RACIAL DISCRIMINATION IN HEALTH CARE INTERVIEW PROJECT

A SPECIAL REPORT

January 2001

A report originally prepared by the Cross Cultural Health Care Program under a contract from Public Health – Seattle & King County

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ACKNOWLEDGEMENTS

The Principal Investigator would like to thank all of the project participants who shared their personal experiences with the interview team and to those who participated in the three advisory forums. Thanks also goes to all of the community organizations that helped facilitate interviews.

Special thanks goes to Georgiana Arnold and Mary Walls for their dedication and perseverance on this project and also to the staff at the Cross Cultural Health Care Program, especially Tom Lonner, Bookda Gheisar, and Clancy Clark. Sincere gratitude also goes to Public Health – Seattle & King County for commissioning this project and to its staff (Michael Smyser, Sandy Ciske, Jim Krieger, Alonzo Plough and others) who were involved with the project's development, review and final printing of the project report.

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CONTEXT

A number of recent studies have documented disparities in specific health services provided to African Americans and have raised the question of whether these disparities might have been due to racial/ethnic discrimination in health care settings. The King County Ethnicity and Health survey conducted in 1995-1996 revealed that nearly one in three (32%) of African Americans residing in Central and Southeast Seattle felt they had been discriminated against when receiving health care services. In order to provide a better understanding of the King County Ethnicity and Health Survey results, 51 African Americans residing in King County were interviewed during 1999 concerning their experiences of racial discrimination when seeking or acquiring health care services.

STUDY HIGHLIGHTS

- Many of the 51 interviewees were able to relate more than one perceived incident of racial discrimination (average of 1.5 events reported per interviewee).

- All interviewees felt that the rude and sometimes differential treatment that they received were racially-motivated.

- The 78 events of perceived racial discrimination were very recent (averaging slightly over two years old. Half of the events occurred within the last 10 months prior to the interview).

- The events were reported widely at many health care facilities throughout King County. Nearly 30 different health care facilities were mentioned, indicating that these experiences were widespread and not confined to a few providers or health care facilities.

- The experiences recounted ranged from reports of rude behavior to incidents of differential treatment. Several blatant examples of both racial insensitivity and of racial slurs being used by attending health personnel were reported. Most interviewees reported being shocked or "surprised" by the events indicating, that they did not expect discriminatory treatment.

- The interviewees perceived the events as being relatively severe (average rating was 8.2 out of a scale of 10 with 10 being "most severe") and long-lasting with most reporting that they still had strong feelings about the events.

- Most interviewees reported changing their health seeking behaviors as a result of the events. Many report that they now actively avoid the offending personnel and/or health care institutions. Some report delaying to seek care due to the negative treatment or due to not knowing where else to go for health care.

Approximately 55% of the African American interviewees had private medical insurance, 22% were Medicaid recipients and 14% were uninsured. Approximately 16% had college degrees, 14% had graduate degrees and another 31% reported having "some college." Interviewees who were college graduates and who had private medical insurance reported many of the more severe events.

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EXECUTIVE SUMMARY

Introduction

There has been a significant increase in the number of researchers who suggest that racism is a factor in both the health status and health-seeking behavior of ethnic minority populations. An increasing number of journal articles have been published by these researchers that identify disparities in the quality of health care provided to African Americans in particular. There has also been some research indicating that African Americans exhibit poorer health status or poorer health outcomes due to their experiences with racism. The health care setting has been viewed as one where any perceived racial discrimination or differential treatment based on race has the potential of not only affecting health care seeking behavior but also affecting long-term health status. However, there have been very few studies that have focused on the perceptions of differential treatment due to race when receiving health care services that are held by African Americans or other ethnic minority groups.

Purpose of Interview Project

Public Health - Seattle & King County (PHSKC), the local public health department in King County, commissioned a survey in 1995 to identify the specific health needs of seven ethnic minority populations with the intent of using the survey information to develop appropriate disease prevention services. One of the 191 questions in the extensive King County Ethnicity and Health Survey asked the respondents if they had ever experienced discrimination based on their race or ethnicity when obtaining health care services. Approximately one third (32%) of the African American respondents residing in Central and Southeast Seattle reported perceived discrimination in health care settings. Motivated by the findings of this earlier survey, PHSKC commissioned the Cross Cultural Health Care Program to conduct an initial follow up study. The Cross Cultural Health Care Program designed and conducted this study, the Racial Discrimination in Health Care Interview Project (Interview Project), to examine perceived experiences of discrimination by African American residents of King County when seeking or using health care services.

The Interview Project was not designed to be a random scientific survey for establishing incidence rates or for identifying problem health care facilities. Rather, it was intended to obtain descriptions of and reactions to those health care experiences that African American residents of King County perceived as being racially discriminatory.

Interview Project Methodology

The Cross Cultural Health Care Program developed a field interview strategy and a questionnaire for assessing events of racial discrimination and racial insensitivity in health care settings. The interview methodology called for confidential in-person

interviews to be conducted with a representative sample of African Americans in order to obtain information on first-hand experiences of perceived racism. Two female African American health professionals were trained in the use of the interview instrument and the strict confidentiality rules governing the Interview Project. The interviews were conducted during the summer and fall of 1999 at community festivals, community institutions and a variety of other public and private locations.

The interview instrument was designed to record from each respondent descriptions of one or more discriminatory events. Respondents were asked to describe the events in their own words, which were recorded in the interviewers' notes and also recorded according to a predefined list of response categories for each interview question. The interviewers were instructed not to prompt the respondents by reading the lists. Although respondents were asked to recount events that occurred during the past 10 years, they were allowed to recount older events if they persisted. The 10-year age limit for events was established to assure that the interview project focused on events that were relatively current.

Demographic information on the respondents, information on the settings and circumstances of the recorded events, and the narrative descriptions of the events of racial discrimination as described in the words of the respondents were recorded and analyzed.

Interview Project Findings

A total of 55 African American residents of King County were interviewed during the study. The respondent group was limited to adults (over 18 years old). Approximately 75% of the respondents were female. While less than 6% of the respondents had less than a high school degree, approximately 16% reported that they had college degrees and 14% reported that the had graduate degrees. Another 41% reported "some college" on the educational status question. Approximately 55% of the respondents had private health insurance coverage, 22% were Medicaid recipients and 14% were uninsured. The respondent population for the Interview Project was viewed as more educated and better insured than the King County African American adult population in general.

The 55 respondents reported a total of 92 perceived events of racial discrimination. All of the events reported by four of the respondents and some of the events that were reported by another five respondents were over 10 years old. The respondent group was adjusted by removing these four respondents from the respondent count and also removing all 14 reported events that were over 10 years old. This resulted in an *adjusted respondent group of 51* and the *adjusted event total of 78*. These 78 reported events were 2.2 years old on average. Therefore, the Interview Project was able to capture relatively recent events.

Respondents cited *differential treatment* due to their race as a common perception in the events that they shared with the interviewers. This perception was expressed in phrases such as:

- "…did not treat us like we mattered."

- "He treated the Caucasian woman better and differently."

One respondent reported that she could hear that several nurses were treating a patient in an adjacent hospital room with more courtesy and respect than she was being treated. After perceiving significant differential treatment in comparison to other patients in two successive visits, another respondent was compelled to take a 15-mile taxi ride to obtain medical care at another medical center.

Respondents reported a *perceived negative attitude* as one of the main expressions of race-based treatment in health care settings. The respondents described such events using the following phrases:

- "They treated us rudely."
- "The intake person was rude and insensitive."
- "She was worse. Treated me like I stunk."
- "The nurses were rude, mean, inattentive and uncaring."
- "The receptionist was cold. She would not look at me."
- "I walk up and she (the receptionist) disregards me. She was cold. She did not look at or speak to me."

The perceived negative attitudes exhibited by health care providers or their staff members were not reported as *hostile* but as uncaring or rude behavior.

Several of the respondents used the term "belittled" in describing their experiences. This term was not on the prepared list of possible responses but was reported in the following fashion:

- "The staff belittled me a lot. Very degrading."
- "The nurse belittled me."

In these and other reported events, the respondents reported that the manner and actions of some health care personnel effectively made them feel less significant than other patients due to their race.

In some of the research on racism in America, the researchers identified *being made to feel as if dumb* as one way in which racist behavior is exhibited. Several respondents in the Interview Project used this phrase in reporting their experiences:

- "He was describing the problem slowly, like I was dumb."
- "The radiologist made a couple of crude remarks, like I was dumb."
- "The doctor told me how to wrap my son's incision, like I was dumb."

Although there were only the above three instances where respondents used this particular phrase to describe an event, the interviewers indicated this perception as an issue in nearly a third of the reported events.

The respondents reported a *sense of being ignored* as another way that they were treated due to their race. The following comments were made regarding this perception:

- "I was in the emergency room at the hospital and I feel that I was ignored due to my race."
- "I was ignored and made to wait a long time."
- "The receptionist told me that I should not have forgotten my medical card. She ignored me and dealt with another woman."
- "The front desk staff ignored me when I asked for help."

There were two respondents that reported that they were *accused of using drugs*. In each case the respondents reported that they did not use drugs and were shocked by the allegation. In one of these events a nurse told a hospitalized respondent: "I know you shoot dope."

Some of the most dramatic events involved the use of racist remarks by health care workers. These events stood out as the more blatant examples of racial insensitivity:

- A respondent (who was a registered nurse) reported that she was told that her daughter's condition was "an African American thing" and encouraged not to worry. Her daughter was eventually diagnosed as having asthma.
- A respondent reported that during a breast biopsy, she asked for a sedative because of her low tolerance for pain. The nurse replied, "You people accepted pain as part of slavery because you tolerate pain so well."
- A male respondent reported that a lab tech at a major medical center joked, "Your skin is so dark that I can't find your veins," and then laughed.
- A respondent called a major medical center and explained that she needed an appointment and the receptionist said, "Fine." A staff nurse walked into the exam room where the respondent was waiting and said, "You people never make appointments, you want to come in whenever you want."
- A respondent reported that she was at a major medical center for a gynecological exam when the attending physician stated, "Being a typical black woman, I bet you haven't dieted in over 20 years."

Such remarks generally surprised and incensed the respondents.

There was one incident reported where a hospital refused treatment to an unconscious patient. Their family members overheard some racial comments during the event. The family sued the hospital and won. The hospital subsequently admitted that treatment was denied based on race and fired a physician, a physician's assistant and a nurse. Although this event occurred three years ago the respondent reported that he and his family thought about and talked about the event often.

Although it was difficult to determine if some of the events were truly race-related, the respondents perceived all of the events as racially motivated. Approximately 85% of the respondents indicated that they were surprised by the event, indicating that they were not predisposed to expect racial discrimination. Many of the respondents reported that the

event caused them to delay, hesitate or avoid obtaining health care services. In just over half of the events, the respondents reported that they registered some complaint about the event, but written complaints were filed in only about 9% of the cases. In nearly two-thirds of the events, the actual providers (or clinicians) were reported as being the perpetrators of the perceived racist behavior. The relatively high severity ratings assigned to these events by the respondents (average rating was 8.2 out of a scale of 10 with 10 being "most severe") indicated that these events were not perceived as minor events in their lives. Most of the events appeared to have made a lasting impression on the respondents, as nearly three-quarters (74%) indicated that they still had strong feelings about the events.

In response to questions about the impact of the events of perceived racial discrimination on their health care seeking behavior, the respondents provided comments such as the following:

- "I vowed never to take my child to _____ Hospital."
- "It was the last time my son would see Dr. _____"
- "I stopped going to _____ Hospital."
- "I did not bring my daughter back to _____ Hospital or that doctor for her checkup in 1999."
- "We only go to _____ Hospital in a real emergency."
- "Even though this situation surrounded the birth of my daughter, it has made me more hesitant as a black man to get health care."
- "I was so ticked off when I went home, that I cut up my _____ card."
- "I have not sought surgery for my other leg. I would like surgery but I guess that I'll find someone else. Sometime my leg hurts."

These are 8 of 23 similar responses cited in the body of the main report. These responses dramatize the level of impact that the events had on the respondents and show that such events motivated many respondents to change providers or to avoid a particular health care facility in reaction to the perceived racial discrimination.

Although the findings of the Interview Project do not answer the question about how widespread experiences of racial discrimination in health care really are, it does seem to validate the assertions of many researchers that perception of discriminatory treatment by health providers produces negative changes in health seeking behavior.

