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# Identification of Variables That Influence the Receipt of Eye Care



## Focus Group Report

National Eye Institute  
National Eye Health Education Program

August 25, 2005

**IDENTIFICATION OF VARIABLES  
THAT INFLUENCE THE RECEIPT OF EYE CARE**

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## **I. EXECUTIVE SUMMARY**

### **Introduction**

Eye diseases, which include diabetic retinopathy, glaucoma, cataract, and age-related macular degeneration (AMD), cause blindness and impaired vision in millions of Americans (Congdon, O'Colmain, Klaver, Klein, Munoz, Friedman, et al., 2004; Kempen, O'Colmain, Leske, Haffner, Klein, Moss, et al., 2004). Despite the preventable nature of vision impairments, many people do not receive recommended screenings and exams to detect possible eye disease (Hartnett, Key, Loyacano, Horswell, and DeSalvo, 2005). Research further indicates that several diseases and disorders of the eye are prevalent in certain racial and ethnic minority communities, and disproportionately affect minority populations more than Whites (Friedman, West, Munoz, Park, Deremeik, Massof, et al., 2004; Varma, Ying-Lai, Klein, and Azen, 2004; Kempen et al., 2004; Higginbotham, Gordon, Beiser, Drake, Bennett, Wilson, et al., 2004). Little empirical work has examined factors that influence the receipt of eye care.

In March and April 2005, 20 focus groups were conducted among members of the general population in Miami, FL; Chicago, IL; and San Francisco, CA. The purpose of this research was to examine factors that influence the receipt of preventive eye care, including both routine screening and care to prevent vision loss, and to examine whether those factors differ by race and ethnicity.

### **Methodology**

Given the exploratory nature of the research, a qualitative research approach was used to examine how factors such as attitudes, knowledge, communication, and culture influence the receipt of preventive eye care and examine whether those factors differ by race and Hispanic ethnicity. Study participants included 180 English-speaking males and females over the age of 40. One hundred eighty participants were recruited to take part in 20 focus groups. Fifty-four participants were self-identified as African American, 54 as Hispanic/Latino, 36 as White, and 36 as Asian. This cohort was chosen to provide a wide representation of the adult American population about how the studied factors might influence the receipt of preventive care for eye disease and vision loss among the different racial/ethnic groups.

A structured discussion guide was developed to guide conversations and probe participants' general health, vision, attitudes, health literacy, communication, and culture. The Theory of Reasoned Action (TRA) was used in the development of the discussion guide. More than 500 peer-reviewed empirical papers have been published

that incorporate the TRA. Of the more than 500 peer-reviewed papers, more than 250 articles used the TRA for research related to health or use of health care services. As outlined in the TRA, a behavior is the result of an intention to perform that behavior. Intentions are formed by a combination of attitudes and subjective norms, which are formed by beliefs people have about themselves and their environment (Ajzen & Fishbein, 1980). The TRA was useful in developing discussion items that reveal beliefs that might influence the receipt of eye care.

Focus group participants were recruited by market research firms in the cities where the groups were held. Recruiters conducted telephone interviews using a participant screener to select eligible members of the population in that city. Potential participants were selected by random-digit-dialing as possible participants in the discussion, based on their Zip code.

This research was conducted in compliance with the Department of Health and Human Services regulations for the protection of human research subjects (45 CFR 46). The study protocol was reviewed by the Institutional Review Board (IRB) at ORC Macro, a contractor of the National Eye Institute (NEI), and by the IRB at the University of Maryland Baltimore County (UMBC) to ensure research involving human subjects complied with relevant Federal regulations. The study protocol qualified for an expedited review through each IRB institution and was approved. Prior to participating in a focus group, each participant was required to read and sign an informed consent form. Participants were assured that any comments made during the discussion would be kept confidential and that they would not be personally identified.

Unabridged transcripts of the focus groups were used as a basis for analysis and were supplemented with notes taken by the researcher. Research content analysis was applied in this study in order to obtain greater clarity of themes and domains that appeared in focus group discussions, as well as to compare and contrast results and findings across different transcripts of different segments of respondents participating in the study. The analysis of the qualitative data contained in the transcripts was facilitated by the use of NVivo qualitative analysis software from QSR. The coding and categorization of discussion data was done via an emergent approach. Codes developed for this project ranged from responses to a particular question provided by the participants (e.g., Have you ever sought information regarding your eyesight/vision?) to discussion of larger concepts such as attitudes about eye exams.

## **Findings**

### **Demographic Information**

Males and females were about equally represented in each of the 20 focus groups. The majority of participants were between the ages of 40 to 49 years. The oldest participant was 75 years. The majority of participants had some college education. Ten participants were reported to have some high school education and 26 participants were reported to have a graduate or professional degree. Participants were approximately equal in terms of marital status. A majority of participants reported to have a household income between \$25,000 and \$49,999 per year and a majority reported having some form of health insurance.

### **Factors That Influence the Receipt of Eye Care**

To quantify the prevalence of themes and concepts, the terms “a few,” “a number,” “several,” “many,” and “majority” were used. For the purposes of this summary, only those factors that were major issues identified by more than half of the participants across the focus groups and those related to race/ethnicity will be discussed. The dominant themes followed by themes relating to race and ethnicity are presented in the text boxes below.

As it relates to attitudes, a majority of participants reported beliefs about eyesight and eye exams that appear to contradict each other. Generally speaking, the majority of participants value their eyesight and healthy vision. At the same time, participants revealed a competing belief that they take their eyesight for granted. Both of these beliefs were said to have influence on whether eye care services were received or not.

Additionally, a number of participants reportedly have an attitude that seeing an eye care professional or obtaining an eye exam is not a necessity. This attitude appears to primarily be driven by fear, denial, the belief that participants’ vision has not changed, that they have never had eye problems to begin with, or that one primarily visits an eye care professional only to get eyeglass and contact prescriptions changed.

## **Factors Reported By the Majority of Participants**

### **Attitude**

- Eyesight and healthy vision are very important.
- My vision has not changed.

### **Knowledge**

- Participants are not knowledgeable about eye diseases and conditions.
- Participants do not seek out information about their eyes.

### **Communication**

- Primary care physicians do not share information with participants about their eyesight.
- Primary care physicians do not conduct basic eye screenings.
- Participants have a good level of comfort in communicating with their primary care physician and/or eye doctor.

The findings also revealed a lack of knowledge or understanding about preventive eye care across each of the three locations. Most participants were somewhat knowledgeable about what a dilated eye exam was. However, the majority of focus group participants were not knowledgeable about eye diseases and conditions such as low vision and diabetic retinopathy.

The majority of participants reported that their primary care doctor does not share information with them about their eyesight. A majority of participants across each of the three cities also reported that their primary care physician no longer looks into their eyes when receiving a physical examination, nor do they conduct vision screenings. In fact, many participants stated that they do not see an eye doctor because their primary care physician makes no mention of it. It was also found that the majority of participants do not seek information about their eyes.

Lastly, the majority of participants stated their overall level of comfort in communicating with their primary care physician or eye doctor was good, very good, or excellent, although many participants reported poor relationships with providers. Good communication with providers can increase participants' knowledge about eye

health and preventive measures to ensure healthy vision. Examples of poor or hampered communication with providers were found to frustrate participants and, in some cases, left them hesitant about seeking followup care.

### **Factors That Differ by Race/Ethnicity**

The majority of the factors identified as influencing the receipt of eye care services for the 180 participants were reported to be factors affecting each of the four racial and ethnic groups studied. However, when examining how culture and communication influence the receipt of eye care, differences were found by race and ethnicity. Although the majority of participants felt good about the way their medical care provider explained health information to them, African American and Hispanic/Latino participants more often reported that they have difficulty understanding medical terminology. Language, primarily among Hispanic/Latino and Asian participants, was also reported to impact communication and the level of understanding that participants have about their health.

#### **Factors Related to Race/Ethnicity**

##### **Culture/Communication**

- African American, Hispanic/Latino, and Asian participants reported using traditional, folk, or home remedies when they experienced problems with their eyes.
- African American and Hispanic/Latino participants more often reported that they have difficulty understanding medical terminology.
- Language, among Hispanic/Latino and Asian participants, was reported to impact communication and the level of understanding that participants have about their health.
- Hispanic/Latino participants noted that preventive medicine is not practiced as it should be within their community.

##### **Additional Factors**

- Undertones of perceived racial and ethnic discrimination and bias were present in statements made by African American and Hispanic/Latino participants.
- Fear and denial about receiving eye examinations were reported by all racial/ethnic groups with the exception of Asian participants.



Cultural factors also influenced the receipt of eye care by race/ethnicity. African American, Hispanic/Latino, and Asian participants reported using traditional, folk, or home remedies when they experienced problems with their eyes before deciding to go to the doctor. In the majority of cases, these remedies were all the care received, as participants reported that these remedies cured any ailments they were experiencing with their eyes. Hispanic/Latino participants noted that within their community, preventive medicine is not practiced as it should be. Also, some of the Hispanic/Latino and African American participants discussed that they are unlikely to go to the doctor unless their condition is really bad. Washing the eye out and taking a “wait and see” approach were reportedly done by African American participants before contacting their primary care physician or eye doctor. African American and Hispanic/Latino participants mentioned that males tend to not like going to the doctor. Lastly, undertones of perceived racial and ethnic discrimination and bias were present in several of the statements made by African American and Hispanic/Latino participants, which may influence the receipt of eye care services.

Other factors that differed by race and ethnicity were fear and denial about receiving eye examinations and class discrimination and bias in the health care system. Fear and denial about receiving eye examinations were reported by all racial/ethnic groups with the exception of Asian participants. African American and Hispanic/Latino participants found doctors or the health care system to be insensitive and discriminating based on economic status and the ability to pay for health care services/type of insurance.

### **Additional Information**

Participants were also asked additional questions not related to the model or to factors that influence the receipt of eye care in order to help the National Eye Institute ascertain sources of health information, beliefs about loss of eyesight, and knowledge about preventive eye care.

### **Sources of Health Information**

In general, participants stated that they get information pertaining to health issues from a number of places. Most participants reported receiving information on health issues from television, radio, their job, journals, or their primary care physicians. The Internet was also reportedly used to gather health information. In terms of the types of health information retrieved from the Internet, the majority of all participants said that they use the Internet to research specific diseases. Participants also reported using the Internet to locate information about the following items:

- Alternative therapies and medicine
- Prescribed medicines/side effects
- Diet information
- Co-payment fees
- Cheaper prescriptions
- Symptoms

### **Knowledge and Prevention**

In each of the focus groups, disease and accidents were mentioned the most as reasons people lose their eyesight. In most of the groups, participants noted wearing sunglasses, getting regular check ups, having proper eyeglass prescriptions, and wearing protective eye wear were steps you could take to prevent eye problems. Several of the minority participants stated they did not know of any preventive steps they could take to preserve their eyesight and that they did not think you could prevent loss of eyesight. Despite that finding, the majority of participants stated that they would go to their primary care physician or eye doctor if they were experiencing problems with their eyesight.

### **What Can Be Done**

The majority of participants spoke of the need for better education about various eye diseases, eye health, and preventive steps to preserve healthy vision to help overcome the obstacles to receiving eye care that were mentioned in the focus group discussions. Participants were asked what additional things they would like to know about eye health. Some of their responses included the following:

- How to prevent eye problems
- How to improve night vision, particularly when driving at night
- Preventive steps to preserve eyesight, particularly with children
- Over-the-counter medicines to treat eye conditions
- Warning signs of potential eye problems
- Information about vitamins that can improve eye health
- How nutrition and exercise can affect eye health
- Cures for blurry vision and dry eyes
- The latest advances in eye treatments and medicine
- Information on floaters

When asked about where they would like to receive eye health information, most participants stated that they would like to receive the information in the mail, via e-mail and the Internet, public education on television, and from their doctor. Lastly, participants were asked, “If there was one thing the National Eye Institute could do to

address some of the barriers to receiving eye care that were mentioned, what would it be?” Participant responses included addressing the cost of eye care services; recognizing cultural differences in receiving eye care; and making eye care more of a health priority by increasing awareness that with regular eye exams, one can prevent many eye disorders.

