to address all other areas included in the initiative. The California HealthCare Foundation (CHCF) takes no position on Proposition 54. The purpose of this issue brief is to assist CHCF and others that fund health-related studies and projects, and their grantees, in assessing how various research methods and resources might be affected by passage of Proposition 54. This issue brief provides an overview of current health-related research using ethnic and racial data and examines a sample of specific research activities and projects, the kinds of racial and ethnic data used in these activities, and the impact the initiative might have on the research methodology and resources used.

Overview of Current Health-Related Research Using Ethnic and Racial Data

California's population is 32 percent Latino, 6 percent African American, 11 percent Asian/Pacific Islander, .05 percent Native American, and 47 percent white. The state's research community studies a vast array of health issues and how these issues affect different racial and ethnic groups. For example, some research focuses on health status, or disease prevalence, and examines illnesses such as cancer, cardiovascular disease, diabetes, high blood pressure, asthma, and HIV/AIDS. Other research examines environmental health problems, such as lead poisoning, pollution levels, and location of hazardous waste materials in proximity to minority and low-income neighborhoods.

Still other veins of research look at access to care: describing the uninsured population, evaluating the ability of preventive and educational programs to reach the communities that need them most, and looking at the makeup of the health care workforce to see how closely it matches, or does not match, the state's patient populations.

Research also is done to assess the quality of care received by different ethnic groups and the possible effects of quality differences on population health. These studies include comparisons of differing levels of treatment for particular diseases, the success or failure of particular groups in communicating with health care providers, and the degree of willingness of patients with varying racial and ethnic identities to follow medical advice. These latter aspects go to the field of cultural and linguistic competence, which seeks to determine how well the health care system does at treating people from a variety of backgrounds and experiences.

At the national level, the Agency for Healthcare Research and Quality (AHRQ),[1] the National Institutes of Health (NIH),[2] the Institute of Medicine (IOM),[3] the Centers for Disease Control and Prevention (CDC),[4] and the U.S. Department of Health and Human Services (HHS)[5] have urged explicit emphasis on the study of health care inequities.

In 1999, the U.S. Congress passed the Healthcare Research and Quality Act, thereby directing the Agency for Healthcare Research and Quality to

> . . . conduct and support research and evaluations, and to support demonstration projects, with respect to . . . the delivery of health care in inner-city and in rural areas (including frontier areas) . . . and health care for priority populations, which . . . include low income groups; minority groups; women; children; the elderly; and individuals with special health care needs, including individuals with disabilities and individuals who need chronic care or end-of-life health care.[6]

In 2002, the Institute of Medicine, after reviewing more than 100 studies of the quality of health care for various racial and ethnic groups, concluded the following:

> Minorities are less likely than whites to receive needed services, including clinically necessary procedures. These disparities exist in a number of disease areas, including cancer, cardiovascular disease, HIV/AIDS, diabetes, and mental illness, and are found across a range of procedures, including routine treatments for common health problems.

The IOM report further noted a lack of adequate data to systematically address these problems:

> Standardized data collection is also critically important in efforts to understand and eliminate racial and ethnic disparities in health care. Data on patient and provider race and ethnicity would allow researchers to better disentangle factors that are associated with health care disparities, help health plans to monitor performance, ensure accountability to enrolled members and payers, improve patient choice, allow for evaluation of intervention programs, and help identify discriminatory practices. Unfortunately, standardized data on racial and ethnic differences in care are generally unavailable. . . . The challenges to data collection should be addressed, as the costs of failing to assess racial and ethnic disparities in care may outweigh new burdens imposed by data collection and analysis efforts.[7]

Proposition 54

Slated to appear on the October 7, 2003, ballot as Proposition 54 is the “Classification by Race, Ethnicity, Color, or National Origin” initiative. The details of how it proposes to amend the California Constitution appear in the sidebar.