Community Forums

In an effort to develop strategies for addressing the findings of the Interview Project, a series of three community forums were held in August and September 1999. The main goals of these forums were to solicit recommendations on ways to address discrimination in health care settings and on the conduct of future studies. Separate forums were held for advocates, consumer/community representatives and for health care provider representatives. Many recommendations were made by each of the three groups of forum attendees and these are summarized in Appendix C of this report.

RACIAL DISCRIMINATION
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FINAL REPORT

I. INTRODUCTION

The Racial Discrimination in Health Care Interview Project (Interview Project) was developed to (1) identify the circumstances and situations in which African American residents of King County experience racial discrimination in health care settings, and (2) recommend strategies for addressing issues of racial discrimination in health care settings. The Interview Project was conducted by The Cross Cultural Health Care Program under a contract from Public Health - Seattle & King County (PHSKC). The Cross Cultural Health Care Program engaged William D. Hobson, MS to serve as the Principal Investigator for the Interview Project. Mr. Hobson collaborated with Thomas Lonner, Ph.D., who serves as The Cross Cultural Health Care Program's Director of Research in the conduct of the Interview Project. Clancy J. Clark, BA provided the data entry, data retrieval and assistance with the data analysis.

II. BACKGROUND

The issue of racial/ethnic discrimination in health care settings was initially addressed in the King County Ethnicity and Health Survey of 1995-96. This study was an extensive (191 questions) random telephone survey of 2,427 individuals designed to identify specific health needs and to stimulate a discussion of appropriate disease prevention services for the seven largest ethnic minority groups in King County. One of the questions on the King County Ethnicity and Health Survey asked if the respondent had experienced discrimination due to his/her race or ethnicity when seeking or obtaining health care. The respondents of Latino/Hispanic, Filipino, and Korean heritage reported having experienced discrimination at rates of 10% or more. However, 29% of the African American respondents residing in Central and Southeast Seattle responded that they had experienced discrimination based on race when obtaining health services.

A related finding from the King County Ethnicity and Health Survey was that most respondents reporting experiences of racial/ethnic discrimination also reported delayed health care seeking behavior at a significantly higher rate than respondents who did not report racial/ethnic discrimination when seeking or receiving health care services. The relatively high frequency of respondents reporting experiences of racial/ethnic discrimination in combination with the correlated finding on delayed health seeking behavior indicated that a much more significant problem existed in this area than previously anticipated. This study established a relative frequency for perceived discrimination but did not capture the content or timeframe of the discriminatory events.

The Interview Project was planned as the initial follow-up study to the findings on racial/ethnic discrimination from the King County Ethnicity and Health Survey. The African American racial group was prioritized as the focus of the *initial* follow up study due to the higher frequency of reported discriminatory events. It was envisioned that the

experience derived from the conduct of the Interview Project would serve as a guide for any subsequent efforts to assess the experiences of the other ethnic groups reporting discrimination in health care services and for developing recommendations to reduce the likelihood of such experiences.

III. STUDY DESIGN AND METHODOLOGY

In preliminary discussions with Public Health - Seattle & King County representatives, it was decided that the best way to gain a clear perspective of the life experiences of African Americans in health care settings was to conduct in-person interviews. It was hoped that the in-person interview format would offer the best setting in which to obtain the types of personal experiences that would be difficult to capture in either a written response format or in a telephone interview format. With this guidance, the Cross Cultural Health Care Program designed and proposed a specific study concept and methodology to meet project objectives within resource limitations.

A. LITERATURE REVIEW

The initial work phase for the Interview Project was the conduct of an exhaustive literature review on the topic of racial discrimination in health care services. The literature review was conducted to identify any research that had direct bearing on the Interview Project and to identify any applicable interview instruments that had been field-tested. A selected bibliography of some of the materials most relevant to this project which were reviewed may be found in Appendix B.

1. Literature Review Methodology

The literature in each of those professional disciplines most closely associated with the topic of the study was explored. The literature focused on the following professional disciplines:

- Public Health
- Health Services Administration
- Health Law
- Civil Rights/Human Rights
- Social Work
- Psychology

This assessment brought a multi-disciplinary perspective to the development of the interview instrument.

The literature review was conducted using the extensive library system and on-line databases available through the University of Washington. An initial review of the literature was conducted using one or more electronic databases in each of the disciplines outlined above. Selected journal articles were then reviewed at four different University of Washington libraries (Health Sciences, Social Work, Law and Government Publications). Those journal articles selected for their applicability to the research topic were reviewed and their bibliographies were scanned for additional references of interest.

The literature review was supplemented with telephone interviews and e-mail communications with many of the authors of the most applicable journal articles. This effort resulted in direct communications with many of the leading researchers on discrimination in health care.

2. Literature Review Findings

It became apparent early in the literature review process that the specific area of interest was that of *perceived racial discrimination.* Therefore, research that dealt with the way that ethnic/racial minorities viewed themselves as being treated in the health care system became the specific focus of the literature review. Of particular interest was research that involved self-assessments of racially discriminatory events.

The primary resource for the *Public Health* literature review was the MEDLINE search-engine. Approximately 400 citations were reviewed. Most of the literature identified in the Public Health area focused on disparities in treatment regimens between African Americans and whites with identical clinical diagnoses. These studies generally reviewed racial disparities in treatment decisions made by medical providers. Studies on this particular topic were more prevalent in recent years, with most of the findings validating significant disparities in medical treatment, including less optimal care and/or inferior care received by African Americans. The second major focus of public health research was on the effects of racism on blood pressure and its associated health effects. Much of this research was focused on the relationship of stress from racist treatment and the associated coping factors with elevated blood pressure. Some of the most significant work in this area was done by Dr. Nancy Krieger, who provided copies of selected interview questions used in her research. A third focus of research in the public health discipline was on racism as a risk factor for poor health outcomes. Some of these studies explored the connection between racist treatment and infant mortality or cardiovascular disease in African Americans.

Much of the research in the public health area was based on the retrospective review of clinical records. Although some of this research involved direct interviews with patients, the interview instruments involved were marginally applicable to the Interview Project. No research was identified in the public health literature that involved the study of individual episodes of discrimination through direct client interviews.

The University of Washington Law Library Catalogue was the initial resource for reviewing the *Health Law* literature. More helpful, however, were the rather extensive writings, bibliographies and the recent book, *Health Care Divided/Race and Healing a Nation* by Mr. David Barton Smith of Temple University. A telephone conversation with Mr. Smith was held to inquire about perceived racist treatment in the health care system from the legal perspective. Telephone communication with the National Health Law Program and the NAACP Legal Defense Fund attorneys identified some interesting legal perspectives on the topic but little on the topic of *discrimination event profiling* as hoped.

The primary resource used for the literature review in the Civil/Rights/Human Rights area was the Government Publications division of the University of Washington Library System. A search was conducted using a special search engine that indexed

governmental publications. The entire listing of the US Commission on Civil Rights was reviewed in addition to applicable US Department of Justice and US Department of Health & Human Services publications. There was very little information applicable to racial/ethnic discrimination in health care identified during this search. Most of the relevant studies were conducted prior to 1980. A total of 343 citations were reviewed which yielded three publications with some reference value. Subsequent inquiries to researchers familiar with this topic area validated the lack of applicable studies by federal agencies on the topic of discrimination in health care. A telephone call to the US Commission on Civil Rights indicated that health care was selected as their major research focus for 1998 and that a major review of health care civil rights issues was under development.

Special search engines including Social Sciences Citation Index, Social Work Abstracts and others available through the University of Washington Social Work Library aided the review of the *Social Work* literature. Approximately 150 citations were reviewed from the social work literature. This part of the literature review yielded a wide variety of studies examining the impact of racism and perceptions of racism. Many of these studies were focused on the assessment of racism as a factor in the lives of ethnic minority individuals and families. A few of these studies attempted to relate discriminatory practices to psychological stress in those affected. Other research projects attempted to assess how discriminatory practices were perceived in the workplace. There was one noteworthy research project identified that attempted to assess specific episodes of racial discrimination through the use of a questionnaire. This particular study was conducted by Dr. Dennis Chestnut of East Carolina University and involved a "Service Perception Test" given to parents/guardians of children with sickle cell disease who were seen at a university medical center. This was the only study found during the entire literature review that focused on perceptions of differential treatment based on race/ethnicity in a clinical setting. A telephone call was held with Dr. Chestnut to discuss his experiences in developing and administering his questionnaire.

The review of the applicable *Psychology* literature was initiated through the PsycInfo online database and the University of Washington Libraries Catalogue. Over 100 citations were reviewed for applicability to the research topic. The preponderance of articles in the psychology literature addressed racial attitude surveys, the impact of racism on the affected individuals, variations in the perceptions of racist events and exploration of the various coping mechanisms used to deal with perceived racist experiences. The most valuable research identified was on the measurement of the intensity of perceived racist events. The "Perceived Racism Scale" by Dr. Maya Dominguez McNeilly et al. and the "Schedule of Racist Events" by Dr. Hope Landrine and Dr. Elizabeth Klonoff were particularly helpful references with regard to *categorizing* episodes of racial discrimination. Telephone conversations were held with Dr. Landrine and Dr. McNeilly to discuss the applicability of their measures to the Interview Project.

3. Summary Observations from the Literature Review

Several observations were made from the literature review that were pertinent to the Interview Project:

- There are indications of actual adverse health effects arising from exposure to racist treatment.
- There are a number of recent, well-designed studies indicating that African Americans receive less optimal and/or inferior health care services when compared to white individuals receiving care from the same medical providers.
- That the science of studying and measuring events of perceived racism is still in its infancy.

The literature review did not identify any examples of research or interview instruments designed specifically to *profile* individual events of perceived racial discrimination.

B. INTERVIEW CRITERIA

After completing the literature review, a set of criteria was developed to guide the development of the interview instrument. These interview criteria were as follows:

- Demographic information to be collected should parallel the demographic information collected by the King County Ethnicity and Health Survey as closely as possible.
- Only adults over 18 years of age would be interviewed.
- Respondents would be assured that any and all information provided would be kept confidential and that the names of respondents could not ever be traced back to them.
- The interview instrument would be designed to appropriately preserve the dignity of the respondents and would be sensitive to the nature of the information being collected.
- The interview instrument would be developed using everyday language to the extent possible to assure that the language used in the questions would pose no barriers to effective information collection.
- The interview questions would be sufficiently comprehensive to capture the essence of episodes of racial discrimination without being too lengthy.
- The questionnaire would be designed to facilitate respondent replies by providing appropriate examples of the types of interactions between the staff of health care provider organizations and their patients that would be considered racially offensive.
- Respondents would be offered the opportunity to refuse to answer any question that might cause them to be uncomfortable.
- Respondents would be allowed to *tell their own story* with a minimum of *prompting* from the interviewers.
- A method of compensating the respondents for their time taken to complete the questionnaire would be developed.
- Respondents would have access to the results of the study if desired.

These criteria guided both the development of the interview instrument and the actual method used in conducting the interviews in the field.

C. INTERVIEW INSTRUMENT DEVELOPMENT

The intent of the Interview Project was to capture clear descriptions of discrimination episodes/racist events experienced by African American residents of King County when receiving health care services from King County-based health care providers. It was determined that three (3) *information components* were required from respondents to adequately fulfill the intent of the study:

1. A rather extensive demographic profile on each respondent
2. A complete set of descriptive information on the actual event
3. A description of how the event impacted the respondent

The fact that each of these components was essential to the study and that each required rather extensive detail yielded a lengthy interview. This factor was one of the major challenges in the interview process.

It was determined in advance that the study would be conducted through an in-person interview format at selected sites in the community. The successful recruitment of respondents for a lengthy interview was identified as another major challenge. It was anticipated that there would be great difficulty in recruiting respondents willing to sit through a lengthy interview. Therefore, a method for obtaining more than one description of a discrimination event from each "willing respondent" was viewed as the best mechanism for obtaining the maximum number of event reports. In order to address this issue, the interview instrument was organized as a set of Specific Event Modules. Each Specific Event Module was designed to capture a complete description of an individual episode of racial discrimination or racist event. The initial Specific Event Module was designed to capture the *most recent* event that a respondent had experienced. A second Specific Event Module was developed to capture the *most severe* event experienced by a respondent provided that their *most recent* event was not also their *most severe* event. Using this methodology the *most severe* event module would only be used if the *most recent* event reported was less severe in nature. The third Specific Event Module allowed respondents to report *additional* episodes of discrimination or racist events that they had experienced.

The interview instrument was drafted with the Specific Event Modules put at the front of the interview and the demographic information at the end. Allowing the respondents to tell their story first was felt to be the best sequence to use in the interviews.