## **Recommendations**

As detailed in the full report, many of the barriers identified to receiving preventive eye care result from an array of different social, cultural, and economic factors. There is a need to comprehend and analyze the role of attitudes, culture, and social variables in the receipt of health care services when developing health and eye care approaches, campaigns, practices, and programs. The findings from this research affirm the importance of health education, communication, and improved physician-patient relationships. In addressing the lack of knowledge about preventive eye care and the barriers identified by study participants, recommendations from this abbreviated list should be considered:

- The majority of participants reported going to their primary care doctor or eye care professional when experiencing problems with their eyes. Information about eye diseases and disorders, as well as preventive measures they can take to avoid such problems, should be made available in these office settings.
- About half of all the participants had a good understanding of what a dilated eye examination was. Efforts should continue to educate the general public about what a dilated eye exam is, the benefits of obtaining such an exam, and the recommended intervals that one should receive dilated eye examinations.
- Formats such as videos, PSAs, and other visual means of communicating information were requested formats by most participants for receiving eye health information. These formats should be widely used to educate and transfer messages about eye health.
- The majority of participants spoke of the need for better education about various eye diseases and information to help the general public prioritize the receipt of preventive eye care. The NEI should consider evaluating other health education and awareness campaigns, such as those used for breast and prostate cancer, to strategically develop future awareness campaigns for eye care.

- As most participants report using the Internet to gather health information, the NEI should continue its efforts to provide timely and up-to-date information about eye health on its Website. To bring attention to certain eye diseases and disorders, the NEI should showcase a particular eye disease or disorder each month on its home page with links to obtain more information about that disease or disorder.
- Several participants reported that they do not prioritize the receipt of eye care services because their physician makes no mention of it. It is important to increase involvement on behalf of primary care providers in the education of Americans about what they can do to prevent vision loss, as this may positively impact the receipt of eye care services.

## II. INTRODUCTION

### A. Purpose of the Study

Eye diseases, which include diabetic retinopathy, glaucoma, cataract, and age-related macular degeneration (AMD), cause blindness and impaired vision in millions of Americans (Congdon, O'Colmain, Klaver, Klein, Munoz, Friedman, et al., 2004; Kempen, O'Colmain, Leske, Haffner, Klein, Moss, et al. 2004). Despite the preventable nature of vision impairments, many people do not receive recommended screenings and exams to detect possible eye disease (Hartnett, Key, Loyacano, Horswell, and DeSalvo, 2005). The purpose of this research is to determine why people do not receive screenings and exams, and more specifically, the role of factors such as attitudes, knowledge, communication, and culture that influence the receipt of preventive eye care that may lead to the early detection of eye disease and disorders.

Statistics indicate that certain racial and ethnic minority populations experience a disproportionate prevalence of eye disease, burden of illness, and morbidity compared to Whites (Friedman, West, Munoz, Park, Deremeik, Massof, et al. 2004; Varma, Ying-Lai, Klein, and Azen, 2004; Kempen, O'Colmain, Leske, Haffner, Klein, Moss, et al. 2004; Higginbotham, Gordon, Beiser, Drake, Bennett, Wilson, et al. 2004). Given the disparities in the prevalence of eye disease and in the rates of screenings, this research sought to examine whether factors that influence the receipt of eye care to prevent possible blindness and vision loss differed by race and ethnicity.

This research, in part, is further prompted by both of the overarching goals of Healthy People 2010, which are to eliminate health disparities among different racial and ethnic groups, and to increase the quality and years of healthy life. Healthy People 2010 is a national health promotion and disease prevention initiative, which outlines health objectives and goals for the Nation. Included in this report were specific objectives for improving the vision of people in the United States during the 2000–2010 decade via prevention, early detection, treatment, and rehabilitation (U.S. Department of Health and Human Services, 2000).

Throughout this study, the National Eye Institute (NEI) used qualitative research methods to provide insight into what factors influence the receipt of eye care for African Americans, Hispanics/Latinos, Caucasians, and Asian Americans. Through a series of focus groups, this study examines how attitudes, knowledge, communication, and culture influence the receipt of eye care.

In gathering information about what impedes or influences the receipt of eye care, health care delivery experts can better address those factors and health disparities, and can develop health interventions and education campaigns to increase the receipt of eye care. The research in this report will contribute to a body of knowledge about reducing eye health disparities and increasing the receipt of eye care to prevent loss of independence and reduced quality of life, which may result from untreated eye diseases and disorders.

With new prevalence data on eye diseases and disorders and the information obtained through this assessment, the Congressionally mandated National Eye Health Education Program (NEHEP) can better design educational materials and programs. NEHEP can also collaborate with other government and non-government agencies that specifically address access-to-care issues in the most efficient and beneficial manner.

## **B. Research Questions**

This research addresses the factors that influence the receipt of care for possible eye disease and vision loss and asks whether those factors differ by race. More specifically, the following research questions were posed for this study:

1. What influences the receipt of eye care?
  - a. What are the attitudes that influence the receipt of eye care?
  - b. How does knowledge (health literacy) influence the receipt of eye care?
  - c. How does communication influence the receipt of eye care?
  - d. What cultural factors influence the receipt of eye care?
2. Do any or all of the above factors differ by race?

## **III. FOCUS GROUP METHODOLOGY**

### **A. Introduction**

To answer the research questions identified above, 180 participants were recruited to take part in 20 focus groups. The study sample included members of the general population who were English-speaking males and females over the age of 40 in Miami, FL; Chicago, IL; and San Francisco, CA. Approximately 54 participants were African American, 54 Hispanic/Latino, 36 White, and 36 Asian. This cohort was chosen to provide a wide representation of the adult American population about how factors such

as attitudes, perceptions, knowledge, communication, and culture might influence the receipt of care for eye disease and vision loss among the different racial/ethnic groups.

## **B. Advantages and Drawbacks of Focus Group Discussion Methodology**

This research incorporated focus group discussion methodology, as it is the most appropriate research technique to collect formative and “information-rich” data. Conducting focus groups is an effective method of listening and collecting information, and an integral way of understanding how people feel or think about an issue, a product, or service (Krueger & Casey, 2000). Group discussions are flexible for exploring respondent awareness, behavior, concerns, beliefs, experiences, motivation, operating practices, and future plans related to a particular topic or issue. Group discussions are particularly helpful for generating an in-depth understanding of issues, since a skilled moderator can amplify individual responses through group comments or individual feedback. A skilled moderator can also follow up or probe certain tangents or views that were unanticipated in the design of the discussion guide, often yielding new information or additional nuances of existing information.

Despite its many advantages, group discussion methodology is not without limitations. Findings from discussion groups are not quantitative, thus they cannot be generalized to the wider public. The results will only describe variables that influence the receipt of eye care for the groups included in the study.

Lastly, group dynamics of focus groups can affect the responses of group members, thus possibly negatively impacting summary results. Focus groups might be dominated by one or a few members in the group, thus subjecting other participants to a “group think” mentality. There also may be instances where the group will feed off of the answers or comments of certain participants (herd effect) and this situation may or may not reflect a participant’s true feelings. However, with the use of a trained moderator conducting the focus groups, this occurrence was minimal.

## **C. Research Design**

People over the age of 40 were selected for study. The National Eye Health Education Program, coordinated by the NEI, provides public and professional education programs that encourage early detection and timely treatment of glaucoma and diabetic eye disease, and the appropriate treatment for low vision, primarily for Americans aged 40 years and older. Additionally, professional recommendations on the frequency of eye

examinations are higher and more consistent for people over 40. The American Optometric Association (AOA) recommends that people over age 40 obtain a comprehensive eye examination every two years, while the American Academy of Ophthalmology (AAO) recommends that people over 40 obtain a comprehensive eye examination every two to four years (American Optometric Association, 2005; American Academy of Ophthalmology, 2005).

Both African Americans and Hispanics/Latinos are purposefully overrepresented in the research design, given the documented growth in the prevalence of eye diseases and disorders within these minority groups (Varma et al., 2004). As mentioned before, one of the overarching goals outlined in Healthy People 2010 is the elimination of health disparities among different racial and ethnic groups (U.S. Department of Health and Human Services, 2000). The identification of variables that influence the receipt of eye care among African Americans, Asians, and Hispanics/Latinos will help health care delivery experts address these documented health disparities, which may ultimately lead to their elimination.

In selecting the cities for conducting focus groups, an attempt was made to choose sites that were geographically dispersed throughout the country and had an adequate representation of the selected ethnic groups in this study. Demographic profiles from the 2000 Census were used to first identify the top 50 cities in the United States by population. After examining the ethnic composition of the selected cities, those that were diverse in terms of both education and income were identified. A diverse representation of cities was selected in terms of race/ethnicity, education, and income composition, in comparison to national averages for the three criteria. Although both income and education are somewhat correlated, differences were noted, where some cities ranked above the national average in terms of education, but below the national average in terms of income (U.S. Census Bureau, 2000).

Both Chicago and San Francisco were selected cities in which to conduct focus groups on each of the four ethnicities, as each city has a higher-than-average proportion of each race/ethnicity. San Francisco was chosen because it ranks higher in both education and income, compared to the national average. Chicago was selected because it ranks lower in income, compared to the national average; although it ranks almost evenly with the national average in terms of education. Miami was selected given its high percentage of both African Americans and Hispanics/Latinos compared to the national average. Miami also ranks lower than the national average in terms of both education and income.



## **D. Recruitment**

Focus group participants were recruited by market research firms in the cities where the groups were held. Recruiters conducted telephone interviews using a participant screener to select eligible members of the population in that city. The participant screener used for this focus group research is included in this report as Appendix A. Potential participants were selected by random-digit-dialing as possible participants in the discussion, based on their Zip code. Recruitment calls were made starting two weeks prior to the dates of the groups. A few days before each focus group took place, the respective recruiting firm sent confirmation letters to each recruited participant that briefly described the method of the focus group discussion and stated the date, time, location, and directions to the focus group facility.

Recruiters at each site were instructed to recruit 12 people to guarantee that at least nine participants would be available at the time of the focus group. Participants in each location received cash incentives compensating them for their time and participation in the group discussion. The amount of these incentives ranged from \$65 to \$70 depending on the location of the focus group. Extra participants who arrived for the focus group discussion received their incentive and were allowed to leave.

## **E. Protection of Human Subjects**

This research was conducted in compliance with the Department of Health and Human Services regulations for the protection of human research subjects (45 CFR 46). The study protocol was reviewed by the Institutional Review Board (IRB) at ORC Macro, a contractor of the National Eye Institute (NEI), and by the IRB at the University of Maryland Baltimore County (UMBC) to ensure research involving human subjects complied with relevant Federal regulations. The study protocol qualified for an expedited review through each IRB institution and was approved.

Prior to participating in a focus group, each participant was required to read and sign an informed consent form. The principal investigator was available to answer any of the participant's questions regarding the focus groups, and participants were permitted to receive payment and depart without taking part in a group if they were not able to provide consent for their participation in the focus group. All of the participants recruited for this project chose to take part in a focus group. The informed consent form for these focus groups is included as Appendix B.

Focus group participants were assured that any comments made during the focus groups were confidential and that they would not be personally identified. Participants were also reminded that the decision to participate was entirely voluntary and that they could choose not to answer a question at any time.

