

Evaluation of the California Health Interview Survey: Cancer Prevention and Control Research, Clinical Practice, and Health Policy

September 2013



Prepared by Clarissa Hsu, PhD and Leah Tuzzio, MPH
Center for Community Health and Evaluation
Part of Group Health Research Institute
www.cche.org



This report summarizes the findings from an evaluation commissioned by the National Cancer Institute Division of Cancer Control and Population Sciences. The goal of the evaluation was to assess the scientific accomplishments, utility and impact of the California Health Interview Survey (CHIS), and obtain guidance on future priority topics for CHIS. The focus of the evaluation was on cancer prevention and control.

Table of Contents

| | |
|-----------------------------------------------------------------------------------------------------------|----|
| Table of Contents..... | 1 |
| Executive summary..... | 1 |
| I. Overview of the California Health Interview Survey: Cancer control research, practice, and policy..... | 2 |
| II. Methods for the evaluation..... | 3 |
| III. Results of the evaluation..... | 5 |
| A. Key assets: Strengths and impact..... | 5 |
| B. Key areas in need of improvement..... | 8 |
| C. Strengths of state and local survey data..... | 12 |
| IV. Conclusion and recommendations..... | 12 |
| V. References..... | 15 |

Appendices

| | |
|---------------------------------------------------------------------|----|
| Appendix A Webinar Agendas..... | 17 |
| Appendix B Biographies: Expert Panelists..... | 19 |
| Appendix C Biographies: Planning Committee..... | 22 |
| Appendix D Table of Contents of Review Materials and Resources..... | 29 |
| Appendix E Synthesis of Panelists' Responses..... | 32 |
| Appendix F Completed Evaluation Worksheets..... | 37 |
| Appendix G: Evaluation Logic Model..... | 57 |

Executive summary

Since 1999, the National Cancer Institute (NCI) Division of Cancer Control and Population Sciences (DCCPS) has funded the inclusion of cancer control items in the California Health Interview Survey (CHIS). CHIS is the largest, most comprehensive state health survey in the United States and covers a diverse population. CHIS has been used extensively to inform cancer research, clinical practice and health policy. In 2013, DCCPS convened an external panel of internationally recognized scientists to formally evaluate the scientific accomplishments, utility, and impact of CHIS related to cancer prevention and control, and to obtain guidance on future priority topics for CHIS. A Planning Committee with members internal and external to NCI developed the evaluation strategy.

Guided by the Planning Committee, the expert panel reviewed the products and accomplishments of CHIS, responded to a set of evaluation questions, and participated in two half-day webinars to discuss evaluation findings and make recommendations to enhance the approach, utility and impact of CHIS. The evaluation findings were synthesized and summarized by evaluators external to NCI using rigorous qualitative data analysis methods. Themes that emerged from the panelists' written responses and discussions were reviewed by the expert panelists and the Planning Committee. This report provides detailed findings about the contributions, utility, and impact of the CHIS cancer-control items, as well as recommendations on areas to prioritize and potential areas of expansion.

The panelists strongly recommended that NCI continue to support and partner with CHIS. Continued support will allow NCI to build on the unique contributions of CHIS to cancer prevention and control research, clinical practice improvements, and health policy development. Overall, the panelists concluded that in cancer control and prevention:

- CHIS serves as a model for state and local data collection in the United States;
- CHIS provides a unique data set that uses advanced sampling and administration methodologies;
- CHIS contributes to the evidence base that influences key changes in cancer research, practice, and policy;
- CHIS includes a range of content areas that embrace the interests of funders, researchers, local and state health departments, community health centers, clinical practices, health plans, policy makers, advocacy groups, and others.

CHIS is a valuable resource that describes the health practices and needs of a racially and ethnically diverse, multilingual population. The expert panel identified numerous scientific accomplishments in cancer prevention and control attributable to CHIS as well as additional opportunities to use and enhance CHIS in the changing health care environment. NCI support for CHIS is recognized as making a critical contribution to providing high quality data on cancer control issues. The evaluation findings highlight the value that researchers place on NCI's investment in CHIS and the potential for CHIS data to make substantial future contributions to cancer-related research, clinical practice, and health policy.

I. Overview of the California Health Interview Survey: Cancer control research, practice, and policy

The California Health Interview Survey (CHIS) is the largest and most comprehensive state health survey in the United States. CHIS is administered to a representative sample of more than 50,000 adults, teenagers and children in California households. CHIS was initially administered every two years and is now administered continuously. It is conducted by telephone in English, Spanish, Mandarin, Cantonese, Korean, and Vietnamese, with Tagalog added in 2013.

For more than a decade (1999-2012), the National Cancer Institute (NCI) has supported CHIS cancer control items. These items assess key topics across the cancer control spectrum such as screening, family history, diet and exercise by collecting population-based, self-reported data. CHIS has also been funded by the California Department of Public Health, California Department of Health Care Services, Robert Wood Johnson Foundation, California Office of the Patient Advocate, California Department of Mental Health, First 5 California, Kaiser Permanente, The California Endowment, and others.

California often leads the country in demographic trends with respect to age, ethnicity, race and the composition of households. The large CHIS sample size, oversampling of some racial and ethnic groups, and policy-relevant content, along with the demographic diversity of California, make CHIS a rich source of population information that is not available in other health surveys. For example, CHIS provides the only robust cancer control estimates in the nation for Asian and Latino subgroups and for American Indians.¹ CHIS is a unique source of data for examining the cancer risk of lesbian, gay, and bisexual populations.^{2,3}

Because CHIS items are comparable to the Centers for Disease Control and Prevention's (CDC) National Health Interview Survey (NHIS) items, CHIS data are used to help NCI anticipate cancer control patterns and trends for diverse populations across the United States as well as in California. CHIS data on California's large and heterogeneous population are used to anticipate patterns and trends in states where racially and ethnically diverse populations are too small to generate a sufficient survey sample. CHIS also gathers data in multiple languages for linguistically isolated groups, greatly enhancing the coverage of estimates for specific racial and ethnic groups. CHIS data have been used by researchers nationwide to study Asian and American Indian/Alaska Native populations. Cross-cultural and detailed racial-ethnic comparisons conducted with CHIS data provide evidence that contributes to the development of culturally appropriate screening intervention strategies nationwide.⁴⁻⁷

A growing area of research focuses on how neighborhoods, the built environment, the use of health services, and other contextual features influence access to health care, health outcomes, and behavior.^{8,9} An example is the study of how diet, physical activity, and active transportation (such as walking or bicycling) influence overweight and obesity status. CHIS data are geocoded, facilitating analysis at the neighborhood level. Several recent papers, for example, used geospatial and CHIS data to analyze the effects of neighborhood development patterns on walking.¹⁰⁻¹² Other analyses using geocoded CHIS data suggest a link between neighborhood social cohesion and walking for leisure.¹³

Research using CHIS data also identified subpopulations for whom access to parks is particularly important in enabling physical activity.¹⁴ Studies analyzing CHIS data contribute to the growing literature on the association between local food offerings and dietary behaviors that lead to obesity.^{15,16}

CHIS is recognized for providing high-quality, timely data for scientists, program planners and policy makers to assess rates, trends and determinants of cancer screening, tobacco use, physical activity, weight, and other cancer-related factors. CHIS data have been disseminated in policy briefs, monographs, peer-reviewed publications, and press releases.¹⁷ CHIS data are accessible to policy makers, researchers, and the general public in several formats. Public use microdata files can be accessed from CD-ROM or downloaded online. Public use data files have been stripped of all identifiers and sensitive questions. Confidential data files can be remotely accessed with prior permission through the Data Access Center at the UCLA Center for Health Policy Research upon submission and approval of an application. Finally, *AskCHIS*, an interactive, online tool, allows the general public to query CHIS data and quickly search for health statistics at the county, regional and state levels.¹⁸ At the time of this evaluation, *AskCHIS* had more than 38,000 registered users who have submitted more than 800,000 CHIS data queries. CHIS and its data collection partner, Westat, are developing a system based on *AskCHIS* for the National Center for Health Statistics to use with NHIS.

NCI periodically evaluates its investment in CHIS. When federal dollars are invested in data from a single state, those data must have clear and explicit value for national efforts. Information from external evaluations helps NCI determine if it should continue to support state-level and local-level surveys. Therefore, in early 2013, as part of due diligence, NCI DCCPS assembled a panel of external experts to evaluate the impact of CHIS data on cancer control research, clinical practice, and health policy. The goals of the external review were to help NCI: (1) understand how CHIS data have been used to advance NCI's mission of cancer prevention and control research, practice, and policy; (2) ensure that the NCI investment in CHIS addresses critical knowledge gaps in the effective delivery of cancer control practices; and (3) determine future priority topics for CHIS. Below is a summary of the methods used to gather and analyze expert input and the key findings from the expert panel.

II. Methods for the evaluation

The panel of external experts consisted of eight internationally recognized scientists in cancer research, epidemiology, health policy, survey methods, health services research, and behavioral and social sciences. NCI DCCPS also convened a Planning Committee of staff from NCI; the University of California, Los Angeles Center for Health Policy Research (UCLA Center); the Center for Community Health and Evaluation (CCHE), the contractor that conducted the evaluation for NCI; and Westat, the contractor that collects and prepares CHIS data for public release on the behalf of the UCLA Center. The Planning Committee designed the evaluation plan and logic model, selected background materials, and developed evaluation questions and discussion points for the expert panel. Brief biographies for the expert panel and members of the Planning Committee are in Appendices B and C.

EVALUATION QUESTIONS

1. How has the CHIS addressed important cancer control priorities?
2. What are the important cancer control priorities or issues that the initiative has not addressed, but could or should?
3. How has the CHIS had an impact on cancer control research, health policy and clinical practice?
4. How can the utility and impact of the CHIS be enhanced?
5. How do state and local health survey data improve our understanding of cancer control science above and beyond the national surveys?

Costs and burden on the panelists were minimized by obtaining written input and conducting discussions by webinar. On April 10, 2013, the panelists participated in an orientation webinar. Subsequently, they reviewed nearly 1400 pages of background materials including articles, fact sheets, policy briefs, the administered CHIS questionnaires, and methods reports (Appendix D). Panelists also provided written responses to five evaluation questions; seven of the eight panelists answered all five questions, and one panelist answered three of the five questions. The evaluation questions were designed by the Planning Committee to assess CHIS impact, strengths, challenges, and priorities; identify

areas in need of improvement; and inform NCI decisions on continued support for CHIS.

Evaluation worksheets with the panelists' responses to the five evaluation questions were analyzed in four steps: (1) A qualitative researcher from CCHE initially coded the panelists' written responses using broad concepts from the evaluation logic model (Appendix G); (2) Using the initial coding as a guide, two qualitative researchers re-read the written responses and came to a consensus on a more detailed set of codes; (3) A primary coder coded all evaluation worksheets using the detailed coding list; (4) A second coder reviewed the coded data to check for consistency and reliability. Panelists' written responses (Appendices E and F) to the five evaluation questions were analyzed using Grounded Theory techniques, which are standard analysis methods to identify patterns and overarching themes in qualitative data.¹⁹
²⁰ Worksheet coding was an inductive and iterative process. Atlas.ti version 6.2 software (Berlin, Germany) was used for data management and coding.

Next, CCHE drafted webinar presentations using the themes and selected quotes from the panelists' written responses (Appendix A). The Planning Committee previewed the webinar presentations and proposed questions to ask during the webinars to expand on the themes identified from the panelists' written responses. The webinars used a qualitative approach called member checking to incorporate the panelists' feedback on the themes to improve the accuracy and description of the themes.

Seven of the eight panelists participated in the webinars on May 21, 2013 and May 31, 2013. Planning Committee members who were available attended the webinars as well. During the two webinars, a CCHE facilitator presented the themes from the written responses and asked the questions developed by the Planning Committee. Webinar discussions allowed the panelists to clarify and expand on their written responses. Panelists also commented on points from the written responses of other panelists.

Analysis of the written responses to the five evaluation questions was combined with analysis of the webinar discussions to generate synthesized results, presented below, that include common themes as

well as unique themes, comments, and ideas. The report includes a summary of the panelists’ major recommendations for potential refinements to CHIS. The panelists and Planning Committee members reviewed the draft report to ensure accurate and complete presentation of results and major recommendations.

III. Results of the evaluation

The panelists provided rich feedback in their written responses and during the webinar discussions. Responses to the five evaluation questions and comments made during the webinars complemented each other and multiple commonalities were observed. Panelists were genuinely engaged in discussions and gave substantive input that described the strengths and limitations of CHIS and provided nuanced ideas about enhancing CHIS.

Results are presented in three sections: key assets, key areas in need of improvement, and strengths of state and local survey data. The information in the three results sections and the key themes presented in each section are from analyses of both the written responses and webinar discussions. Supporting quotes from panelists are included to elaborate on the themes.

A. Key assets: Strengths and impact

Evaluation questions 1 and 3 asked panelists to describe how CHIS addressed important cancer control priorities and had an impact on cancer control research, clinical practice, and health policy. Table 1 shows the recurring themes regarding the strengths and impacts of CHIS identified by the panelists, with the number of times each theme was mentioned in panelists’ written responses for questions 1 and 3 combined.

Table 1. Themes in response to question 1, “How has the CHIS addressed important cancer control priorities?” and question 3, “How has the CHIS had an impact on cancer control research, health policy and clinical practice?”

| Recurring Theme | # Mentions |
|-----------------------------------------|------------|
| Determinants of health | 7 |
| Population-level data and policy | 6 |
| Publicly available and user-friendly | 6 |
| Diverse and large sample | 5 |
| Model survey tool | 5 |
| Highly disseminated | 5 |
| Consistent, yet flexible, and adaptable | 3 |
| Geographic and spatial data ability | 3 |

Determinants of health. CHIS includes a wide variety of questions on demographics, lifestyle, and modifiable risk factors and behaviors, with a unique breadth of topics in cancer prevention and control. The in-depth CHIS data allow researchers to perform analyses designed to better understand social determinants of health: “The range of measures the CHIS includes...is important for exploring distal associations (such as social determinants) that hold clues for new prevention strategies.” Many of the economic, social and cultural questions included in CHIS are not available in other health surveys.

Population-level data and policy. Public health program planners use population-level data from surveys such as CHIS and several panelists underscored the demand for evidence-based data. Population-level data are used in discussions at the federal, regional and community levels to support health care changes, policy decisions, and quality improvement efforts. For example:

“CHIS informs us as to ‘where we are’ in terms of key health metrics at the population level – how many people are compliant with cancer screening recommendations, how many adolescents are using tobacco products and the changing prevalence of common chronic conditions like diabetes and hypertension that are important comorbidities for cancer. Without knowing these results in population subgroups planning and resources activities are working in the dark.”