In order to capture the impact of the actual events of racial discrimination or racist episodes on the respondents, a set of questions was incorporated into each Specific Event Module. The questions included a subjective severity rating, a description of the impact that the incident had on seeking health services in the future and an assessment of whether there were lingering "strong feelings" about the incident.

A draft interview instrument was developed incorporating the elements described above. The draft interview instrument was forwarded to Public Health - Seattle & King County for review and comment. Most of the comments received were subsequently

incorporated into the final draft of the interview instrument (see copy of interview instrument in Appendix A).

D. INTERVIEW SITE SELECTION

As outlined in the initial proposal for the Interview Project, a search for appropriate interview sites was conducted. A set of *site selection criteria* were developed to guide this process:

- Sites that were used by significant numbers of African Americans.
- Sites that exhibited a comfortable environment for African Americans.
- Sites that were physically located in the various communities where African Americans were known to reside.
- Sites that offered a space where an interview could be held in confidence and the respondents' replies could not be overheard.
- Sites that offered an opportunity to obtain interviews with the full range of African Americans residing in King County (geographic and socioeconomic).
- Health agency or institution facilities would not be used as interview sites.

In addition to the criteria for the interview sites, a set of desirable attributes for the actual interview space within the interview sites was developed. These *desirable attributes for interview spaces* were as follows:

- Complete privacy from being overheard
- Comfortable seating
- Minimal distractions
- Leisurely pace in the area

The identification of appropriate interview sites proved to be one of the major challenges in the conduct of the Interview Project. The use of beauty parlors and barbershops were initially proposed based on their successful use for community blood pressure screening initiatives. Church events were proposed as interview sites for the same reason. However, the length of the interview proved to be problematic for church sites and the required confidential interview space requirement eliminated barber shops and beauty parlors. Most of the interviews were therefore conducted at service agencies, community centers, community festivals and other community events.

E. HUMAN SUBJECTS REVIEW

At the request of Public Health – Seattle & King County, the Interview Project was submitted to the University of Washington's Human Subjects Division for review. It was determined that as the information on respondents was to be kept completely anonymous and that the study posed no "risk" to respondents, an application for *exemption* from the full review was appropriate.

The Human Subjects Review process application was submitted under the name of the Principal Investigator to the Department of Public Health and Community Medicine. On June 7, 1999 a Certificate of Exemption was issued indicating that the Interview Project had been reviewed and approved as "exempt research."

F. INTERVIEWER SELECTION AND TRAINING

Two interviewers were hired. Both were African American women with Masters level education in health sciences. Both interviewers also had extensive experience in working with community programs and were ideal staff for this aspect of the project.

A half-day training session was conducted for the interviewers on July 1, 1999. All aspects of the interview instrument were reviewed and discussed and the interview protocol was reviewed. Some recommendations made by the interviewers during the training session were incorporated as minor modifications to the interview instrument.

It was initially planned that the Principal Investigator would conduct a portion of the interviews. After two interview pretests, the Principal Investigator determined that it would be highly preferable for the interviews to be conducted by female interviewers. It was postulated that using female interviewers would enhance the comfort level of the mostly female respondents. During the pretest, it also became apparent that African American males were less than comfortable in discussing personal health/medical related issues with another male in an interview setting. Based on this observation, the study was conducted using the two female African American interviewers only.

G. THE INTERVIEWS

The actual interviews were conducted between July and November 1999. During this period interviews were scheduled at community events and with respondents on an individual basis. Materials used in the recruitment of participants (e.g., announcements, flyers, introductory statements, etc.) are included in Appendices D-G.

Many attempts were made to establish interview sites at community centers in Seattle and South King County. The summer months are exceptionally busy for community centers, making efforts to establish interview sites extremely difficult and mostly unsuccessful. Some of the interviews were conducted at the Garfield Community Center in Seattle's Central Area (neighborhood).

Several community service agencies were contacted regarding the possibility of conducting Interview Project interviews in their facilities. Most of these efforts were unsuccessful due to the lack of a practical interview space and the inability to identify agency managers who would support the interview project logistics. At one site there was an almost universal reluctance among the African American seniors to participate in "another survey." The length of the interview and the small amount of the gift certificate ($10.00) appeared to be deterrents to participation.

The most productive interview sites were community festivals. Although most community festival attendees were not interested in being surveyed, there was a large enough group that the small percentage of interested individuals generated was sufficient to keep the interviewers busy. A key factor in the volume of interviews was that a single interview could take approximately 45 minutes. Therefore, 5 to 6 interviews would take a major part of the day of one interviewer. The *Central Area Community Festival* and the *Columbia City Days* festival were the two main festivals used for interviews.

Many other Interview Project respondents were recruited by *word of mouth*. Often a respondent would recommend another individual to the interviewers, who would contact that individual and arrange an in-person interview. This was the most productive method used for recruiting respondents.

Several community organizations were contacted to have the Interview Project conducted at one or more of their group functions. The only such group to respond positively to this request was an African American sorority. This sorority invited the Interview Project team to a Saturday meeting in Southeast Seattle where members were encouraged to participate. This single event proved to be one of the more productive during the study.

The logistics associated with the conduct of a lengthy in-person interview represented a major challenge in the Interview Project. The demographic information section alone would be considered a lengthy interview. Allowing respondents to "tell their story" about a particular incident often required 15-20 minutes or more. The limited availability of "good" interview sites was also a major factor affecting the study. The seasonal schedule of some community facilities was a factor in this area. Although these factors challenged the conduct of the study, they were overcome. These factors did, however, limit the number of respondents and partially resulted in the lower than anticipated number of interviews conducted.

The interviewers recruited respondents by approaching individuals who appeared to be African American and asking them if they had had any experiences of racial discrimination when seeking or acquiring health care that they would share with the interviewer. This approach purposefully limited the sample to African Americans who had experienced an *event*. As a result of this approach, the data presented do not speak to the frequency of discrimination events in the African American population. The previous Ethnicity and Health Survey indicates the relative frequency of such experiences through a random telephone survey. **The Interview Project only attempts to characterize the types of events experienced by African American residents of King County**.

IV. INTERVIEW PROJECT FINDINGS

A total of 55 interviews were conducted. The data was entered directly from the original interview forms to WORD and EXCEL computer programs. Summaries of the various components of the data were produced and analyzed.

A. DEMOGRAPHIC DATA **(TABLES 1 AND 2)**

All of the 55 respondents were verified as self-describing African Americans at the start of each interview. In addition, all of the respondents verified King County as the area where they received their health care services. This group of 55 respondents was adjusted down to 51 respondents in order to achieve a study group that reported only *recent* discrimination events (see full explanation of this adjustment in next section). Therefore, the demographic information on respondents profiled in this section is exclusively based on the *adjusted* respondent population of 51 respondents.

Table 1. Description of Respondent Age, Residence, and Education.

	Men	% of Men	Women	% of Women	Total	Percent of Total
Total Number of Respondents Surveyed	**13**	**100%**	**38**	**100%**	**51**	**100.0%**
Age Group						
18 to 34	3	23.1%	16	42.1%	**19**	**37.3%**
35 to 54	9	69.2%	18	47.4%	**27**	**52.9%**
55 to 64	1	7.7%	0	0.0%	**1**	**2.0%**
65 and older	0	0.0%	4	10.5%	**4**	**7.8%**
Residence by Area						
North Seattle	1	7.7%	1	2.6%	**2**	**3.9%**
Central Seattle	5	38.5%	11	28.9%	**16**	**31.4%**
Southeast Seattle	3	23.1%	11	28.9%	**14**	**27.5%**
West Seattle	2	15.4%	4	10.5%	**6**	**11.8%**
South King County	2	15.4%	11	28.9%	**13**	**25.5%**
Education						
Less than high school diploma/equivalent	0	0.0%	3	7.9%	**3**	**5.9%**
High school diploma/equivalent	5	38.5%	7	18.4%	**12**	**23.5%**
Some college	5	38.5%	16	42.1%	**21**	**41.2%**
College	2	15.4%	6	15.8%	**8**	**15.7%**
College graduate	1	7.7%	6	15.8%	**7**	**13.7%**

Table 2. Description of Respondent Occupation, Marital and Health Insurance Status.

	Number Responding	Percent of Total
Total Number of Respondents Surveyed	**51**	**100.0%**
Occupation (some respondents identified more than one category)		
Employed by someone else	34	66.7%
Self-employed	6	11.8%
Out of work	6	11.8%
Unable to work	4	7.8%
Retired	3	5.9%
Employed part-time	2	3.9%
Homemaker	1	2.0%
Other	2	3.9%
Marital Status		
Single	19	37.3%
Married	9	17.6%
Member of unmarried couple	8	15.7%
Divorced	7	13.7%
Widowed	4	7.8%
Separated	3	5.9%
No response	1	2.0%
Health Insurance Status		
Private	24	47.1%
Medicaid	9	17.6%
None	7	13.7%
Combination of Sources	5	9.8%
Medicare	3	5.9%
No Response	2	3.9%
Other	1	2.0%

Females were 75% (n=38) of the interview population and males were 25% (n=13). Over two-thirds (69%) of the males interviewed were in the 35-54 years age group and 23% were in the 18-34 years age group with only a single male over the age of 55 (8%). The distribution of female ages was quite different. The 35-54 age group was also the largest with female respondents but this group represented only 47% of the total. The 18-34 age group represented 42% of the female respondents, with 11% in the 65+ group.It appeared that younger and older African American men and older, middle age women were underrepresented in the study.

The area of residence within King County was identified according to seven areas (see map in Appendix H). The distribution of respondents among these seven residency areas appears to profile the distribution of the total African American population among these areas. Approximately 31% of the respondents resided in Seattle's Central Area and 28% resided in Southeast Seattle. South King County residents accounted for 26% of respondents with North Seattle at 4%. West Seattle residents accounted for 12% of the total, while there were no residents recorded for North King County neighborhoods. There were no significant variations between males and females according to residency area.

It was decided that asking the respondents to identify their income would put an undue stress on the overall comfort level of the interviews. The interview instrument, therefore, included several surrogate indicators of socioeconomic status. Educational level was the most significant of these socioeconomic indicators. With respect to this indicator, less than 6% of the respondents had less than a high school degree. Approximately 16% reported that they had college degrees and 14% reported that the had graduate degrees. Another 41% reported "some college" on the educational status question. Further analysis of these data indicated that males with less than a high school education were un-represented and females with some college are over-represented

With respect to health insurance coverage, approximately 55% of the respondents had private health insurance coverage, 22% were Medicaid recipients and 14% were uninsured. In general, the respondent population for the Interview Project was viewed as more educated and better insured than the King County African American adult population overall.

B. EVENT SPECIFIC DATA **(TABLE 3)**

The 55 respondents reported a combined total of 92 discrimination events and racist episodes. A *discrimination event* is an instance where an ethnic minority individual receives less desirable treatment than received by members of the majority race. A *racist episode* occurs when a direct remark or overture of a racist nature is made to a racial/ethnic minority individual. As these two categories tend to overlap and as the distinctions between the two are not always clear, both categories are combined for purposes of this analysis and are referred to in this analysis simply as *events*.

Table 3. Description of Discrimination Events.

	Number of Events	Percent of Total Events
Total Number of Events Less than 10 Years Reported	**78**	**100.0%**
Time Since Event Occurred:		
Range = 0.02 to 10 years		
Mean = 2.2 years (standard deviation = 2.86 years)		
Median = 0.82 years		
Target of Discrimination (multiple responses allowed)		
Self (respondent)	68	87.2%
Child of respondent	7	9.0%
Friend of respondent	2	2.6%
Spouse of respondent	1	1.3%
Other relative of respondent	5	6.4%
Event by Provider/Facility Type (multiple provider/facilities allowed)		
Hospital in-patient	20	25.6%
Doctor's office	14	17.9%
Medical center out-patient	12	15.4%
Community clinic	9	11.5%
Emergency facility	7	9.0%
Urgent care center	3	3.8%
Other	9	11.5%
Personnel Involved in Event (multiple responses per event allowed)		
Physician	46	59.0%
Nurse	30	38.5%
Front desk staff	18	23.1%
Medical assistant	8	10.3%
Dentist	5	6.4%
Billing clerk	1	1.3%
Dental assistant	1	1.3%
Pharmacist	1	1.3%
Lab technician	1	1.3%
Emergency personnel	1	1.3%
Security	1	1.3%
Other	25	32.1%
Type of Perceived Discrimination (multiple responses allowed)		
Differential treatment	50	64.1%
Perceived negative attitude	36	46.2%
Treated as dumb	22	28.2%
Made to wait	13	16.7%
Ignored	11	14.1%
Pain ignored	11	14.1%
Inflicted unncecessary pain	5	6.4%
Racial slur	4	5.1%
Harassed	3	3.8%
Being watched	2	2.6%
Exhibited fear	1	1.3%
Other	32	41.0%

An attempt was made to focus on recent events by prompting the respondents to identify only those events that occurred during the past 10 years. This event age limit was set to ensure a focus on events that were more reflective of relatively *current* experiences. However, 9 of the 55 respondents reported events that were from 14 to 39 years old. Of these 9 respondents, only 4 reported events that were *only* over 10 years old, whereas, 5 of these 9 respondents reported events that were both more than and less than 10 years old. Those 4 respondents who reported events that were only over 10 years old were dropped from the primary data analysis (as referenced in the previous section) yielding the adjusted respondent group of 51.