## **F. Discussion Guide**

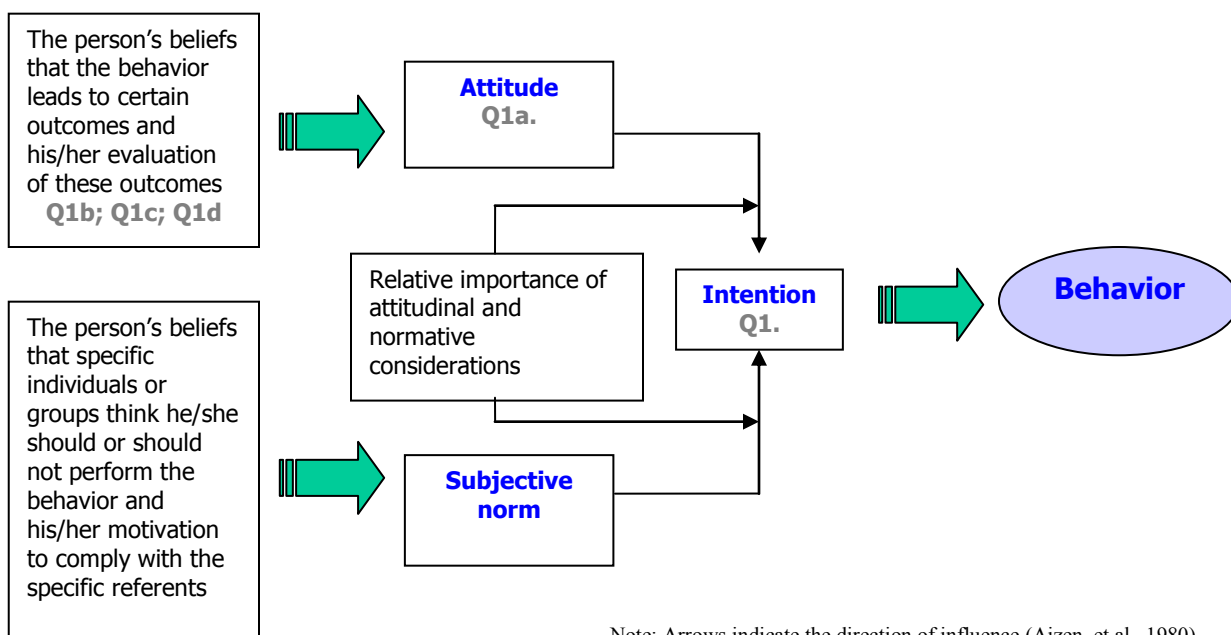
A structured discussion guide was developed to guide conversations and probe participants' general health, vision, attitudes, health literacy, communication, and culture. The moderator/discussion guide used for this focus group research is included as Appendix C. The Theory of Reasoned Action (TRA) is a theoretical framework that was partly used to guide the development of the discussion guide and assist the researcher in identifying how attitudes, perceptions, knowledge, culture, and communication might influence the receipt of eye care.

### **Theory of Reasoned Action**

The primary goal of the TRA is to predict and understand an individual's behavior. The TRA views a person's intention to perform (or not to perform) a behavior as the immediate determinant of an action. Ajzen and Fishbein (1980) state that a person's intention is a function of two basic determinants, one personal in nature, and the other social in nature. The personal factor (which was evaluated in this research), termed attitude toward the behavior, is simply a person's general feeling of favorableness or unfavorableness for that concept (Ajzen & Fishbein, 1980). The second determinant of intention, termed subjective norm, is one's perception that most people who are important to them think they should or should not perform the behavior in question. According to the TRA, if a person has a favorable attitude toward a behavior and perceives that others who are important to him think he should perform that behavior, that person will be more likely to have intentions to do so and engage in that behavior (Ajzen & Fishbein, 1980).

Figure II-1 summarizes how behavior is determined by intention and how that is a function of attitudes and social norms, which ultimately comprise a person's beliefs. The figure also has the research questions (Q1 a.b.c.d.) transposed on top of it.

**Figure II-1: Theory of Reasoned Action**



Prior to the discussions, the discussion guide was pilot tested among employees from ORC Macro to examine the ease and comprehension of discussion topics and probes. This testing prompted the revision of some questions and the addition of probes for clarity.

## **G. Conduct of the Groups**

Each focus group was exclusively composed of members from a particular ethnic group. A focus group entirely composed of one racial and ethnic group was thought to better facilitate an open dialogue among participants and enhance the comprehension and analysis of focus group data. Eight focus groups were conducted in Chicago, IL, and San Francisco, CA, and four focus groups were conducted in Miami, FL. Two focus groups were conducted among each of the four racial and ethnic groups in Chicago and San Francisco. In Miami, FL, two focus groups were conducted among African American and Hispanic/Latino racial and ethnic groups. As in the other two cities, each focus group was exclusively composed of members from that particular ethnic group.

Participants were asked to complete a demographic information sheet that was developed to capture general characteristics and other relevant information about focus group participants, such as age, marital status, and prior diagnosis of several eye conditions. The Participant Demographic Information Sheet used for this focus group

research is included as Appendix D. Before the discussion began, participants were asked to read and sign the informed consent form.

All of the focus groups conducted for this research were held in professional focus group facilities, each equipped with a one-way mirror and observation room. The focus groups in Miami, FL, were videotaped and audiotaped. The focus groups in Chicago and San Francisco were audiotaped. A trained and experienced moderator facilitated all 20 focus group discussions.

The duration of each focus group was approximately one and one-half to two hours. The moderator facilitating the groups followed the moderator's guide throughout each discussion, and was careful to ensure that each group discussed all topics in the guide. At the conclusion of the discussion, participants were offered a selection of debriefing materials provided by the National Eye Institute with general information about vision health.

All 20 groups occurred without incident. They were completed as scheduled with no irregularities with a total of 180 participants. Table II-1 illustrates the composition of the focus groups, with their schedules and locations:

**Table II-1: Composition and Schedule of Focus Groups**

Group No.	Date	Time	Race/Ethnicity
<b>Miami, FL</b>			
Group 1	Mar. 9	5:30 P.M.	Hispanic/Latino
Group 2	Mar. 9	8:00 P.M.	Hispanic/Latino
Group 3	Mar. 10	5:30 P.M.	African American
Group 4	Mar. 10	8:00 P.M.	African American
<b>Chicago, IL</b>			
Group 5	Mar. 21	5:30 P.M.	Caucasian
Group 6	Mar. 21	8:00 P.M.	Caucasian
Group 7	Mar. 22	5:30 P.M.	Asian
Group 8	Mar. 22	8:00 P.M.	Asian
Group 9	Mar. 23	5:30 P.M.	Hispanic/Latino
Group 10	Mar. 23	8:00 P.M.	Hispanic/Latino
Group 11	Mar. 24	5:30 P.M.	African American
Group 12	Mar. 24	8:00 P.M.	African American
<b>San Francisco, CA</b>			
Group 13	Mar. 30	5:30 P.M.	African American
Group 14	Mar. 30	8:00 P.M.	African American
Group 15	Mar. 31	5:30 P.M.	Asian
Group 16	Mar. 31	8:00 P.M.	Asian
Group 17	Apr. 1	5:30 P.M.	Hispanic/Latino
Group 18	Apr. 1	8:00 P.M.	Hispanic/Latino
Group 19	Apr. 2	10:00 A.M.	Caucasian
Group 20	Apr. 2	12:30 P.M.	Caucasian

All dates are 2005

During each focus group session, participants shared their attitudes, beliefs, and personal experiences that were reported to influence their receipt of eye care.

## H. Data Analysis

Data analysis consists of examining, categorizing, tabulating, or otherwise recombining the evidence to address the initial propositions of a study (Yin, 1984). Unabridged transcripts of the focus groups and notes taken by the principal investigator were evaluated using the content analysis method.

### 1. Content Analysis

Content analysis has been defined as a systematic, replicable technique for compressing many words of text into fewer content categories, based on explicit rules of coding (Krippendorff, 1980). Content analysis enables researchers to sift through large volumes of data with relative ease in a systematic fashion (General Accounting Office, 1996). Content analysis can be a useful technique for allowing us to discover and describe the focus of individual, group, institutional, or social attention (Weber, 1990).

Research content analysis was applied in this study in order to obtain greater clarity of themes and domains that appeared in focus group discussion, as well as to compare and contrast results and findings across different transcripts of different segments of respondents participating in the study.

## **2. NVivo**

The analysis of the qualitative data contained in the transcripts was facilitated by the use of NVivo qualitative analysis software from QSR. NVivo allows a researcher to import and code textual data; edit the text; retrieve, review and recode coded data; search for combinations of words in the text or patterns in coding; and import or export data from and to quantitative analysis software.

NVivo aided data analysis with its extensive range of tools used to support and improve standard qualitative analysis techniques. The tools include the following:

- Creating, importing, and editing rich text documents (such as focus group transcripts)

The transcripts from all the groups were included in the analysis. The electronic versions of the transcripts were imported into NVivo as rich text files (ordinary plain text) and placed in a single project to allow for analysis across all of the transcripts. Each transcript was labeled with a description of the segment of participants to which they related (race/ethnicity; location of focus group). Each document was titled at the top of its first page to note the consecutive number of the group and the date, time, and location of the group.

- Coding and annotating the transcripts

To facilitate analysis, NVivo allows for the creation of a set of codes and annotations (“The Code Book”) for each project. The codes represent different categories for which relevant data was recorded in the transcripts. Codes developed for this project ranged from responses to a particular question provided by the participants (e.g., Have you ever sought information regarding your eyesight/vision?) to discussion of larger concepts (e.g., Why is your eyesight important to you?). The coding and categorization of discussion data was done via an emergent approach. With *emergent coding*, mutually exclusive and exhaustive categories were established, following a preliminary examination of the data by the principal investigator and a second person from ORC Macro. The two individuals independently

reviewed transcript material and came up with a set of features that form a checklist. Next, the two individuals compared notes and reconciled any differences that showed up on their initial checklists. Lastly, the principal investigator used a consolidated checklist to independently apply coding.

- Creating coding reports

The main function of creating coding reports was to bring together text recorded at a given code (or category) throughout all transcripts included in the project. The coding reports were generated many times during the course of data analysis in order to test and validate emerging topics and concepts.

- Contrasting data between different paired segments through generation of document sets

The data labeled with each code were compared and contrasted by subdividing these data sets according to the two variables by which the focus group were divided.

1. Race and Ethnicity
2. Location of Focus Group

Segregating those sets (termed “document sets” within the NVivo software) for each issue provided the means for analyzing each topic for which a code was established (e.g., What are the attitudes that influence the receipt of care for Caucasians as opposed to the attitudes that influence the receipt of care for African Americans?).

- Searching data

Throughout the data analysis, the researcher used the special-purpose tool integrated into NVivo that facilitates searching for any text and keyword phrases, and finding relationships among data. The search tool was able to isolate words or phrases that occurred within data classified under a selected code from all transcripts or a selected group of transcripts.

## IV. DEMOGRAPHICS OF PARTICIPANTS

The demographic information reported in this section reflects the people who showed up at the focus group facility to participate in the discussion groups, of which 180 were kept as participants in the discussion groups. The data provided below were obtained from the demographic information sheets completed by potential participants before the focus group discussions began. Additional tables that display the demographic profiles of the participants broken out by each location are included as Appendix E.

The data presented below are cumulative numbers of participants for all the groups with their demographic descriptors broken down by (1) gender, (2) age, (3) education, (4) marital status, (5) household income, (6) health insurance status, and (7) type of primary care practice. It is important to note again that African American and Hispanics/Latinos were overrepresented in this study.