Panelists discussed how CHIS provides researchers and policy makers with data that help them study health issues and advocate for policies and programs. Local-level CHIS data can be used to identify “hot spots” of health care needs, disadvantages, and barriers for effective distribution of resources and interventions. CHIS has influenced local policy changes, “such as the marketing of sugar-sweetened beverages and the prohibition of new fast food restaurants in south Los Angeles.” CHIS also allows longitudinal evaluation of policy changes. For example, researchers use CHIS data to assess changes over time in the characteristics of people who are uninsured or have different types of insurance. Several evaluators mentioned that CHIS informed local and national policy, and health care reform such as the Affordable Care Act (ACA) and the California Health Benefits Review Program. One panelist noted that “[CHIS] provided valuable estimates of the number of California residents who would become eligible for coverage under the Affordable Care Act and clearly illustrated the gap in insurance coverage that will remain after implementation of the ACA.” Another panelist mentioned that CHIS has an impact on health policy because CHIS data are used to project population health care needs and unmet needs. For example, CHIS was used in the California Simulation of Insurance Markets (CalSIM) to estimate enrollment, premiums, and expenditures in California’s Health Exchange.

Publicly available and user-friendly. The public availability of CHIS data was named as another key asset. Easy access to CHIS data facilitates use in grant writing, grant awarding, health-related strategic planning, and analyses of the health care marketplace. One panelist stated, “philanthropic organizations like The California Endowment, and a number of other foundations, now inform their grant making...they use the CHIS as part of their priority setting but also to target groups and areas for funding.” Health care delivery organizations such as Kaiser Permanente use CHIS to learn about their service area and inform service area expansion based on population needs. CHIS data are accessible to researchers ranging from students to experts in specific health issues; this accessibility democratizes research and creates research opportunities.

The panelists commended the UCLA Center for creating, maintaining, and improving CHIS through community participation; making the data publicly accessible through downloadable data sets; and designing user-friendly analytic tools. The value of easy-to-use publicly accessible data “has helped communities be less passive recipients of research, but more active and engaged participants in the research process.” The ease of use and accessibility of CHIS data are also a benefit to lay audiences who use this data to learn about their communities. In this regard, several panelists mentioned that the AskCHIS tool has increased the usability of CHIS data. Panelists were also intrigued by a new tool the UCLA Center is developing called *AskCHIS Neighborhood Edition*. This Web interface will provide users with geographic estimates of health data generated at the zip code, city, county, and legislative district levels. This tool will support community health needs assessments that comply with state law requirements and the ACA. CHIS has also contributed to NCI’s development of HD*CALC, a health disparities calculator.

Diverse and large sample. Panelists noted that the large, representative CHIS sample has a wide range of demographic characteristics that allows CHIS data to be used to answer a variety of important cancer control-related questions. For example, robust samples in small geographic areas allow researchers to explore diverse social and cultural contexts that could influence cancer prevention and control-related health behaviors, beliefs, and attitudes.

Administering CHIS in multiple languages allows researchers to examine health concepts, constructs, and differences in cancer control behaviors among people who speak different languages. This feature advances survey methodology because CHIS translates concepts in a way that helps “understand the social and cultural concepts of health, disease, and risk that populations maintain and that are different from one another.” CHIS also informs dissemination and implementation science with data on effective ways to implement and scale up interventions in different cultural and linguistic populations.

CHIS data allow researchers to evaluate associations between characteristics of subpopulations (e.g., uninsured people, immigrants) and health problems, health status, and access to care. As one panelist stated:

“CHIS includes multiple racial and ethnic groups with the explicit goal of understanding the similarities and differences across these groups. The inclusion of groups such as African American, Native Americans, Asian Americans, and Latinos helps refine theories that contextualize or link race and ethnicity to health.”

Model survey tool. CHIS was recognized as a model survey for other states and health surveys. Panelists from two states, Texas and Wisconsin, said they use CHIS and NHIS data sets to make comparisons to their own state data. Panelists described this strength by commenting that CHIS “builds capacity across the country and raises the standard for surveys in this class.” The UCLA Center was recognized for sharing the technical details of how they built CHIS so it can be replicated by others: “even an investigator outside of California [can] compare their state or regional data from NHIS or BRFSS to more in-depth data from the CHIS.” One panelist suggested that CHIS established survey design standards that are used as a model by grassroots survey developers.

Highly disseminated. CHIS data are free, accessible and easy to use by constituents ranging from researchers to community-based organizations and health departments. The data are widely disseminated through both formal and informal channels. High-quality peer-reviewed publications are an important dissemination mechanism since they influence clinical practice, policy, and program planning. Nearly 300 publications have used CHIS data, with one-third related to cancer control.²¹ Panelists were impressed with tools such as AskCHIS that make the data available for simple statistical analyses. Panelists noted multiple uses of CHIS data in analyses, white papers, and policy briefs. They acknowledged the academic value of CHIS, including use by students as a rich secondary data resource and a helpful tool for learning basic statistics.

Consistent, yet flexible, and adaptable. CHIS includes a core set of questions that are included each time the survey is administered. Other survey items are added or rotated in alternate years to address emerging concerns important for planning, policy development and clinical practice. Panelists commended CHIS for its consistency and flexibility in adding and rotating questions. Several panelists commented that a strength of CHIS is that it changes over time and reflects dynamic research evidence, health policy changes, and clinical practices. This flexibility is a unique feature of CHIS that facilitates investigation of new topics and emerging trends and stimulates research precipitated by changes in medical practice, for example when screening guidelines change or are developed. One panelist commented, “The best [feature] for CHIS addressing cancer control priorities is its ability to be flexible from survey to survey, and to add new questions if deemed appropriate.”

Geographic and spatial data ability. Inclusion of geographic and spatial data was recognized as another key asset of CHIS that is not offered in national surveys. Geocoded data can be disaggregated to the census tract level to describe neighborhood characteristics. For example, “you can look at the average level of unemployment within a tract, or the average level of poverty or percentage of minority speakers and have those features that might be accounting for some variation.” Geocoded data are also useful for identifying potential “hotspots” of risk associated with proximity to sources of carcinogens (e.g., air pollution, pesticides). Geocoded data informs program planners and policy makers in developing community-level programs to reduce cancer risk.

B. Key areas in need of improvement

Although CHIS has many strengths, the panelists suggested several areas in need of improvement and expansion. The themes from the panelists’ responses to evaluation questions 2 and 4 were complementary. Below are panelists’ ideas for cancer control priorities and issues that CHIS could or should address, but have not yet undertaken, and panelists’ suggestions to enhance the utility and impact of CHIS. Table 2 shows recurring themes and the number of times each theme was mentioned in panelists’ written responses for questions 2 and 4 combined.

Table 2. Themes in response to question 2, “What are the important cancer control priorities or issues that the initiative has not addressed, but could or should?” and question 4, “How can the utility and impact of the CHIS be enhanced?”

| Recurring Theme | # Mentions |
|---------------------------------------------|------------|
| New content | 8 |
| Link to other data sets | 6 |
| Response rates | 4 |
| Marketing, accessibility, and dissemination | 4 |
| Suggested data analysis approaches | 3 |

New content. Panelists were aware of constraints in the number of questions CHIS can ask, but had many suggestions about specific new content areas. However, the panelists had no clear agreement on how to prioritize new data areas, although one suggestion was to solicit help from data users on setting priorities or looking at NCI’s Provocative Questions Initiative, a list of questions developed by the research community to stimulate NCI to use science in innovative and effective ways. Specific data areas included:

- **Psychosocial factors:** *“Including perceptions of risk, sense of control, and level of stress that are thought to mediate resiliency and adaptability, and are currently viewed as proxies for differential susceptibility in populations...and trust and support that mitigate the stress response.”*
- **Intergenerational discussion of cancer control and prevention topics:** *“To examine the influence of parents on children or commonalities around certain kinds of behaviors.”*
- **Harmful exposures:** *“Self-reported chemical exposures in the household, occupational setting, and neighborhood would augment monitored and modeled pollution data and provide information on omissions and bias in risk estimation.”*
- **Cigarette and non-cigarette types:** *“Smoking of little flavored cigars (cigarillos), bidis, blunts, kreteks and other highly-carcinogenic, non-cigarette products by adults and youth.”*
- **Awareness of exposures and preferences:** *“When you are looking at the impact of clean air or local policies...to ask the respondents about their perception and exposure or awareness of the policies.”*
- **Behavioral economics:** *“CHIS could be used to better understand how economic incentives might be used to improve dietary intake and increase physical activity in low-income populations.”*
- **Patient activation and engagement:** *“A question that asks the respondent for an assessment of where responsibility lies to be aware of cancer prevention/control behaviors...what is the balance? Such as between self, government, health care provider, media.”*

- **Health services:** *“More on health care service utilization, access, cost, and utility to explore clinical quality of cancer care measures.”*
- **Quality of life:** *“Self-reported health, quality of life measures, activities of daily living, things that are short and medium-term outcomes in some of the health systems changes.”*

Link to other data sets. The panelists had a robust discussion on enhancing CHIS by linking to other data sets such as biomarker data or registry or hospital data that are routinely collected by health systems and plans. The panelists saw opportunities for “cross agency fertilization.” For example, the Environmental Protection Agency, Centers for Population Health and Health Disparities, and NCI could collaborate on cumulative risk assessments and co-fund data collection. A specific suggestion was to link CHIS to the nationwide toxic-release inventory that includes geocoded toxic-release sites. These data could be analyzed for the intersection of environmental toxins and patterns of chronic disease, premature death, and disability. Another suggestion was linkage to electronic health record data, which could provide insight on how health system changes affect cancer control and prevention efforts. One thought was that “CHIS may take a leadership role in helping to answer how to link these kinds of larger surveys at a population level to inform clinical practice, this would involve more partnerships with clinicians.” A CHIS-electronic health record linkage could take advantage of frequently collected data such as “health histories and health behaviors, as well as vital measurements and a blood draw, and an inventory of health services utilization and costs of care.” Linking CHIS to cancer registry data, population-level information on mammography occurrence, and incidence and mortality rates could improve the value of CHIS. CHIS data have been linked to biomarker and biospecimen data (e.g., saliva or blood) and panelists suggested expanding this feature. A panelist reported, “Such an investment would greatly enhance the NCI’s genomic research agendas and understanding of racial and ethnic disparities in cancer susceptibility.” One suggestion was integrating or linking CHIS to existing biospecimen and biomarker data collections efforts such as the California Biomonitoring program.

Response rates. Considerable discussion focused on finding ways to increase survey response rates through new technologies such as handheld devices. CHIS, like many phone surveys, has experienced a drop in response rates over the last several years. Panelists expressed concern about response rates and minimizing selection bias and suggested that now is an opportune time to address these issues and potentially increase the sample size:

“It may be timely to explore alternative methods of data collection from hand held devices, tablets and other new technologies. This is the coming era of mHealth [mobile health] and the population will likely be becoming more familiar and comfortable with new technologies as young, savvy populations age up and health systems make more use of these technologies in routine care.”

Marketing, accessibility, and dissemination. While the accessibility of CHIS data was seen as an important asset, panelists felt that CHIS could be marketed to an even larger audience. The use and value of CHIS could be more actively and broadly marketed through investigator-initiated grants, increasing the number of users, and analyses. Many panelists became aware of new opportunities to use CHIS data during the webinars—illustrating the need to showcase and market CHIS data more broadly. For example, CHIS has been used to recruit unique subpopulations of people to participate in

supplemental studies. Partnering with other organizations could market CHIS more broadly, and thus increase resources, sample size and depth of data. For example, CHIS partnered with The California Endowment, which provided resources for additional follow-up with CHIS participants at Building Healthy Communities sites. Another suggestion was to market CHIS to organizations implementing the ACA and to emerging Accountable Care Organizations since these agencies could use CHIS to improve the health of an entire population. Marketing of CHIS could be through user workshops, creation of new tools, and demonstrations of analytic modules and existing tools such as AskCHIS. Suggestions to increase the dissemination of results using CHIS data included diversifying publication types, creating funding announcements that target CHIS use, and working with journal editors on cancer control supplements that create incentives for using CHIS data.

Suggested data analysis approaches

Population-based analysis for local needs

Panelists suggested new ways to analyze CHIS data. One discussion focused on the value of CHIS in informing health care and public health systems about the health of entire populations, not just people with insurance. Another suggestion was for communities and states to analyze and use CHIS population-level data to determine relative needs for distribution of health care resources such as clinics (e.g., free-standing, school-based, church-based). For example, one panelist from outside of California pointed out the value of local data for prioritizing funding requests:

“We’re able to target resources to those areas that are in the greatest relative need... The philanthropic sector does much more than the government does. Those are the people writing the checks because they are convinced of the needs in a particular jurisdiction... Establishing the relative prioritization is something you can only get by having local level data.”

Natural experiments

Panelists suggested that CHIS could be even more valuable if natural experiments could be evaluated using CHIS data to determine how policies influence behavior changes or cancer control outcomes.

“If you’re thinking about evaluating interventions, you really need longitudinal data to have a stronger design and that can be done by using panel approaches...as communities begin to think about affordable care and Accountable Care Organizations, [this approach] may be more effective in certain communities than [cross-sectional approaches] that could provide information about the population level changes.”

If CHIS data were available as longitudinal panels for stratified analyses, researchers could assess changes over time within race/ethnicity groups or within communities of different socioeconomic status. Panelists discussed matching responders and non-responders by demographic and socioeconomic characteristics, and using quasi-experimental techniques to measure changes over time. One specific suggestion was to use a quasi-experimental design to assess changes in non-use of services and non-response over time. This could tell us, “are we missing surveys from [certain groups of] people we want to influence in terms of access, screening or other health services?”

C. Strengths of state and local survey data

NCI was particularly interested in how the expert panelists from California and other regions of the United States assess the value of using national resources to support CHIS, which yields data from a single state. Panelists were asked to comment specifically on the value of the CHIS state and local data. Their responses indicated two key strengths of state and local data over national data. Table 3 shows the recurring themes, and number of times each was mentioned for question 5.

Table 3. Themes in response to question 5, “How do state and local health survey data improve our understanding of cancer control science above and beyond the national surveys?”

| Recurring Theme | # Mentions |
|----------------------------------------|------------|
| Informs policy and program development | 6 |
| Archetypal survey | 5 |

Informs policy and program development. CHIS data inform the development of policy and program planning and help researchers, policy makers and health advocates understand the impact of local health policies and cancer control and prevention efforts. State and local health surveys are “crucial to determining precisely where the health problems and needs are in a state, and hence fundamental to targeting local interventions to high-risk geographic areas and groups.” Relying on surveys that aggregate data nationally can mask important local or state differences in the demographic composition of the population, local risk factors, local access to care, Medicaid eligibility, and state-specific regulation. Thus, state and local data are needed to understand which policies and cancer control efforts might be effective for a particular population.

