A Participatory Approach to Designing a Community Health Survey

A Report on the Survey Development Process

Part of the

Catalyzing Public Policy to Improve Community Health Project

http://www.sinai.org/urban/originalresearch/rwj/index.asp

Prepared by

Ami M. Shah, MPH, Project Coordinator
Cynthia Williams, MS, Co-Principal Investigator
Jaime Delgado, Survey Design Committee Member
Steven Whitman, PhD, Principal Investigator

Funded by the Robert Wood Johnson Foundation, Grant No. 043026
February 2003

Contact Information

Ami Shah, MPH
Sinai Urban Health Institute
Mount Sinai Hospital
California at 15th Street, K-439
Chicago, IL 60608
773-258-6569
773-257-5680 (fax)
shaam@sinai.org

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Synopsis

One of the greatest challenges facing public health professionals today is the elimination of racial and ethnic disparities in health. This report offers one strategy to begin reducing such disparities by employing community-based participatory research (CBPR) methods to gather local health data needed for this endeavor. We describe the process of developing a survey intended to capture the health status of six racially and ethnically diverse communities in Chicago. The process demonstrates the value of CBPR approaches in defining the health of these communities and serves as a model in helping activists and policy makers understand its context. It also illustrates how community input can complement the knowledge and skills of researchers in acquiring such data for local action and advocacy in the short term, and greater knowledge and community development in the long term.

Acknowledgements

We wish to acknowledge the following individuals who participated in the Survey Design Committee and helped with the design of the *Improving Community Health Survey*: Joe Ann Bradley, Concepcion Chavarria, Jade Dell, Angela Ellison, Jesse Green, Jocelyn Hirschman, Helen Margellos, Linda Miller, Jacqueline Mosley, Jamila-Ra, Ed Rafalski, Cassandra Robinson, Xochitl Salvador, Maurice Schwartz, Abigail Silva, Phil Smith, Feliz Villafane de Palacios, and Anna Yuan. Without their thoughtful input and commitment to the project, this report and the health survey would not have been possible.

Introduction

Community based participatory research (CBPR) is one approach to strategically design and implement initiatives to eliminate ethnic and racial health disparities, one of the overarching goals of the Healthy People 2010 objectives.[1] Partnering with community agencies to conduct community-based research has proven not only to be most beneficial for the quality of the research,[2-3] but also, and more significantly, for the purpose of education or effecting social change.[4] In balancing research with action, CBPR demonstrates how the research process is just as important as the final outcome of eliminating health disparities because it empowers communities to plan and promote their own health.[5-9]

While several research projects have encouraged community involvement to carry out health initiatives,[10-11] the effectiveness of these activities has sometimes been limited by the gaps in local health data.[12] For instance, data on health behaviors or individual risk factors, which often determine health outcomes, are critical to guiding strategies for the elimination of health disparities but unavailable at the community level.[13] Similarly, research recognizes the diversity of subpopulations, such as differences in the health resources and needs of Hispanic or African American communities, however, the available local data are often inadequate to be translated into effective programs and health policy for such groups.[14] Existing health data, often based on larger statewide or national data sets, are essentially averages of local community data and do not decipher the social determinants affecting local health.[15-16] It is thus necessary to collect data that could capture the cultural and community context of health in order to accurately reflect the characteristics, perspectives and health profiles of diverse communities.

Our hypothesis is that with such appropriate local level data and strong community participation, communities will be armed with adequate health information to guide health plans and strategically target interventions to improve the health of vulnerable populations, and ultimately eliminate racial and ethnic health disparities. This report discusses how we employed CBPR approaches to develop and implement a community survey in order to meet these local health data needs. We describe the process by which the survey was designed and implemented and the nature of the survey instrument. Finally, we discuss the kinds of information that will be obtained, the policy impact expected and interventions that might be applicable. Throughout the report we emphasize the importance of community support at all stages of these research efforts.