The reported events of racial discrimination were similarly adjusted by eliminating all 14 events that were over 10 years old. This adjustment yielded an **adjusted event total of 78 events**. The **average of 1.5 events/respondent** indicated the average number of events that the interviewers were able to record from this group during the interview process.

Within the study group of the 78 events that were equal to or less than 10 years old, **the average age of the events was about 2 years and 3 months. However, half of these events (the median age of the events) occurred within 10 months of the interview**. The Interview Project was therefore able to capture relatively recent events.

The reported acts of discrimination were predominately directed toward the respondents, with the next highest category being directed toward their children. This gave a very high percentage of *direct experience* accounts of the reported events.

Respondents were prompted to recount events that occurred in any type of health care settings. Approximately 41% of the reported events occurred in major medical centers/hospitals and another 9% were reported as occurring in "emergency facilities." Approximately 18% of the reported events occurred in physicians' offices. The remaining incidents were reported to have occurred in a wide variety of other settings.

Respondents frequently reported that several categories of health care personnel were the perpetrators in a single event. Of the total of 139 *health care staff citations* made by the respondents, 93 were against clinicians (67%). The reviews conducted of the respondents' comments indicated that direct health service delivery personnel were the primary source of the perceived offensive behaviors, with support personnel implicated to a lesser degree.

The interviewers were instructed to record the actual nature of each event according to 12 different perception categories as displayed in Table 3. The interviewers only prompted the respondents by reading the list of possible categories when absolutely necessary. Very few respondents required prompting in this area. Respondents reported that a racial slur was used in approximately 5% (4) of the events. These cases stand apart from the other perception categories as more definitive racist episodes that indicate overtly racist behavior. These 4 events when compared to the relatively small number of total respondents (n=51) indicated a higher than anticipated frequency of well-defined, overt racist behavior. This observation is not intended to diminish the relative importance of

the other more frequently mentioned perceptions of *differential treatment* and *being treated as if dumb*.

C. PERCEIVED DISCRIMINATION

The respondents reported a wide variety of events in response to the interview questions. **The respondents showed no hesitation in recounting the events and in most cases were eager to recount their experiences**. Many respondents expressed an appreciation for the fact that Public Health – Seattle & King County had commissioned the Interview Project.

1. Perceptions of Differential Treatment

As noted in the statistical summary provided in the previous section, the respondents identified *differential treatment* as their most common perception when recounting the events. This perception was reported in 50 of the 78 recorded events (64%). In these cases the respondents reported being able to distinguish the manner in which they were treated as being different from the manner in which others were being treated or different from their perception of the *norm*. Phrases such as the following were used to describe events in which *differential treatment* was perceived:

- "…did not treat us like we mattered."
- "He treated the Caucasian woman better and differently."
- "They treated us like we were second class citizens."

In one particular instance a respondent was hospitalized for the delivery of her baby in a major medical center. She reported that she and her guests were treated rudely by the staff nurses and that she could overhear the same nurses providing more courteous care to patients in other rooms.

Another respondent who was a nursing educator with a graduate degree was referred to a physical therapist located at a major medical center. This respondent reported that she "felt that she did not want to touch me." After complaining to her primary care physician, she was referred to another physical therapist.

One of the more graphic descriptions of differential treatment came from a respondent who went to a private physician's office in the major medical center in her community for an initial pregnancy check. After getting what she described as minimal treatment (stomach measurement only) she observed a Caucasian woman who "came in for the same thing and got an ultrasound." On a second visit she observed the same differential treatment and "…made a big fuss to get my ultrasound." This differential treatment motivated the respondent to take a 15-mile taxicab ride to another medical center out of frustration with the care that she received in her community.

2. Perceived Negative Attitude

The respondents cited a perceived negative (racist) attitude as the second most common perception in the 78 events. This perception was identified in 36 of the 78 events (46%).

The respondents most often reported rude behavior, being treated less seriously or being belittled as accounting for their perception that the staff of health care delivery agencies exhibited a negative attitude. The respondents felt that the *negative attitude* directed toward them was due to their race. The term "attitude" was used as a perception category as it has been a common expression used by African Americans to describe perceived verbal or non-verbal coldness or hostility directed from one person to another. The respondents described such incidences using the following phrases:

- "They treated us rudely."
- "Staff was rude, very cold."
- " The intake person was rude and insensitive."
- "However, there was one male nurse who was very rude. He spoke to me very mean."
- "I felt the setting was unfriendly"
- "She was worse. Treated me like I stunk."
- "The nurses were rude, mean, inattentive and uncaring."
- "The receptionist was very cold. She would not look at me."
- "They were giving me the brush off."

One respondent reported two events that occurred at a major specialty medical center. The respondent reported:

> "I walked up and she (the receptionist) disregards me. She's cold! She did not look at or speak to me. The only thing that keeps me from going off is that I understand this (manner)."

In a second event at the same specialty medical center, the respondent reported that:

> "The woman totally ignored me."

Commenting on this experience, this respondent made two rather profound statements:

> "These incidents remind me that I'm just a nigger in King County."
> "Going to the doctor is always a struggle. To be heard, to be listened to is something I have to fight for."

Other respondents reported perceiving a sense that they were being taken less seriously due to their race. The respondents used the following phrases to describe their perceptions of a *negative attitude* manifested in this way:

- "…I felt that they did not take me seriously."
- "I did not feel that the physician was interested."
- "He looked at me like he wasn't interested in what I was saying."

One well-defined reaction that some respondents had to a perceived negative attitude was the sense that they were being *belittled*:

- "The staff belittled me a lot. Very degrading."
- "The nurse belittled me."

A respondent who was a computer science engineer with a graduate degree took her daughter to a major medical center for treatment of her asthma. When the daughter asked the attending medical resident a question, she reported that:

> "He yelled at her and cursed. He then caught himself. The patient in the next area even commented to the resident on his inappropriate treatment of my daughter. When I complained to the resident he responded that he was used to dealing with kids in Tacoma who he characterized as 'undisciplined children' and that he assumed that kids in this area were the same."

The respondent in this case filed a written complaint and was subsequently informed that the medical resident was barred from further training in that hospital. The respondent also commented that:

> "I was afraid that my daughter might be afraid to come back to the hospital (for asthma treatment)."

3. Perceptions of Being Treated as if "Dumb"

Respondents frequently reported being treated *as if they were dumb* in health care settings. Respondent comments used to describe these events included the following:

- "He was describing the problem slowly, like I was dumb."
- "The radiologist made a couple of rude remarks, like I was dumb."

In a third event, a female attorney reported an incident that occurred just one week prior to the interview when she was in a private specialist's office in Seattle to have her son's circumcision examined. Her pediatrician's office had referred her to this specialist when her regular pediatrician was out of town. This respondent reported that:

> "The physician did not speak to me when I spoke to him to say hello. He acted as if he was not interested in what I was saying. He told me how to wrap my son's incision, like I was dumb. He described the procedure slowly, like I had never taken care of a child before."

In commenting on this experience, the respondent made the following two (2) statements:

> "I felt like I was being treated like a welfare mom."
> "Chalk it up as another experience in Seattle."

Respondents indicated that they felt that they were being treated as if they were dumb in a total of 22 of the 78 events (28.2%).

4. Perception of Being Ignored

The respondents reported a sense of being ignored in 11 of the 78 events (14%). Respondents used the following phrases and sentences to describe their perception of being ignored:

- "I was in the emergency room at the hospital and I feel that I was ignored due to my race."
- "I was ignored and made to wait a long time."

- "The receptionist told me that I should not have forgotten my medical card. She ignored me and dealt with the woman behind me."
- "I had tendonitis and was in pain. I was made to wait a long time. I was ignored."
- "Front desk staff ignored me when I asked for help."
- "I felt that I as a person was ignored."

5. Inappropriate Allegations

There were two respondents who reported instances of being accused of using drugs. In each case the respondents reported that they did not use drugs and were shocked at the allegation. These events were described as follows:

- "The doctor wanted to know if I always asked for specific drugs. Treated me as if I were drug shopping."
- "The nurse said, 'I know you shoot dope.'"

In reporting these events, the respondents felt that the allegation of illegal drug use or drug shopping was due to their race.

6. Perceived Racist Remarks

Some respondents reported that health care personnel made what they perceived to be racist remarks in the course of providing health care services. These events stood out as some of the more blatant examples of racial insensitivity reported by the respondents. These incidents were as follows:

- A respondent (who was a nurse at a major hospital) was told that her daughter's condition was "an African American thing." Her daughter was eventually diagnosed as having asthma.
- A respondent reported the lab tech in a major hospital joked, "Your skin is so dark that I can't find your veins" and then laughed.
- A respondent called a major medical center and explained that she needed to come in without an advance appointment and the receptionist said, "Fine." A staff nurse entered the exam room where the respondent was waiting and without closing the door said, "You people never make appointments, you want to come in whenever you want."
- A respondent reported that she was at a major medical center for a gynecological exam after her regular physician retired. During a blood draw the attending physician stated, "Being a typical Black woman, I bet you haven't dieted in over 20 years."

One event reported by a respondent who was a computer programmer with private insurance occurred just one month prior to the interview. The respondent reported:

> "I was going to have a breast biopsy and asked for a sedative because I have a low tolerance for pain. My doctor specifically recommended something for pain. The nurse refused to give me something for pain. The nurse said, 'You people accepted pain as part of slavery because you tolerate pain so well.' I called my doctor who called the head of the hospital. I refused to stay. I was going to leave. My doctor came down to the facility to confront them. Another nurse came to

> give me the medication. After I received the medication, I had the procedure. My doctor had to do prescription management after the procedure."

This respondent filed a written complaint against the nurse and made the following comments to describe her reaction to this event:

> "I have never been treated like this."
> "I will not go to this (unnamed) facility."
> "I am still in pain from this experience. How many experiments do they have to do on us."

In most of these cases of perceived racist remarks the respondents reported being both surprised and incensed.

7. Implied Racist Medical Practice Patterns

There was one event that indicated the possible existence of racist practice patterns among private medical practices. This event was reported by a mental health therapist who had a graduate degree. This respondent was told by a physician in outside Seattle that he was retiring from practice. When the respondent asked for a recommendation of a replacement physician, her physician replied:

> "Don't you know there are doctors who don't want to treat black people"

The respondent stated that she did not return to that physician to continue her prenatal care.

8. Report of a Validated Racial Incident

One major racial incident was identified during the Interview Project that could not be categorized as an event where "perception" was an issue. In this case the respondent was taken to a Seattle hospital when he was unconscious from a seizure. The hospital refused to treat the respondent and transferred him to another hospital. The respondent's family sued the hospital and won. The respondent reported that the hospital eventually acknowledged that they had denied treatment based on race. The respondent further reported that a physician, nurse and physician's assistant were fired as a result of this incident. This incident occurred three years ago but the respondent reported, "I think about this all the time. My family and I still talk about this."

This event was the only report of legal action taken as a result of racially discriminatory treatment.

D. ASSESSMENT OF PERCEIVED DISCRIMINATION

An effort was made to categorize the reported events to facilitate an overall analysis. A synopsis of all the events was made and the events were grouped according to the respondent's self-assessment of the severity of the event on a 1 to 10 scale. This self-assessed severity-based analysis did not seem to provide any useful insights or establish any trends. It seemed that the sensitivities and individual personalities of the respondents determined their sense of the severity of the events.

The other method developed to summarize the reported events was directed at the content of the information provided about each event. The intent of this summary was to group the events by the possibility that true racial discrimination had occurred in the reported event. The method designed to summarize the reported events in this manner was to group them as *probable*, *possible* and *not probable* racial discrimination. The 78 reported events were grouped as follows using this approach:

- 28 event reports indicate p*robable* racial discrimination or racist events (36%).
- 45 event reports indicate p*ossible* racial discrimination or racist events (58%).
- 5 event reports indicate that racial discrimination was n*ot probable* (6%).