Archetypal survey. As mentioned previously, CHIS is a model for other state and local population health surveys. The high impact of CHIS on health policy and prevention efforts suggests that other states would benefit from implementing their own surveys. Further, CHIS data can be used in conjunction with data from other states and localities; for example, comparisons to the health risks and needs of California populations might inform policies in other states and regions. CHIS data can also be used in conjunction with state or regional data collected by NHIS, National Health and Nutrition Examination Survey, Medical Expenditure Panel Survey, Behavioral Risk Factor Surveillance System, US Census, and Area Resource File.

IV. Conclusion and recommendations

CHIS is the largest state health survey in the United States and an important population-based tool for research, clinical practice improvements, and health policy development. State surveys such as CHIS describe how local context affects health, such as how the political, social, physical, and economic environment in which people make health choices affects cancer development. In addition, the diverse population of California means that CHIS data inform national cancer prevention and control efforts.

The UCLA Center, which developed and maintains CHIS, and CHIS co-funders, particularly NCI, are dedicated to improving the utility and capacity of CHIS to inform cancer prevention and control

research, clinical practice, and health policy. In addition to the many strengths of CHIS and examples of its impact, the panelists made the following recommendations to enhance CHIS.

1. Ensure that measures included in CHIS and analytic tools continue to be innovative and bold. CHIS should continue to use its scientific process to ensure that the concepts capture the diverse cultural interpretations of illness and health. Measures to add or continue include:
 - Stress, trust, social support;
 - Intergenerational transmission of knowledge, perceptions, attitudes and behaviors;
 - Environmental exposure (e.g., known carcinogens);
 - Tobacco use beyond cigarettes;
 - Patient activation, engagement and motivations;
 - Use of health services; and,
 - Quality of life.
2. Expand use and uptake of CHIS data through marketing, training, and funding opportunities such as NCI Funding Opportunity Announcements (FOA). The goal is for more researchers, students, local and state health departments, community health organizations, health systems, and health plans to be aware of the utility of CHIS and accessibility of its data. Specific suggestions include:
 - Determine who is and is not using CHIS to inform targeted approaches to increase use.
 - Develop FOAs to encourage use of CHIS data and educate the community more broadly about existing FOAs that might benefit from CHIS data.
 - Host CHIS-user workshops and conferences to engage and assist people in using CHIS.
 - Work with journal editors to develop supplements focused on CHIS.
3. Create a collaborative data model by linking CHIS to different data sources (e.g., electronic health records, registries, biomarker data) and working with other agencies to make CHIS an even more versatile resource.
 - Link CHIS with electronic health record data from Epic, eClinicalWorks, Centricity, etc.; with registries like SEER or CDC's Cancer Registries; with national health surveys like the Behavioral Risk Factor Surveillance System-California; or with biomarker data from the California Biomonitoring program.
4. Continue to use community input to determine the content and rotation of questions and to improve data collection methods. Data usability could be enhanced by incorporating guidance from CHIS users.
 - Engage the community through social media or other web-based applications and tools (e.g., wiki sites, blogs).
5. Continue NCI's investment in CHIS.
 - Long-term, stable funding would ensure that questions of high priority to NCI are consistently included in future CHIS versions.

The expert panel expressed strong support for CHIS and for NCI to continue its support and partnership on this project. They commended NCI for its early investment in developing CHIS, which was recognized as contributing to major gains and accomplishments in cancer prevention and control. Overall, the panelists commended CHIS as a resource and model, not just for California, but for the nation.

V. References

1. National Healthcare Quality & Disparities Reports. July 2013. Agency for Healthcare Research and Quality, Rockville, MD. <http://www.ahrq.gov/research/findings/nhqrdr/index.html>. Accessed 8-20-2013.
2. Boehmer U, Miao X, Linkletter C, Clark MA. Adult health behaviors over the life course by sexual orientation. *American journal of public health*. Feb 2012;102(2):292-300.
3. Tang H, Greenwood GL, Cowling DW, Lloyd JC, Roeseler AG, Bal DG. Cigarette smoking among lesbians, gays, and bisexuals: how serious a problem? (United States). *Cancer causes & control : CCC*. Oct 2004;15(8):797-803.
4. Ponce NA, Babey SH, Etzioni DA, Spencer BA, Brown ER, Chawla N. *Cancer Screening in California: Findings from the 2001 California Health Interview Survey*. Los Angeles, CA: UCLA Center for Health Policy Research; 2003.
5. Kandula NR, Wen M, Jacobs EA, Lauderdale DS. Low rates of colorectal, cervical, and breast cancer screening in Asian Americans compared with non-Hispanic whites: Cultural influences or access to care? *Cancer*. Jul 1 2006;107(1):184-192.
6. Kagawa-Singer M, Pourat N, Breen N, et al. Breast and cervical cancer screening rates of subgroups of Asian American women in California. *Medical care research and review: MCRR*. Dec 2007;64(6):706-730.
7. Maxwell AE, Crespi CM. Trends in colorectal cancer screening utilization among ethnic groups in California: are we closing the gap? *Cancer epidemiology, biomarkers & prevention : a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology*. Mar 2009;18(3):752-759.
8. Lui CK, Wallace SP. A common denominator: calculating hospitalization rates for ambulatory care-sensitive conditions in California. *Preventing chronic disease*. Sep 2011;8(5):A102.
9. Cordasco KM, Ponce NA, Gatchell MS, Traudt B, Escarce JJ. English language proficiency and geographical proximity to a safety net clinic as a predictor of health care access. *Journal of immigrant and minority health / Center for Minority Public Health*. Apr 2011;13(2):260-267.
10. Wen M, Kandula NR, Lauderdale DS. Walking for transportation or leisure: what difference does the neighborhood make? *Journal of general internal medicine*. Dec 2007;22(12):1674-1680.
11. Huang L, Stinchcomb DG, Pickle LW, Dill J, Berrigan D. Identifying clusters of active transportation using spatial scan statistics. *American journal of preventive medicine*. Aug 2009;37(2):157-166.
12. Berrigan D, Pickle LW, Dill J. Associations between street connectivity and active transportation. *International journal of health geographics*. 2010;9:20.

13. Brown ER, Babey SH, Hastert TA, Diamant AL. Half of California adults walk less than one hour each week. *Policy brief (UCLA Center for Health Policy Research)*. Dec 2005(PB2005-9):1-8.
14. Babey SH, Hastert TA, Yu H, Brown ER. Physical activity among adolescents. When do parks matter? *American journal of preventive medicine*. Apr 2008;34(4):345-348.
15. Babey SH, Wolstein J, Diamant AL. Food environments near home and school related to consumption of soda and fast food. *Policy brief (UCLA Center for Health Policy Research)*. Jul 2011(PB2011-6):1-8.
16. Truong K, Fernandes M, An R, Shier V, Sturm R. Measuring the physical food environment and its relationship with obesity: evidence from California. *Public health*. Feb 2010;124(2):115-118.
17. UCLA Center for Health Policy Research. California Health Interview Survey publications. 2012; <http://healthpolicy.ucla.edu/publications/Pages/default.aspx>. Accessed 3-12-2013.
18. UCLA Center for Health Policy Research. California Health Interview Survey publications. 2012; <http://healthpolicy.ucla.edu/chis/data/Pages/overview.aspx>. Accessed 3-12-2013.
19. Glaser BG, Strauss AL. *The discovery of grounded theory: strategies for qualitative research*. Chicago: Aldine Pub. Co.; 1967.
20. Strauss AL, Corbin JM. *Basics of qualitative research: grounded theory procedures and techniques*. Newbury Park, Calif.: Sage Publications; 1990.
21. Brown ER, Kincheloe J, Breen N, Olson JL, Portnoy B, Craddock Lee SJ. States' Use of Local Population Health Data: Comparing the Behavioral Risk Factor Surveillance System and Independent State Health Surveys. *Journal of public health management and practice: JPHMP*. Jan 3 2013.

Appendix A Webinar Agendas



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health
National Cancer Institute
Bethesda, Maryland 20892

Evaluation of the California Health Interview Survey (CHIS)

Webinar discussion #1

Tuesday, May 21, 2013

Noon – 4 p.m. Eastern

Agenda

| Time | Topic | Facilitator |
|------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------|
| 15 minutes | Welcome & Introductions | Nancy Breen |
| 1 hour | Evaluation question #3: <i>How has the CHIS had an impact on cancer control research, health policy, and clinical practice?</i> <ul style="list-style-type: none"> • Synopsis of expert panel responses • Group discussion | Leah Tuzzio |
| 1 hour | Evaluation question #4: <i>How can the utility and impact of CHIS be enhanced?</i> <ul style="list-style-type: none"> • Synopsis of expert panel responses • Group discussion | Leah Tuzzio |
| 15 minutes | Break | |
| 1 hour | Evaluation question #5: <i>How do state and local health survey data improve our understanding of cancer control science above and beyond the national surveys?</i> <ul style="list-style-type: none"> • Synopsis of expert panel responses • Group discussion | Leah Tuzzio |
| 15 minutes | Wrap-up | Nancy Breen |

Appendix A Webinar Agendas



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health
National Cancer Institute
Bethesda, Maryland 20892

Evaluation of the California Health Interview Survey (CHIS)

Webinar discussion #2

Friday, May 31, 2013

2 – 5 p.m. Eastern

Agenda

| Time | Topic | Facilitator |
|------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------|
| 15 minutes | Welcome & introductions | Nancy Breen |
| 1 hour | Evaluation question #1: <i>How has the CHIS addressed important cancer control priorities?</i> <ul style="list-style-type: none"> • Synopsis of expert panel responses • Group discussion | Leah Tuzzio |
| 15 minutes | Break | |
| 1 hour | Evaluation question #2: <i>What are the important cancer control priorities or issues that the initiative has not addressed, but could or should?</i> <ul style="list-style-type: none"> • Synopsis of expert panel responses • Group discussion | Leah Tuzzio |
| 30 minutes | Wrap-up | Nancy Breen |

Appendix B

Biographies: Expert Panelists



Todd Gilmer, Ph.D.

Professor and Acting Chief, Division of Health Care Sciences, Department of Family and Preventive Medicine, University of Southern California at San Diego

Todd Gilmer received his Ph.D. in economics from the University of Washington in 1997. His research has focused on three areas: health insurance/risk adjustment, diabetes, and mental health services. Dr. Gilmer specializes in research design and data analysis, the use of large data sets including those from Medicare, Medicaid, and commercial health plans, national surveys and census data, and mixed data sets that combine epidemiological data with health insurance claims, and the evaluation of community based interventions to improve chronic disease care to low-income populations. He has recently finished several studies examining the Faces of Medicaid, describing Medicaid beneficiaries and their chronic conditions, Medicaid spending across states, and the relationship between Medicaid and Medicare spending.



Robert Hiatt, M.D., Ph.D.

Professor and Chair, Department of Epidemiology and Biostatistics; Director of Population Sciences and Associate Director, Comprehensive Cancer Center, University of California at San Francisco

Robert Hiatt, M.D., Ph.D., was trained in medicine at the University of Michigan and in epidemiology at the University of California Berkeley. He is Board Certified in Preventive Medicine and is a past president of the American College of Epidemiology and the American Society for Preventive Oncology. He was the first Deputy Director of the Division of Cancer Control and Population Sciences at the National Cancer Institute, where he oversaw cancer research in epidemiology and genetics, surveillance, and health services research. His current research interests include cancer epidemiology—especially breast cancer—cancer prevention and screening, health services and outcomes research, the social determinants of cancer, the environment and early development.



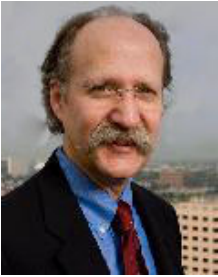
Hope Landrine, Ph.D.

Professor of Public Health and Psychology and Director of the Center for Health Disparities, East Carolina University

Hope Landrine received her Ph.D. in Clinical Psychology from the University of Rhode Island, postdoctoral training in Social Psychology at Stanford University, and postdoctoral training in Cancer Prevention and Control as a National Cancer Institute Fellow in the Department of Preventive Medicine at the University of Southern California Medical School. Prior to joining ECU, she was the Director of Multicultural Research at the American Cancer Society. Her research focuses on neighborhood and sociocultural factors in cancer disparities, and on community-based strategies for reducing health disparities.

Appendix B

Biographies: Expert Panelists



Stephen Linder, Ph.D.

Professor and Associate Director, Institute for Health Policy, University of Texas at Houston

Stephen Linder is a Professor at the University of Texas School of Public Health in the Division of Management, Policy & Community Health and Associate Director of UT's Institute for Health Policy. He received his Doctorate in Political Science from the University of Iowa and served on the Faculties of UCLA and of Tulane University before coming to the UT School of Public Health. In recognition of excellence in teaching, he has received the McGovern Teaching Award, the University of Texas Board of Regents Teaching Award and was named a Piper Professor by the Minnie Stevens Piper Foundation. Dr. Linder currently heads three projects at the Institute for Health Policy: Research Into Action, a knowledge translation initiative; Methods for Cumulative Risk Assessment; and the Health of Houston Survey.



William Rakowski, Ph.D.

Professor of Behavioral and Social Sciences, Brown University

William Rakowski earned his Ph.D. in Human Development and Family Studies from Penn State University. His research focuses on behavioral science strategies for cancer control, with an emphasis on utilization of cancer screening procedures. He has extended the Transtheoretical Model ("stages of change") to the study of cancer screening, by both instrument development and the evaluation of individually tailored interventions. He also conducts behavioral epidemiology research on population-level datasets (e.g., NHIS, BRFSS, HINTS, CHIS), to identify factors correlated with receipt of cancer screening. Dr. Rakowski's most recent investigations address the receipt of regular/repeat cancer screening.



Patrick Remington, M.D., M.P.H.

Professor of Population Health Sciences and Associate Dean of Public Health, School of Medicine and Public Health, University of Wisconsin-Madison

Patrick Remington earned a B.S. degree in molecular biology and a M.D. from UW-Madison, and a M.P.H. degree from the University of Minnesota. His research focuses on developing methods to measure the health of communities and communicate this information to the public and policy makers. He is currently co-directing the RWJ-funded "County Health Rankings" project that ranks the health of the counties in all 50 states and examines strategies to improve population health. Dr. Remington worked for 15 years in public health practice, as an epidemiologist at the CDC and Chief Medical Officer at the Wisconsin Division of Public Health. Since joining the UW in 1997, he has served as Associate Director of the Carbone Cancer Center, was director of the Population Health Institute, and was the founding director of the Master of Public Health Program. He has authored or co-authored over 300 publications and teaches courses on public health practice to undergraduate, medical, and public health students.

Appendix B

Biographies: Expert Panelists



David Takeuchi, Ph.D.