Background

In many ways Chicago represents an ideal social laboratory in which to conduct initiatives to eliminate ethnic and racial disparities in health. First, in Chicago these disparities are large and expanding, which is in direct contradiction to the goal of reducing them.[17-18] This may be compared to the progress of the United States, which has shown some improvement in selected health-status indicators.[19] Second, Chicago is a very diverse city. Among its almost 3,000,000 people is a population that is 36% non-Hispanic Black, 31% non-Hispanic White, and 26% Hispanic.[20] There is a prominent need for health information on such distinct communities if we are to develop appropriate and effective health interventions. Lastly, Chicago has been divided into 77 officially designated community areas since 1942 (Figure 1).[21] These areas, which tend to be homogenous due to Chicago's extreme segregation,[22] often guide health funding, services, analyses, and community activity. They are thus ideal for study and intervention.

In Chicago, like most urban settings in the U.S., much health data remain unavailable at the community level. Data that do exist and which can be geocoded to the community level are those that come from birth certificates (e.g., low birth weight proportions, proportion of women who smoke during pregnancy), death certificates (all death rates), some communicable disease registries (e.g., AIDS, TB, STDs) and the census (e.g. median income, education level). Though such data are very important, they do not offer enough insight into special health needs of unique communities, nor do they help explain the determinants of health for targeted interventions. Furthermore, these sources do not offer any description of behavioral risk factors, which certainly affect health.

Community level data that can only be obtained from surveys include measures such as: health behaviors (e.g., smoking, cancer screening, exercise and diet); virtually all morbidities (e.g., asthma, diabetes, hypertension); access to care (e.g., insurance, transportation); perceived health status; and descriptions of the perceived social environment (e.g., stress, discrimination). Although surveys have produced some of these data elements, data from most health surveys are available only at the national level (National Health Interview Survey-NHIS, National Health and Nutrition Examination Survey-NHANES) or state level (Behavior Risk Factor Surveillance System-BRFSS).[23] Only a few surveys are available at the city level (BRFSS, Youth Risk Behavior Survey), and none that we know of are available at the community level.

In a city as large and diverse as Chicago, it is clear that interventions and policy decisions would be best implemented at the community level, further emphasizing the need for community level health information. Without such community level data, documenting and eliminating racial and ethnic disparities seem most daunting.

Project Description

In an effort to obtain community level health information, the Sinai Health System (SHS) sought and received funding from the Robert Wood Johnson Foundation to implement a two-year project, *Catalyzing Public Policy to Improve Community Health*. The project has two main objectives: (1) to conduct an in-depth, random, face-to-face household survey in six diverse community areas of Chicago (Phase I); and (2) to utilize the information derived from the survey to develop policy initiatives that will bring effective health interventions and needed resources to these communities with the goal of eliminating racial and ethnic health disparities (Phase II).

At the outset of this proposal it was well understood that the generation, conduct, and implementation of the survey, along with the dissemination of results for improved policy and effective interventions, would not be possible without strong community-based participation. Community-based representatives and organization leaders have contributed to and guided the design of this survey by ensuring that it reflects the complex nature of health in these communities.

Survey Design

Targeted Community Areas

After extensive consultation with community leaders, health care providers and epidemiologists, six of Chicago’s seventy-seven community areas were selected to participate in this survey. These six were chosen to reflect the rich diversity of Chicago residents. Appendix A describes these community areas (CAs) and Figure 1 shows their locations. North Lawndale (29) and South Lawndale (30) are the two primary communities served by the Sinai Health System. North Lawndale is predominantly Black and South Lawndale is predominantly Mexican. Norwood Park (10) was selected to represent the predominantly White far northwest side while Roseland (49) was selected to represent the predominantly Black far south side. Finally, West Town (24) and Humboldt Park (23) were selected because they are CAs in transition: West Town is about half White and half Hispanic (most of whom are Puerto Rican or Mexican) and Humboldt Park is about half Black and half Hispanic (most of whom are Puerto Rican or Mexican). In addition to representing the well-known diversity of Chicago, these six community areas are notable for strong community-based organizations and political representation at the city, state, and federal levels by individuals very concerned with the health and well being of their constituents.