Prohibition Against Classifying by Race by State and Other Public Entities
Section 32 is added to Article I of the California Constitution as follows:

Sec. 32. **(a)** The state shall not classify any individual by race, ethnicity, color or national origin in the operation of public education, public contracting or public employment.

(b) The state shall not classify any individual by race, ethnicity, color or national origin in the operation of any other state operations, unless the legislature specifically determines that said classification serves a compelling state interest and approves said classification by a 2/3 majority in both houses of the legislature, and said classification is subsequently approved by the governor.

(c) For purposes of this section, “classifying” by race, ethnicity, color or national origin shall be defined as the act of separating, sorting or organizing by race, ethnicity, color or national origin including, but not limited to, inquiring, profiling, or collecting such data on government forms.

(d) For purposes of subsection (a), “individual” refers to current or prospective students, contractors or employees. For purposes of subsection (b), “individual” refers to persons subject to the state operations referred to in subsection (b).

(e) The Department of Fair Employment and Housing (DFEH) shall be exempt from this section with respect to DFEH-conducted classifications in place as of March 5, 2002. (1) Unless specifically extended by the legislature, this exemption shall expire ten years after the effective date of this measure. (2) Notwithstanding DFEH’s exemption from this section, DFEH shall not impute a race, color, ethnicity or national origin to any individual.

(f) Otherwise lawful classification of medical research subjects and patients shall be exempt from this section.

(g) Nothing in this section shall prevent law enforcement officers, while carrying out their law enforcement duties, from describing particular persons in otherwise lawful ways. Neither the governor, the legislature nor any statewide agency shall require law enforcement officers to maintain records that track individuals on the basis of said classifications, nor shall the governor, the legislature or any statewide agency withhold funding to law enforcement agencies on the basis of the failure to maintain such records.

(h) Otherwise lawful assignment of prisoners and undercover law enforcement officers shall be exempt from this section.

(i) Nothing in this section shall be interpreted as prohibiting 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.

(j) Nothing in this section shall be interpreted as invalidating any valid consent decree or court order which is in force as of the effective date of this section.

(k) For the purposes of this section, “state” shall include, but not necessarily be limited to, the state itself, any city, county, city and county, public university system, including the University of California, California State University, community college district, school district, special district, or any other political subdivision or governmental instrumentality of or within the state.

(l) This section shall become effective January 1, 2005.

(m) This section shall be self-executing. If any part or parts of this section are found to be in conflict with federal law or the United States Constitution, the section shall be implemented to the maximum extent that federal law and the United States Constitution permit. Any provision held invalid shall be severable from the remaining portions of this section.

Source: American Civil Rights Coalition, the group that is sponsoring Proposition 54 (www.acrc1.org).

Many medical and health-related activities would almost certainly *not* be affected by the passage of Proposition 54 because activites are not carried out by state personnel or entities and/or the activities meet one of the explicit exemption criteria set forth in the initiative language. Examples of such activities include:

- Research or project work carried out by private universities and nonprofits that does not rely on data collected by state entities;
- Research and project work where all data used meets the "patient record" or "medical research subject" exemption criteria (Section 32[f]);
- Research and project work where all data used meets the exemption criteria for information required to maintain eligibility for federal programs (Section 32[i]).

Examples of Projects that Might Be Affected by Proposition 54

In preparing this issue brief, a wide range of health-related research studies and projects were reviewed and analyzed. The review and examples chosen were meant to be illustrative not exhaustive. There were a number of studies and projects that most likely would not be affected by Proposition 54 because they were assumed to meet the Section 32(f) exemption criteria for "medical research subjects and patients" (hereafter referred to as the "medical research subjects and patients" exemption) or Section 32(i) exemption criteria to "establish or maintain eligibility for any federal program, where ineligibility would result in a loss of federal funds to the state" (hereafter referred to as the "federal program participation" exemption). These projects are not included in the issue brief. For example, several major categories of work, including projects relying solely on Medicaid or SCHIP data or Census Bureau research presumably would meet the "federal" exemption criteria; work conducted by private nonprofit institutions, such as Children's Hospital Oakland, would not fall under Proposition 54, as the data in question is not collected by a state agency or entity.