Professor and Dorothy Book Scholar, Associate Dean for Research, Graduate School of Social Work, Boston College

David T. Takeuchi, Ph.D., is currently Professor and Dorothy Book Scholar and the Dean for Research in the Graduate School of Social Work at Boston College. He is a sociologist with postdoctoral training in epidemiology and health services research. His research focuses on investigating the social, structural, and cultural contexts that are associated with different health outcomes, especially among racial and ethnic minorities. He also examines the use of health services in different ethnic communities. He received the Legacy Award from the Family Research Consortium for his research and mentoring and the Innovations Award from the National Center on Minority Health and Health Disparities for his research contributions. He was honored with the University of Washington 2011 Marsha Landolt Distinguished Mentor Award. Last summer, he was elected into the Washington State Academy of Sciences and the Sociological Research Association.



Robert Valdez, Ph.D., MHSA

Executive Director, RWJF Center for Health ; RWJF Professor, Family and Community Medicine and Economics; Associate Director, Office of Community Health, University of New Mexico

Robert Valdez received his Ph.D. from the RAND Graduate School for Public Policy Studies, specializing in studies of health care financing and quality of care for children. He currently conducts policy analyses and research at the University of New Mexico (UNM), and through UNM's Office of Community Health, is engaged in improving the delivery and quality of health services across New Mexico. Dr. Valdez is internationally recognized as an expert on health service research methodology, the U.S. health care system, and health policy analysis. He has served as Senior Advisor to the White House, as Deputy Assistant Secretary for Health at DHHS, and on numerous national advisory boards. On the state and local levels, Dr. Valdez has provided policy analysis on issues related to the uninsured and Medicaid. He is the author of numerous studies on children's health and health care finance.

Appendix C

Biographies: Planning Committee

Associate Director, Applied Research Program, NCI



Rachel Ballard-Barbash, M.D., M.P.H.

Associate Director, Applied Research Program, National Cancer Institute

Rachel Ballard-Barbash, M.D., M.P.H., serves as the Associate Director of the Applied Research Program in DCCPS at NCI. The program's mission is to understand how and why cancer care and control activities in the United States influence patterns of care and trends in cancer burden through evaluation of patterns and trends in cancer-associated health behaviors and risk factors, health care services, economics, and outcomes, including patient-reported outcomes. She has published widely in the areas of physical activity, diet and weight both at the individual, population, and policy level, and on cancer quality of care in the area of screening and treatment. She trained in environmental sciences, internal medicine, pediatrics, clinical nutrition, preventive medicine.

Planning Committee



Michael Brick, Ph.D.

Vice President and Co-Director, Survey Methods Unit, Westat

Mike Brick is a Vice President and co-Director of the Survey Methods Unit at Westat, and is a research professor in the Joint Program in Survey Methodology at the University of Maryland. Prior to joining Westat in 1984, he was a mathematical statistician at three federal government agencies for about 11 years. He has a Ph.D. in statistics from American University, is a Fellow of the American Statistical Association, and is an elected member of the International Statistical Institute. He has published in a variety of journals on topics including sampling, weighting, and bias evaluation.



David Grant, Ph.D.

Director, California Health Interview Survey, UCLA Center for Health Policy Research

David Grant, Ph.D., is the Director of the California Health Interview Survey (CHIS) at the UCLA Center for Health Policy Research. Dr. Grant joined the CHIS team in 2001 and became project director in 2006. He is responsible for all aspects of CHIS, including the planning, data collection, and dissemination phases of CHIS. For 20 years, David Grant has been involved in applied social research at academic and public agencies. In addition to population health and survey methodology, his research has focused on urban poverty and demography. Grant received his undergraduate degree at the University of Michigan and his master's and doctorate degrees (1998) in sociology at UCLA.

Appendix C

Biographies: Planning Committee



Chris Hafner-Eaton, Ph.D., M.P.H.

Health Policy Analyst, National Institute of Nursing Research

Chris Hafner-Eaton serves as a Health Science Policy Analyst at the NIH National Institute of Nursing Research. Recently, she completed a Comparative Effectiveness Research and Patient Center Outcomes Research detail to the NIH Office of the Director. Dr. Hafner-Eaton also teaches a NIH Graduate Health Policy and Management FAES course. She earned several Interdisciplinary degrees including her Ph.D. in Public Health (Health Services Research/policy) and M.P.H. in Behavioral Sciences and Health Education from UCLA.



Carrie Klabunde, Ph.D.

Epidemiologist, Health Services and Economics Branch, National Cancer Institute

Carrie Klabunde, Ph.D., is an Epidemiologist in the Health Services and Economics Branch of the NCI. Dr. Klabunde conducts and manages research to evaluate the organization and delivery of cancer care, with an emphasis on cancer screening delivery in primary care practice. She has expertise in designing and implementing probability sample surveys that assess health care provider knowledge, attitudes, recommendations, and practices regarding various aspects of cancer control. She has directed state and national surveys on a variety of cancer screening topics, and is the NCI scientific coordinator for the [Cancer Control Supplement to the National Health Interview Survey](#). She chairs the NCI-sponsored [International Cancer Screening Network](#). She is also responsible for an extramural research program to improve the utilization, delivery, and outcomes of colorectal cancer screening in the US. She has published extensively in peer-reviewed journals on a variety of cancer control topics, particularly provider practices in cancer control.



Sarah Kobrin, Ph.D., M.P.H.

Program Director, Applied Cancer Screening Research Branch, National Cancer Institute

Sarah Kobrin, Ph.D., M.P.H. has been working in the field of cancer control for more than 15 years. She is currently a Program Director in the NCI's Process of Care Research and Science of Research and Technology Branches. Dr. Kobrin manages projects related to health behavior theory; informed decision making, particularly under uncertainty; and measurement. She leads the Behavioral Research Program's Advanced Training Institute on Health Behavior and has written about the use of health behavior theory in intervention research. Her research includes development of a scale, based on attitudes rather than beliefs, to assess perceptions of breast cancer risk. With a team at NCI, she led development of a measure of the process of decision making about screening with the PSA test for prostate cancer. Prior to moving to the NCI in December 2003, Dr. Kobrin was a Walther Post-Doctoral Fellow at the Duke University's Cancer Prevention and Control Program. She trained at the University of North Carolina at Chapel Hill School of Public Health.

Appendix C

Biographies: Planning Committee



Benmei Liu, Ph.D.

Survey Statistician, Surveillance Research Program, National Cancer Institute

Benmei Liu, Ph.D., is a Survey Statistician in the [Statistical Methodology and Applications Branch](#) (SMAB) of the Surveillance Research Program (SRP) at the NCI. At SMAB, she is responsible for survey methodology projects such as handling issues that are related to the design and analysis of surveys. She also initiates and manages collaborative analyses with scientists from NCI and other government agencies and academic centers. Her primary research areas include developing proper statistical methods for resolving scientific problems encountered in complex surveys and health data analysis, small area estimation for cancer risk factors and screening behaviors, and imputation methods for complex survey data. Prior to joining NCI, Dr. Liu worked as a statistician at Westat on a variety of survey projects.



Richard Moser, Ph.D.

Program Director, Science of Research and Technology Branch, National Cancer Institute

Richard Moser is a Program Director in the Behavioral Research Program's (BRP) Science of Research and Technology Branch (SRTB), housed within the Division of Cancer Control and Population Sciences (DCCPS) at the NCI. He provides analytic support for BRP's research projects, including research design, statistical methodology, and program evaluation. Dr. Moser serves as the Health Information National Trends Survey's (HINTS) data coordinator and as the liaison for NCI's Cancer Prevention Fellowship Program. He directs the Grid-Enabled Measures (GEM) project, which is a web-based portal to promote the use of standardized health research measures and data sharing using technologically-mediated social participation. Dr. Moser's research interests include statistical methodology, health cognitions, and end-of-life issues. Before joining NCI, he worked at the Palo Alto, California, Veterans Affairs Hospital performing alcoholism research, taught statistics at several Bay Area psychology graduate programs, and consulted for a leading statistical software company. He is an author or co-author on more than 65 peer-reviewed journal articles and several book chapters spanning a range of topics including survey methodology, analytic procedures, health behaviors, and innovative uses of data.

Appendix C

Biographies: Planning Committee



Ninez Ponce, Ph.D.

Principal Investigator, California Health Interview Survey, UCLA Center for Health Policy Research; Associate Professor, UCLA Fielding School of Public Health

Ninez A. Ponce, B.S. (UC Berkeley), M.P.P. (Harvard), Ph.D. (UCLA), is the principal investigator of the California Health Interview Survey (CHIS). She is an associate professor in the UCLA Fielding School of Public Health's Department of Health Policy and Management and associate director of UCLA's Asian American Studies Center. Dr. Ponce devised the rationale and implementation of Asian ethnic oversamples and the cultural and linguistic adaptation of the survey. The CHIS is conducted in English, Spanish, Cantonese, Mandarin, Korean and Vietnamese, and is currently being fielded in Tagalog. In 2008, she received the National Institutes of Health Merit Award for Multicultural Survey Research. In 2009, She was a member of the Institute of Medicine's Subcommittee on the Standardized Collection of Race, Ethnicity and Language Data.



Barry Portnoy, Ph.D.

Senior Advisor, Office of Disease Prevention, Office of the Director, National Institutes of Health

Barry Portnoy serves as senior advisor for disease prevention for the Office of Disease Prevention (ODP), Office of the Director, NIH. His current responsibilities include coordinating and stimulating collaborative prevention research projects across the NIH. Prior to joining ODP, Dr. Portnoy was with the NCI Division of Cancer Prevention. He also served as the NCI coordinator for the Department of Health and Human Services Healthy People 2000 and 2010 Objectives. He serves on a number of trans-NIH committees such as the OppNet Steering Committee for Basic Behavioral and Social Sciences, the NIH's Prevention Coordinators Committee and the NIH Nutrition Coordinating Committee. He has held academic appointments at the University of Virginia and the University of Maryland. He also served as an evaluation consultant to the National High Blood Pressure Education Program, the National Institute of Arthritis and Musculoskeletal Disease, the Office of Disease Prevention and Health Promotion and the Department of Education. He holds a doctoral degree in public health education. His research interests include the design and evaluation of chronic disease prevention and control interventions.

Appendix C

Biographies: Planning Committee



Larry Solomon, Ph.D.

Senior Evaluation Scientist, Office of Science Planning and Assessment, National Cancer Institute

Larry Solomon has 25 years of experience in program evaluation and public policy analysis. The major portion of this experience has been obtained in the public health and scientific research program areas. Larry has been affiliated with NCI's Office of Science Planning and Assessment's Program Assessment Branch since September 2005. In his role, he participates in a wide range of evaluation and assessment activities. Prior to joining NCI, Larry served as a senior health research evaluator for the NIH Office of Evaluation. Before joining the NIH, Larry served as a senior analyst for the U.S. Government Accountability Office (GAO). Larry has also served as a researcher at the Oak Ridge National Laboratory. He holds a Ph.D. in Sociology from North Carolina State University.



Gordon Willis, Ph.D.

Cognitive Psychologist, Office of the Associate Director, Applied Research Program, National Cancer Institute

Gordon Willis, Ph.D., is Cognitive Psychologist in the Office of the Associate Director of the Applied Research Program. Dr. Willis attended Oberlin College, and received a Ph.D. in Cognitive Psychology from Northwestern University. He now works in the area of the development and evaluation of surveys on cancer risk factors, and focuses on questionnaire pretesting. He has written the book "Cognitive Interviewing: A Tool for Improving Questionnaire Design." His research interests have recently turned to cross-cultural issues in self-report surveys and research studies, and in particular the development of best practices for questionnaire translation, and the development of pretesting techniques to evaluate the cross-cultural comparability of survey questions.

Appendix C

Biographies: Planning Committee

Planning Committee Staff



Nancy Breen, Ph.D.

Economist, Health Services and Economics Branch, Applied Research Program, National Cancer Institute

Nancy Breen earned her Ph.D. from the Department of Economics at the Graduate Faculty of the New School for Social Research in New York City. Dr. Breen's research in the Health Services and Economics Branch at NCI focuses on how social inequalities are related to health outcomes, with special emphasis on cancer screening, the entry point to health services delivery for screenable cancer sites, where disparities first emerge along the cancer continuum. Dr. Breen served as NCI project officer to the National Health Interview Survey (NHIS) from 1999-2009, and she has served as NCI project officer to the California Health Interview Survey (CHIS) since 1999. Dr. Breen coordinates the CHIS Cancer Control Supplement Team at NCI, and some of her publications have explored using CHIS in creative ways to examine cancer screening in specific populations and localities.



Clarissa Hsu, Ph.D.

Research Associate and Program Manager, Group Health Research Institute

Medical anthropologist Clarissa Hsu (Ph.D.) is a research associate and program manager with Group Health Research Institute's Center for Community Health and Evaluation (CCHE). Dr. Hsu has significant expertise and experience in qualitative and mixed methods approaches to evaluating health and health care related topics. Dr. Hsu's research contributes to improving health by investigating clinical quality improvement measures, the effectiveness of community-based health improvement programs and health promotion policy, patient-centered care and healing, and complementary and alternative medicine (CAM). Dr. Hsu has served as principal and co-investigator for a variety of single and multisite projects, providing expertise in qualitative and mixed-methods evaluation and fostering a better understanding of how to improve the health of individuals and their communities through the research and evaluation of clinical, behavioral, and community/environmental interventions.

Appendix C

Biographies: Planning Committee



Leah Tuzzio, M.P.H.

Senior Project Manager, Group Health Research Institute

Leah Tuzzio is a senior project manager at the Group Health Research Institute in Seattle, WA. From 2005 - 2013, she was the Project Director for the NCI-funded Cancer Research Network (CRN), a consortium of HMOs studying the effectiveness of cancer control interventions. She oversaw all programmatic activities of the CRN and contributed to scientific and methodologic components of several CRN studies. She has worked on studies of the diffusion of cancer therapies, cancer survivorship, chronic illness care, quality of care, innovations in practices and health systems, and community outreach and evaluation. She studied anthropology and biology at the University of California, San Diego. Her master's in Public Health is from Emory University's Rollins School of Public Health.



Charlotte Hafer

Project Management and Operations Planning Representative Sr., IS&GS, Lockheed Martin Corporation

Charlotte Hafer has worked as a project manager, management analyst, and research analyst on contracts with the U.S. Department of Housing and Urban Development, the U.S. Department of Health and Human Services, and the U.S. Department of Education for the last 19 years. Her work has focused particularly on housing and community development programs at the federal level, including those related to public housing, economic development, drug elimination, homelessness, housing assistance, and HUD-sponsored research. She completed her B.A. and doctoral comprehensives and orals at the University of Maryland, College Park in the areas of international economic development, international relations, and political theory.