### A. Gender<sup>1</sup>

Males and females were about equally represented in each of the 20 focus groups, with 49.5 percent male and 50.5 percent female. Table III-1 illustrates the demographic profile of participants by gender.

**Table III - 1: Demographic Participant Profile: Gender**

			Gender		Total
			Male	Female	
<b>Ethnicity</b>	Hispanic/Latino	Count	28	25	53
		% within Ethnicity	52.8%	47.2%	100.0%
		% within Gender	29.5%	25.8%	27.6%
	African American	Count	26	33	59
		% within Ethnicity	44.1%	55.9%	100.0%
		% within Gender	27.4%	34.0%	30.7%
	Caucasian	Count	23	21	44
		% within Ethnicity	52.3%	47.7%	100.0%
		% within Gender	24.2%	21.6%	22.9%
	Asian	Count	18	18	36
		% within Ethnicity	50.0%	50.0%	100.0%
		% within Gender	18.9%	18.6%	18.8%
<b>Total</b>	Count	95	97	192	
	% within Ethnicity	49.5%	50.5%	100.0%	
	% within Gender	100.0%	100.0%	100.0%	

<sup>1</sup> Demographic information on gender is based on the number of participants who were recruited and showed up for participation in the discussion groups.



## B. Age<sup>2</sup>

The majority of participants were between the ages of 40 to 49 years. The oldest participant was 75 years. The average ages of participants in San Francisco was 54.29 years. The average age of participants in Miami was 55.3 years, and the average age of participants in Chicago was 52.02 years. Table III-2 illustrates the demographic profile of participants by age.

**Table III - 2: Demographic Participant Profile: Age**

			Age				Total
			40-49	50-59	60-69	70+	
<b>Ethnicity</b>	Hispanic	Count	17	17	11	9	54
		% within Ethnicity	31.5%	31.5%	20.4%	16.7%	100.0%
		% within Age	21.5%	28.8%	26.8%	60.0%	27.8%
	African American	Count	31	17	9	2	59
		% within Ethnicity	52.5%	28.8%	15.3%	3.4%	100.0%
		% within Age	39.2%	28.8%	22.0%	13.3%	30.4%
	Caucasian	Count	15	14	13	2	44
		% within Ethnicity	34.1%	31.8%	29.5%	4.5%	100.0%
		% within Age	19.0%	23.7%	31.7%	13.3%	22.7%
	Asian	Count	16	11	8	2	37
		% within Ethnicity	43.2%	29.7%	21.6%	5.4%	100.0%
		% within Age	20.3%	18.6%	19.5%	13.3%	19.1%
<b>Total</b>	Count	79	59	41	15	194	
	% within Ethnicity	40.7%	30.4%	21.1%	7.7%	100.0%	
	% within Age	100.0%	100.0%	100.0%	100.0%	100.0%	

<sup>2</sup> Demographic information on age is based on the number of participants who were recruited and showed up for participation in the discussion groups.

### C. Education<sup>3</sup>

The majority of participants had some college education (33.3% of participants). Ten participants were reported to have some high school education (5.1% of participants) and 26 participants were reported to have a graduate or professional degree (13.3% of participants). Table III-3 illustrates the demographic profile of participants by education.

**Table III - 3: Demographic Participant Profile: Education**

			Education					Total
			Some HS	HS Grad GED	Some College	College Graduate	Grad School Prof Degree	
<b>Ethnicity</b>	Hispanic	Count	4	12	13	19	6	54
		% within Ethnicity	7.4%	22.2%	24.1%	35.2%	11.1%	100.0%
		% within Education	40.0%	36.4%	20.0%	31.1%	23.1%	27.7%
African American		Count	3	12	31	7	7	60
		% within Ethnicity	5.0%	20.0%	51.7%	11.7%	11.7%	100.0%
		% within Education	30.0%	36.4%	47.7%	11.5%	26.9%	30.8%
Caucasian		Count	0	6	13	19	6	44
		% within Ethnicity	.0%	13.6%	29.5%	43.2%	13.6%	100.0%
		% within Education	.0%	18.2%	20.0%	31.1%	23.1%	22.6%
Asian		Count	3	3	8	16	7	37
		% within Ethnicity	8.1%	8.1%	21.6%	43.2%	18.9%	100.0%
		% within Education	30.0%	9.1%	12.3%	26.2%	26.9%	19.0%
<b>Total</b>		Count	10	33	65	61	26	195
		% within Ethnicity	5.1%	16.9%	33.3%	31.3%	13.3%	100.0%
		% within Education	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

<sup>3</sup> Demographic information on education is based on the number of participants who were recruited and showed up for participation in the discussion groups.

## D. Marital Status<sup>4</sup>

Participants for each of the 20 focus groups were approximately equal in terms of marital status (49.7% of participants were single; 50.3% of participants were married). Participants who are recorded as single reported their marital status as being single, divorced, widowed, or other. The majority of Caucasian and African American participants were reported to be single, 61.4 percent and 60.0 percent, respectively. Table III-4 illustrates the demographic profile of participants by marital status.

**Table III - 4: Demographic Participant Profile: Marital Status**

			Marital Status		Total
			Single	Married	
<b>Ethnicity</b>	Hispanic	Count	22	32	54
		% within Ethnicity	40.7%	59.3%	100.0%
		% within Marital Status	22.7%	32.7%	27.7%
	African American	Count	36	24	60
		% within Ethnicity	60.0%	40.0%	100.0%
		% within Marital Status	37.1%	24.5%	30.8%
	Caucasian	Count	27	17	44
		% within Ethnicity	61.4%	38.6%	100.0%
		% within Marital Status	27.8%	17.3%	22.6%
	Asian	Count	12	25	37
		% within Ethnicity	32.4%	67.6%	100.0%
		% within Marital Status	12.4%	25.5%	19%
<b>Total</b>	Count	97	98	195	
	% within Ethnicity	49.7%	50.3%	100.0%	
	% within Marital Status	100.0%	100.0%	100.0%	

<sup>4</sup> Demographic information on marital status is based on the number of participants who were recruited and showed up for participation in the discussion groups.

## E. Household Income<sup>5</sup>

The majority of participants reported to have a household income between \$25,000 and \$49,999 per year (34.4% of participants). African American participants reported no income and income less than \$15,000 per year more than the other ethnic groups. Caucasians were more likely than the other ethnic groups to report having a household income of \$100,000 or more per year. Table III-5 illustrates the demographic profile of participants by household income.

**Table III - 5: Demographic Participant Profile: Household Income**

			Household Income (\$)						Total	
			No Income	< 15,000	15,000–24,999	25,000-49,999	50,000-74,999	75,000-99,999		100,000+
<b>Ethnicity</b>	Hispanic	Count	1	1	9	22	13	4	4	54
		% within Ethnicity	1.9%	1.9%	16.7%	40.7%	24.1%	7.4%	7.4%	100.0%
		% within Household Income	20.0%	7.7%	33.3%	33.3%	33.3%	14.3%	28.6%	28.1%
African American	Count	3	8	10	19	9	9	2	60	
		% within Ethnicity	5.0%	13.3%	16.7%	31.7%	15.0%	15.0%	3.3%	100.0%
		% within Household Income	60.0%	61.5%	37.0%	28.8%	23.1%	32.1%	14.3%	31.3%
Caucasian	Count	0	3	3	11	10	9	7	43	
		% within Ethnicity	.0%	7.0%	7.0%	25.6%	23.3%	20.9%	16.3%	100.0%
		% within Household Income	.0%	23.1%	11.1%	16.7%	25.6%	32.1%	50.0%	22.4%
Asian	Count	1	1	5	14	7	6	1	35	
		% within Ethnicity	2.9%	2.9%	14.3%	40.0%	20.0%	17.1%	2.9%	100.0%
		% within Household Income	20.0%	7.7%	18.5%	21.2%	17.9%	21.4%	7.1%	18.2%
<b>Total</b>	Count	5	13	27	66	39	28	14	192	
		% within Ethnicity	2.6%	6.8%	14.1%	34.4%	20.3%	14.6%	7.3%	100.0%
		% within Education	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

<sup>5</sup> Demographic information on household income is based on the number of participants who were recruited and showed up for participation in the discussion groups.

## F. Health Insurance<sup>6</sup>

The majority of participants reported having some form of health insurance. Eighty-five point one percent reported having insurance, 13.4 percent reported having no insurance, and 1.5 percent reported not knowing whether they had insurance. African American and Hispanic/Latino participants were more likely to report not having health insurance compared to the other ethnic groups. Fifty percent of the African American participants reported that they did not have health insurance. Table III-6 illustrates the demographic profile of participants by insurance status.

**Table III - 6: Demographic Participant Profile: Health Insurance**

			Health Insurance			Total
			Have It	Don't Have It	Don't Know	
<b>Ethnicity</b>	Hispanic	Count	48	5	1	54
		% within Ethnicity	88.9%	9.3%	1.9%	100.0%
		% within Health Insurance	29.1%	19.2%	33.3%	27.8%
	African American	Count	45	13	1	59
		% within Ethnicity	76.3%	22.0%	1.7%	100.0%
		% within Health Insurance	27.3%	50.0%	33.3%	30.4%
	Caucasian	Count	39	4	1	44
		% within Ethnicity	88.6%	9.1%	2.3%	100.0%
		% within Health Insurance	23.6%	15.4%	33.3%	22.7%
	Asian	Count	33	4	0	37
		% within Ethnicity	89.2%	10.8%	.0%	100.0%
		% within Health Insurance	20.0%	15.4%	.0%	19.1%
<b>Total</b>	Count	165	26	3	194	
	% within Ethnicity	85.1%	13.4%	1.5%	100.0%	
	% within Health Insurance	100.0%	100.0%	100.0%	100.0%	

<sup>6</sup> Demographic information on health insurance is based on the number of participants who were recruited and showed up for participation in the discussion groups.

## G. Type of Primary Care Practice<sup>7</sup>

The majority of participants reported receiving health care services from a Health Maintenance Organization (HMO) (49.2% of participants). Of those with health care, 30.8 percent reported receiving health care services in a private practice setting. Caucasian participants were more likely than the other ethnic groups to report receiving health care services in a private practice setting. Within ethnic groups, Asians, African Americans, and Hispanics/Latinos reported receiving more care in HMO settings than in the other type of primary care practice settings. Table III-7 illustrates the demographic profile of participants by type of primary care practice.

**Table III-7: Demographic Participant Profile: Primary Care Practice**

			Primary Care Practice				Total
			Private	HMO	Other	Missing	
<b>Ethnicity</b>	Hispanic	Count	17	31	4	2	54
		% within Ethnicity	31.5%	57.4%	7.4%	3.7%	100.0%
		% within Practice Type	28.3%	32.3%	12.5%	28.6%	27.7%
	African American	Count	17	18	18	2	60
		% within Ethnicity	28.3%	38.3%	30.0%	3.3%	100.0%
		% within Practice Type	28.3%	24.0%	56.3%	28.6%	30.8%
	Caucasian	Count	18	17	7	2	44
		% within Ethnicity	40.9%	38.6%	15.9%	4.5%	100.0%
		% within Practice Type	30.0%	17.7%	21.9%	28.6%	22.6%
	Asian	Count	8	25	25	1	37
		% within Ethnicity	21.6%	67.6%	8.1%	2.7%	100.0%
		% within Practice Type	13.3%	26.0%	9.4%	14.3%	19.0%
<b>Total</b>	Count	60	96	32	7	195	
	% within Ethnicity	30.8%	49.2%	16.4%	3.6%	100.0%	
	% within Practice Type	100.0%	100.0%	100.0%	100.0%	100.0%	

<sup>7</sup> Demographic information on type of primary care practice is based on the number of participants who were recruited and showed up for participation in the discussion groups.