Because the initiative language is brief, several exemption categories have not been defined in sufficient detail to definitively determine at this time whether certain activities and data sources would be interpreted as exempt. It is unclear, for instance, how broadly the category "medical research subjects and patients" might be interpreted, particularly in the area of public health data collection and surveying. It is also unclear whether data collected lawfully under the "medical research subjects and patients" exemption or "federal program participation" exemption could then be legally sorted or analyzed for other research or project use by "state" officials (including researchers in public universities).

The examples below are intended to highlight research and projects within the broad area of health care and public health that might be affected by Proposition 54 because the manner in which the data is collected and used does not clearly or definitively meet the initiative's exemption criteria. The examples cited include programs at the state, county, and local levels and across the academic, clinical, and community health domains because of the definition of "state" in Section 32(k) of the initiative:

> . . . "state" shall include, but not necessarily be limited to, the state itself, any city, county, city and county, public university system, including the University of California, California State University, community college district, school district, special district, or any other political subdivision or governmental instrumentality of or within the state.

State Projects

California Cancer Registry

The project. Administered by the Department of Health Services, the California Cancer Registry is a statewide program that tracks the frequency, severity, and types of cancers that afflict California residents of all racial and ethnic groups.

Data sources and uses. Some of the data used by the California Cancer Registry is supplied by patients' doctors and hospitals, which are required by the state to report the race and ethnicity of their patients, as well as other information. To determine the cancer rate among groups—or the total number of people in an ethnic group, both with and without cancer—the registry relies on data collected by the demographic research unit of the California Department of Finance. To develop these numbers, the Department of Finance uses sources as wide ranging as school enrollment records and birth and death certificates.

The California Cancer Registry also collects its own information on behavior and risk factors for certain cancers—such as those caused by tobacco use—through random telephone surveys of Californians, both healthy and sick, which include questions about diet, exercise, screening habits, and racial and ethnic identity.

The data from the Department of Finance is used to calculate the denominator when determining the rate of particular cancers among various ethnic groups.

Findings. The reports from the California Cancer Registry point out stark differences in disease rates by groups. Different racial and ethnic groups have a higher prevalence of different cancers. For example, white women are far more likely to get breast cancer than other women; African American men are top candidates for prostate cancer; Latina women suffer the highest rate of invasive cervical cancer; and individuals who are Asian/Pacific Islander contract much more stomach and liver cancer.

Potential impact on data sources and uses. The doctor, hospital, and laboratory records used for the California Cancer Registry data are presumed to be exempt under the "medical research subjects and patients" exemption. That is, the registry will still be able to include racial and ethnic classifications under the exemption that allows racial classification of "medical research subjects" or "patients." The Department of Health Services should be able to sort and analyze the data received from doctors and hospitals by race or ethnicity under the same exemption. The patient records exemption would only apply, however, if the measure were interpreted to allow state agencies to analyze any lawfully collected data; whether Proposition 54 would be interpreted to allow such secondary use is unclear. Similarly, the "medical research subjects and patient" exemption would only apply if the cancer patients in the registry records were included in the definition of "medical research subjects" on the grounds that the registry was in fact conducting medical research about the incidence of disease; it is unclear as to whether Proposition 54 will be interpreted in this manner.

The population estimates developed by the California Department of Finance appear likely to be affected by the measure. Some of the underlying data used by the department—like racial/ethnic information on school records or birth and death records—might not be available if the measure passes. To the extent that population data is available from other sources (federal sources, private sources, or state sources falling under one of the measure's exceptions) it is unclear whether the state agency would be allowed to perform any secondary analysis on that data on the basis of race. This might depend on whether the secondary use of population estimates is treated as classifying an *individual* on the basis of race. If the department can compile population estimates without classifying individuals, it might be able to develop these estimates without violating the measure. If not, the activity would presumably not be allowed if Proposition 54 passes, as none of the current exemptions appears to apply to this activity.