Appendix D

Table of Contents of Review Materials and Resources

1. Overview (38 pages, total)

i. **The California Health Interview Survey: An Invaluable Resource for Cancer Control Research, Policy, and Practice**

For more than a decade (1999-2013), NCI has supported CHIS questionnaire items across the cancer control continuum. This document provides an overview of CHIS's unique contributions to cancer control research, policy, and practice and highlights findings from selected key publications. (12 pages)

ii. **Policy by Numbers: Using Data to Dispel Myths and Inform Decisions**

This article relates the story of the UCLA Center for Health Policy Research and its California Health Interview Survey (CHIS) through the vision of its founding principal investigator, Dr. E. Richard Brown, and the advocacy of Dr. Ninez Ponce, now principal investigator of CHIS. (7 pages)

iii. **NCI Poster: Designing Regional Surveillance Systems to Inform Local Health Actions: CHIS**

This poster provides a snapshot of how the UCLA Center develops each survey cycle, collects data, disseminates results and measures the impact of CHIS. (1 page)

iv. **NCI CHIS Fact Sheet**

This fact sheet from NCI provides background information on CHIS, and information on the use of survey results and funding sources for CHIS. It includes links to other CHIS resources, including AskCHIS, the online data query system; reports, policy briefs and fact sheets about CHIS; and public-use data files and documentation. (2 pages)

v. **NCI Workshop: Maintaining and Enhancing Representativeness of State Health Surveys**

This report summarizes the proceedings of a workshop on "Maintaining and Enhancing Representativeness of State Health Surveys: Lessons for the California Health Interview Survey (CHIS)", held in 2009. The workshop brought together leading survey methodologists to discuss the most pressing issues confronting the California Health Interview Survey and other telephone surveys. The discussion focused on the representativeness of population-based surveys with large, ethnically diverse populations and alternative approaches to random-digit-dial landline surveys given the continued growth of cell-phone-only households and declining response rates. Participants explored alternative data collection options for the future. (~5 pages)

vi. **CHIS Peer Reviewed Journal Articles**

This is a complete list of all 96 CHIS peer reviewed articles (hyperlinked to their PubMed abstracts) in the areas of cancer screening and cancer control; diet and nutrition; obesity; and physical activity supported by NCI. (11 pages)

2. CHIS: Making an Impact (109 pages, total)

i. **CHIS "Making an Impact"**

This fact sheet describes how CHIS data has been utilized by public and private sector organizations to assist their work and to advocate for new laws and policies designed to promote healthy choices and greater access to health care. Evidence of the impact of CHIS data is also provided by its acceptance as credible and relevant by policymakers and advocates working on all sides of the health care reform debate in California. (4 pages)

ii. **Over 2.2 Million Low-Income California Adults Are Food Insecure; 658,000 Suffer Hunger (2002)**

CHIS 2001 found that more than 2.24 million low-income adults in California have difficulty affording food, with one out of three "food insecure" adults experiencing episodes of hunger. This article discusses the demography of hunger in California and participation in government nutrition programs among those affected. It ends with policy recommendations encouraging that the reach of existing nutrition programs be expanded. The food security questions on the 2001 survey were asked of individuals in households whose incomes were estimated to be less than 200 percent of the federal poverty level, with the interview focusing on the lack of resources or money that led to food insecurity over the prior 12-month period. Only persons living in households with telephones were surveyed. (8 pages)

Appendix D

Table of Contents of Review Materials and Resources

iii. **More California Teens Consume Soda and Fast Food Each Day Than Five Servings of Fruits and Vegetables (2005)**

More than two-thirds of California adolescents drink soda every day and nearly half consume fast food, while only one-quarter eat five or more servings of fruits and vegetables. This policy brief examines consumption of soda, fast food, and fruits and vegetables by adolescents based on data from the 2003 California Health Interview Survey. Policy recommendations are presented to address high rates of soda and fast food consumption and comparatively low intake of fruits and vegetables by California teens. (8 pages)

iv. **Bubbling Over: Soda Consumption and it's Link to Obesity in California (2009)**

Data from CHIS 2005 show that drinking sweetened beverages is common among California adults, adolescents, and children. This brief examines geographical variation in soda consumption and discusses the linkages between the consumption of sweetened drinks, overweight and obesity, and health risks associated with overweight and obesity. (8 pages)

v. **Two-Thirds of California's Seven Million Uninsured May Obtain Coverage Under Health Care Reform (2011)**

According to CHIS 2009, almost 4.7 nonelderly adults and children of the 7 million Californians who were uninsured for all or part of 2009 will be eligible for insurance as a result of health care reform legislation. Eligible Californians will obtain coverage either through Medi-Cal or through subsidies to purchase private health insurance in the new California Health Benefit Exchange (CHBE), which will also be open to uninsured persons who do not qualify for subsidized premiums. Enrolling such large numbers of uninsured individuals may pose challenges, however. (6 pages)

vi. **Cancer Screening in California: Findings from the 2001 California Health Interview Survey (2003)**

This report describes cancer screening in California based on data from the 2001 CHIS. It examines screening rates for cervical, breast, colorectal, and prostate cancers by race and ethnicity, income, insurance coverage, usual source of care, and English proficiency. It provides local-level estimates of screening rates for California counties and county groups. The report makes several recommendations including the promotion of screening among immigrant communities, education about the importance of cancer screening in the absence of any symptoms or problems, and support for exemplary screening programs. (75 pages)

3. CHIS Questionnaires and related documentation (1324 pages, total)

These are the questionnaires that were administered as part of the 2001, 2003, 2005, 2007, and 2009 CHIS.

- i. **2001 Adult, Adolescent, Child, including NCI-sponsored Complementary and Alternative Medicine (CAM) fielded to a subset of respondents.** [98, 48, 70, and 45 pages, respectively. Conducted in English, Spanish, Cantonese, Mandarin, Korean, Vietnamese, Khmer.]
- ii. **2003 Adult** [107 pages. Conducted in English, Spanish, Cantonese, Mandarin, Korean, Vietnamese.]
- iii. **2005 Adult** [143 pages. Conducted in English, Spanish, Cantonese, Mandarin, Korean, Vietnamese.]
- iv. **2007 Adult and Adolescent** [148 and 48 pages, respectively. Conducted in English, Spanish, Cantonese, Mandarin, Korean, Vietnamese.]
- v. **2009 Adult and Teen** [181 and 45 pages, respectively. Conducted in English, Spanish, Cantonese, Mandarin, Korean, Vietnamese.]

CHIS covers numerous health-related topics, including asthma, sources of care, physical activity, diet, doctor visits, mental health, and health insurance coverage. Core CHIS questions are repeated every year to measure shifts over time. New questions are added each survey year to study emerging public health concerns.

- vi. **2011 Survey Topics** (2 pages)
- vii. **2009 Survey Topics** (2 pages)
- viii. **2007 Survey Topics** (2 pages)
- ix. **2005 Survey Topics** (2 pages)
- x. **2003 Survey Topics** (2 pages)
- xi. **2001 Survey Topics** (2 pages)

Appendix D

Table of Contents of Review Materials and Resources

These reports describe the weighting and variance estimation methods used in CHIS 2007 and 2009. They present the steps used to create the analytical weights for analyzing the data from the adult, child, and adolescent interviews. (2007 report: 218 pages; 2009 report: 161 pages)

- xii. **Report 5: Weighting and Variance Estimation including raking dimensions and factors, non-landline telephone adjustments, combining samples, and imputation (2007 and 2009)**

4. CHIS in Light of Other State and Local Health Surveys (30 pages, total)

- i. **States' Use of Local Population Health Data: Comparing the Behavioral Risk Factor Surveillance System and Independent State Health Surveys (2012)**

This article identifies and compares key features of independent comprehensive state health surveys (SHS) with those of the Behavioral Risk Factor Surveillance System (BRFSS) for addressing the need for statewide and local population health data. Comprehensive independent SHS were identified in 11 states and BRFSS surveys were identified in all 50 states. The authors found that the BRFSS and independent SHS each meet some key state and local data needs but result in data gaps and inefficient use of resources. Surveys could more effectively and efficiently meet future needs for comparable data if they were coordinated across states and at the national, state, and local levels. (7 pages)

- ii. **Independent State Health Surveys: Responding to the Need for Local Population Health Data (cleared by NCI; unpublished/PLEASE DO NOT SHARE)**

For this study, the authors conducted semi-structured interviews with representatives of nine state health surveys (SHS) to identify 1) core elements that help SHS meet the need for local data; and 2) strategies employed in creating SHS. They found that policy makers require local population health data to draft evidence-based public health policy; a "champion" is required to acquire funding and stakeholder support; and challenges include lack of consistent funding and uniform standards. Opportunities to support SHS include providing consistent funding; technical assistance and training to foster best practices, quality standards, and comparability across states; and an organization for SHS researchers to share resources, information, and experiences. (23 pages)

Appendix E

Synthesis of Panelists' Responses

Evaluation question #1: *How has the CHIS addressed important cancer control priorities?*
 (Summarized under Key Assets)

| Evaluator ¹ | Distillation of Key Points |
|------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | <ul style="list-style-type: none"> • Extensive coverage of populations. • Only source of cancer control data including American Indians. • Provides data that inform NCI's cancer control priorities. |
| 2 | <ul style="list-style-type: none"> • Population-based survey that includes social and contextual factors. • Informs interventions, policy and determinants of health. • Diverse and large sample that is administered in multiple languages. • Geocoded data describes contextual effects that inform policy and program planning. |
| 3 | <ul style="list-style-type: none"> • Breadth of topics. • Responsive to changing demands and issues. • Diverse and large sample. • Population-level data that can be used in local cancer control planning. • Widely disseminated and data is used in many publications. • Trainings to use the data and other tools are a resource. • Funded by many agencies while other states have had budget cuts. |
| 4 | <ul style="list-style-type: none"> • Consistent, continuous statewide survey with a breadth of topics. • Geocoded data which allows for multi-level analyses. • Publicly accessible. • User-friendly tools like AskCHIS. • Flexible, capacity to modify and add questions. |
| 5 | <ul style="list-style-type: none"> • Questions are informed through community input to meet local needs. • Survey methods improve through quality assurance and improvement. • Population-based survey that is widely disseminated. • Geocoded data which allows for sub-group analyses. • Model survey for other state and local surveys. • Publicly accessible and user-friendly. • Informs health policy and health promotion and literacy campaigns. |
| 6 | <ul style="list-style-type: none"> • Describes statewide cancer rates and cancer disparities. • Defines state and local health priorities and includes priority populations. • Informs policy-level interventions and the allocation of resources. |
| 7 | <ul style="list-style-type: none"> • Diverse and large sample. • Breadth of cancer control topics. • Uses advanced survey methods. |
| 8 | <ul style="list-style-type: none"> • N/A |

Evaluator¹ - Evaluator Codes; data are presented without attribution

Appendix E: Synthesis of Panelists' Responses

Evaluation question #2: *What are the important cancer control priorities or issues that the initiative has not addressed, but could or should? (Summarized under Key Areas in Need of Improvement)*

| Evaluator ¹ | Distillation of Key Points |
|------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | <ul style="list-style-type: none"> • Collect biological samples and markers particularly from Asian, Latino and American Indian populations. • Examine behavioral economic interventions. |
| 2 | <ul style="list-style-type: none"> • Cross-sectional data can be used to assess trends, but they don't establish causal linkages or describe how groups change over time. Track individuals by diagnosis or risks. • Plan policy experiments. • Collect biological samples and markers. Test methods to link biological samples with social variables to describe correlates of cancer risk and diagnoses. • Test alternative sampling strategies and methods to improve response rates. • Increase community input and dissemination by publishing the successes and failures of establishing a model population-based survey. |
| 3 | <ul style="list-style-type: none"> • Limited internal validity. • Use CHIS to evaluate the effectiveness of interventions and natural experiments. • Not exactly comparable to other statewide health interview surveys. |
| 4 | <ul style="list-style-type: none"> • Modify or remove questions that are under-used and include questions based on users' interests. • Add questions like timeliness of receipt of abnormal results; reasons for never having been screened; household instability; perception of who is responsible to be aware of cancer prevention and control; intergenerational discussion about cancer prevention and control. |
| 5 | <ul style="list-style-type: none"> • Add questions on: psychosocial factors; social factors; harmful exposures. • Be a leader in generating population-based risk measures. |
| 6 | <ul style="list-style-type: none"> • Add questions on smoking of cigarillos, etc. and other highly-carcinogenic, non-cigarette products. |
| 7 | <ul style="list-style-type: none"> • Contribute more to health services research and comparative effectiveness research. • Add questions on clinical quality of cancer care. |
| 8 | <ul style="list-style-type: none"> • N/A |

Evaluator¹ - Evaluator Codes; data are presented without attribution

Appendix E: Synthesis of Panelists' Responses

Evaluation question #3: *How has the CHIS had an impact on cancer control research, health policy, and clinical practice?* (Summarized under Key Assets)

| Evaluator ¹ | Distillation of Key Points |
|------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | <ul style="list-style-type: none"> • Being available to community organizations and informing the health department and legislature. • Highly disseminated through peer-reviewed publications and national health policy. • Culturally appropriate survey and available in multi-languages. • Used to inform analytic tools and surveillance software. |
| 2 | <ul style="list-style-type: none"> • Dissemination of findings that have led to health policy changes. • Creation of tools like AskCHIS. • Publicly accessible data. • An opportunity of researchers from minority groups to study cancer control issues confronting their communities. |
| 3 | <ul style="list-style-type: none"> • Dissemination of findings that inform policy makers and public health practitioners although it is difficult to assess the cause of change in cancer control policies. • Publicly accessible data. |
| 4 | <ul style="list-style-type: none"> • Publicly accessible data. |
| 5 | <ul style="list-style-type: none"> • Breadth of topics. • Used to explore distal associations to inform new prevention strategies. |
| 6 | <ul style="list-style-type: none"> • Defines health priorities and priority populations. • Informs policy-level interventions and the allocation of resources to improve health. |
| 7 | <ul style="list-style-type: none"> • Serves as a statewide surveillance tool and model to other states. |
| 8 | <ul style="list-style-type: none"> • Informs local and national health policy. • Highly disseminated through health policy reports. • Large and diverse population. • Used to study health disparities and health needs. |