## V. FINDINGS

The findings from the focus groups will be described in three parts: 1) factors that influence the receipt of eye care; 2) factors that differ by race/ethnicity; and 3) additional information. In an attempt to semi-quantify the prevalence of themes and concepts, the following terms were used: “few,” “a number,” “several,” “many,” and “majority.” The terms “few,” “a number,” and “several” are used to convey that 5–25 percent of the total respondents identified or mentioned a particular theme or concept. The term “many” is used to convey that 26–50 percent of the total respondents identified or mentioned a particular theme or concept. Lastly, the term “majority” is used to convey that 51 percent or more of the total respondents identified or mentioned a particular theme or concept. This categorization will serve as the framework for presenting and analyzing the study findings in the following sections. A number of quotations from the study participants are included. In some sections, the codes MS, FS, and MOD are used. MOD is used to indicate that the moderator was speaking, MS indicates that the speaker was male, and FS indicates that the speaker was female.

### A. FACTORS THAT INFLUENCE THE RECEIPT OF EYE CARE

In general, the majority of participants in each of the three cities and four ethnicities rated their health as either good or fair. When rating their general health on a scale of one to 10, with one being the worst and 10 being the best, a majority of participants rated their health within the range from seven to 10. One Hispanic/Latino participant in Miami stated, “From one to ten, I would say eleven. I’m good. I’m good. I feel good.” A Caucasian participant in San Francisco stated, “I would say 8-1/2. I’m also healthy. I have diabetes, but it is well controlled. And I had some cataract surgery, so otherwise I have been in good health.”

Several participants rated their health as poor. A few participants noted that they had high blood pressure, heart conditions, diabetes, or glaucoma. When using a scale of one to 10, the lowest any participant rated their health was a three. A Hispanic/Latino participant in San Francisco stated, “I would say a five [MOD: What does a five mean to you?] Five means it’s not as good as it should be. If I was to follow directions from the doctors, it would probably be better.”

A majority of participants also indicated that they had seen a doctor at least once in the past year. Most participants had seen a doctor between two and six times in the past year. However, several participants among the three cities had not seen a doctor at all. Participants in the Asian groups were least likely to have seen a doctor in the past year

compared to the other racial and ethnic focus groups in Chicago. Several participants in San Francisco reported seeing a doctor more than 15 times in the past year. When asked, “When was the last time you saw a regular doctor?” one African American participant in Miami stated, “A regular doctor, oh man. I haven’t been in a while.” [MOD: What’s a while?] Years. Yeah, years.” An Asian participant in San Francisco commented, “My normal answer would probably be once or twice a year but in the last year, it’s probably been over 20 times. I had a major bacteria infection at the beginning of the year.”

The majority of participants also have seen an eye care professional and had an eye exam within the past two years. Among the Caucasian and African American groups in Chicago, all of the participants had seen an eye doctor in the past one to two years. In Miami, one African American participant, who had been diagnosed with strabismus in 1980, stated that he had not been back to an eye doctor since. Another African American participant stated that he is a diabetic and has never been to an eye doctor. In San Francisco, while the majority of participants had seen an eye doctor in the past two years, several African American, Hispanic/Latino, and Asian participants said it had been longer than four years since they had seen an eye doctor.

The following discussion explores the factors that influence the receipt of eye care.

## **1. Attitudes**

In each of the 20 focus groups, various attitudes about eyes, the health care system, and seeing a primary care physician or eye care professional were discussed. Attitudes according to the theoretical model in which this research was developed, the Theory of Reasoned Action, are simply a person’s general feeling of favorableness or unfavorableness toward a particular concept (Ajzen & Fishbein, 1980). Attitudes are based on beliefs or information individuals hold about themselves and their environment. Generally speaking, people form beliefs about an object by associating it with various characteristics, qualities, and attributes. Automatically and simultaneously, people acquire an attitude toward that object.

### **Eyesight**

In each of the focus groups, participants discussed attitudes about their eye health, the importance of eyesight, and beliefs that were found to influence the receipt of eye care. Generally speaking, the overwhelming majority of participants value their eyesight and healthy vision. The favorable attitude that participants have about their eyesight is



driven by beliefs that their eyesight is indispensable. However, a number of participants also stated a competing belief that they take their eyesight for granted. Both of these beliefs were reported to have influence on whether eye care services were received or not, and did not vary by race/ethnicity or location of the group.

### **Eyesight is Important**

An overwhelming majority of participants found eyesight to be very important to them. Many participants stated that their eyesight is critical for them to function, to make a living, or even enjoy simple things that they do in life. A number of participants stated that losing their eyesight would be the worst thing that could happen to them. Participants also said that without their eyesight, they would be less independent; less productive; and unable to see their children, families and the world around them, all of which would be devastating to them. When discussions moved to people who are blind, participants described them as courageous and amazing.

- “I want to see, I want to see my children. I want to see friends, strangers, flowers, just the world...To me, it’s [eyesight] the most important sense.” (Group 15; Asian; San Francisco, CA)
- “I might postpone a dental appointment, but I’ll never postpone the optical appointment.” (Group 6; Caucasian; Chicago, IL)
- [MOD: I’m going to read five things to you. Losing your memory, losing your hearing, losing an arm or a leg, losing your speech, losing your eyesight.] “I can lose all of them except my eyesight.” (Group 4; African American; Miami, FL)
- “You’re less independent. If you have very poor eyesight or no eyesight, you’re dependent on a seeing eye dog, Braille reading. When you’re seeing all your life and then to lose your eyesight completely, it’s pretty dramatic. All sorts of accidents would happen to you.” (Group 6; Caucasian; Chicago, IL)
- “I have my own experience back in 1989. My face was burned. And my eyelashes was burned also. But the pain was so awful they took me to [the] emergency [room]. And I was unconscious. And when I woke up, I didn’t see nothing. I mean, I was blind for a few hours. And to me that was very ... I mean, that was the worst thing that happened to me. Because again, I’m very independent. And I was having, you know, my baby was just born. And I said, ‘My God. I mean, please give me my eyes back. Because I want to see my baby. And I want to take care of him.’ It’s a bit different when you’re born blind than when an accident happen[s]. And I was in a lot of treatment. And thank God, I got my eyesight. It was just a few hours. But to me, I thought it was forever.” (Group 1; Hispanic/Latino; Miami, FL)
- “I have a lot of fear for blind people...you know...I also feel so sad for them...how they can manage to do anything...how they can be around to know what’s going

on...what color is this or... I think it's horrible." (Group 10; Hispanic/Latino; Chicago, IL)

- "Oh, to me eyesight is just so important -- because I have very limited eyesight. It's just -- I have worn glasses since I was 8 years old. If I don't have my glasses on, I feel like I'm totally blind. I just can't imagine. I give credit to these people who are blind and are walking the streets and going out. They are so courageous. Amazing." (Group 17; Hispanic/Latino; San Francisco, CA)
- "I think you need a lot of courage. When I went to see the movie Ray, I mean...it's incredible...you need a lot of courage; you need somebody that would be with you all the time...pushing you to do things." (Group 10; Hispanic/Latino; Chicago, IL)
- "I couldn't see my kids change and the things they do every day. That would just kill me. I couldn't see my loved ones, things I like doing, my ceramics, I would be a lot less productive...It's critical. It's the input of the world." (Group 20; Caucasian; San Francisco, CA)
- "I mean basically I'm not familiar with existing without sight and I really don't know how they would function or be able to survive or have a living or even enjoy simple things that I do in life without vision. It's just a scary thought." (Group 4; African American; Miami, FL)

Participants were confronted with five things that could happen to them: loss of memory, eyesight, an arm or a leg, speech, or hearing. When asked to rate which loss would be the worst, among all of the groups, loss of eyesight and memory were noted as the worst things that could happen. However, loss of memory was selected as the worst thing that could happen slightly more often than loss of eyesight.

### **People Take Their Eyesight for Granted**

A critical belief about eyesight that emerged in almost every focus group was that people take their eyesight for granted. Although this belief seems to contradict the overall favorable attitude about eyesight, many people stated that this particular belief exists. This belief did not seem to vary based on race/ethnicity or location of the focus group. When asked why people take their eyesight for granted, many participants commented that they did not know why, or that they were born with eyesight and always expect it to be there.

- [MOD: Do you think that we take our eyes for granted?] "Yeah. As valuable as they are to us, I think we take them for granted." (Group 10; Hispanic/Latino; Chicago, IL)
- "Generally speaking, I don't see that eyes are that related to health. I mean you could be in tremendous and good health...Olympic athlete and you have an eye stigmatism where you require glasses. It's as simple as that. So I don't see it as a health issue until other

factors come into play...like diabetes and things like that. (Group 10; Hispanic/Latino; Chicago, IL)

The following excerpt comes from Group 6; Caucasian, Chicago, IL.

- MOD: Do you think people take their eyesight for granted?  
FS: No.  
FS: I do.  
MOD: Why do you say that, Ruth?  
FS: I think there's a lot of people unless you have a problem, they're not going to go get their eyes examined. I hadn't gone in over two years. And I'm borderline glaucoma. And I had these other things that are family related. And I haven't gone.  
MOD: Why? Is it like Judy that you don't want to hear bad news?  
FS: No. I just don't bother. So maybe just not upper in my head to go.  
MOD: And considering your family experiences, what would it take for you to?  
FS: Just to do it. Just to have that mindset that that's what I need to do.  
FS: You think you're going to be passed over. You think it's not going to happen to you. Well, maybe it won't happen at this generation or something like that.  
MS: Well, I certainly took it for granted until I had that accident. But after the doctor discharged me after I was going quite a few sessions. And my eyes have remained the same. And I have not gone to an eye doctor. I haven't needed to go to an eye doctor. And I just recently had a job interview where they did test my eyes. So I knew I hadn't deteriorated at all. So I don't feel the need to go yet. But as soon as I see any change whatsoever in my vision, I will go. Because I now know where there's a good doctor.

The following excerpt comes from Group 17; Hispanic/Latino, San Francisco, CA.

- MS: I'm very negligent when it comes to my eye care. I just put on my glasses. They say you're supposed to keep a lubricant, keep it clear. They have eye solution that they sell. They have -- what's it called? Something tears to keep your eyes lubricated or keep them clean. None of that stuff. I take them for granted.  
MOD: So he takes his eyesight for granted. Do you think that most of you take your eyesight for granted?  
FS: Yes.

- FS: I think so.
- MOD: Why do you think that is?
- MS: Most people are born with very good eyesight, so they don't concentrate on that. Take it for granted.
- FS: I don't get my examinations, check-ups like I should. In fact, I'm overdue.
- MOD: I'm going to ask you about that in a minute.
- MS: From my own experience, if it wasn't for this test [a work-related eye screening], I wouldn't even give it a second thought about my eyesight. I guess taking it for granted, thinking that it won't ever happen to me -- get in a car accident, get socked in the eye. Lose your eyesight in one form or another. Somebody sand blasting and the sand hits your eye or something. It could be a whole variety of different things. I don't feel comfortable saying it, but just taking it for granted.

## **Eye Exams**

In each of the 20 focus groups, getting an eye examination was mentioned as one way in which people can prevent loss of eyesight and preserve healthy vision. However, a number of participants have the attitude that seeing an eye care professional is not a necessity. This attitude appears to be driven primarily by fear, denial, the belief that participants' vision has not changed, that they have never had eye problems to begin with, or that one primarily visits an eye care professional to get their prescriptions changed. The attitude that seeing an eye care professional is not a necessity seems to contradict participants' general attitudes and values about the importance of eyesight and healthy vision, particularly since it relates to visiting an eye care professional, which was said to prevent the loss of eyesight. Participants who reported not seeing a primary care physician in the past year also said that they did not feel the need to. The attitude that seeing an eye care professional is not a necessity appeared to be consistent across each of the three cities and each of the four race/ethnicities, although some of the more pronounced examples came from the African American focus groups.