In determining the placement of an event in one of the above three categories, the event descriptions were reviewed to determine if any definitive sign of racial discrimination was reported. In one case a respondent reported that a nurse was putting on makeup when she was in labor. This event was placed in the n*ot probable* category, as the allegation did not appear to be racially motivated. Most of the events fell into the middle or p*ossible* category as there was reason to suspect that race was the primary factor but race could not be established as the definitive factor based on the information provided. **Over one third of the reported events had sufficient information to indicate the probability that race was the primary factor in the event.**

It should be noted that five (5) of the 45 events in the *Possible* discrimination category contained some reference to "medical coupons" or Medicaid as a factor in the event. There was in each case an indication that Medicaid status was a contributing factor. However, none of these respondents distinguished Medicaid status as the only reason for the reported event.

E. IMPACT OF THE EVENTS ON THE RESPONDENTS **(TABLE 4)**

Several questions in the Interview Project were designed to assess the *impact* that the discriminatory events had on the respondents. One of these questions asked if the respondent was surprised by the occurrence of the event. The respondents reported being "surprised" in 66 out of 78 events (85%). This question was also included to assess the degree to which the respondents were either predisposed or generally expecting discriminatory treatment. If a majority of the respondents had indicated a lack of surprise, it *may* have indicated the existence of preconceptions or a personal predisposition to perceive differential treatment based on race. The fact that over 8 of 10 respondents indicated that the event was a surprise to them tends to eliminate the existence of such a predisposition as a factor that influenced the study data. The interviewers recorded the comment that "I was really surprised!" on a significant number of the interview forms.

Table 4. Impressions and Long-Term Response to Event.

	Number of Events	Percent of Total Events
Total Number of Events Less than 10 Years Reported	**78**	**100.0%**
Perceived Severity of Event (scale from 1 to 10 with 10 being the worst possible) **Range = 2 to 10** **Mean = 8.2 (standard deviation = 2.2)** **Median = 9**		
Surprised that Event Occurred?		
Yes	66	84.6%
No	9	11.5%
No response	3	3.8%
Still has Strong Feelings About the Event?		
Yes	58	74.4%
No	16	20.5%
No response	4	5.1%
How Has the Event Impact How Respondent Seeks Health Care Services? (multiple responses to each event permitted)		
More hesitant to seek health care services	21	26.9%
Avoid health care facility	20	25.6%
No change	20	25.6%
Avoid provider	18	23.1%
Stopped using specific services	12	15.4%
Avoid personnel	8	10.3%
Uses services less frequently	6	7.7%
Other	57	73.1%

A question was included in the interview instrument that asked if the respondents still had strong feelings about the event. Respondents reported that they *still* had strong feelings about the event in 74% of the cases. Although the extent of the strong feelings was not assessed, it does appear that there is some lasting emotional impact associated with the reported events

The respondents were asked to provide a self-assessment of the *severity* of the events on a scale of 1 to 10, with 10 being the most severe. The average severity rating given to the group of 78 events was 8.2 with 9 as the median score. This average severity rating indicated that these event reports were generally perceived to be quite severe by the respondents.

The respondents were asked to identify the impact that the event had on their health care seeking behavior. In response to this question almost equal numbers of respondents indicated that they became *more hesitant to receive health care services, avoided a particular provider, avoided the health care facility, or made no change.* Almost one-third of the respondent "result identifiers" fell into the *other* category. The results of this study question indicate a wide variety of individual responses to the events. Approximately, 85 of the 162 comments (53%) in this area identified some delay, hesitation, or avoidance in seeking health care services as a result of the event.

F. COMPLAINTS MADE BY RESPONDENTS **(TABLE 5)**

The respondents reported that they registered a complaint in 42 of the 78 events (53.8%). The types and methods of the complaints varied considerably. However, only 9 respondents reporting that they complained actually filed a written complaint. Most of the complaints were made verbally to the offending party or to the health care facility.

Table 5. Frequency and Type of Respondent Complaints.

	Number of Events	Percent of Total Events
Total Number of Events Less than 10 Years Reported	**78**	**100.0%**
Made Complaint after Event?		
Yes	**42**	**53.8%**
Type of Complaint:		
Complained verbally to individual (% of those who made complaint)	16 (38.1%)	
Complained verbally to superior (% of those who made complaint)	12 (28.6%)	
Made written complaint (% of those who made complaint)	9 (21.4%)	
Other form of complaint (% of those who made complaint)	21 (50.0%)	
No	**32**	**41.0%**
Considered filing a complaint?		
No (% of those who did not make a complaint)	28 (87.5%)	
Yes (% of those who did not make a complaint)	2 (6.3%)	
Unknown (% of those who did not make a complaint)	2 (6.3%)	
No response	**4**	**5.1%**

Very few of those who didn't register a complaint actually considered filing a written complaint, with most indicating that they did not consider filing a complaint.

When asked if they had complained about the event that they had just described, the respondents had a variety of comments:

- "I was offered sympathy but no apology by one black nurse. I was pregnant. I was stressed to find another doctor. This was not the time to fight."
- "I did nothing to complain. I just vented. Let off steam."
- "I was more concerned with my daughter's health. My daughter's health was more important than the incident."
- "When I got firm with them and they found out that I was a college graduate, it changed their attitude."
- "I wish I had filed a lawsuit against them."
- "I just wish I had said something. Maybe I thought that it wouldn't do any good."
- "I am suing the dentist. We have to get the paperwork from our attorney."
- "I just wanted to forget about it."
- "I forgot it and forgot the woman (nurse) and put the past behind me."
- "I expect white personnel to act this way."
- "I felt completely helpless."
- "It does not make sense for me to carry this. I have enough problems without this. I can take that energy and apply it to something positive."

The comments listed above not only summarize the range of responses to the inquiry about complaints regarding the events, but also captures the respondents' sense of frustration.

G. RESULT OF DISCRIMINATORY EVENTS

The respondents generally provided rather succinct statements describing the immediate and longer-term result of a discriminatory event. The following comments are representative of the range of answers given when respondents were asked whether the event had an impact on their health seeking behavior or when they were asked if they still had strong feelings about the event:

- "I just went somewhere else."
- "I will take my kids but I will only go (to medical care) if I am in pain. I don't like doctors."
- "I avoided the physician assistant."
- "I stopped going to _____ Hospital."
- "I vowed never to have another child at _____ Hospital."
- "It makes you think twice before going to the doctor. You are less trusting."
- "Made me not want to go back there."
- "I was ticked off so bad that when I got home, I cut up my _____ card."
- "It was the last time my son would see Dr. _____."
- "I changed doctors. I took control of my son's care."
- "I don't let my daughters go there for nothing."

- "I did not bring my daughter back to _____ Hospital or that doctor for her checkup in 1999."
- "I have not sought surgery for my other leg. I would like surgery but I guess that I'll find someone else. Sometimes my leg hurts."
- "I will no longer use_____ Health Center."
- "I don't have too much confidence in_____ Clinic."
- "If I could find another hospital, my daughter would not go there."
- "As a result of that incident, I'm on the lookout for a new doctor."
- "I don't go back to him (the physician). I avoid him now."
- "I didn't go back for treatment. My condition is the same."
- "I don't go to that doctor anymore."
- "I see them only when I need real urgent care."
- "We only go to the _____ Hospital in a real emergency."
- "Even though this situation surrounded the birth of my daughter, it has made me more hesitant as a black man to get medical care."
- "Even though I can negotiate the system, it reminded me that I will always confront racism."

The comments listed are from 23 separate events and seem to capture the respondents' sense of gravity of the events. **These comments indicate that discriminatory events do have an effect on health seeking behavior. These comments also indicate that the respondents often chose to change providers or to avoid a particular medical provider in response to perceived discrimination.**

V. REVIEW OF THE COMMUNITY FORUMS

A series of three (3) community forums were held as part of the Interview Project. These community forums were designed to:

- Obtain comments and recommendations on the conduct of the Interview Project and future studies.
- Obtain comments and recommendations regarding potential system change and other action to address discrimination in heath care settings.
- Obtain observations and opinions on the preliminary data from the Interview Project.

The Cross Cultural Health Care Program facilitated each of these meetings and tape recordings were made of the proceedings.

A community forum for advocates was held on August 17, 1999. A total of 13 representatives of consumer advocacy organizations attended the meeting. The discussion at this forum tended to center on the effective resolution of complaints from health care consumers regarding discrimination. There was a consensus at this forum that improved public information would assist in the effective resolution of problems regarding discrimination in health care.

A community forum for consumer/community representatives was held on August 18, 1999. Six individuals who worked directly with ethnic minority residents of Seattle's

low-income communities attended this forum. The participants spent much of the meeting affirming their own experiences and those reported by a large number of their clients. Most of the specific recommendations made at this forum were directed at the importance of facilitating easier methods for consumers to register their complaints and concerns regarding the care that they received from health care providers.

A forum for health care provider representatives was held on September 1, 1999. This forum was the largest of the three and was attended by 24 representatives. This forum produced many observations on the reported events from the health care provider perspective. Several of the attendees took the opportunity to profile the recent efforts of their agencies to improve communication with ethnic minority patients and alleviate discrimination.

A summary of the comments and recommendations made at the series of three community forums is included in Appendix C.

VI. SUMMARY

The Interview Project was able to conduct interviews with an adjusted study population of 51 African Americans. All of the individuals in this study population both resided in and received their health services in many different parts of King County. Respondent characteristics represented a variety of ages and socioeconomic backgrounds. More than half of the respondents were privately insured and 30% had college or graduate degrees. The respondent group reported an adjusted total of 78 events of racial discrimination that were an average of 2.2 years old, making them relatively recent.

The discrimination episodes and racist events reported by the respondents indicated that African American King County residents had perceived differential treatment in a wide variety of health care settings. Nearly 30 different health care facilities in all parts of King County were mentioned, indicating that these experiences were widespread and not confined to a few providers or health care facilities. The Interview Project respondents reported that the actual health care providers (clinicians) were most often the perpetrators of the perceived discrimination. The respondents identified a wide variety of *coping mechanisms* for dealing with the events with many indicating that their health-seeking behavior was negatively affected by the reported event.

Based on a review of the information provided by respondents, there were very few events reported where race-based treatment was viewed as being *not probable*. Although a substantial percentage of the reported events were categorized as *possibly* race based as opposed to being *probably* race based, **the perception of the respondents was that all of the reported events were racially motivated**. Whether the events in question were or were not racially motivated does not alleviate the respondents' perceptions and the associated impacts of those perceptions. The relatively high self-reported severity ratings of the events reported by the respondents indicates that these were not perceived as minor events in their lives. Nearly three quarters of the respondents reported that they still harbored strong feelings about the events.

The findings of the Interview Project provide support to the assertions of an increasing number of researchers who suggest that racism might be a pervasive factor affecting both the health-seeking behavior and the health status of African Americans.

Appendix A.

Interview Instrument

Introduction

We are conducting a survey of African American residents of Seattle/King County. We are interested in your experiences as an African American in using health care services. We are specifically interested in knowing whether you have been treated unfairly due to your race when seeking or acquiring health care services. This Fact Sheet (that I am giving you) outlines the important information on the study.

The results of the survey will be used to make recommendations to local authorities that could help eliminate any discriminatory practices against African Americans by health care providers in the Seattle/King County area.

We will not ask for your name or your exact address. Any information you give cannot be traced to you in any way.

We are providing those who complete the survey with a $10.00 gift certificate. This $10.00 gift certificate is good towards any purchase of $10.00 or more at _____.

Would you be willing to answer our survey questions?

Thank You!!!

You can refuse to answer any question and still continue with the interview.

Survey Eligibility Confirmation

Ok, to begin, we must ask you three questions to confirm that you are eligible for this survey.

1. First, do you consider yourself to be of the African American race?
   01 Yes
   02 No
2. Second, are you at least 18 years old?
   01 Yes
   02 No
3. Do you receive your health care services in King County?
   01 Yes
   02 No

Fine. You are eligible for this survey. Would you like to continue?

Note: If either of the answers tot he above three questions is no, thank the respondent and state that you have been instructed to limit the survey at this time.

B. Discrimination Episodes/Racist Events

The main purpose of this survey is to hear about any specific incidents of unfair or bad treatment that you felt was due to your race, when seeking medical care services for yourself or your family.