Evaluator¹ - Evaluator Codes; data are presented without attribution

Appendix E: Synthesis of Panelists' Responses

Evaluation question #4: *How can the utility and impact of CHIS be enhanced? (Summarized under Key Areas in Need of Improvement)*

| Evaluator ¹ | Distillation of Key Points |
|------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | <ul style="list-style-type: none"> • Increase the sample size. • Show data by regions within counties. • Collect biological samples, at least for a subset of the sample. |
| 2 | <ul style="list-style-type: none"> • Market the use of the data through user workshops. • Increase dissemination through publishing policy reports in scientific journals and develop a special journal issue to incentivize using CHIS data. |
| 3 | <ul style="list-style-type: none"> • Make CHIS available in every state. • Link CHIS data to other health information data that is readily available. • Market the access and the use of the data that is available on-line. • Make data on the representativeness of the sample and response rates available. |
| 4 | <ul style="list-style-type: none"> • NCI should help decide which questions to skip periodically to make room for new questions. |
| 5 | <ul style="list-style-type: none"> • Incorporate user feedback in enhancing CHIS. • Through users' needs assessment, market and expand the use of the data to increase its outreach. • In AskCHIS, include visual geographic displays of population data. • Link CHIS data to administrative data |
| 6 | <ul style="list-style-type: none"> • Increase dissemination in various ways at the community-level to encourage community-level action to improve health. • Include area-level measures of poverty and segregation. |
| 7 | <ul style="list-style-type: none"> • Increase response rates and explore alternative data collection methods other than the telephone. |
| 8 | <ul style="list-style-type: none"> • Improve the level and stability of funding to provide more consistent questions to support longitudinal analyses. • Collect clinical and health services utilization data on a subset of CHIS respondents. |

Evaluator¹ - Evaluator Codes; data are presented without attribution

Appendix E: Synthesis of Panelists' Responses

Evaluation question #5: *How do state and local health survey data improve our understanding of cancer control science above and beyond the national surveys?* (Summarized under Strengths of State and Local Survey Data)

| Evaluator ¹ | Distillation of Key Points |
|------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | <ul style="list-style-type: none"> • Describes social, political, economic, and physical environment. • Used in policy simulations and health research. • Describes how health policies, and control and prevention efforts are implemented. |
| 2 | <ul style="list-style-type: none"> • Describes depth of cancer control measures, while national surveys provide breadth. • Adds new knowledge that is specific to a particular locality or group. • Serves to test methods and sampling strategies that can enhance national surveys. |
| 3 | <ul style="list-style-type: none"> • Describes local context and should be used as a model for other states and communities. • Link to health system data. |
| 4 | <ul style="list-style-type: none"> • Ability to evaluate local-level census-track data. • Representative data of local areas. |
| 5 | <ul style="list-style-type: none"> • Patterns of disease are linked to local data. • Ability to assess geographic differentiation and to identify “hot spots”. • Describes social context. • Ability to assess health disparities. |
| 6 | <ul style="list-style-type: none"> • Identifies where health problems and needs are to help target interventions. |
| 7 | <ul style="list-style-type: none"> • Covers a diverse population. • Can be used to compare to other state or national health surveys. |
| 8 | <ul style="list-style-type: none"> • N/A |

Evaluator¹ - Evaluator Codes; data are presented without attribution

Appendix F
Completed Evaluation Worksheets
Evaluation of the California Health Interview Survey (CHIS)

Evaluator #1

1. How has the CHIS addressed important cancer control priorities?

Perhaps one of the most important ways that CHIS addresses U.S. cancer control priorities is through its extensive coverage of populations, particularly Asian, Latino, and American Indian populations that largely are not adequately examined by other data sources. In fact, it is among the only sources of cancer control data to inform efforts among American Indians available. This allows NCI to ensure products of cancer control research that effectively applies to all segments of the U.S. population. It also has allowed NCI to effectively monitor health inequalities experienced by populations largely ignored in other national monitoring and surveillance systems.

The CHIS has provided data in support of a number of cancer control areas that inform NCI's priority efforts. It has provided basic information for making epidemiological estimates, introduced new survey research methods (e.g., mixed land-line and mobile phone sampling frames), provided information about modifiable risk factors such as tobacco and alcohol use. Furthermore, the data collected provides the basis for understanding the behavioral and psychological of diverse populations at risk for cancer furthering our understanding individuals healthy and unhealthy behaviors such as dietary intake and exercise,

2. What are the important cancer control priorities or issues that the initiative has not addressed, but could or should?

Unlike the National Health Interview Survey, the CHIS has not engaged in large scale collection of biological samples because it has largely been conducted over the years as a telephone survey. The NCI has not invested in the CHIS to collect biospecimen and biomarker to validate survey response data or to advance the nation's biospecimen infrastructure, particularly among Asian, Latino, and American Indian populations. Such an investment would greatly enhance the NCI's genomic research agendas and understanding of racial and ethnic disparities in cancer susceptibility.

Nor has the NCI used the CHIS to examine behavioral economic interventions. For example, the CHIS could be used to better understand how economic incentives might be used to improve dietary intake and increase physical activity in low-income populations or other tobacco control measures that California communities continue to test and explore.

3. How has the CHIS had an impact on cancer control research, health policy, and clinical practice?

The CHIS has had both impact at the state and national levels. The many reports and availability of data to community organizations has played a major role in informing California's health department and legislature. It has played a key role allowing California decision makers to gain access to information about a wide range of risk factors, including obesity and health behaviors and explore protective factors.

Appendix F

Completed Evaluation Worksheets

Nationally, investigators have contributed many peer-reviewed publications and contributed to our understanding of cancer control as well as inform national health policy for American Indians cared for by the Indian Health Service. It has provided information for ethnic populations and demonstrated that health interviews can be created that are culturally appropriate for populations that speak languages other than English and Spanish. The NCI intramural research program has used CHIS data to construct cancer control tools such as HD*Calc, software used to monitor health disparities as well as used these data for making estimates of important behavioral factors to prevent cancer in the U.S. population.

4. How can the utility and impact of CHIS be enhanced?

Given that California reflects or amplifies the characteristics of the nation, as it's population accounts for about 10 percent of the entire U.S. population. Allowing for additional small area estimates by increasing its sample size could enhance the CHIS. For example the sample currently only allows county level estimates for a few of the state's larger counties. Ideally, we could learn a lot from the CHIS with a more robust sampling of the rural counties. Ideally, we could learn even more about the larger counties by allowing for regions within counties to be examined more closely. For example, Los Angeles County is an expansive region with locations within it that are rural while others are highly industrial urban settings. Understanding how these environmental, both physical and socio-economic affect cancer would provide considerable insight for control and prevention efforts nationally.

As I have written above the CHIS would be further enhanced by including the collection of biological specimens and biomarker information for at least a share of the sample. This would allow the CHIS to further enhance the information collected by the NHIS, particularly as it affects smaller racial and ethnic populations.

5. How do state and local health survey data improve our understanding of cancer control science above and beyond the national surveys?

State and local data allow us to better understand the social, political, and economic environment as well as the physical environment that people live in and within which they make behavioral choices that affect their health. These data allow for making estimates that are important for policy simulations and other kinds of research.

Local and state survey data can also allow us to better understand how health policies and control and prevention efforts operate. Most ordinances are implemented in local jurisdictions, such as those that implement tobacco control efforts or control access to sugar-laden products such as the selling of soft drinks in schools can only be understood by studying variations across local jurisdictions. This can only be done through local and state surveys such as the CHIS.

Other Comments (optional): N/A

Appendix F Completed Evaluation Worksheets

Evaluator #2

1. How has the CHIS addressed important cancer control priorities?

It is evident from existing data, published articles and book chapters, and public reports that biological and genetic factors do not by themselves explain who is likely to have a cancer diagnosis, seek treatment, or receive appropriate care. Contextual and social factors are equally if not more important in identifying who gets sick, screened, and treated in different and diverse communities. CHIS is a well-regarded population-based survey that provides useful data on the social and contextual factors that affect different facets of cancer control. These data are especially useful to investigate prevention and access to health care issues – both of which are critical components of the Affordable Care Act. CHIS provides data that can be used to assess the factors that help distinguish between respondents who have a cancer diagnosis or at risk for cancer and those who do not have a diagnosis or not at risk. Knowledge of these factors is particularly useful for interventions and policy decisions. Similarly, not everyone who has cancer symptoms or who is at risk for cancer is screened or accesses care in a timely manner. The population based survey provides data that can assess the demographic, lifestyle, attitudinal and behavioral factors that are associated with screening and access.

CHIS has a distinct advantage of including multiple racial and ethnic groups in its sampling plan. Accordingly, the data has the potential to identify similarities and differences across groups, not only in prevalence estimates but in the factors associated with cancer and risk. Geneticists and social scientists generally agree that race as a biological or essentialist construct lacks empirical support and is an obsolete conceptualization as originally conceived. For example, genetic studies find that there are few genetic differences across racial groups. Contemporary social scientists also challenge essentialist notions of race by arguing that people make attributions about groups based on stereotypes and prejudices that are tied to some physical traits. Despite the ambiguities and complexities of racial categories, *race still matters*. Racialized categories carry with them implicit and explicit images and beliefs about racial groups that form the basis and rationale for treatment of group members. These stereotypes form the basis for the treatment of individuals within racial groups. Race is particularly meaningful when group members are denied equal opportunity and access to power and desired goods and resources. The concept of ethnicity is often used interchangeably with race. Ethnicity refers to the sense of community or identification with others on the basis of language, nationality, or cultural characteristics. Race and ethnicity overlap because members of a racial group may share a similar history and cultural bond. What separates the two from each other is that race involves distinguishing physical attributes, as seen by group members or others, make it difficult to change racial identities; ethnicity is the more malleable concept. African Americans are more often included in cancer research than other racial and ethnic minority groups – even though the volume of research activities and studies on cancer control issues confronting African Americans are still rather limited. More often than not, when race comparisons are made, investigations typically focus on establishing differences between African Americans and Whites. Thus, like much of the available empirical literature in other subject areas, the experiences of other racial and ethnic groups are not adequately captured. The CHIS includes multiple racial and ethnic groups with the explicit goal of understanding the similarities and

Appendix F

Completed Evaluation Worksheets

differences across these groups. The inclusion of groups such as African Americans, Native Americans, Asian Americans, and Latinos helps refine theories that contextualize or link race and ethnicity to health. Moreover, CHIS has the capability to move beyond the overall Asian category to examine specific ethnic groups within it.

The demographic characteristics of the United States and, in particular, its racial and ethnic composition has changed radically over the past century and demographers predict that the country will undergo even more changes over the next 50 years. Immigration accounts for a large part of the demographic shift in the U.S. A major difference between the rise in the immigrant population in the early 1900's and the current increase is the countries of origin. In the early part of the 1900's, most of the immigrants came from Europe and Canada; the more recent immigration has come primarily from Asia and Latin America. This demographic transformation has strong implications for researchers, policy makers, and service providers alike. Since recent immigrants may speak languages other than English, language can influence knowledge and behaviors about diets, nutrition, exercise, medical care that in turn affect health. Language can also affect access to care and medical treatment. In the conduct of a survey, language can also affect entry into communities and response and completion rates. CHIS researchers have gained extensive experience in conducting the survey in multiple languages and have the capacity to examine how language is associated with cancer control risk and outcomes. This experience has the potential to inform the substance of cancer control and the methods for conducting research in immigrant communities.

CHIS has the capacity and potential to examine large contextual and community level effects on cancer control measures. The two past decades have been marked by a resurgence of interest in the influence of place on health and health behaviors. For the most part, however, studies supposedly about the effects of place have actually been based on the aggregated characteristics of individuals as measured in censuses or other surveys. Typically, the proportion of variance in health behaviors explained by these limited operationalizations of place have been small, prompting some to suggest that place has only a limited effect on individual behavior. These weak effects are more likely due to inadequate conceptualization, operationalization, and measurement of "place effects." The CHIS has geocoded data that provides the means to define characteristics of neighborhoods and examine their effects on cancer control measures independent of individual and clinical measures. These types of analyses provide policy makers with potential community level changes that can be made to reduce the risk for cancer diagnoses.

2. What are the important cancer control priorities or issues that the initiative has not addressed, but could or should?

CHIS is a series of cross-sectional surveys conducted in California. The response in Question 1 highlights a few important features of CHIS especially the social and contextual factors that may influence health. The cross section data can be useful in assessing trends in the prevalence and correlates of cancer control measures, but they are unable to establish causal linkages or how groups change in their behaviors over time. One possibility to consider is to track individuals by diagnosis or risks to better gauge the factors associated with change over time.

Appendix F

Completed Evaluation Worksheets

Another possibility is to plan policy experiments for different neighborhoods and monitor how policies influence changes in behavior and ultimately cancer control outcomes.

CHIS has the potential to test different methods for collecting biological markers in its population survey. Given its large sample size, there are challenges, especially expense, that can limit the collection of biological markers. However, testing methods and procedures can help the field in linking biological markers with social variables to better understand the correlates of cancer risk and diagnoses in different ethnic and linguistic communities.

On a related note, survey response rates have significantly dwindled over the past two decades. CHIS may be able to test alternative sampling strategies and methods (e.g., address based samples, multiple sample frames, use of mobile technologies) to access relatively rare populations and to increase response rates in the general population.

It is apparent that CHIS has spent considerable effort in establishing community collaborations in receiving input in the development of the survey content, gaining access to communities, sharing insights for data analyses, and disseminating results. CHIS could provide more publications that highlight its successes and failures in community collaborations and dissemination particularly in establishing models that can be used in other states and communities.

3. How has the CHIS had an impact on cancer control research, health policy, and clinical practice? Comment on this issue for California specifically and for the U.S. overall.

As indicated earlier, CHIS seems to have been successful in disseminating findings to policy makers and researchers. They have created mechanisms such as *askCHIS* that serves as a model for other states and NHIS. The findings have also led to policy changes such as the marketing of sugar-sweetened beverages and the prohibition of new fast food restaurants in South Los Angeles.

CHIS is successful in training the next generation of researchers studying cancer control by making the dataset publically available in a timely manner. Most of the publications on cancer control include researchers not formally affiliated with CHIS. In addition, the CHIS data allows researchers from different minority groups to conduct analyses and write scientific papers on cancer control issues confronting their communities. These types of opportunities are relatively rare and help build the pool of minority researchers doing research on cancer control.

4. How can the utility and impact of CHIS be enhanced?

CHIS may want to consider a series of user workshop to publicize and make the dataset used more widely across the country. There are established models for user workshops such as Fragile Families and ADD Health.

Sixty-percent of the cancer control reports and articles have been published within the past five years (2008-2012). This large percentage holds true for the specific areas of cancer control listed in the CHIS overview (physical activity; diet; obesity; tobacco control and alcohol

Appendix F

Completed Evaluation Worksheets

consumption; and cancer screening). This increase publication activity over the previous five years probably reflects the maturity of the survey, the lag time before publication, public awareness about CHIS, and more sophisticated mechanisms to make the dataset available to researchers. While the suggested workshops help to publicize the CHIS, CHIS can engage in at least two other strategies to publish findings in scientific journals. First, develop follow up mechanisms to submit policy reports to journals. It is not clear whether policy reports cited in the CHIS documents are later published in scientific journals. Second, work with journal editors to develop special sections or issues of journals around cancer control themes to create incentives for using CHIS data.

5. How do state and local health survey data improve our understanding of cancer control science above and beyond the national surveys?