References. http://www.ccrcal.org; http://www.dof.ca.gov

County Projects

Los Angeles County Health Survey—Los Angeles County

The project. The Los Angeles County Health Survey, conducted by the county Department of Health Services—Public Health, annually surveys residents about a wide range of health issues.

Data sources and uses. The most recent random telephone survey interviewed 8,300 adults and 6,000 parents of children under the age of 17. Questions range from access to care, insurance status, use of health care, and preventive services and disease management techniques to health behaviors such as smoking, exercise, and drinking habits. Respondents are asked their income, education level, and racial/ethnic identity. The information is used to guide the county's health policy priorities and to correct and enhance outreach and education efforts about such varied topics as Sudden Infant Death Syndrome (SIDS), breast-feeding, and chemical dependency.

Findings. The 1999–2000 survey revealed that African Americans in Los Angeles are three times more likely than the overall population to place infants on their stomachs to sleep. This finding demonstrated that the "Back to Sleep" campaign—a Sudden Infant Death Syndrome prevention effort that encourages the practice of putting infants to sleep on their backs—was not reaching the African American community effectively. Higher death rates among African American babies from SIDS were also reflected in county data.

In Los Angeles, the survey found that Latinas are the most likely to breast-feed their babies, and white mothers are second most likely; African American mothers are the least likely to do so. Across the board, wealthier mothers were more likely to breast-feed, as were mothers who are recent immigrants. The data were made available to organizations that promote breast-feeding and health care providers who treat pregnant women and babies, to help them to target specific populations for education and outreach.

Potential impact on data sources and uses. This project relies on a random telephone survey of Los Angeles County residents, conducted for a county agency. It is unlikely that the survey or subsequent use of the data in project development would meet the initiative's exemption criteria for a number of reasons. The survey is conducted by a county, and would therefore be included under the "state" definition in Section 32(k). The survey subjects, selected at random and questioned on a broad range of demographic, health and lifestyle issues—would most likely not meet the criteria for "medical research subjects and patients," and data is not drawn from official doctor, hospital, or patient records. Finally, many of the public health interventions carried out using the information gathered in the survey rely on the data being sorted and classified by race and ethnicity. Unless the county could show that the data was necessary to "maintain eligibility for federal programs" (the federal program participation exemption), it is likely that the collection and use of this data would not be allowed, as no other exemptions appear to apply.

Reference. http://www.lapublichealth.org/ha/haprog.htm

Local Projects

African Americans Building a Legacy of Health, A Project of Community Health Councils, Inc.—Los Angeles

The project. This local program is part of the REACH (Racial and Ethnic Approaches to Community Health) 2010 Initiative, which is a national demonstration project of the Centers for Disease Control and Prevention. It focuses on three specific communities in southern California—South Los Angeles, northern Long Beach, and eastern Inglewood—and targets more than 500,000 African Americans who live in these areas. The project seeks to address their disproportionate incidences of cardiovascular disease and diabetes through education, prevention, and policy efforts. The hands-on project provides direct education about these health conditions and promotes changes within the community—such as bringing in farmers markets and asking grocery stores to stock milk with just 1 percent fat—that would make it easier for people to apply the prevention advice they receive.

Data sources and uses. Data was supplied by the Los Angeles County Department of Health Services—Public Health and the California Department of Health Services (DHS) programs on diabetes control and prevention and heart disease and stroke prevention. The data was used to determine the need for the project and to choose the communities to work with. Ultimately, the data will be used to measure the anticipated improvements.

Findings. The data show that, in Los Angeles County, the death rate among African Americans' due to heart disease is 78 percent higher than that of the overall population. Los Angeles County's Health Survey reports that African Americans also suffer from obesity, heart disease, and diabetes at a higher rate than other groups.