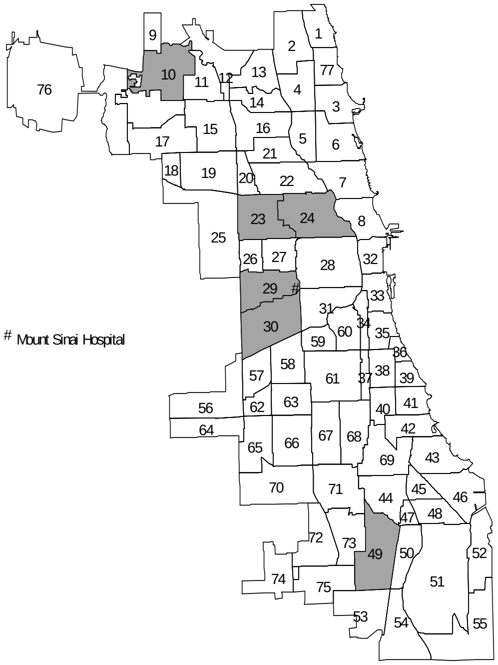

Figure 1: Map of Chicago Community Areas

The Survey Design Committee

Participatory research defines a working collaboration in which all those affected by an issue are involved with the generation, practice and impact of research on policy and social change.[24] A Survey Design Committee (SDC) was organized with this in mind, based on professional contacts with community leaders from the targeted CAs. The SDC was comprised of public health epidemiologists, community members and advocates, policy makers, and health administrators, who collaborated to design this comprehensive community health survey epitomizing CBPR practices.[25-26]

Community representatives were invited to join the SDC by the co-principal investigator of this study (CW), who is the Director of Family Education at the Sinai Community Institute, an organization that coordinates more than 25 community-based programs for the SHS. Community members were affiliated with social service agencies, government and educational programs, and other local community based organizations (CBOs) from the target CAs and/or their neighboring areas. In addition to the community members, three vice presidents of the SHS became active members of the SDC. The Committee was staffed by members of the Sinai Urban Health Institute, a group of epidemiologists at the SHS. Appendix B presents a complete list of all SDC members and their affiliations.

Designing the Survey

Regular meetings were held over fifteen weeks to develop a survey instrument that would capture the social forces and individual risk factors affecting poor health in these six diverse Chicago CAs. Though there was no monetary incentive, the majority of the committee members attended almost all six meetings. When unable to attend, they often offered input via email or phone. It is also important to note that there was continuity in the Committee demonstrating each individual's commitment to the process.

The principal investigator (SW) and co-principal investigator (CW) of the project facilitated the meetings, which initially revolved around selecting topics for the survey. Proposed survey topics include health conditions such as hypertension, asthma and diabetes, and well-known behavioral risk factors such as smoking, alcohol, diet and exercise. There was an energetic dialogue about the relevance of specific topics to committee members' work and the health of communities they serve. For instance, drug abuse was presented as an issue known to be a problem in some CAs. However, it was decided by the SDC not to include this topic on the survey because they felt adequate information about community drug use was already known and that asking sensitive questions to individuals in their homes would not be appropriate or realistic. Similarly, SDC agreed to keep or eliminate certain topics depending upon whether answers to specific questions seemed relevant to policy improvements or potential interventions.

At the same time, many members of the committee proposed topics they felt were important to learn about, such as reusing cooking oils, grocery shopping habits, mental health services, needle exchange programs, and use of alternative medicines. These ideas illustrate the crucial nature of tailoring the survey for the targeted CAs and demonstrate the importance of involving community representatives in survey design.

Ultimately, the committee members agreed on a final list of topics for the survey with about 400 questions in the Adult module and 80 in the Child module (Appendix C). These topics can be categorized as: health conditions (e.g., hypertension, depression, other chronic conditions), health behaviors (e.g., eating habits, tobacco or alcohol use, and physical activity), access to health care (e.g., insurance coverage, use of alternative medicines, having a primary care physician), health status (e.g., quality of life, stress management), and other social or environmental factors (e.g., perceived racism, violence and other SES measures).

Questions for each topic were then selected or created. To ensure comparability with city, state and national data, some questions were adopted from existing national surveys such as BRFSS, NHANES, NHIS and the Medicare Health Outcomes Survey. Other questions came from validated scales used in social science research (e.g., Perceived Stress Scale, Experienced Racism Scale, the Anger Scale and the HRQOL scale). When questions were not readily available in the literature, such as questions on cooking habits, these were developed jointly by the SDC drawing from its epidemiological expertise and community experience.