National surveys can provide the breath of cancer control measures over a wide range of geographic areas and state and local survey data can provide added depth for specific areas. For example, national cancer control survey data may show that education is strongly associated with smoking with people with lower levels of education smoking more than people with higher levels. Local survey data can examine this association in more detail for groups that are not easily covered in national surveys. In this same example, the CHIS may find that the educational association may not hold up among immigrants and that other dimensions of the immigration experience may show a strong association with smoking. The point is that local and state surveys not only complement national surveys, but they can also add new knowledge about cancer control that are specific to a particular locality or about groups that are not adequately sampled in national studies.

Local and state surveys can help test methodological and sampling strategies that can enhance national surveys. As indicated above, one potential direction for CHIS is to be a site to test alternative methods of sampling and survey technology that can fortify the science of cancer control. CHIS may be able to do it more expeditiously and efficiently at the state or local level than national studies.

Other Comments (optional): N/A

Appendix F

Completed Evaluation Worksheets

Evaluator #3

1. How has the CHIS addressed important cancer control priorities?

CHIS has clearly addressed leading cancer control priorities in California, and in the Nation. The strengths of CHIS are well documented in the materials that were sent for review. Several highlights include:

- CHIS includes a wide variety of subject areas, ranging from tobacco to breast and cervical control.
- Is responsive to changing demands, and can include issues that are relevant to cancer control.
- The large sample size and diverse populations permits CHIS to examine cancer control issues in special populations (that are difficult to address in nationally represented surveys).
- Similarly, the large sample size permits detailed estimates for local communities, thus increasing its relevance and potential use in local cancer control planning and evaluation.
- CHIS promotes the dissemination and use of the data, through trainings and online resources.
- CHIS has a long-standing track record and significant financial support from a variety of agencies. This is unusual at present, as other states have seen budget cuts and surveys being eliminated.

2. What are the important cancer control priorities or issues that the initiative has not addressed, but could or should?

The CHIS is limited in the following ways:

- CHIS (and telephone surveys in general) has good external, but limited internal validity. CHIS is best at providing information about California and its subpopulations, but is limited in its internal validity. This is best assured using surveys that measure individuals precisely, using in-person examinations (e.g., NHANES) and collect a wide variety of individual and contextual variables.
- There is a great need in cancer control to advance the evidence base of “what works” in community-based and health policy interventions. Nearly all of the publications listed in the materials are descriptive in nature, describing risk factor or health screening rates, or looking at correlations in the population. CHIS could be more useful if it was designed to evaluate the effectiveness of interventions, such as natural experiments that result from differences in the implementation of programs and policies across the state.
- As pointed out in the materials, CHIS is not comparable to the health interview surveys conducted in other states (e.g., Wisconsin has a statewide in-person survey called the “Survey of the Health of Wisconsin (SHOW)).

Appendix F

Completed Evaluation Worksheets

3. How has the CHIS had an impact on cancer control research, health policy, and clinical practice? Comment on this issue for California specifically and for the U.S. overall.

In order to have impact, the information from CHIS must be disseminated. The publication record is outstanding, ranging from peer-reviewed research to publications that can be used by policy makers and public health practitioners.

However, dissemination alone does not necessarily lead to changes in health policies or clinical practice. The true impact of CHIS on cancer control outcomes is difficult to assess, as the factors responsible for changes in cancer control policies are complex and difficult to measure. A temporal association between the release of a report and a change in a policy or program supports the hypothesis that CHIS caused this change, but this is weak causal evidence, at best.

Therefore, one must trust the “logic” of cancer control and public health surveillance. The CHIS provides information to public health professionals and policy makers, and this information is available for use for program planning and policy advocacy.

4. How can the utility and impact of CHIS be enhanced?

The utility and impact of CHIS could be enhanced by extending the program to every state and community:

- Consider stronger links and connections to health information that is collected by providers in the HER. Given the high cost of survey data in general, and the increasing difficulty in reaching people by telephone, cancer control programs will need to find more cost effective sources of health information, such as from local health systems and payers, and be able to develop methods to collect comparable data that are already available.
- Continue to promote the access and use of online data. Note—when I tried to sign up as a user, I was not able to get an account. I emailed technical assistance, and discovered that I had gone to a website that is restricted, and I was redirected to the website for the general public.
- There is relatively little information about the representativeness of the sample (e.g., non-response), nor the ways that CHIS will be addressing declining response rates and new forms of social media (if this information is available, I did not see it). This represents a major challenge for all survey research. This information should be considered as part of a critical review of the limitations of the current system.

5. How do state and local health survey data improve our understanding of cancer control science above and beyond the national surveys?

All politics is local—so all data should be local. The most compelling examples of impact of CHIS has been with cancer control issues in California. The methods used in CHIS could be disseminated to other states, and even communities.

Appendix F

Completed Evaluation Worksheets

The report states that “Before CHIS, only limited data were available on the use of cancer screening among specific subpopulations, particularly Latinos, Asians, and American Indians/Alaska Natives.” This statement is only partially true, since data exists within health systems, it’s just that these health systems/payers do not use the information and/or do not share the information publically. The value of CHIS would be significantly enhanced if the methods were adapted to include data that is routinely collected, such as in the EMR, or in health assessments that are being done more frequently by health plans.

Other Comments (optional):

In sum, CHIS is an extremely valuable cancer control resource, not only for California, but for the nation. Some of the challenges are inherent to all surveys (e.g., high costs, non-response).

However, quality is only one dimension in assessing the value of a surveillance system—the other is cost. I could not find the total costs, and cost per interviewed subject. This information is critical if other states and communities are considering developing comparable systems.

In the end, I think that it’s important to answer this question: Will CHIS be considered truly successful, if it is only conducted in California, and is not a model that is replicated throughout the nation?

Appendix F

Completed Evaluation Worksheets

Evaluator #4

1. How has the CHIS addressed important cancer control priorities?

CHIS is a great resource for cancer control because it is a statewide survey done on an every-other-year schedule. This regular periodicity of the survey creates a unique archive of data with a broad range of questions. In contrast, the BRFSS is also an important source of data, but its “core module” has a very basic set of questions, so the core BRFSS is not as rich a resource as the CHIS. By design, the NHIS cannot be a statewide source of data.

In addition, the ability of CHIS data to be linked to geographical/spatial data is significant. CHIS really is a model for linking a state-wide survey on individual participants to higher-level variables, to allow multi-level analyses.

In regard to addressing cancer control priorities and public access... The CHIS has a fundamental premise of being accessible to users. The AskCHIS feature is a convenient and significant resource. CHIS has also shown readiness to modify its content and procedures to add questions and investigate methodological issues.

The best resource for CHIS addressing cancer control priorities is its ability to be flexible from survey to survey, and to add new questions if deemed appropriate. I am very impressed by the ability of the CHIS team to review the content of the CHIS and add questions.

2. What are the important cancer control priorities or issues that the initiative has not addressed, but could or should?

One piece of advice I'd have for the NCI staff & CHIS staff is to review the cancer-relevant questions of the CHIS surveys and determine if any questions are being under-utilized when it comes to peer-reviewed publications. Do the same thing if possible with regard to data requests from AskCHIS. If there are gaps in CHIS cancer-related publications and/or data requests, some of it may be due to user-based interests and queries, not to the CHIS content itself.

Some things I'd be interested in are: (1.) for those with a prior cancer diagnosis, the length of time between the abnormal result and being notified; (2.) reasons for never having been tested for breast, cervical, and colorectal cancer, for people 15 years older than the eligibility criteria; (3.) household instability (including domestic violence) as a factor associated with non-performance of cancer-relevant health practices; (4.) perhaps “politically incorrect” or sensitive to ask, but a question that asks the respondent for an assessment of where responsibility lies to be aware of cancer prevention/control behaviors...what is the balance? – such as between self, government, health care provider, media; (5.) A question about intergenerational discussion of cancer prevention/control topics... does it happen at all?

Honestly, I don't know if the above questions can be addressed with current questions in the CHIS. I'd have to look at the specific surveys.

Appendix F

Completed Evaluation Worksheets

3. How has the CHIS had an impact on cancer control research, health policy, and clinical practice?

I am not able to evaluate this question. There are no “impact” criteria that I can draw on. However, the volume of inquires to AskCHIS does strongly indicate that the surveys and database are known and considered useful enough to be utilized.

4. How can the utility and impact of CHIS be enhanced?

It seems to me that the CHIS has been flexible and responsive to the need for modification to address methodological aspects of data collection, especially in light of the downturn of response rates.

And, the AskCHIS feature is based on the best of intentions to bring data to public relevance as quickly as possible. Honestly, I don't see how CHIS can do any better in its delivery to the public.

That said, I expect there are behind-the-scenes planning meetings for the content of the next CHIS survey, and maybe even the one after that. I don't know the membership/contributors to those meetings, but from my experience in similar meetings for other surveys, I expect there are “interests” being represented and advocated for question content. Assuming that there is limited “X” space for NCI-sponsored questions. I would therefore advocate for a 5-year plan for NCI involvement. Have your planning committee decide on questions that can be skipped for one cycle, to allow other content/questions, such as in the areas listed in the response for Question 2.

5. How do state and local health survey data improve our understanding of cancer control science above and beyond the national surveys?

The limitations of national survey data for application to state and local cancer control are evident to anyone who understands literature on correlates of health behaviors, morbidity, and mortality. I was primary author for a paper that examined the consistency of correlates of cancer screening across USA Census regions, using the BRFSS. The consistency across Census regions was only modest, and those analyses could not drill down to lower levels of aggregation.

National-level survey data are the best we have for tracking overall utilization, as an aggregate data point. That said, I can't speak for non-screening cancer-related behaviors, but the self-report bias in those surveys (BRFSS, NHIS) is to overestimate recent screening. I don't particularly trust the exact accuracy of screening estimates from either survey... though I have more faith in the NHIS than the BRFSS. And even with self-report bias considered, one should expect that national-level data are not representative locally or in small areas. Unfortunately, I'm not at all sure why self-report from local or small-area samples is any more reliable than self-report in national-level surveys. So, call me ambiguous on this question/topic. I think that from an NCI/governmental perspective, the key consideration is to know where to put their money into the least unreliable data source.

Other Comments (optional): N/A

Appendix F

Completed Evaluation Worksheets

Evaluator #5

1. How has the CHIS addressed important cancer control priorities?

There are five, unique components to the CHIS strategy that distinguishes it from other approaches: 1) it is adapted at the front-end to meet local needs and conditions by insuring a broad base of input on issues across stakeholders, policymakers and researchers; 2) it has built-in trial-and-error learning features that lead to methodological improvements in each round; 3) population-based data are generated at a sufficient resolution-level to permit both spatial and sub-group analyses of unmet needs and disparities; 4) dissemination of results takes place in multiple forms and through a variety of access points and training support; 5) it plays a critical role as a model for state and local health surveys that builds capacity across the country and raises the standard for surveys in this class.

When these features are applied to cancer control priorities not only are unique kinds of evidence produced, but this evidence is also made publically accessible and targeted to decision-makers in forms they can use. Without it, there would be little sub-county or sub-group data of comparable worth and few sustained efforts to study such data trends over time. Further, a number of beneficial policy decisions on ACA implementation and behavior change would arguably not have been made due to a lack of sufficient evidence to justify their cost or impact. Finally, the utility of these data in targeting and then tailoring health promotion and literacy campaigns among those sub-groups in greatest need cannot be matched by other means.

2. What are the important cancer control priorities or issues that the initiative has not addressed, but could or should?

There are two kinds of mediating factors in cancer risk that would be useful to include in future surveys. Both are related to stressors. The first is psychosocial factors including perceptions of risk, sense of control, and level of stress that are thought to mediate resiliency and adaptability, and are currently viewed as proxies for differential susceptibility in populations. The second is social factors, such as trust and support that mitigate the stress response. CHIS' current efforts to measure cohesion and discrimination are important measures in this class.

A third set of measures would address harmful exposures directly. Self-reported chemical exposures in the household, occupational setting, and neighborhood would augment monitored and modeled pollution data and provide information on omissions and bias in risk estimation.

All three of these would provide evidence consistent with the principle of cumulative (as opposed to single cause, pathway or agent) risks. Measures of cumulative risk have been adopted as tools for risk screening in California and are under development in other states. CHIS could provide leadership in how best to generate population-based risk measures that are valid and reliable.

Appendix F

Completed Evaluation Worksheets

3. How has the CHIS had an impact on cancer control research, health policy, and clinical practice? Comment on this issue for California specifically and for the U.S. overall.

The most important impacts have come as a function either of the range of measures the CHIS includes or of their resolution down to sub-populations and (in a more limited way) the sub-county level. The range is important for exploring distal associations (such as social determinants) that hold clues for new prevention strategies. The emphasis on sub-population comparisons provided evidence on the magnitude of health disparities and had design implications for prevention strategies.

4. How can the utility and impact of CHIS be enhanced?

The initial design of the CHIS-2001 included an elaborate series of input opportunities and procedures, described collectively as CBPR. These built support for the concept and gave many participants a stake in the outcome. In short, it promoted use of the results and reputational capital for the entire enterprise. Although I could find no further documentation on these front-end activities in subsequent years, my impression is that it was replaced by technical and subject-matter panels, weighted heavily in favor of sponsor input. While the level of use witnessed by AskCHIS is admirable, the question is, are there potential users, say, at the local level, who are not currently being reached? Might there be issues under the radar, so to speak, that could only be detected through a return to the initial model of input?

To establish this, there needs to be a clearer connection made between what happens on the front end with selected input processes and the pattern of use at the back end. As the input process becomes routinized, there may be a tendency to narrow the focus to match the interest of sponsors. This becomes more complicated with the advent of a subscription model of support, where proprietary information is selectively disseminated. The high-visibility impacts on policy decisions may be sufficient to justify the CHIS investment, but it is unclear how deep the impact is and could be. Are the concerns of less data-savvy community-based organizations being addressed and, at the other end, are they at ease in accessing data and using it for their own purposes? What are the barriers and costs that they face in participating on either end? The deep impact I suggest requires a different kind of investment in outreach to focus on those organizations not being served by the data, at least in its current form.

The utility of AskCHIS and the public use file could be substantially enhanced through the inclusion of geographic units as variables (including sub-county units, where possible) and geographic displays of population data across units. The ability to create and display maps, for those without GIS resources, will expand the range of data uses and make the CHIS more versatile and accessible. This is especially important in community organizations made up of service providers, who have little or no analytical capacity to process or analyze CHIS data in its current form. Visual displays can also be used effectively in grass roots organizations where volunteers may have little data expertise.

There have been published studies that connected survey data with administrative data of different kinds. The question is, can the CHIS public-use data set (and AskCHIS) include these data directly in the same way that data on geographic units might be included? For example,

Appendix F

Completed Evaluation Worksheets

vital statistics (say, age-adjusted, cause-specific mortality rates, or rates of premature death by cause) might be included as reference points when comparing geographic or subpopulation rates of chronic disease or health risk behaviors. In effect, these data could be an overlay for self-reported rates of related conditions or preventive services by geographic unit.