### **My Vision Hasn't Changed**

One of the major reasons reported by the majority of participants for not receiving or seeking eye care services was because they believed that their vision had not changed. This belief supports the attitude of participants that seeing an eye care professional is not a necessity. Many of these participants reportedly never had problems with their eyes, or they felt that the eyeglass and contact prescriptions they have were sufficient for them to perform everyday activities such as reading and driving.

- “Well, these glasses are perfect so I go to movies and you know, everything looks great. I can see everything I thought I could see three years ago.” (Group 15; Asian; San Francisco, CA)
- “Well, my vision has basically stayed the same since 1999. So that’s why I haven’t gone. And I haven’t noticed any difference, either. And I’ve been wearing glasses since I was two, I think.” (Group 17; Hispanic/Latino; San Francisco, CA)
- [MOD: When was the last time you saw an eye doctor and who did you see?] “I don’t even know. Not since I’ve lived here and that was ‘88 so what’s that, 17 years ago? It’s been a long time. I don’t need glasses. I have nothing wrong with my vision, I have no pain, I just kind of, know that they’re fine.” (Group 20; Caucasian; San Francisco, CA)

The following excerpt comes from Group 3; African American, Miami, and illustrates the significance of the attitude that seeing an eye care professional is not necessary, as it has prevented the receipt of eye care of one individual for almost 25 years.

- MOD: When was the last time you saw an eye doctor and had your eyes examined? Start with Gary.
- MS: The last time, to be honest with you, it was 1980. The last time I got my eyes checked. No, these glasses are reading glasses. The last time I had my eyes checked was in 1980 when I had my last pair of glasses.
- MOD: That’s 25 years, brother. Why haven’t you gone to a doctor in the last 25 years?
- MS: Well, I haven’t had the need to go. I know that’s no excuse.
- MOD: Okay, for 25 years.
- MS: 25 years ago.
- MOD: Anthony?
- MS: I’ve never seen an eye doctor.
- MOD: You’ve never seen an eye doctor? You’ve never seen an eye doctor?
- MS: Not even for diabetes screening? [The participant earlier in the discussion revealed that he was a diabetic.]
- MS: No.
- MOD: Why not?
- MS: Because like I said, I’ve never had problems with my eyes. The only time I had problems with my eyes was when my diabetes was really bad. And I didn’t even know I had it [diabetes] then.

The following excerpt comes from Group 4; African American, Miami, FL.

- MOD: Okay. For those of you who haven't been [to have your eyes examined] in the last two or three years, why is it that you didn't go or that you haven't gone in that amount of time?
- MS: I didn't think I had no need. I basically just use these fluxtall glasses anyhow just to read with. That's the main problem I have with my eyes.
- MOD: Okay. Deborah?
- FS: Because it doesn't seem necessary.
- MOD: Okay. What would make it, let me ask Louis, first. Louis, you said you haven't been, two or three years at least, why not?
- MS: Busy building my empire. (Laughter)
- MOD: Okay, so let me get back to you, Deborah. You said you didn't go, why?
- FS: Didn't feel like it was necessary. The glasses that I have are doing their job, so, if it's not broken, don't need to fix it.

#### **For Eyeglass and Contact Prescriptions Only**

Another belief underlying participants' attitude that seeing an eye care professional is not a necessity is that many participants (as also alluded to in the preceding excerpts) indicated that the primary reason for visiting an eye care professional was to check on or change their eyeglass or contact prescription and not to examine the overall health of the eye. Only a few participants were noted to see an eye care professional for preventive measures and to check on the general health of their eyes.

- [MOD: Under what circumstances would you go to an eye doctor? Especially for those who haven't gone in, I would say, two or three years.] "[If] my eyeglass doesn't work for me anymore, this one, this level, then I would go. (Group 7; Asian; Chicago, IL)
- "A lot of times when you think of a doctor, in general you're going to go for some other illness unless you're having a problem seeing. You're not going to go for preventative [eye] care... especially when you're in your 20s and 30s, you don't do that. You just don't do it. You don't think about it. You're invincible." (Group 5; Caucasian; Chicago, IL)
- "I was going to say it's interesting that we go, for example, in my case I go yearly for a checkup. And I do not go quite as often to the eye doctor. It's only when I run out of contact lenses or a prescription or I feel that my prescription is outdated. And I feel a need to go and have the checkup done. (Group 1; Hispanic/Latino; Miami, FL)

- [MOD: Is having your prescription updated the primary reason for having your eyes examined?] “Yes. But if there was to be a dramatic change in my vision, I would go immediately to an ophthalmologist.” (Group 15; Asian; San Francisco, CA)

The following excerpt comes from Group 14; African American, San Francisco, CA.

- MOD: Okay. Is that the primary reason for going to the eye doctor, is to make sure your prescription hasn’t changed?  
 FS: For me.  
 MOD: For anybody else?  
 MS: Yes.  
 MS: Yeah. For me, too.  
 FS: Mm-hmm. If everything is still reading right, why bother?
- “Oh, like I said, I have diabetes so I have a need to check to make sure if my diabetes is controlled, the blood vessels in my eyes and so forth.” (Group 15; Asian; San Francisco, CA)
- “I go to my eye doctor, optometrist. [MOD: Why?] Because it’s important. [MOD: But when you go are you going to just update your prescription or?] No. I get my glaucoma test and all kinds of tests.” (Group 20; Caucasian; San Francisco, CA)

### **Fear and Denial**

Fear and denial were other beliefs the focus group participants mentioned that serve as barriers to receiving an eye exam. These beliefs fall along the lines of “what people don’t know won’t hurt them.” As a result, several participants said they avoid seeking clinical services. A few participants also noted they fear undergoing surgery and other procedures that are necessary to improve or correct their vision. Participants mentioned that denial influences the receipt of eye care due to notions that eye injuries or disease are unlikely or will not happen to them. Fear was not reported by any of the Asian groups, perhaps because, as reported in one of the San Francisco Asian groups, that “most [Asian] people are very comfortable with western medicine and know the benefits.”

- [MOD: What do you do when you have problems with your eyesight?] “Some people do nothing because of fear. Some people don’t want to know. [MOD: What do you mean, do nothing because of fear?] I think there are some, and I know a couple of people, as long as they don’t know what’s wrong, they’re okay with it. There is that fear of knowing.” (Group 4; African American; Miami, FL)

- “I had a really bad experience a few years back with my grandmother. God rest her soul. My dad’s mother. She died at ninety...she was 93 when she passed away. The last I would say seven or eight years of her life, she lived with glaucoma. And she refused to...not glaucoma. She had cataracts. And she refused to get [it] operated [on]. Because she was scared. And there was no way in the world that any other family members, not even my father or her husband, my grandfather, could talk her out of it. [MOD: And what was she afraid of?] She was afraid of the operation. And she finally lost her sight.” (Group 2; Hispanic/Latino; Miami, FL)
- “We had one fellow that was in the tool room that had a piece of steel catch in his left eye. And he wouldn’t have it taken care of. He was supposed to have the eye removed. Well, he didn’t do it and he didn’t do it. And after awhile, they said if you don’t take it out, you’ve got to take the other eye out too. [MOD: Do you know why he never went to get that taken care of?] People are in denial about everything. They just don’t want to go. They don’t want to face the fact that they’re not well.” (Group 5; Caucasian, Chicago, IL)

The following excerpt comes from Group 6; Caucasian, Chicago, IL.

- FS: That was about two years ago the first time I went, ten years [to have an eye exam]. So I really never do go. But I have to start going. It’s just hard to force myself to.
- MOD: Why is that, Judy?
- FS: I don’t know. Because I’m diabetic. And I’m afraid if my eyes are bad, they’ll put me on insulin. And I don’t know. I’m just scared.
- MOD: Okay. Now, you say you’re afraid if your eyes are bad, they’ll put you on insulin.
- FS: Yeah. Because then they’ll say it’s affecting parts of your body. And you’re going to have to go on insulin. I’m close to that. And that’s why I’m scared.
- MOD: Do you think about what would happen if you don’t go?
- FS: Yeah.

In the prior examples, fear was illustrated as a barrier to receiving eye care services. However, one Caucasian participant in San Francisco commented that because fear about potentially losing her eyesight is not presented in the media with the same urgency as other health conditions, she has not prioritized receiving eye care services. The following excerpt comes from Group 19; Caucasian, San Francisco, CA.

- MOD: What gets in the way of you receiving eye care services?



- FS: For me “fear” is the operative word. I wouldn’t miss my yearly mammogram for a lot of money, so to speak. But I might miss my yearly eye exam. It’s just, somewhere in my head, the mammogram on a scale of whatever is in my fear quotient. [Therefore I insist on] making sure that I am protected as much as I can be in that regard. But an eye exam, I’m not frightened enough. I feel confidence still, that my eyes are okay even though I have family history [of eye disease]. In fact, what I’m saying isn’t even rational.
- MOD: What you’re saying is you don’t have enough fear.
- FS: Yeah, right. It’s more life or death even though I’m not worried about, I don’t have a family history of breast cancer. The media and what you know from the statistics, makes it more frightening as a woman, just more frightening so I wouldn’t miss that.
- MOD: When you say the media what do you mean?
- FS: Well, they come out quite a bit with what’s going on and what’s happening. There are clusters of breast cancer and now the statistics are 2 in every 8 or 10 women. It’s very prominent in that, the breast cancer rate has been going up rather than decreasing.

## Health Care System

### Time

One attitude that was found to influence the receipt of general health care services and the receipt of eye care is that many of the participants found the health care system to be a hassle and a negative experience overall. This finding is attributable to a number of beliefs, one of which is that receiving eye and/or health care services is extremely time consuming and that there is not enough time provided to have a pleasing physician-patient encounter.

- “I feel rushed. [MOD: What do you mean, rushed?] It’s like, ‘Hi, nice to see you.’ Where you going? Okay. What’s wrong with you? Okay. See ya, next week.” (Group 15; Asian; San Francisco, CA)
- “For me, I haven’t been to a doctor. I would say I am disappointed with them. I feel like I’m in a chop shop when I go. I feel like I am being rushed and there is no personal level of interaction between myself and the doctor.” (Group 7; Asian; Chicago, IL)
- “For just a regular checkup if you go see your primary. From the moment you walk into that office and you see 50, 60 people sitting around there waiting to see the doctor.

I mean, in 15, 20 minutes, everybody in this area is not going to get the same kind of treatment. I mean, they're in for... each and every individual person is in for one specific thing. But, I mean, let's say, for example, you know that your problem is not severe, but it's thought provoking. You don't have three hours to sit there waiting for this guy to see you. That's the problem these days. You have to dedicate at least two, three, maybe four hours of your time." (Group 2; Hispanic; Miami, FL)

- "Okay. I belong to Kaiser, and nowadays you see nurse practitioners. I have a problem with that. [MOD: Okay.] And you don't seem to be able to get around that. This is the way this particular HMO is set up unless you really, to me, have some situation where you're about just ready to croak. Then you actually see a licensed physician. And everything is just, you're shuffled in like herd, like cattle." (Group 13; African American; San Francisco, CA)
- "Our company has Affordable Benefits Administrators out of Los Angeles. And they contracted out to different providers. And, in fact, they change almost every year so we have a different set of doctors. So that's not been real helpful. And the smaller practices seem to have [pay] a little bit better care or attention to the patients. But I notice that they are in such limited time increments. Like they can only see you for 15 minutes and they are really in and out. They really don't have a lot of time to spend with you. And the secret is if you get the last appointment of the day, the doctor will spend more time with you." (Group 16; Asian; San Francisco, CA)
- "I don't really like have a regular doctor. I want to know who I'm going to. I want to be able to communicate with him. See what kind of feeling I get. They [providers] don't want to do that. They don't have time for that. You talk to their nurse. (Group 6; Caucasian; Chicago, IL)

A number of participants noted problems with scheduling appointments and having long wait times in doctors' offices.