Each member of the committee played a critical role in the survey design. Community members brought to the table health concerns unique to residents in their CAs. They generated new ideas on potential risk factors, and offered a knowledge base unknown to researchers and policy makers. Health care providers offered a service delivery angle and addressed challenges often experienced in reaching populations at risk. Finally, public health researchers contributed knowledge of existing surveys and assessment tools and skills in validating questions to ensure reliable data results.

After several weeks of discussions, it was apparent that the survey was getting very long and needed to be shortened to keep within the proposed time frame. For a one-hour survey, it was estimated that 450 questions could be asked. With this in mind, the Committee worked several hours at a final evening meeting to make the 550-question instrument fit this limit. Important decisions had to be made about which questions to keep and which to eliminate. In the midst of good spirit but notable fatigue, some 100 questions were whittled away.

Survey Implementation

Administrating the Survey

Some studies have shown that sampling through residential telephone lines may not locate members of vulnerable subpopulations, which most often have the greatest health needs.[27] In order to accurately reflect the health profile of these community areas and to capture populations at risk, this survey was implemented face-to-face in the respondent's home by an experienced university survey organization.

Sampling

Fifteen census blocks were sampled from each of the six-targeted CAs to randomly select 300 households for this study, for a total of 1,800. From these blocks, 37 households on each block were randomly selected to complete about 20 interviews. Each selected household received an advance letter informing them about the project and the interviewers' visit. Letters were signed jointly by a CBO representative, the co-principal investigator (CW) and the principal investigator (SW) from SHS.

At each household visit, an initial screen was completed from which a randomly selected adult respondent aged 18-75 and child 12 years or younger were selected employing the Troldahl-Carter-Bryant method.[28] The first portion of the interview asked the selected adult about his/her health, and the second asked the primary caretaker of the selected child about the child's health status and concerns. On average, the adult interview lasted about one hour and the child interview lasted about 20 minutes. Respondents were given the option to conduct the interview in either English or Spanish.

With the plan of visiting each household for the interview already established, the community members on the SDC recognized a unique opportunity to distribute much-needed health information to each household. We felt that this would not only benefit the residents of the communities, but also that it was also our responsibility in carrying out community-based research. Educational materials from the Illinois and Chicago Departments of Public Health were collected and informational packages on a variety of health topics such as diabetes and asthma management, cancer screening, cholesterol and high blood pressure, child immunizations, health insurance, and accessing local resources were distributed to every surveyed household. Because it was impossible to address all health concerns, a note card was also included in each package for households to request additional free materials from the Sinai Community Institute.

In addition to the information packages, respondents were given $40 for their time and feedback on the Adult portion of the survey, and $20 for the Child portion.

Quality Assurance

Following the development of the survey, the instruments were pre-tested in English and Spanish. Interviewers were solicited from the community areas through local newspapers. About twenty interviewers were trained and hired to administer the survey. More than half came from or reside in one of the six CAs. All 20 are culturally sensitive to the communities in which they are interviewing.

Finally, the proposal, along with the appropriate informed consent forms, was submitted to and approved by all relevant Institutional Review Boards.

Presenting the Survey to the Community

In conveying information about the survey to respondents and others, the need for a project logo emerged. The Survey Committee had already agreed that it would be best for the advance letters to be from CBOs participating in the research process. The logistics of this however became difficult and inconsistent because households from each CA would receive stationery from a different CBO, and the mailing envelopes from each CBO were not easily available. After many considerations, an image was developed to capture the underlying aim of the project, 'Improving Community Health' (Figure 2). In keeping with the participatory approach of designing the survey, the artwork illustrates the many hands involved in building the survey and ultimately in achieving the goals of the project.

Figure 2: Survey Logo

Discussion

Impact of the Participatory Process

Knowing that a sound CBPR process is essential to the integrity of the end product (our survey), we have described in this paper how individuals with various levels of community knowledge, experience and perspective complement the skills and expertise of researchers, health care providers and administrators. Though CBPR may vary in degrees of participation, we believe the process of designing this survey went beyond the traditional research strategy because all participants were involved in defining the research topics under investigation. Furthermore, all intend to be involved in analyzing, interpreting and disseminating the results.