4. During the past 10 years (in Seattle/King County) have you ever experienced any incidents of discrimination due to your race when seeking or obtaining health care?
   01 Yes (Continue survey)
   02 No (go to #7)

5. How often have you experienced such events?
   01 _____times during the last 12 months.
   02 _____times during the last 3 years.

03 _____times during the last 5 years.
04 _____times during the last 10 years.

6. Will you assist us in identifying the types of racial discrimination incidents experienced by African Americans seeking or obtaining health care by recounting one or more instances that you have experienced or observed first-hand ?
   01 Yes (see note below)
   02 No (go to #8)

(***Note: Go to Specific Event Modules***, in the following order: **most recent**; **most severe**; **additional**.)

7. There are different things that could happen to you or your family members that you might call discriminatory. We are open to hear about any of these experiences, such as times where a doctor, or any of the other office clerical, nursing, or professional staff:

   - talked down to you
   - displayed an "attitude" while serving you
   - watched you more closely than others
   - did not treat you with dignity and respect
   - ignored you
   - gave you poor service compared to other patients
   - used a racial slur
   - acted as if they were afraid of you
   - acted as if they thought you were not smart
   - acted like they thought your were dishonest
   - actually harassed you

   Understanding that these are among the many incidents that could be considered discriminatory events, during the past 10 years (in Seattle/King County), have you ever experienced any incidents of discrimination due to your race?

   01 Yes (Go back to #5)
   02 No (Go to #8 below)

C. Specific Event Module -- MOST RECENT

Although we realize that it is sometimes uncomfortable to recount incidents in which you feel that you were treated unfairly because of your race, we would greatly appreciate your sharing of some of your experiences with us.

1. Exactly how long ago was the LAST time that you felt that you (or a member of your family) were treated unfairly due to your race when attempting to get or actually receiving health care services?
   01 _____days ago
   02 _____months ago
   03 _____years ago

2. Who actually experienced the act(s) of discrimination?
   01 Your self
   02 Your spouse
   03 Your child
   04 Another relative (specify:_____)
   05 A friend who you accompanied

3. Where did this occur?
(*Note: If respondent does not clearly define location, then read list of locations*)
01 As a hospital in-patient
02 As a medical center out-patient
03 Urgent Care Center
04 Emergency Facility
05 Doctor's office
06 Community clinic or community health center
07 Health department center
08 VA Hospital
09 Nursing home
10 Mental health center
11 Family planning clinic
12 Dentist Office
13 Chiropractor
14 Naturopath
15 Accupuncturist

4. Would you share the name of this place?

5. Please describe what happened?

5A. Type of personnel involved:
(Do not read)
(*Note: Circle all that apply*)
01 Front desk staff
02 Billing clerk
03 Medical assistant
04 Nurse
05 Physician (doctor)
06 Dentist
07 Dental Assistant
06 Pharmacist/Pharmacy Tech
07 Lab Tech
08 X-ray Tech
09 Emergency Personnel
10 Medical Transport/Ambulance Personnel
11 Supervisory Personnel
12 Volunteers
13 Security
14 Other _____

5B. Type of incident:
(Do not read)
01 Perceived negative (racist) attitude
02 Differential treatment
03 Being watched more closely than others
04 Made to wait longer
05 Harassed
06 Racial slur
07 Exhibited fear
08 Treated as if dumb
09 Ignored
10 Pain ignored
11 Inflicted unnecessary pain
12 Other _____

6. How would you rate the severity of the incident on a scale of 1 to 10 with 10 being the worst possible?

7. Were you surprised by this incident?
   01 Yes
   02 No
   03 Expected (*Note: Enter only if information volunteered*)

   Detail:

8. Were there other things that could have influenced the way you were treated? (*Note: If necessary, make the distinction between rude vs. race-based behavior*, if asked give examples of it being very busy at the time of the incident.)

   01 Yes, specify _____
   02 No

9. Did you complain about this incident
   01 Yes (go to #9A, #9B, and #9C)
   02 No (go to #9)

   Detail:

   9A. Specifically, how did you complain?
   01 Verbal complaint to the offending individual
   02 Verbal complaint to the offending individuals
   03 Filed written complaint (go directly to #10)
   04 Other_____

   9B. When did you complain?
   01 At the time of the event
   02 Immediately after the event
   03 Same day as the event
   04 Within several days of the event
   05 Within a week of the event
   06 Within a month of the event
   07 More than a month after the event
   08 Don't remember

   9C. What happened as a result of your complaint?
   (***Note: Go to #10 after completing 9A, 9B & 9C)***)

10. What type of written complaint did you file?
    01 Sent written complaint
    02 Obtained form and filed official complain
    03 Filed complaint with Federal Agency:_____(OCR, HCFA, etc.)
    04 Filed complaint with Seattle Civil (Human) Rights Agency (Commission)
    05 Filed complaint with King County Human Rights Agency (Commission)
    06 Filed complaint with Washington State Human Rights Agency (Commission)
    07 Took legal action in_____court

    10A. When did you file this complaint?
    01 At the time of the event
    02 Immediately after the event
    03 Same day as the event

04 Within several days of the event
05 Within a week of the event
06 Within a month of the event
07 More than a month after the event
08 Don't remember

10B. What happened as a result of your complaint filing?

11. Did you consider filing a complaint?
01 Yes (go to #9A)
02 No (go to #10)

11A. Why didn't you file a complaint?
01 Did not know how
02 Thought that it would do no good
03 Was afraid
04 Didn't have the time
05 Not important enough
06 Satisfied with response
07 Other_____

12. How did this event impact your seeking of health care services?
(*Note: Circle all that apply*)
01 Use services less frequent
02 Stopped using specific services, Specify_____
03 More hesitant to seek health care services
04 Avoid specific personnel, Specify: _____
05 Avoid provider
06 Avoid health care facility
07 No change
08 Other _____

Details:

13. Do you still have strong feelings about this event?
01 Yes
02 No
Details:

14. Was this *most recent* event the *most severe* (or *worst*) one that you have ever experienced?

01 Yes (ask if there is another event that can be shared and go to ADDITIONALevent module)
02 No (go to MOST SEVERE event module)

(Note: If no additional modules will be filled out return to Question #7 in the main questionnaire.)

D. Specific Event Module – MOST SEVERE

We would appreciate your sharing with us the details of the discrimination event that you felt to be the most severe. However, if you do not have to answer any question that makes you too uncomfortable.

15. When did this MOST SEVERE incident occur?

16. Who actually experienced the act(s) of discrimination?
    01 Your self
    02 Your spouse
    03 Your child
    04 Another relative (specify:_____)
    05 A friend who you accompanied

17. Where did this occur?
(*Note: If respondent does not clearly define location, then read list of locations*)
    01 As a hospital in-patient
    02 As a medical center out-patient
    03 Urgent Care Center
    04 Emergency Facility
    05 Doctor's office
    06 Community clinic or community health center
    07 Health department center
    08 VA Hospital
    09 Nursing home
    10 Mental health center
    11 Family planning clinic
    12 Dentist Office
    13 Chiropractor
    14 Naturopath
    15 Accupuncturist
    16 Other _____

18. Would you share the name of this place?

19. Please describe what happened?

    19A. Type of personnel involved:
    (Do not read)
    (*Note: Circle all that apply*)
        01 Front desk staff
        02 Billing clerk
        03 Medical assistant
        04 Nurse
        05 Physician (doctor)
        06 Dentist
        07 Dental Assistant
        06 Pharmacist/Pharmacy Tech
        07 Lab Tech
        08 X-ray Tech
        09 Emergency Personnel
        10 Medical Transport/Ambulance Personnel
        11 Supervisory Personnel
        12 Volunteers
        13 Security
        14 Other _____

    19B. Type of incident:
    (Do not read)
        01 Perceived negative (racist) attitude
        02 Differential treatment
        03 Being watched more closely than others

04 Made to wait longer
05 Harassed
06 Racial slur
07 Exhibited fear
08 Treated as if dumb

20. Would you rate the severity of the incident on a scale of 1 to 10 with 10 being the worst possible?

21. Were you surprised by this incident?
01 Yes
02 No
03 Expected

Detail: (*Note: Enter only if information volunteered*

22. Were there other things that could have influenced the way you were treated, such as it being very busy at the time? (*Note: If necessary, make the distinction between rude vs. race-based behavior)*
01 Yes, Specify
02 No

23. Did you complain about this incident
01 Yes (go to #23A, #23B, and #23C)
02 No (go to #25)

Detail:

23A. Specifically, how did you complain?
01 Verbal complaint to the offending individual
02 Verbal complaint to the offending individuals
03 Filed written complaint (go directly to #10)
04 Other_____

23B. When did you complain?
01 At the time of the event
02 Immediately after the event
03 Same day as the event
04 Within several days of the event
05 Within a week of the event
06 Within a month of the event
07 More than a month after the event
08 Don't remember

23C. What happened as a result of your complaint?

24. Did you file a <u>written</u> complaint?
01 Yes (go to #24A, #24B, and #24C)
02 No (go to #26)

24A. What type of written complaint did you file?
01 Sent written complaint to: _____
02 Obtained form and filed official complaint
03 Filed complaint with Federal Agency:_____(OCR, HCFA, etc.)
04 Filed complaint with Seattle Civil (Human) Rights Agency (Commission)
05 Filed complaint with King County Human Rights Agency (Commission)
06 Filed complaint with Washington State Human Rights Agency (Commission)
07 Took legal action in _____ Court

24B. When did you file this written complaint?
01 At the time of the event
02 Immediately after the event
03 Same day as the event
04 Within several days of the event
05 Within a week of the event
06 Within a month of the event
07 More than a month after the event
08 Don't remember

24C. What happened as a result of your complaint filing?
(***Note: Go to #26 after completing 24A, 24B & 24C***)

25. Did you consider filing a complaint?
01 Yes (go to #25A)
02 No (go to #26)

25A. Why didn't you file a complaint?
01 Did not know how
02 Thought that it would do no good
03 Was afraid
04 Didn't have the time
05 Not important enough
06 Satisfied with response
07 Other _____

26. Did you complain in any other way?
01 Yes (go to #26A, #26B, and #26C)
02 No (go to #27)

26A. What type of complaint?
01 Verbal complaint to the offending individual
02 Verbal complaint to the offending individuals supervisor (or coworker)
03 Other: _____

26B. When did you complain?
01 At the time of the event
02 Immediately after the event
03 Same day as the event
04 Within several days of the event
05 Within a week of the event
06 Within a month of the event
07 More than a month after the event
08 Don't remember

26C. What happened as a result of your complaint?

27. How did this event impact your seeking of health care services?
(*Note: Circle all that apply*)
01 Use services less frequent
02 Stopped using specific services, Specify_____
03 More hesitant to seek health care services
04 Avoid specific personnel, Specify_____
05 Avoid provider
06 Avoid health care facility

07 No change
08 Other _____

Details:

28. Do you still have strong feelings about this event?
01 Yes
02 No

Details:

29. Have you experienced <u>other</u> incidences of racial discrimination when seeking or obtaining health care services that you can share with us?
01 Yes (go to ADDITIONAL event module)
02 No (return to Question #7 in main questionnaire)

E. Specific Event Module -- ADDITIONAL

If you are willing, we would like you to share the details of <u>another</u> discrimination in health care event with us. We would like to remind you that you do not have to answer any question that makes you too uncomfortable.

30. When did this event occur?

31. Who actually experienced the act(s) of discrimination?
01 Your self
02 Your spouse
03 Your child
04 Another relative (specify:_____)
05 A friend who you accompanied

32. Where did this occur?
(*Note: If respondent does not clearly define location, then read list of locations*)
01 As a hospital in-patient
02 As a medical center out-patient
03 Urgent Care Center
04 Emergency Facility
05 Doctor's office
06 Community clinic or community health center
07 Health department center
08 VA Hospital
09 Nursing home
10 Mental health center
11 Family planning clinic
12 Dentist Office
13 Other _____

33. Would you share the name of this place?

34. Please describe what happened?

34A. Type of personnel involved:
(Do not read)
(*Note: Circle all that apply*)
01 Front desk staff

02 Billing clerk
03 Medical assistant
04 Nurse
05 Physician (doctor)
06 Dentist
07 Dental Assistant
06 Pharmacist/Pharmacy Tech
07 Lab Tech
08 X-ray Tech
09 Emergency Personnel
10 Medical Transport/Ambulance Personnel
11 Supervisory Personnel
12 Volunteers
13 Security
14 Other _____

35B. Type of incident:
(Do not read)
01 Perceived negative (racist) attitude
02 Differential treatment
03 Being watched more closely than others
04 Made to wait longer
05 Harassed
06 Racial slur
07 Exhibited fear
08 Treated as if dumb

36. Would you rate the severity of the incident on a scale of 1 to 10 with 10 being the worst possible?

37. Were you surprised by this incident?
01 Yes
02 No
03 Expected)

Detail: (*Note: Enter only if information volunteered)*

38. Were there other things that could have influenced the way you were treated, such as it being very busy at the time? (*Note: If necessary, make the distinction between rude vs. race-based behavior*)
01 Yes, specify _____
02 No

39. Did you file a written complaint?
01 Yes (go to #32A, #32B, and #32C)
02 No (go to #33)

39A. What type of complaint did you file?
01 Sent written complaint to: _____
02 Obtained form and filed written complaint
03 Filed complaint with Federal agency: _____ (OCR, HCFA, etc.)
04 Filed complaint with Seattle Civil (Human) Rights agency (Commission)
05 Filed complaint with King County Human Rights agency (Commission)
06 Filed complaint with Washington State Human Rights Agency (Commission)
07 Took legal action in_____ Court

39B. When did you file this complaint?
01 At the time of the event

02 Immediately after the event
03 Same day as the event
04 Within several days of the event
05 Within a week of the event
06 Within a month of the event
07 More than a month after the event
08 Don't remember

39C. What happened as a result of your complaint filing?