5. How does state and local health survey data improve our understanding of cancer control science above and beyond the national surveys?

There are three major ways. The first is about context. From the perspective of an ecological model of health, most patterns of disease are linked in some definite way to the local context. Without being able to model the key factors in this context, we are left with proximate causes at the level of individual characteristics. We can account for aggregate patterns that are averaged over contexts (one context per respondent), relegating their effects to unexplained error. Alternatively, we can represent context empirically through the shared experiences and practices of people who function within them. Local survey tools can capture these with open ended responses of multiple respondents from each context.

The second is about geography. Local surveys allow one to compare adjacent areas within a given jurisdiction, controlling for shared characteristics, such as governance, but permitting variation in a number of group and neighborhood characteristics that are related to health and risk. This supports precision in assigning needs to specific areas and creates a built in metric for determining relative advantage and disadvantage across comparable areas. This level of resolution supports the identification of “hot spots” or areas with multiple needs, disadvantages and barriers to health opportunities.

The third is about social groups. Paralleling geographic differentiation, local surveys permit differentiation by social standing, ethnic and racial identification, and other ascriptive characteristics common to groups experiencing disproportionate risk burdens and health inequalities. Health inequalities linked to such social differences can then be related to the geographic patterns of concentration that reinforce them. The interaction of place and social status implicated in health inequalities will be missed by surveys that do not permit multiple cases to be drawn from prominent sub-populations and local settings.

Other Comments (optional):

The CHIS has set the standard for how population health surveys should be done. In itself, this demonstration would be important for many others attempting to replicate its scope in other locations. But the CHIS team did much more. They actively (and generously) disseminated the technical details of how the CHIS was done, so that survey capacity could be built elsewhere. This service to the science often goes unnoticed. The new Network for State and Local Surveys will formalize the diffusion of CHIS innovations and provide for mutual support within the independent, health survey community, continuing this legacy.

Appendix F

Completed Evaluation Worksheets

Evaluator #6

1. How has the CHIS addressed important cancer control priorities?

CHIS data have been critical to documenting cancer and cancer-related disparities in California (CA). Thus, the CHIS continues to play a major role in defining state and local health priorities and priority populations, and contributes to determining policy-level interventions and the allocation of resources to populations and communities to improve health in CA.

2. What are the important cancer control priorities or issues that the initiative has not addressed, but could or should?

One important cancer control issue that the CHIS does not address is the troubling and increasing smoking of little flavored cigars (cigarillos), bidis, blunts, kreteks and other highly-carcinogenic, non-cigarette products by adults and youth – with youth exhibiting the highest prevalence. Although a few nationwide surveillance systems (e.g., the 2011 Tobacco-Use Supplement of the Current Population Survey [TUS-CPS]) recently have begun to assess use of these products among youth and adults, most (e.g., BRFSS) nationwide systems do not, and statewide systems like the CA BRFSS and CHIS (2007 and 2009) likewise do not. Incidence of smoking-related cancers is up to 112% higher among smokers of bidis and kreteks, but the prevalence of bidi/kretek smoking in CA remains unknown. Likewise, the cancer-risks associated with polytobacco use (simultaneous smoking of cigarettes and other products such as cigarillos, blunts etc.) remain unknown. Use of these products (identified by brand name as in the TUS-CPS) needs to be included in the CHIS. My own studies of random, door-to-door, statewide samples in CA indicate that use of some of these products is common (i.e., 57%) among young, Black male cigarette smokers. This might inevitably explain Black men's puzzling high incidence of smoking-related cancers despite smoking fewer cigarettes per day and initiating smoking later in life than Whites. Prevalence data are needed on smoking each of these non-cigarette products, and examination of associated cancer- and other health-risks are needed as well, for adults and youth in CA, of all ethnic groups.

3. How has the CHIS had an impact on cancer control research, health policy, and clinical practice? Comment on this issue for California specifically and for the U.S. overall.

As noted above, CHIS data have played a role in defining priorities and priority-populations in CA, in the allocation of resources to improve health, and in policy-level changes to improve health – particularly where ethnic/racial disparities are concerned.

4. How can the utility and impact of CHIS be enhanced?

Broader dissemination of findings to communities, community organizations, and community leaders would be useful in that it can encourage community-level action to improve health; dissemination beyond journal articles and the CHIS website is needed. Likewise, inclusion of area-level measures of poverty and of segregation would enhance documentation and understanding of the local context of health problems and health needs, and so enhance efforts to target interventions and policies to improve health in specific high-risk communities. Area-level data also need to be included in the CHIS public-use datasets so that researchers

Appendix F

Completed Evaluation Worksheets

can conduct the much-needed analyses of area-level disparities. At present, area-level data are not widely available.

5. How does state and local health survey data improve our understanding of cancer control science above and beyond the national surveys?

State and local data are crucial to determining precisely where the health problems and needs are in a state, and hence fundamental to targeting local interventions to high-risk geographic areas and groups.

Other Comments (optional):

The CHIS is an invaluable resource that I've used for many years in my own research. For example, I used 2001 CHIS data in the publication on CA Latinos below, and am using 2006-2007 CHIS data in several manuscripts currently under review.

Corral, I., & Landrine, H. (2008). Acculturation and ethnic-minority health behavior. Health Psychology, 27(6), 737-745.

Appendix F

Completed Evaluation Worksheets

Evaluator #7

1. How has the CHIS addressed important cancer control priorities?

Because of its size (~50,000 per year) and the diversity of the California population it surveys the CHIS is able to collect, analyze and interpret data on cancer control risk factors, screening behaviors, health services utilization and other factors key to cancer control research. Priorities in the areas of reducing cancer-related health disparities, improved communication about cancer prevention and control and improving survey research methodologies are among those that have been key. The increased use of cell phones and reduced response rates to random digit dialing approaches have been especially challenging for a broad range of survey research. Because the CHIS is able to examine these methodologic issues in diverse populations it brings data to the table important to the field generally.

2. What are the important cancer control priorities or issues that the initiative has not addressed, but could or should?

The Affordable Care Act (ACA) is highlighting the need for comparative effectiveness and patient centered research to improve care. The CHIS has supported efforts in health services research but could do much more to meet the coming challenge for evidence of effectiveness.

More could be done to understand the challenges to the application of “precision medicine” in the area of health care service utilization, acceptability, costs and utility.

Exploration of clinical quality of cancer care measures may also be an area where CHIS could contribute population survey data across health system models, geography and age-gender-race/ethnic categories.

3. How has the CHIS had an impact on cancer control research, health policy, and clinical practice? Comment on this issue for California specifically and for the U.S. overall.

In general CHIS has had the most impact on cancer control research, health policy and clinical practice in California. But because it is really the only source for high quality data from a state-based survey nationally, it provides information that had informed the practices in other states. Like all such tools the CHIS is basically a surveillance tool in the same general category as a cancer registry. But it is important to remember that surveillance serves at least two major purposes. One is that it informs us as to “Where we are” in terms of key health metrics at the population level. For example, it tells us how many people are compliant with cancer screening recommendations, how many adolescents are using tobacco products and the changing prevalence of common chronic conditions like diabetes and hypertension that are important co-morbidities for cancer. Without knowing these results in population subgroups planning and resource activities are working in the dark. Second, surveillance data help generate hypotheses for research. When we note an increasingly wide disparity, a new trend, or data on the use of a new technology, it generates ideas for investigation that can be of direct benefits to populations in California and the rest of the nation.

Appendix F

Completed Evaluation Worksheets

Because it covers only California it has been critical to be able to compare its results to those of the National Health Interview Survey (NHIS), which covers the whole country but not in as much depth and with fewer respondents per geographic area. This can be done because of the similarity of questions between the two surveys and this capacity markedly increases the value of the NHIS.

4. How can the utility and impact of CHIS be enhanced?

Little was said in the literature provided about the current response rates for the CHIS. What this reviewer read was only that rates had been diving toward 20% and methodologic research with cell phones and other novel approaches were being explored. Obviously the impact of the CHIS would be markedly improved if there was a higher and more robust response rate than 20 or even 50%. It may be timely to explore alternative methods of data collection from hand held devices, tablets and other new technologies. This is the coming era of mHealth and the population will likely be becoming more familiar and comfortable with new technologies as young, savvy populations age up and health system make more use of these technologies in routine care.

5. How does state and local health survey data improve our understanding of cancer control science above and beyond the national surveys?

This is easy for a California researcher to answer since compared to the NHIS or the BRFSS, it is simply larger, covers a more diverse population and covers a population under study. But even for an investigator outside California to be able to compare their state or regional data from NHIS or BRFSS to more in-depth data from the CHIS, adjusting for differences in key characteristics like insurance coverage, it is a highly valuable tool. It is hard, in fact, to consider the great loss that might result from it not being available.

Other Comments (optional):

The rapid dissemination practices and public face that the UCLA Center for Health Policy Research has been able to manage have been excellent and a boon to justifying the public good that comes from this taxpayer investment.

Appendix F

Completed Evaluation Worksheets

Evaluator #8 [I do not have a background in cancer control, and would therefore prefer to focus my responses in two areas]:

1. N/A
2. N/A
3. **How has the CHIS had an impact on cancer control research, health policy, and clinical practice? Comment on this issue for California specifically and for the U.S. overall.**

The CHIS has had a major impact on health policy in California. Each wave of CHIS has resulting in a substantial policy report, "The State of Health Insurance in California." This report outlines the prevalence of health insurance coverage in the state overall, by county and region, by type of coverage and by important demographic subgroups. The last report was able to document the effects of the great Recession on health insurance coverage including the deterioration of individual market and the expanding role that Medi-Cal and Health Families play in providing coverage for those who are most vulnerable. The report also demonstrated the persistence of health disparities and the effect of insurance on access to care. A follow up report based on these data, "Two-Thirds of California's Seven Million Uninsured May Obtain Coverage Under Health Care Reform," provided valuable estimates of the number of California residents who would become eligible for coverage under the Affordable Care Act (ACA) and clearly illustrated the gap in insurance coverage that will remain after implementation of the ACA.

CHIS is unique in its ability to identify racial and ethnic groups across a population of over 33 million persons; as such, it has been an invaluable resource to studying health disparities by race/ethnicity and citizenship status. Their report "Diabetes in California" illustrated disparities in diabetes diagnoses and access to diabetes care, highlighting variations among whites, blacks, Latinos, and Asians, as well as variations by Asian and Latino subgroups. Particularly striking was the high prevalence among Filipinos that was not shared by other Asian ethnicities. CHIS has been used to estimate need for and disparities in mental health services among those who are seriously and persistently mentally ill; these estimates have supported planning of mental health services under the Mental Health Services Act. CHIS has also been used to document major public health issues relation to nutrition policy including both food insecurity and overconsumption of soda and fast food.

CHIS has supported at least two other major health policy efforts that are less well documented in their reports. CHIS data on insurance coverage by market segment provides baseline data for health insurance mandate analyses that are conducted by the California Health Benefits Review Program (CHBRP). CHBRP is housed in the Office of the President of the University of California. CHBRP staff coordinate teams comprised of UC faculty to evaluate the medical effectiveness, cost impact, and public health impact of health insurance mandate bills that are introduced into the California Legislature. CHBRP provides a rare example of unbiased, non-partisan analyses and has a direct and immediate impact on the legislative process. CHIS data

Appendix F

Completed Evaluation Worksheets

has also been used as the basis of the California Simulation of Insurance Markets (CalSIM). CalSIM is being used to estimate enrollment, premiums, and expenditures in California's Health Exchange, Covered California. This is a second example of CHIS having a real time impact in a crucial health policy arena.

4. How can the utility and impact of CHIS be enhanced?

Even in its current form, CHIS is poised to provide the most complete and precise analyses of the impact of the ACA on insurance coverage, access to care, and outcomes in a major population that can be subdivided among detailed demographic subgroups. However, I can suggest two options for improving the utility and impact of CHIS.

One recommendation is to improve the level and stability of funding with the goal of providing more consistency in the questions. One result of patchwork funding is that some questions do not persist for more than one or a few waves of CHIS. Some of this is fine: a goal of CHIS is to impact health policy in real time, and the value of some questions is time limited. However, there is also value in supporting longitudinal analyses, and it would be nice to have continued use of standard scales to track health outcomes over time.

My second recommendation is a bit more ambitious, but would provide a trove of valuable data: to collect clinical and health service utilization data on a subset of CHIS respondents. This component could be modeled on the MEPS and could include information on health histories and health behaviors, as well as vital measurements and a blood draw, and an inventory of health services utilization and cost of care.

5. N/A

Appendix G: Evaluation Logic Model

| Key Question(s) to be addressed | Information Required | Information Source(s) | Data Collection Methods | Data Analysis Methods | Limitations | Potential Conclusions from Analyses |
|------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------|--------------------------------------|-------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|
| 1. Has the CHIS addressed important cancer control priorities? | Goals of the CHIS; variables and key indicators that specifically correspond to program goals | Program documents; focus group sessions with nationally recognized experts, interviews with CHIS key users | Analysis of program documents; summary of focus group discussions and interviews | Qualitative analysis | Most data and indicators are not subject to quantitative analysis | Progress achieved by CHIS toward meeting cancer control priorities in science, program and policy innovation. |
| 2. What are the important cancer control priorities or issues that the initiative has not addressed, but could or should be? | Priorities that have been addressed; emerging issues that have not been | Program documents; focus group sessions with nationally recognized experts | Analysis of program documents; summary of focus group discussions and interviews | Qualitative analysis | Some priorities/issues may not be evident | Future orientation of cancer control items on CHIS – priorities/issues that can and should be addressed |
| 3. How has CHIS impacted cancer control research, health policy, and clinical practice? | Documented relevance of CHIS for publications, health programs, policy statements, and clinical practice guidelines | CHIS publications, CHIS references in health program or policy statements, and CHIS references in clinical practice guidelines. This information is summarized in CHIS "Impact Statements." | Quantitative analysis | Quantitative analysis | Data collection efforts that may be difficult to implement may be identified. | New data sources that can be used for evaluation |
| 4. How can the utility and impact of CHIS be enhanced? | Pending results of key questions # 1, 2, and 3 are there ways in which CHIS cancer control items can be modified to better address existing issues and focus on emerging issues? | Focus group sessions with nationally recognized experts, interviews with CHIS key users | Summary of focus group discussions and interviews | Qualitative analysis | Some priorities/issues may not be evident | Future orientation of CHIS – priorities/issues that can be addressed |
| 5. Should continued support of CHIS be a high priority of NCI? | Information gathered as a result of questions 1-4 above. | Results of questions 1-4 above. | Analysis of program documents; summary of focus group discussions and interviews, quantitative analysis | Qualitative and qualitative analysis | Some data and indicators may not be available | Whether and how NCI should continue to support CHIS. |