Without the CBPR process, the content of the survey would not have been as far-reaching or sensitive to the targeted communities. The community perspective allowed the topics to range beyond the usual national health surveys and included questions on health behaviors, barriers and risk factors that are appropriate to Puerto Rican, Mexican and African American communities in Chicago. In addition to offering health concepts that were most important to the CAs, the SDC members were instrumental in ensuring that the results are relevant to and appropriate for the development of interventions and strategies to reduce racial, ethnic and/or socio-demographic disparities.

Ultimately, with the participation of representatives from community organizations, we will take the analyses and interpretations of the findings to the broader community for ecological validation. Ecological validity refers to the extent to which the health profile revealed by the survey matches the reality experienced by the communities in question. By asking the communities to participate in such validation, we will maintain the integrity and instill greater confidence and ownership of the data, thus increasing the likelihood that communities will turn knowledge into action.[29]

Lessons Learned

After the survey construction process was complete, the project coordinator (AS) conducted one-on-one interviews with all community representatives in order to better understand their experience of the process. The discussions were quite informative and insightful for future designs of community health surveys. Though all thirteen of the community Committee members expressed satisfaction with the final survey instrument, some offered recommendations on how to improve the process of developing the survey. First, it was suggested to allow more time to understand community health concerns and design the instrument. Though this project allowed 3-4 months for the survey development, some Committee members suggested either having a longer time to explore the topic areas and design of the questions, or meeting more frequently to flesh out topics and areas of interest. Second, it was noted that it would have been helpful to divide into smaller (5-6 people) subcommittees on community specific health topics. Lastly, it was suggested to hear directly about the community health concerns from residents through organized focus groups. This would also give researchers, health providers and policy makers a greater opportunity to listen and understand the community and its cultural context of health.

Overall, committee members also learned from one another, which is another outcome of CBPR. Researchers and health care providers described having a unique opportunity to ‘break out of the institutional’ walls of research and service delivery in order to better understand the needs and experiences of those they served. They believed they gained some community perspective to conducting research. Community representatives stated that they learned how to measure health indicators and how to identify information that might be most relevant for changing policy and seeking funding. Most did not have previous experience in survey design and stated they benefited by building some research and evaluation skills.

Expected Results

We expect that effective community interventions and programs will emerge when the survey results become available. For instance, we will have an estimate of the prevalence of asthma (undiagnosed and diagnosed) for all six community areas, which will be comparable to state and national statistics. To complement the prevalence rates, we will have information on individual risk factors such as data on the home environment (smoking in the home and use of home remedies); service delivery utilization (access to primary care provider and use of emergency department); and clinical management (written plan, medication type). With a comprehensive look at asthma rates in these communities and information to assess how and why asthma rates may be high in some communities but not in others, there is an opportunity to develop strategies for interventions to improve health and eliminate health disparities. Since Chicago is one of the cities hardest hit by asthma such information could not be timelier.[30-31]

Another example of how information from the health survey may serve as an instrument to improve health is our idea to influence tobacco settlement funds for targeting smoking cessation programs. Thus far in Illinois, settlement funds have generally not been spent addressing health issues.[32] It is our hope that with information about varying smoking rates in different communities we might stimulate debate on how these funds are being used. For example, a recent study of smoking in Harlem found that 44% of adults in Harlem smoked.[33] This may be compared to 23% nationally.[34] We expect even greater variation among our six community areas. For example, if the smoking proportion is 10% in one of the community areas and 45% in another, then we would hope this would be a clarion call for funding to ameliorate these differences.

The battery of about 500 questions will illuminate literally dozens of such issues. We are eager to pursue as many of them as possible through CBPR approaches. Plans are already underway to continue the established working relationships for the next phases of the research project -- data interpretation and dissemination. Without CBPR, the local health data collected in the survey will not have its greatest impact. Assuming that data from this survey will provide evidence of existing racial and ethnic disparities, we are optimistic that community-based organizations, community leaders, policy makers and health care providers will be able to improve the health of such at risk populations.

Model for Other CBPR Projects

The survey design approach presented in this paper may serve as a model for developing a community health survey. It demonstrates the importance of involving community members and service providers in research design and describes an experience in which researchers, health administrators, and community members built trusting relationships and the capacity for future research activities.