Potential impact on data sources and uses. Two of the data sources used in this study are presumed exempt; one is not. Data collected from the Los Angeles County Department of Health Services—Public Health is presumed exempt under the "federal program participation" exemption (Section 32[i]). Data from the California Department of Health Services Diabetes Control and Heart Disease and Stroke Prevention Programs is presumed exempt under either or both of the "medical research subjects and patients" or the "federal program participation" exemptions. It is therefore assumed that these activities would be allowed to continue if Proposition 54 passes.

As outlined in the previous example, however, data from the Los Angeles County Health Survey is not presumed to meet any of the initiative's exemptions. If researchers were unable to continue to use the Los Angeles County Health Survey data in this program, they would have to develop another way to target communities for outreach and to track improvements or changes over time.

References. http://www.chc-inc.org/REACH2010; http://www.lapublichealth.org/ha/haprog.htm

Union of Pan Asian Communities (UPAC), Asian/Pacific Islander Teen Suicide Prevention Program—San Diego

The project. This local program provides individual and group counseling to suicidal teenagers in San Diego's Asian/Pacific Islander communities. Since 1995, UPAC's Teen Suicide Prevention Program has been going into high schools, colleges, and community organizations to give presentations about suicide prevention—and presenters often leave with the names of teens that need help.

Data sources and uses. Data come from the San Diego Unified School District's Youth Behavior Risk Survey, which questions public school students about a variety of health-related experiences and identifies respondents by race and ethnicity. Data are used to identify groups of adolescents with suicidal thoughts or tendencies and to develop outreach and counseling programs to assist them and their families.

Findings. Since 1990, teenage Filipina girls have emerged as the group with the highest rate of suicide ideation among all students. Other students of Asian or Pacific Island heritage also reported having more suicidal thoughts and desires than children from other ethnic groups. The survey, conducted every two years, continues to show this pattern. Girls report that family pressure is the number one cause of their suicidal thoughts, while boys report that problems with romantic relationships bother them the most.

The program has been able to identify that the difference in expectations between parents' traditional beliefs and children's experiences as recent immigrants to the United States often create crises around these issues. For Asian/Pacific Islander teens, the warning signs include overachieving and habitual quietness—behaviors that might not indicate problems in children from other cultures. Since its inception, the UPAC program has treated several hundred teens each year, and to date no one in the program has attempted suicide.

Potential impact on data sources and uses. The San Diego Unified School District's Youth Behavior Risk Survey is not presumed exempt under the "medical research subjects and patients" or "federal program participation" exemptions. The survey, which asks a broad range of demographic, health and lifestyle questions of high school students, is unlikely to be interpreted as a "medical research" survey, nor its participants as "medical research subjects." Nor are doctor, hospital, or other "patient" records used in this project. The school district would be considered a "state" entity under the initiative's definition, and would be prohibited from collecting, sorting, and classifying data on race and ethnicity. Therefore if the initiative were to pass, it would be very likely that the District's ability to collect and work with this data would be affected.

References. http://www.upacsd.com; http://www.sandi.net

Academic Projects

California Health Interview Survey

The project. Researchers at the University of California, Los Angeles conduct the largest statewide health survey in the country to assist the state legislature in allocating resources for improving health care through such things as outreach for public programs or educational efforts focused on prevention and screenings.

Data sources and uses. The California Health Interview Survey (CHIS), released for the first time in 2002, collects data from more than 55,000 randomly selected Californians and asks them about everything from tobacco use to what they eat, how much they drink, how much they earn, if they read to their children, whether there is violence in their home, if they have health insurance, if they get cancer screenings, or if they are chronically ill or disabled.

The survey is conducted over the phone in English, Spanish, Mandarin, Cantonese, Korean, Vietnamese, and Cambodian. Respondents are asked nine questions on race and ethnicity out of 288 total questions. CHIS informs the California health policy community what is happening and to whom, with regard to health care issues. It also serves as an information source for the state legislature for budgeting and policy purposes.