(***Note: Go to #41 after completing #39A, 39B & 39C***)

40. Did you consider filing a written complaint?
01 Yes (go to #40A)
02 No (go to #41)

40A. Why didn't you file a written complaint?
01 Did not know how
02 Thought that it would do no good
03 Was afraid
04 Didn't have the time
05 Not important enough
06 Satisfied with response
07 Other _____

41. Did you complain in any other way?
01 Yes (go to #34A, #34B, and #34C)
02 No (go to #35)

41A. What type of complaint did you make?
01 Verbal complaint to offending individual
02 Verbal complaint tom offending individual's supervisor (or coworker)
03 Other: _____

41B. When did you complain?
01 At the time of the event
02 Immediately after the event
03 Same day as the event
04 Within several days of the event
05 Within a week of the event
06 Within a month of the event
07 More than a month after the event
08 Don't remember

41C. What happened as a result of your complaint?

42. How did this event impact your seeking of health care services?
(*Note: Circle all that apply*)
01 Use services less frequent
02 Stopped using specific services, Specify_____
03 More hesitant to seek health care services
04 Avoid specific personnel, Specify_____
05 Avoid provider
06 Avoid health care facility
07 No change
08 Other _____

Details:

43. Do you still have strong feelings about this event?
    01 Yes
    02 No
    Details:

    Unless there are additional discriminatory events that you wish to share with us, we would like to continue with some other questions.

    (***Note: Move to another ADDITIONAL event module or return to main questionnaire at question #7***)

F. Demographics

The following series of questions will help to learn more about you and aid in assembling our survey information.

44. How long have you lived in Seattle/King County?
    01 Less than 1 year
    02 One year to 3 years
    03 Three years to 5 years
    04 Five years to 10 years
    05 Over 10 years
    06 Over 20 years
    07 Over 30 years

45. Please indicate where you live in the Seattle/King County on this map.
    01 Area 1
    02 Area 2
    03 Area 3
    04 Area 4
    05 Area 5
    06 Area 6

46. What is the name of the neighborhood where you live? _____

47. How long have you lived in your current neighborhood?
    01 Less than 1 year
    02 One year to 3 years
    03 Three years to 5 years
    04 Five years to 10 years
    05 Over 10 years
    06 Over 20 years
    07 Over 30 years

48. Please indicate which Seattle/King County area that you have lived in for the longest time.
    01 Area 1
    02 Area 2
    03 Area 3
    04 Area 4
    05 Area 5
    06 Area 6

50. How long did you live in this other neighborhood?
    01 Less than 1 year

02 One year to 3 years
03 Three years to 5 years
04 Five years to 10 years
05 Over 10 years
06 Over 20 years
07 Over 30 years

51. Do you mind giving us your age by indicating which age group that you are in?
    01 18-34 years
    02 35-54 years
    03 55-64 years
    04 65+

52. Are you:
    01 Married
    02 Divorced
    03 Widowed
    04 Separated
    05 Single
    06 A member of an unmarried couple

53. You are:
    01 Male
    02 Female

54. What is the highest level of education that you have completed?
    01 Less than high school
    02 High school degree or GED
    03 Some college
    04 College degree
    05 Graduate degree

55. Are you currently:
    01 Employed by someone else
    02 Self-employed
    03 Employed part-time
    04 Out of work
    05 Homemaker
    06 Retired
    07 Unable to work

    08 Other_____

G. Health Insurance Status

Now, I would like to ask you some questions about your health insurance coverage.

56. What kind of health care insurance or coverage do you have *now*?
    01 None (go to #18A and #18B)
    02 Medicaid (Healthy Options, coupons, or assigned managed care plan)
    03 Medicare
    04 Private (includes BS, BC, HMO, employer paid, etc.)
    05 Veterans Administration
    06 CHAMPUS
    07 Military
    08 Washington State Basic Health Plan

09 Refused Coverage
10 Other _____
11 Combination _____and_____
12 Don't know

56A. What is the main reason you do not have any health care insurance coverage? (Do not read)
01 Employer does not offer insurance
02 Lost job and lost insurance benefits
03 Separation from spouse or domestic partner and lost benefits
04 Turned down by insurance company
05 Couldn't afford to pay for insurance
06 Didn't seek insurance
07 Eligible, but did not sign up for insurance
08 Out of work, but would have insurance if provided by employer
07 Refused coverage by carrier
08 Other _____
09 Don't know

Details:

56B. How long have you been without health care insurance?
01 _____days
02 _____months Period without insurance converted into days:
03 _____years _____
(***Note: Go to #57***

57. In the past 12 months, was there any time that you did not have any health insurance or coverage?
01 Yes (Go to #19A and #19B)
02 No (go to #20)

57A. What is the main reason you do not have any health care insurance coverage? (Do not read)
01 Employer does not offer insurance
02 Lost job and lost insurance benefits
03 Separation from spouse or domestic partner and lost benefits
04 Turned down by insurance company
05 Couldn't afford to pay for insurance
06 Didn't seek insurance
07 Eligible, but did not sign up for insurance
08 Out of work, but would have insurance if provided by employer
09 Refused coverage by carrier
10 Other _____
11 Don't know

Details:

57B. How long were you without health care insurance?
01 _____days
02 _____months Period without insurance converted into days:
03 _____years _____

H. Health Status and Utilization of Health Care Services.

Now, I would like to ask you a few questions about your health status and your use of health services.

58. Would you say that in general your health is:
    01 Excellent
    02 Very Good
    03 Good
    04 Fair
    05 Poor

59. How many times per year, on average, do you see a doctor or other health professional for your own care?
    01 None
    02 Once
    03 Two to 5 times
    04 Six to 9 times
    05 Ten or more times
    06 Don't remember

60. How many times per year, on average, do you take your children or other family member(s) to see a doctor or other health professional?
    01 None
    02 Once
    03 Two to 5 times
    04 Six to 9 times
    05 Ten or more times
    06 Don't remember

I. Close Out

Thank you very much for participating in this survey!!

Here is a $10.00 gift certificate that is good toward any purchase at _____.

Appendix B.

Selected Bibliography

APPENDIX B

RACIAL DISCRIMINATION IN HEALTH CARE PROJECT

BIBLIOGRAPHY

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Appendix C.

Comments and Recommendations from the Community Forums

APPENDIX C

RACIAL DISCRIMINATION IN HEALTH CARE PROJECT

SUMMARY OF COMMENTS AND RECOMMENDATIONS FROM THE COMMUNITY FORUMS

RECOMMENDATIONS REGARDING THE CURRENT SURVEY

Suggestion that we need to look at whether African-Americans are reporting experiencing more physical pain when receiving routine medical care.

Suggestion that we need to inquire equally about the positive experiences that African-Americans may have in receiving care and the content of those experiences.

Suggestion that we add administrators to our list of persons in a health-care setting who might be involved in a discriminatory act.

Suggestion to continue to distinguish carefully between racism and actual discriminatory actions (differential treatment based on race) in our writing.

Suggestion that we need to focus more on the type of personnel who are involved in these incidents and how well we can identify them.

RECOMMENDATIONS REGARDING FUTURE STUDIES

Suggestion that in future studies, we try to identify the relationship between a particular negative event and the length of time that the patient had been with this particular provider or provider organization.

Suggestion that in future iterations of this study with immigrants that we include more examples or types of discrimination, such as completing more forms, not being provided with an interpreter, fear of the immigration and naturalization service, fear of reprisal.

Suggestion that in the future, when we inquire about events, that we ask how could this service or issue have been handled better by the provider, from the patient's point of view.

Suggestion that, in the future, when asking about positive experiences, that we explore in detail the basic elements of that positive experience and place them into a model of better care.

Suggestion that, in the future, we ask about those perceived discriminatory acts which are construed to be acts of omission (neglect, oversight, uncaring attitude, lack of ethnic provider staff, bad facility, badly dressed staff) rather than commission (volitional

racism), which might reveal more about systems issues. This might also lead to some understanding about which parts of the system negatively affect all patients, regardless of race or ethnicity.

Suggestion that, in the future, we include and compare the experiences of different racial and ethnic groups to see what practices and experiences are common across all patient populations and those which are specific to race, ethnicity, and poverty. "Perhaps they engage in outrageous behavior to all of their patients, regardless of race."

Suggestion that research needs to be aimed at health status findings related to more and less aggressive care, based on race.

Suggestion that more effort needs to be placed on identifying ethnicity and national origin correctly and early in the patient's relationship with the organization. This question must be posed directly to patients.

Suggestion to conduct focus groups with providers and/or patients as the next step in discovering the experience of discrimination.

Suggestion to follow the progress of developing scales to measure racial discrimination in mental health services.

Suggestion that focus study needs to address how TANF is being implemented and affecting the health care of the poor.

RECOMMENDATIONS ON RESOLVING THE PROBLEM

Suggestion that what is needed is a mix of punitive (laws, regulations, contract requirements, enforcement) and incentive solutions.

Suggestion that provider organizations apply these survey techniques to their own to organizations and particularly to their patients, to see how well they are performing as perceived by the patients. These organizations should assign someone (ombudsperson) to with a specific responsibility to conduct surveys and analyze complaints, to capture data on events as they occur. .

Suggestion that the state use its insurance regulatory powers to insist that insurance companies audit compliance and sanction provider organizations that fail to overcome discriminatory practices and manage complaints about discrimination properly.

Suggestion that questions about discriminatory practice be included in standard customer service and satisfaction (e.g., CAHPS) in an and expectation surveys mandated by the state and/or purchasers and/or insurance companies. Some suggest that insurance companies are in the best position to influence their vendors' behaviors.

Suggestion that complaints that are not acknowledged and dealt with properly by provider organizations need an immediate neutral alternative track outside the provider organizations, perhaps in state government, that is widely advertised to the public. Complaints that involved in perceived racial discrimination should be treated as a special case, not combined with other forms of complaint. Combining racial discrimination with other categories of complaints makes racial discrimination appear far less visible.

Suggestion that the criteria for a nondiscriminatory workplace need to be established and monitored -- mission, orientation, training, manuals and so on. This embeds the practices in the organizations rather than having a separate complaint system that has no attachment to day-to-day management of the organization.

Suggestion to create and use volunteer corps who could provide rights education and complaints counseling to patients. Volunteers should be recruited to match the important demographic characteristics of the served communities.

Suggestion that targeted training opportunities be provided to physicians and other health-care providers about discrimination and its avoidance.

Suggestion that a coalition of powerful forces is really required to move health-care institutions in new directions, starting with the public health bureaucracy and its bully pulpit function and public education.

Suggestion that the standards for training to nondiscrimination and multiculturalism need to be placed very high and to be monitored very closely because of the extreme variability in the quality of training that is currently available.

Suggestion to provide training in nondiscrimination to medical residents, nurses, and physicians in major hospitals, get them out of the hospitals and into the community, community clinics, homes, and projects to see what is really going on.

Suggestion that, when speaking to health institutions, one must first compliment them on their mission and intention to become more culturally competent and/or less discriminatory. This is then followed by focusing on increased cultural competency, holding people accountable for that competency, and challenging institutions to employ more diverse providers.

Suggestion that whatever training is provided needs to be continuous, not just a onetime thing. It needs to be delivered in graduated stages, matching the stages of developing awareness of one's own discriminatory behavior.