One of the most remarkable aspects of this work might have been the tremendous spirit of respect and collegiality that permeated the SDC. In one of the most segregated cities in the United States, a Committee consisting of Black, Mexican, Puerto Rican and White people, and men and women, worked together with a common goal in mind: to design an excellent survey that would elicit results to implement effective interventions to improve health. Although there were many passionate and even heated exchanges and discussions, there was not one incident of disrespect. No doubt this level of interaction enhanced us all.

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Appendix A. Race/Ethnicity, Population and Median Household Income: US, Chicago and Selected Chicago Community Areas, Census 2000

	% NHW	% NHB	% H	Total Population	Median HH Income
United States	69	12	13	281,421,906	$41,343
Chicago	31	36	26	2,896,016	$38,625
Humboldt Park	3	47	48	65,836	$28,728
North Lawndale	1	94	5	41,768	$18,342
Norwood Park	88	1	6	37,669	$53,402
Roseland	1	98	1	52,723	$38,237
South Lawndale	4	13	83	91,071	$32,320
West Town	39	9	47	87,435	$38,915

- NHW = Non-Hispanic White
- NHB = Non-Hispanic Black
- H = Hispanic
- HH = Household

Appendix B. Organizations Represented on the Survey Design Committee

ORGANIZATION	SURVEY COMMITTEE PARTICIPANT
Big Brothers Big Sisters, Humboldt Park	Phil Smith, Community Coordinator and Resident of Humboldt Park
Block Club Federation, Humboldt Park	Feliz Villafane de Palacios, Director and Resident of Humboldt Park
Chicago Department of Public Health, Behavioral Health Division	Jamila-Ra, Program Manager, Chicago Department of Public Health and Co-Chair of the Cook County West District Community Health Council
Chicago Youth Centers, Roseland	Cassandra Robinson, Chicago Youth Centers and Resident of Roseland
Community Action Group, North Lawndale	Jo Ann Bradley, Executive Director and Resident of North Lawndale
Community Outreach Intervention Program, School of Public Health, UIC	Jaime Delgado, Director
Chicago Cook County Community Health Council	Anna Yuan, Executive Director
El Hogar del Nino, South Lawndale	Concepcion (Connie) Chavarria, Program Director and Resident of Pilsen (South Lawndale)
Sinai Community Institute (SCI)	Jesse Green, Community Coordinator Xochitl Salvador, Community Coordinator Cynthia Williams, Director of Family Education[1]
Sinai Health System (SHS)	Linda Miller, Vice President, Care Management Ed Rafalski, Vice President, Strategic Planning Maurice Schwartz, Vice President, Medical Affairs

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ORGANIZATION	SURVEY COMMITTEE PARTICIPANT
Sinai Urban Health Institute (SUHI)	Jade Dell, Research Coordinator Jocelyn Hirschman, Epidemiologist Helen Margellos, Epidemiologist Abigail Silva, Senior Epidemiologist Ami M. Shah, Project Coordinator Steven Whitman, Director[2]
Westside Future, West Town	Angela Ellison, Executive Director

[1] Co-Principal Investigator
[2] Principal Investigator

Appendix C. Survey Health Topics

Adult Module

Access and utilization of health care services (e.g. medical care, mental health, emergency care, alternative medicines)

Health insurance coverage

Quality of life measures (e.g. self-perceived health status, health status compared to others, mental health, functional impairment)

Preventative services (e.g. cancer screening, self-exams, HIV-STD testing, blood pressure and cholesterol measures, prenatal care)

Health conditions (e.g. asthma, diabetes, hypertension, depression, obesity, malnutrition)

Health behaviors (e.g. smoking prevalence, alcohol use, physical activity, diet/nutrition, grocery shopping practices, anger and stress management)

Parenting practices (e.g. disciplining skills, infant sleep position)

Environment (e.g. alcohol, community violence, racism)

Child Module

Access and utilization of health care services (e.g. medical care, mental health care, emergency care)

Health conditions (e.g. asthma (diagnosed and undiagnosed) and diabetes)

Health behaviors (physical activity, diet/nutrition, smoking in the household)