Findings. According to survey results, the vast majority of White women get pap smear screenings for cervical cancer, but a large proportion of non-English-speaking Asian women do not. The findings raise issues about the need for more effective outreach to the Asian community.

The survey also measures the gap between eligibility and enrollment in public health care programs such as Medi-Cal and Healthy Families. Understanding who makes use of these public programs among those who qualify, or if there is a lack of participation along racial or ethnic lines, informs the state legislature as its members decide whether and how to continue outreach efforts, specific communities to target for attention, and where to spend money.

Potential impact on data sources and uses. The survey of more than 55,000 randomly selected Californians is carried out by a "state" agency as defined in the initiative, and does not appear to meet the initiative's "medical research subjects and patients" or "federal program participation" exemptions. The survey does not rely on doctor, hospital or other "patient" records and it is unlikely that the randomly selected participants would be interpreted to be "medical research subjects," as the data collection entity—the University of California—is not conducting a specific medical or disease-related study. It is therefore assumed that the UC researchers' ability to continue this study would likely be affected if the initiative were to pass.

References. http://www.healthpolicy.ucla.edu; http://www.chis.ucla.edu

Physicians Study

The project. The "Physicians Study" on participation in Medi-Cal is a mail survey of California physicians conducted by researchers at the University of California, San Francisco (UCSF) Center for California Health Workforce Studies.

Data sources and uses. Over the last decade, the composition of health care providers has been more heavily scrutinized, as policymakers examine efforts to better distribute doctors into underserved areas and to provide linguistically and culturally competent care to California's diverse population. Researchers at the UCSF Center for California Health Workforce Studies examine this issue every few years with a mail survey of California physicians that requests information about physicians' practices, their participation in managed care or doctors' groups, the kinds of patients they treat, the languages they speak, and their race and ethnic identity. The results of the surveys are intended to help the medical community assess whether the physician workforce is responsive to the needs of the California public and assist policymakers and medical educators in deciding about the use of incentives to diversify the workforce, such as loan repayment programs or other recruitment vehicles.

Findings. More than 30 percent of the California residents are Latino and many speak only Spanish. Can doctors handle this patient load? Are Latino doctors the only physicians who speak Spanish? The UCSF surveys are intended to make these distinctions clear. Other key findings of the work show that African American and Latino physicians are more likely than White physicians to work in underserved areas, such as inner cities. From a policy standpoint this means that, as long as minorities are underrepresented in the health care workforce, minority populations will continue to be underserved in their communities. Similarly, African American doctors are more likely to serve Medi-Cal patients, while Latino doctors are more likely to care for the uninsured, which implies that poor people have better access to care when there are more practicing minority doctors. The findings provide policymakers and medical educators with data to help them determine the need for incentives to diversify the workforce.

Potential impact on data sources and uses. The UCSF mail survey of California physicians are carried out by a "state" agency as defined in the initiative, and do not appear to meet the initiative's "medical research subjects and patients" or "federal program participation" exemptions. The survey does not rely on doctor, hospital, or other "patient" records and physicians being asked demographic questions would likely not be interpreted to be "medical research subjects." The information collected in this survey is not used to establish or maintain eligibility for a federal program. It is therefore assumed that the UC researchers' ability to continue this study would likely be affected if the initiative were to pass.

Reference. http://futurehealth.ucsf.edu

The Interpersonal Processes of Care Survey

The project. The Interpersonal Processes of Care Survey is a phone poll conducted by UCSF researchers of 1,600 San Francisco patients with chronic illnesses, such as diabetes and high blood pressure. The effort seeks to improve the quality of care delivered to chronic disease patients by developing interventions appropriate to patients from a variety of racial, ethnic, and language backgrounds.