- "I'm very satisfied with my doctor except the waiting time. It's a long wait. Two hours is a long wait." (Group 1; Hispanic; Miami, FL)
- "I think they just need to improve the scheduling. They overbook. And I know that it's a financial decision for them, but they just overbook. Waiting time. My time is as important to me as theirs is to them. The waiting time." "I agree with you, because on my doctor's wall he says if you're 15 minutes late then you have to reschedule. But I can sit in there for two hours and I got to pay." (Group 4; African American; Miami, FL)

At the same time, positive attitudes about receiving care are developed when general beliefs about the health care system and experiences are reversed. Participants were more likely to have better experiences and receive health care services when they

believed that their doctor took a sufficient amount of time to spend with them and allowed them time to communicate and ask questions.

- “My doctor is pretty good. They take the time. If I want to ask questions he’s there or she’s there. And they take as much time as I need. Not as much time as I need, but sufficient time.” (Group 4; African American; Miami, FL)
- [MOD: In general, how would you describe your experiences with medical care provided by doctors?] “Very good! [MOD: Very good. When you say very good, what do you mean?] I get good care, timely care. They appear to be interested in what I’m talking about. They spend a lot of time with me.” (Group 12; African American; Chicago, IL)

### **Physician–Patient Relationships**

Several participants also reported that they have stifled relationships with their providers where they feel that their health care providers do not adequately address their health care needs. This lack of attention, in turn, leads to an unfavorable attitude about the health care system and encounters with providers. Many participants mentioned that their providers do not know them. Participants also spoke of how providers are quick to treat conditions with medication and do not take the time to develop relationships and investigate what may be underlying the illness. Participants who were unsatisfied with their experiences with health care providers or doctors said they were impersonal and inconsiderate. This belief did not seem to vary based on race/ethnicity or location of the focus group; however a higher number of these types of comments were stated in the San Francisco, CA, focus group.

- “I think they try, but they don’t really know you. [MOD: What do you mean?] Like maybe they misunderstand you -- they diagnose you, but I think sometimes they don’t really try to get down to the bottom of what’s really bothering you. It’s like they’re making decisions too fast. The encounter is very brief. They are just prescribing medication, instead of trying further to look into it what is bothering you.” (Group 18; Hispanic; San Francisco, CA)
- “I’m dissatisfied with my physician. [MOD: Why is that?] I thought the bedside manner could have been better. I thought he asked some questions and he didn’t really listen to my answers. That frustrates me to no end.” (Group 20; Caucasian; San Francisco, CA)
- “Well, it’s [experiences with health care providers] not like when I was growing up. You knew your doctor like you knew your next door neighbor. Nowadays you go into these clinics and everything. I mean it’s like an assembly. They process you in and out and there’s maybe a bunch of people all waiting, and they don’t know you.

They're pretty much like you said, prescribing medication or getting unnecessary surgery. They rush everything." (Group 18; Hispanic; San Francisco, CA)

- "Yeah, I would say in general I don't have good communication. My gynecologist and I have good communication. Her son used to be my student. But then she's very good. I'm very, very fortunate. But my primary care physician, it's a group. It's just a waste of time. To be honest, I haven't even been back for my physical. Because when I had to go for a fasting blood test to check my cholesterol, I went in and I had to wait two hours and I didn't have breakfast and I was starving and then they took the damn test and they never tested for cholesterol. So it was a whole waste of time. A waste of a day off of work and I got the tests back and they had never done it and so I thought. [MOD: And did you say anything to them about it?] No, they are so busy and it was the nurses doing it and I just said, 'Oh my Lord.' So I just figured I'm not going to take the \$400 cholesterol medicine, the one they offered me was \$30 a month. I'm not going to spend \$30 a month. So I just eat a low cholesterol diet and do everything that I can do myself without taking the medicine that you pay \$400, and it would destroy your liver anyway." (Group 3; African American; Miami, FL)
- "Like I said, in the last year, I've seen a doctor 12 or 15 times, and they don't know me. They know what my illness is, but they don't know me. I think that's an important part of being able to treat me, is to know who and what I am, to be able to treat me properly." (Group 18; Hispanic; San Francisco, CA)
- [MOD: Have you ever felt that your doctor did not understand you or your illness?] "Yeah, that's why I keep changing primary doctors. [MOD: What do you mean by that?] I didn't even go yet. I haven't [been] checked up for three years now. [MOD: Okay.] You know, I almost have this feeling that every time I see my primary physician, I am just like antique and like I'm a number and that's it. After my number, she goes out, 'See you, bye,' like, I'm not really satisfied with her." (Group 15; Asian; San Francisco, CA)

## **Health Care System Organizational Culture**

Other beliefs that were identified and shown to impact participants' attitudes about the health care system and, ultimately, their desire to seek eye care services were that: 1) the health care system is highly disorganized and complicated; 2) health care providers are heavily influenced by the pharmaceutical industry; and 3) their providers may or may not treat them with a "human" element. Another influence that was noted to impact experiences with health care providers was pressure from insurance companies to reduce cost, which for a number of participants meant reduced time with patients and inability to receive certain procedures. These beliefs, as well, did not seem to vary based on race/ethnicity or location of the focus group.

- "They make it so hard to talk to the right person. You can't get in touch with the right person. It's all, you got to talk to this department, who doesn't talk to that department, then you got to call this number and this number and it's completely frustrating. It's frustrating, it's disorganized, they don't try to simplify it, they don't make it easy for you, there's nothing having to do with customer service, it's just one frustrating step after the other. I think there has to be a better way." (Group 20; Caucasian; San Francisco, CA)
- "I think the insurance companies are more of a problem than the doctors. You have open heart surgery and they want you home in three days now. Insurance companies are just pushing you out the door to go home." (Group 6; Caucasian; Chicago, IL)
- "I put going to the doctor like going to the bank. I just don't want to do it. There's just something about the, you know, like the culture of banks. And the culture of hospitals. I just don't want to be there." (Group 14; African American; San Francisco, CA)
- "If you have a sudden onset of a problem, whatever it maybe, negligence like they said or accident or whatever, you should not have to have a referral to your doctor. It should be like women that can go to the gynecologist without a referral. A skin doctor who I know pretty well led the fight to not have a referral to go to the skin doctor. The same thing should apply to the eye doctor. It's that important in my opinion. [MOD: So are you saying for most health plans you have to have a referral for an eye doctor?] Oh, yes. Many plans, they don't cover eyes." (Group 1; Hispanic; Miami, FL)
- "I feel like you're going through a mill. I miss the old days when your doctor would sit down and take time with you and you didn't feel like patient number 8197-005." (Group 15; Asian; San Francisco, CA)
- "I think my doctor is good, but I think he's in with the pill company, too... [MOD: And what do you mean by that?] I went to this guy and he prescribed this cholesterol pill for me and it cost four hundred and some dollars. And he wanted me to take three pills a day. I said I ain't taking that." (Group 3; African American; Miami, FL)

- “I would rate my health care experiences about a six. [MOD: What does that mean?] It could be better. Sometimes you’re treated like you’re just a number. And if you don’t have a particular doctor, I don’t find it as accommodating as it should be.” (Group 17; Hispanic/Latino; San Francisco, CA)
- “Yeah, generally I have a negative attitude toward the whole medical ... I don’t know if it’s industry or the medical world generally. I’ve had enough bad experiences. I’ve had family members who’ve had bad experiences. I’ve read some really bad experiences that people have had with doctors or in hospitals. And I often think that they don’t really seek a cure. And they treat symptoms. Not ophthalmologists necessarily, but the whole medical field. They often just treat symptoms. They use drugs heavily. They’re into drugs and surgery rather than preventative care. They don’t know much about nutrition and its role in preventing conditions from developing, symptoms from developing. And so I generally stay away from them.” (Group 6; Caucasian; Chicago, IL)
- “I go to Kaiser, and they follow up on everything. They go the extra yard. Yeah, they’re great – appointments and everything... I think what’s important for me is that they recognize that there’s a human being right there. I’ve been fortunate enough to have physicians that have called daily to see how you’re doing and that’s just a routine complementary call. They really want you to call back and discuss it.” (Group 20; Caucasian; San Francisco, CA)
- “Because my husband and I are both retired. And our medical plan changes. So once I’m familiar with one plan, my husband’s company gets insurance through his previous job changes. And I will have to learn everything about the new plan. So it’s very difficult. And it’s complicated. Because sometimes the doctor that we’re seeing doesn’t take the new plan. So then we have to start looking for another doctor. And it happened to us recently the last five years we had to switch doctors two and three times. And then finally, the company changed again to the previous plan. And we were able to come back to this doctor again, the one that we liked. So it’s a little bit confusing because of the system.” (Group 1; Hispanic/Latino; Miami, FL)
- “I would give it [my health care experiences] a zero. [And why is that?] They just don’t serve their patients like they should, especially for the money that they get – the insurance companies. I can do better than that, and I’m not even a doctor. (Group 17; Hispanic/Latino; San Francisco, CA)

### **Distrust of the Health Care System**

Another belief found to impact participants’ attitudes about the health care system and possibly influence the receipt of eye and/or health care services is distrust of the health care system. In Chicago, Caucasian participants reported distrust the health care system more than other racial and ethnic groups. One Caucasian participant commented that one has to self-educate about every aspect of the health care system. If

people do not and something bad happens, it is their fault. A number of participants stated that health care is a business that is concerned about cost and the bottom line and cannot be trusted. This belief did not seem to vary based on race/ethnicity or location of the focus group.

- “But you know ... I’ve had an experience here recently where my mom had a stroke. She fell and had to go into rehab. And she was in rehab about 60 days and I can honestly say that for those people that were in this facility, about 150 people, if you didn’t have someone there checking on you, on a regular basis, those people were mistrusted. I mean, I witnessed that. But we were there to ensure that she got good care. So, yeah, I do mistrust.” (Group 4; African American; Miami, FL)
- “My sister-in-law was complaining about headaches and she belonged to an HMO. They kept saying no, there’s nothing wrong with you, it’s all in your head, there’s nothing wrong with you, it’s all in your head. They kept on because they didn’t want to send her to a specialist. So finally when she opted out into another plan, and then they researched that and found out there was ... she had some pressure, they had to go in there and correct it. And all the time she was with the HMO they said it was in her head. With those people the bottom line is money. It’s not about health care. It’s about business, and business is about making money. That’s why I don’t trust them.” (Group 11; African American; Chicago, IL)
- “I distrust it because I feel that you’re just another number.” “The distrust that I have with the health insurance business is that you go to a doctor. And the doctor prescribes something. And many times, you have to get authorization from the company. So the company, they don’t even trust their doctor, whatever he prescribes. And then somebody that maybe makes ten, fifteen dollars an hour is the one that gives the authorization to the pharmacy and says what your doctor prescribed was okay.” (Group 2; Hispanic/Latino; Miami, FL)
- [MOD: Do you distrust the health care system?] “Yes. Various friends of mine have submitted bills and they don’t pay and they give you the runaround, and I’m sure everybody at this table knows somebody who has been in that predicament. And they want to take care of business. Do the right thing; they don’t do the right thing. You have to go through hoops and write letters and call your Congresswoman and do all kinds of things.” (Group 20; Caucasian; Chicago, IL)
- “I think the health care system...they lobby for the doctors and the pharmacists so they [can] make money... So I don’t think that they have the general population [’s] health in mind. There’s drugs out there... drugs and things that are known to be proven, but they won’t let it in [the system will not allow for the use of certain drugs] because they don’t want to lose money, maybe to Canada or whoever.” (Group 7; Asian; Chicago, IL)

## 2. Knowledge

Knowledge also appeared to have an influence over whether one receives eye care or not, as it relates to the beliefs and attitudes one has about receiving eye care. It seemed evident that participants form intentions to take action as described in the theoretical model based on whether information is provided to them. Generally speaking, participants in the three locations were not very knowledgeable about eye health. Several of the minority participants in Chicago and San Francisco stated they knew nothing about preventive eye care and that they did not think one could prevent loss of eyesight. The majority of participants mentioned disease and accidents as reasons people lose their eyesight. Most participants were somewhat knowledgeable about what a dilated eye exam was. However, the majority of focus group participants were not knowledgeable about eye diseases and conditions. The majority also reported that people should have their eyes checked once or twice a year.