Suggestion to educate the public, both the groups and individuals, empower them regarding their rights and procedures they can follow to effectuate those rights, and encourage their assertiveness and control. Consumers need to be taught to be better consumers; they need to have practical skills and to feel more capable of handling their own situations. People also need to be provided a place in which they are validated and

listened to.

Suggestion to inform upper management about what is going on at the "worker bee" level, things that management may not know about.

Suggestion to have outreach workers and facility staff meet to discuss in their different perspectives on the community, the served populations, and organizational practices.

Suggestion that everyone start with the presumption that the organization or provider has some racist practices, until demonstrated otherwise.

Suggestion that the medical associations and hospital associations join in partnerships to address this problem systematically.

Suggestion that advocates sell the shame of public health outcomes to community health organizations, to stimulate an understanding of the relationship between health status and discrimination.

Suggestion that recommendations around antidiscrimination or cultural competence training be carefully thought out, given the gap between training and downstream practice and the high rate of worker turnover, which increases the cost and decreases the impact of such training.

Suggestion that much customer service training produces little or no impact without defined competencies and performance measures.

Suggestion that the results of provider satisfaction surveys be widely publicized to the general public and to that provider's customers.

Suggestion that it is necessary for provider staff to express and demonstrate cultural competence to one another, not only to patients. Persistence is the key in building such systems.

Suggestion that the community requires more direct access to information about providers, such as a listing of African-American providers in the community, posters advertising welcoming providers, and help lines to call and get information. Help lines must meet the language needs of the calling public. Volunteer "sister to sister" contacts will enable patients to be informed of those providers and provider organizations which welcome them and serve them properly.

Suggestion that provider organizations ask their patients about their real life experiences with that organization, not just look at the numbers in standard customer satisfaction surveys. It is also suggested that the surveys and interviews be conducted in multiple languages, assuring sufficient representation of each significant ethnic or racial group.

Suggestion that union membership and union rights do not protect an employee who

discriminates against other employees or patients on the basis of race.

Suggestion that insurance plan, provider organization, and state and local complaints systems be client friendly. In they are too often used to measure this scale of problems or improvements, but are not reflective of the actual discrimination that occurs.

Suggestion that there be more expanded advertisement and use of state agency help lines to address the information needs and complaints of the public.

Suggestion that video, conferences, and workshops all be used in educating people how to implement nondiscriminatory practices.

Suggestion that provider organizations should put their patients rights and complaints procedures information probably on posters accessible to the public.

Suggestion that the First Steps model would be useful in creating a model to diminish discriminatory practices and outcomes. This model is based thoroughly on unequivocal research findings.

PERSONAL OBSERVATIONS ON RACISM IN HEALTH CARE

Suggestion that the response to discriminatory acts may be shaped, in part, by the ability to absorb the negative and get on with one's life.

Suggestion that there is a difference between the desire to file a formal complaint and the desire to simply have an effective corrective action.

Suggestion that pharmacy is an often overlooked service where small acts of discrimination or neglect can have powerful downstream effects on health status.

Suggestion that in discriminatory experiences, class issues may be as significant in same-race patient and provider encounters as race is in cross-race encounters.

Suggestion that the CHIP application process does not address the special-needs posed by race or ethnicity, nor how to reach non-English speaking populations.

Suggestion that some people perceive that they are required to fill out more forms than are others or that they are delayed longer in receiving care, whether or not these requirements meet the legal threshold of discrimination.

GENERAL RECOMMENDATIONS ON RESEARCH IN THIS AREA

Suggestion that more emphasis be placed on getting the patients' point of view on their own health status and way they are treated, rather than relying on information produced

by practitioners.

Suggestion that we consider the reasons why, based on experience, people with health insurance seem to complain more about their care than people without health-care insurance.

RECOMMENDATIONS ON DISSEMINATION OF FINDINGS

Suggestion that the findings of this study be widely disseminated to the general public, civil-rights agencies, provider organizations, and government.

Suggestion that the findings, the "evils", be publicly shared in understandable bite-sized pieces that are understandable to and will help organize the communities.

Suggestion that the findings of discrimination studies need to be afforded to civil-rights agencies and federal purchasers of health-care.

RECOMMENDATIONS ON HEALTH DEPARTMENT SPECIFIC ACTIONS

Suggestion that the public health director needs mechanisms and arguments based on vested interests (risk reduction, profitability, shame, health status, service, market share) to encourage public agency, insurance, and provider organization management buy-in on the issues raised, to acknowledge the existence of problems sufficiently for them to move agency and line staff to take appropriate actions and behaviors, to exercise sanctions on discriminatory systems and staff.

Appendix D.

Placard Advertising
the
Interview Project

APPENDIX D
RACIAL DISCRIMINATION IN HEALTH CARE PROJECT

PLACARD ADVERTISING THE INTERVIEW PROJECT

We Need Your Help!

We are conducting **a survey of African American residents of Seattle and King County about your experiences as an African American in using health care services.** We want to know how you have been treated when seeking or getting health care services.

The survey results will be used to assist in improving the cultural awareness of doctors and hospitals and to assist in eliminating racial discrimination in health care services.

A **$10 gift certificate to Safeway** will be provided to those who complete the survey.

A trained interviewer will ask you the survey questions. You don't have to write anything.

We will not ask your name, address or other identifying information.

The survey is anonymous and confidential.

Appendix E.

Interview Project Announcement

APPENDIX E
RACIAL DISCRIMINATION IN HEALTH CARE PROJECT
INTERVIEW PROJECT ANNOUNCEMENT

RACIAL DISCRIMINATION & HEALTH SURVEY

The Cross Cultural Health Care Program of Seattle is conducting a survey of African American residents of Seattle and King County to document experiences of racial discrimination in health care. The Seattle/King County Department of Public Health is funding the survey. The study questionnaire has been reviewed by the University of Washington Human Subjects Review Committee, which has validated its methodology for assuring complete confidentiality of all persons interviewed. African American women who are health professionals are administering the survey. Results of the survey will be used to make improvements in the cultural competence of local health care systems to serve African Americans.

If you have experienced racial discrimination while seeking or getting health care for yourself or your family members, the interviewers would very much like to hear your story. You do not have to give your name or address or any other personal identifiers, which makes the survey completely confidential. A $10 gift certificate to Safeway will be provided to those that complete the survey.

Appendix F.

Introductory Statement
for the
Interview Project

APPENDIX F
RACIAL DISCRIMINATION IN HEALTH CARE PROJECT
INTRODUCTORY STATEMENT FOR THE INTERVIEW PROJECT

Hello my name is _____

We are conducting a survey of African American residents of Seattle/King County. We are interested in your experiences as an African American in using health care services. We are specifically interested in knowing whether you have been treated unfairly due to your race when seeking or acquiring health care services. This Fact Sheet (that I am giving you) outlines the important information on the study.

The results of the survey will be used to make recommendations to local authorities that could help eliminate any discriminatory practices against African Americans by health care providers in the Seattle/King County area.

We will not ask your name or your exact home address. Any information that you give cannot be traced to you in any way.

We are providing those who complete the survey with a $10.00 gift certificate. The $10.00 gift certificate is good toward any purchase of $10.00 or more at Safeway.

Would you be willing to answer our survey questions?

Thank You!!!

You can refuse to answer any question and still continue the interview.

Appendix G.

Participant Fact Sheet

APPENDIX G
RACIAL DISCRIMINATION IN HEALTH CARE PROJECT
PLACARD ADVERTISING THE INTERVIEW PROJECT

SURVEY PARTICIPANT FACT SHEET

The Discrimination and Health Survey is being conducted by The Cross Cultural Health Care Program with funding from the Seattle/King County Department of Public Health.

Only persons of the African American race who reside in Seattle or other parts of King County are being surveyed at this time.

Neither the name, address nor any other identifying information will be asked of those being interviewed during the survey. The survey has been carefully designed so that no one can trace the responses given back to those people interviewed.

Any person interviewed can refuse to answer any question and still continue the survey.

Those who complete the survey will receive a $10.00 gift certificate to Safeway that is good toward any purchase of $10.00 or more.

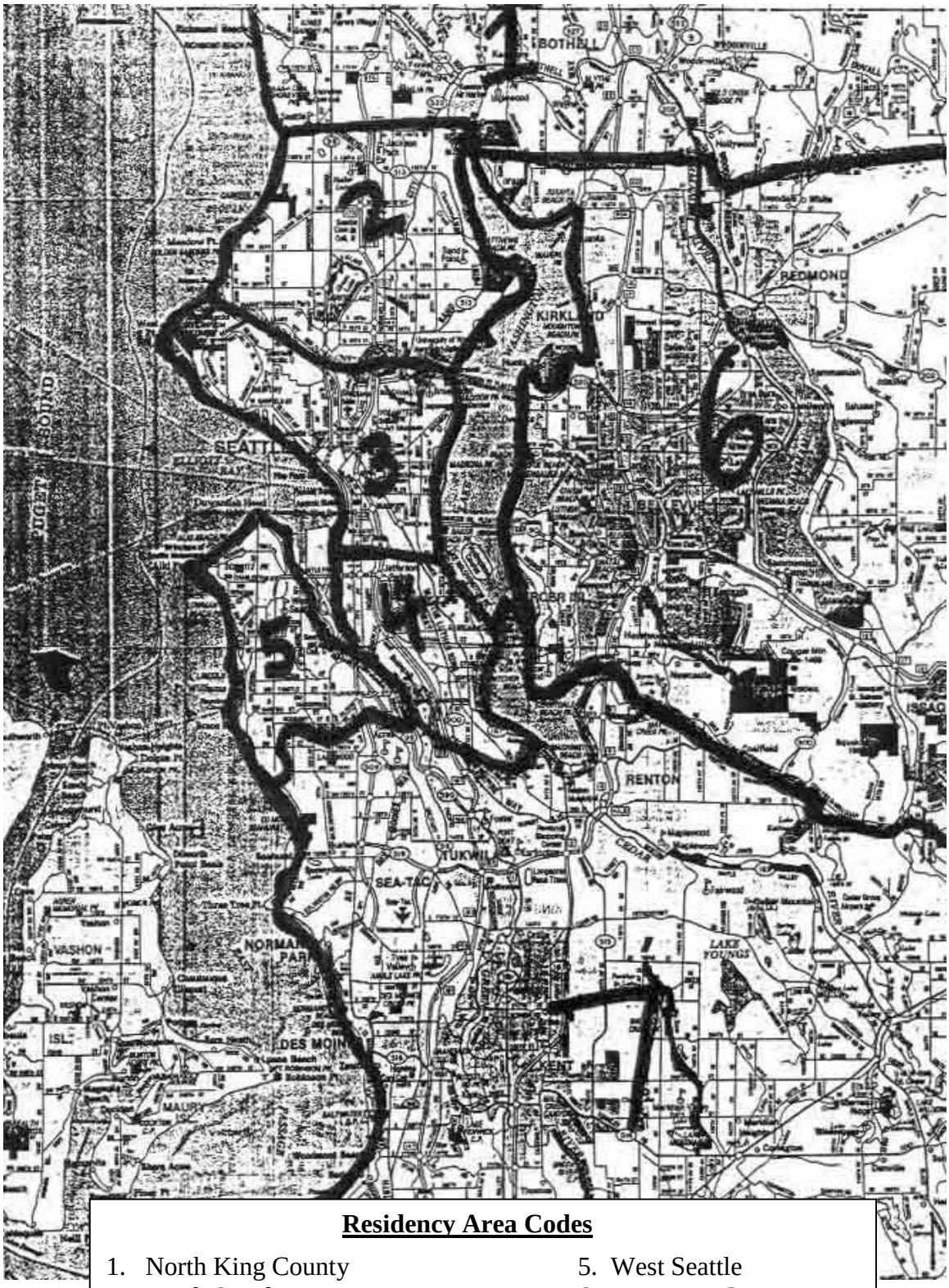
The results of the survey will be used to make recommendations to local authorities and health care providers that could improve cultural awareness and help eliminate any discriminatory practices found to exist among local health care providers.

A summary of the results of the survey should be available by mid-September. A copy of this summary can be obtained by calling the Cross Cultural Health Care Program at 206-326-4161 and requesting the *Discrimination and Health Survey* summary.

Appendix H.

Residency Area Map and Code

APPENDIX H
RACIAL DISCRIMINATION IN HEALTH CARE PROJECT
RESIDENCY AREA MAP AND CODES



Residency Area Codes

1. North King County
2. North Seattle
3. Central Seattle
4. Southeast Seattle
5. West Seattle
6. East King County
7. South King County