Data sources and uses. A group of researchers at UCSF developed and conducted the 2001 Interpersonal Processes of Care Survey. The questions included: What happens when chronically ill patients go the doctor? How is their illness discussed—their options for managing it, their patterns of medication? Do they feel listened to? Do they understand what they are told? Does their improved or declining health reflect their exam-room experiences? Does it matter whether they're White or African American, English- or Spanish-speaking? Some 1,600 patients with chronic illnesses were surveyed by phone in the first phase of the survey. The adult respondents had all been seen at one of eight outpatient settings in San Francisco, and those clinics provided the researchers with the patients' names, addresses, phone numbers, date of last appointment, and racial and ethnic identity.

Phase two of the research, which is currently underway, includes an effort to match each individual's answers with his or her clinical data to see if there is a relationship between better doctor-patient rapport and better health, or the converse. Further, researchers plan to show which particular groups of patients have trouble or success communicating with their physicians and how that is reflected in their health status.

Findings. The results of this research will be used to develop methods to improve quality of care for the chronically ill in each racial and ethnic category. The experience of researchers has been that the race and ethnic information recorded at the clinic is typically wrong about half the time and it is necessary to have telephone interviewers ask the question again, to learn how patients identify themselves, rather than the category to which they were assigned by clinic staff. The researchers expect to find differences of experience and of health status based on racial, ethnic, and language groups.

Potential impact on data sources and uses. Patient records from San Francisco clinics are presumed to be exempt under the "medical research subjects and patients" exemption. However, it is unclear whether the phone surveys of chronic disease patients that are drawn from those records would meet exemption criteria. This project raises the question of whether "secondary" classification, sorting, or other use of lawfully obtained data would be interpreted to be legal under the provisions of the initiative if it were to pass. It is unclear whether the measure would be interpreted such that data collected lawfully under one of the exemption criteria, for a specific use (e.g. data about a medical research subject, for use in a particular medical research study, or data necessary to maintain eligibility for a federal program, for the purposes of establishing or maintaining eligibility for that program) could be lawfully sorted or classified for any other purpose, by any other individual, organization or entity.

Reference. Anna Napoles-Springer, Ph.D., Assistant Professor, UCSF Division of General and Internal Medicine, Department of Medicine.

National Projects

Agency for Healthcare Research and Quality

The project. The Agency for Healthcare Research and Quality (AHRQ) is the leading federal funder of health services research. In 2001, California researchers were awarded $25.9 million from the agency, which represents 10 percent of all contracts and 12 percent of all grants distributed nationwide for that year. Public universities such as the University of California at San Francisco, Los Angeles, Davis, and San Diego were among key recipients of these funds.

Data sources and uses. One of the top priorities for AHRQ research is the study of disparities in health care delivery to racial and ethnic groups.[8] To compete for this money, California researchers must describe the population they will study and effectively demonstrate the need for the proposed work.

Potential impact on data sources and uses. Collecting data on race and ethnicity is not an explicit requirement to apply for AHRQ funds, but without the ability to do that, AHRQ officials say that California researchers would be handicapped when competing with those in other states who have free reign to collect and use such data. The potential impact of Proposition 54 on researchers competing for AHRQ funds depends on several factors.

The definition of "state" in the initiative includes many California research institutions: Under Section 32(k) " 'state' shall include, but not necessarily be limited to, the state itself, any city, county, city and county, public university system, including the University of California, California State University, community college district, school district, special district, or any other political subdivision or governmental instrumentality of or within the state." Therefore, it is assumed that these institutions would be prohibited from gathering, sorting, or classifying information and data that does not otherwise meet the initiative's exemption criteria.

If the initiative were to pass, to lawfully collect data on public health issues, researchers would presumably have to show that the information being collected met one or more of the initiative's exemptions, that is, that it could reasonably be classified as "medical research" or represent an analysis of "patient records," or be necessary to "establish or maintain eligibility for any federal program, where ineligibility would result in a loss of federal funds to the state." While many research projects would meet these criteria, many would not, and many others would be subject to interpretation of whether the collection and use of the data meets or fails to meet one of the initiative's exemption criteria.

This project also raises the issue of the interpretation of "secondary" use of data, i.e. whether information collected lawfully under one of the exemption criteria, for a specific use (e.g. data about a medical research subject, for use in a particular medical research study, or data necessary to maintain eligibility for a federal program, for the purposes of establishing or maintaining eligibility for that program) could subsequently be sorted or classified for any other purpose, by any other individual, organization or entity without violating the initiative's provisions.

Reference. www.ahrq.org

Summary

This issue brief is intended to assist CHCF and others that fund health-related studies and projects, and their grantees, in assessing how various research methods and resources might be affected by passage of the initiative. It provides an overview of current health-related research using ethnic and racial data and examines a sample of specific research activities and projects, the kinds of racial and ethnic data used in these activities, and the impact the initiative might have on the research methodology and resources used. Most projects cited use multiple data sources. In many cases, one or more of the sources meet exemption criteria while others do not or the exemption status is unclear.

The examples discussed in the issue brief raise questions about the exemption status of various research methodologies and sources. Because the initiative language is brief, several exemption categories have not been defined in sufficient detail to definitively determine at this time whether certain activities and data sources would be interpreted as exempt.

Medical and health-related data and activities that would most likely *not* be affected by the passage of Proposition 54 include those that are not collected or carried out by state personnel or entities and/or that meet one of the explicit exemption criteria set forth in the initiative language. Examples of such activities include:

- Resarch or project work carried out by private universities and nonprofits that does not rely on data collected by state entities;
- Resarch and project work where all data used meets the "patient record" or "medical research subject" exemption criteria (Section 32[f]); and
- Research and project work where all data used meets the exemption criteria for information required to maintain eligibility for federal programs (Section 32[i]).

Visit www.chcf.org for links to the official proponent and opponent Web sites, official supporter and opponent lists, news coverage, and poll data related to Proposition 54.

Endnotes

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[1] AHRQ Preliminary Policy on Inclusion of Priority Populations in Research: "It is the policy of AHRQ that the overall portfolio of health services research it conducts and supports shall include the following priority populations: inner city; rural; low income; minority; women; children; elderly and those with special health care needs, including those with disabilities and individuals who need chronic care or end-of-life health care." (http://www.ahrq.gov/fund/prioritypop.htm)

[2] NIH Policy and Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research – Amended October 2001: "The guidelines ensure that all NIH-funded clinical research will be carried out in a manner sufficient to elicit information about individuals of both sexes/genders and diverse racial and ethnic groups and…to examine differential effects on such groups. Since a primary aim of research is to provide scientific evidence leading to a change in health policy or standard of care, it is imperative to determine whether the intervention or therapy being studied affects women or men or members of minority groups and their subpopulations differently." (http://grants1.nih.gov/grants/funding/women_min/guidelines_amended_10_2001.htm)

[3] "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care," Institute of Medicine. Brian D. Smedley, Adrienne Y. Stith, and Alan R. Nelson, Editors (2002); "Unequal Treatment: What Health Care Providers Need to Know about Racial and Ethnic Disparities in Health Care." Institute of Medicine. March 2002. National Academy of Sciences.

[4] CDC Office of Minority Health (www.cdc.gov/omh/amh/amh.htm).

[5] U.S. Department of Health and Human Services, Office of Minority Health (www.omhrc.gov/omh/sidebar/aboutomh.htm).

[6] The Healthcare Research and Quality Act of 1999 (federal) directed AHRQ "to conduct and support research and evaluations, and to support demonstration projects, with respect to the delivery of health care in inner-city and rural areas; and health care for priority populations, which include low income groups, minority groups, women, children, the elderly and individuals with special health care needs, including individuals with disabilities and individuals who need chronic care or end-of-life health care."

[7] Institute of Medicine, 2002.

[8] AHRQ Preliminary Policy on Inclusion of Priority Populations in Research.