### Sharing of Eye Health Information

A major theme that emerged from this research was that when participants visit their primary care physicians, their physician does not share information with them about their eyesight. Only several participants reported that their primary care physician shared information with them about their eyes, which in most cases was in reference to a patient's diabetes. In San Francisco, only three of the 75 participants said their primary care physician had shared information with them about their eyesight. The majority of participants also reported that their primary care physician does not conduct a basic eye screening during general physical examinations. The following descriptions illustrate how receiving eye care may not be prioritized due to a lack of focus on eye care and on sharing of eye health information between primary care physicians and patients.

- “You know, like these primary care doctors, they only, they only check certain things, then they send you to a specialist, this, specially that. I never heard of a primary care doctor checking my eyes, ever. I’ve been going to this guy a long time. I just had one [a general physical examination]. [MOD: And they didn’t look and see?] No.” (Group 3; African American; Miami, FL)

The following excerpt comes from Group 4; African American, Miami, FL.

- MOD: Has your primary care physician ever shared information with you about your eyesight?



FS: You know, I'm going to be honest with you, not mine.

FS: Nor mine, either.

MS: No.

MS: Me either.

FS: She don't do no talking about it.

- "My doctor told me that if I don't take care of my diabetes, I know that diabetes tears down the walls of your veins. And somehow some way, it affects the muscles in your eye, and if I don't take care of it, that's what's going to happen to me." (Group 3; African American; Miami, FL)

The following excerpt comes from Group 16; Asian, San Francisco, CA.

- MOD: Has your primary care physician ever shared information with you about your eyesight?  
FS: No.  
MS: No.  
MS: Not much.  
MS: It's not in his expertise.  
MOD: Nobody says yes. [Group agreement] Okay.

The following excerpt comes from Group 18; Hispanic/Latino, San Francisco, CA.

- MOD: Has your primary care physician ever shared information with you about your eyesight?  
MS: The only conversations that I have with my primary doctor is when I ask to be sent to the optometrist. And that was it.  
MOD: Anyone else, has your primary care physician ever shared any information with you about your eyesight?  
MS: No.  
MS: No.  
FS: It would be good if they did.  
FS: I guess if there is problems they have to, usually the primary care physician doesn't see eye problems. He doesn't tell you probably because there is nothing wrong.  
MOD: Did you say you had diabetes?  
FS: Yes.

MOD: And has your primary care physician ever said anything to you about your eyesight?

FS: Let me see, lately of course I've been going, I don't remember when I first experienced diabetes which was quite a few years ago whether the doctor told me be careful about your vision or not. I also read a lot of information about diabetes and that's how I got information. That is what I remember. I don't remember the doctor telling me.

### **Participants Don't Look for Eye Health Information**

It was noted by the majority of participants that they do not seek out information about their eyes. The participants who did seek information about their eyes typically were looking for information about symptoms they were experiencing, or for more information about conditions that friends and family might be experiencing. Lack of knowledge about general eye care sought on behalf of the participants may have an influence on the receipt of eye care. A majority of focus group participants are not knowledgeable about eye diseases and conditions. The term "diabetic retinopathy" was rarely mentioned, even though a number of participants were reported to have diabetes. Most participants only knew about cataracts and glaucoma. The following excerpt comes from Group 10; Hispanic/Latino, Chicago, IL.

- MOD: Have you ever looked for other information other than having an eye exam? Have you ever looked in a magazine or Internet...library, newspaper? Have you ever specifically looked for information about eyesight or vision?  
MS: Oh no. No...no.  
FS: No.  
MS: No.  
MS: I guess I take it for granted.  
MOD: Okay. Would everybody else agree with that? You take it for granted?  
MS: I think because...in my case because my eyes are good so far, where I don't see the need to do that.
- [MOD: Have any of you ever looked for any information regarding your eyes or your vision?] "I've had no eye problem[s] and no vision [problems]. I haven't found it necessary to inquire." (Group 11; African American; Chicago, IL)
- [MOD: Why do you think we have such a lack of knowledge about eye care?] "It's hard to say because information is out there." (Group 1; Hispanic/Latino, Miami, FL)

- “Well, I recently was looking to find some information about macular degeneration. [MOD: And what is macular degeneration? What did you find out?] I don’t know how to tell you what it is. I mean, it’s degenerate, macular degenerate.” (Group 6; Caucasian, Chicago, IL)
- [MOD: What eye disease do you know about?] “Um, blindness.” [MOD: Well blindness usually results from the eye diseases.] “Don’t know, man.” (Group 14; African American; San Francisco, CA)

The following excerpt comes from Group 10; Hispanic/Latino, Chicago, IL.

- MOD: What kind of eye diseases do they [eye doctors] check for?  
MS: What do you mean?  
MOD: What kind of eye diseases? When you say check for eye diseases...what do you....?  
MS: Glaucoma and diabetes also, but I’ve been told when they see diabetes in your eyes, it’s already too late.  
MOD: Okay. Is glaucoma the only disease you people know about?  
FS: No.  
MS: Cataracts.  
MS: Anything else?  
MS: Macular degeneration.  
MS: Low vision.  
MOD: Low vision? Okay. Anybody heard of low vision before?  
MS: I heard about it, but I’m not too sure. Isn’t that something where you can only see a certain height or something like that? It’s exactly...in other words, your eyes...you can’t see above a certain horizon or something like that?

### **Lack of Publicized Eye Health Information**

Several participants also noted that in the media, there is a lack of information provided about the importance of eye health and increased awareness of eye disease and low vision, especially in comparison to other diseases such as breast cancer. The lack of increased awareness and published information about eye health, for several participants, was reported to affect their prioritization of receiving eye care services. Participants also reported not receiving information via other sources such as PSAs.

The following excerpt comes from Group 10; Hispanic/Latino, Chicago, IL.

- MOD: What feelings do you have about the health care system that might get in the way of you going to an eye doctor?

FS: The system?

MS: Well, maybe the system doesn't make that that important.

MOD: Okay. What do you mean by that Lou?

MS: Well, because we don't see enough of that...like they talk about cholesterol, they talk about all these other illnesses and you never hear them say too much about diabetes. I mean about eyes; that maybe diabetes affects your eyes and so forth and so forth. Ya know.

MOD: Right. Okay.

MS: Maybe that's why you don't get enough information or enough awareness to make you a little bit more cautious or to follow up or check out something like that.

MOD: Do other people agree or disagree with that?

FS: I agree.

MS: I agree.

(EVERYONE SEEMS TO AGREE)

MS: Generally, eye diseases isn't going to kill you like heart disease would kill you...ya know...but just cause you to lose your eyesight...that's all, but not kill you.

MS: Yeah, but that's the attitude.

MS: I know.

MS: Where they're kind of giving you that it's not that important and it is that important.

- "I would also like to see it [eye health information] in the talk show circuit. If Oprah and Dr. Phil had something on eye care, preventing memory loss, hearing loss, you know loss of your limbs, loss of your eyes, people would take notice because it's something that they can believe and trust those sources of information. If it's in Oprah Magazine I tell you, you can change the United States just like that, because she is very influential. Very powerful." (Group 16; Asian, San Francisco, CA)
- [MOD: Have any of you ever seen any kind of public service announcement about eye diseases or eye care, preventive eye care, eye health?] "I was just speaking about that. I mean, for women, there's a lot of those PSAs around, you know, like breast cancer and what not and about self-examination. I kind of remember a PSA, a couple or a few years ago, I don't know which actor who they had talk about [what to do] if you

saw floaters. I guess when she mentioned it, you knew, [you had] floaters or flashes, you should go see your doctor. But that was years ago. (Group 15; Asian, San Francisco, CA)

- [MOD: Have any of you ever heard any messages or advertisements or public service announcements about how to care for your eyes?] “No. Not really...just how to buy frames is about all.” (Group 10; Hispanic/Latino, Chicago, IL)
- [MOD: What do you know about eye health?] “Basically nothing ‘cause nothing ever comes on the TV that talks about any eye disease. [MOD: Nothing about eyes.] “Or on the radio. Ever. Unless they pushin’ drugs, they’ll tell you about that.” (Group 14; African American, San Francisco, CA)
- [MOD: So have any of you ever heard any advertisements on how to take care of your eyes?] “No, never.” (Group 8; Asian, Chicago, IL)

The following excerpt comes from Group 5; Caucasian, Chicago, IL.

- MOD: What else would you like to know about eye health?  
FS: Put a spot on television, things like the heart and cancer society and things do.  
MS: And arthritis.  
FS: Yeah, all these foundations, they give you information and a real snap shot on television and radio.  
MOD: Have any of you ever seen any public service announcements about any eye diseases or eye care?  
FS: No.  
MS: Never.

### **3. Communication**

Communication was reported to be a very important component of doctor and patient interactions. Communication was not reported as frequently to influence the receipt of eye care as some of the other researched variables such as attitude and culture. However, communication seemed to be a critical factor that influences whether one has a pleasant or unpleasant experience and attitude about seeing an eye care professional or primary care physician. The majority of participants said that their level of comfort in communicating with their primary care physician or eye doctor was good, very good, or excellent, and that they have a good relationship with their doctor.

The following excerpt comes from Group 18; Hispanic/Latino; San Francisco, CA.

- FS: Okay.
- MOD: What do you mean by okay?
- FS: I have good communication. I can ask things and they will explain to me what is going on or what the medication [is] that they prescribed to me. And I can talk to him about what communication. I've seen him for awhile.
- MOD: Others?
- FS: I have a pretty good relationship with my ophthalmologist and I've been seeing him for 20 years. In terms of my primary, they are unaware of what I do and have never -- the different primary doctors I've had over the years, they've never so much as asked about my vision. I don't even look at it as something that they need to deal with. I take care of it myself.
- MOD: But let's talk about communication, period. What's your level of comfort with communication?
- FS: Oh, it would be fine if I had an issue or something to bring up. But I would probably just go directly to my ophthalmologist. I wouldn't even talk to my primary care physician.
- MOD: I'm talking about for any medical condition.
- FS: Good.

Despite the overall high level of comfort in communicating with providers, many participants shared examples of poor or hampered communication with their providers, which left them frustrated and, in some cases, hesitant to seek followup care. In some examples, improved communication between providers and patients would lead to more followup care and receipt of eye care services. Discussions about communication did not seem to vary based on either race/ethnicity or location of the focus group. The following descriptions illustrate how poor communication between patients and providers negatively impacted beliefs and attitudes about receiving health care services such as eye care.

## **Time**

Generally speaking, a number of participants stated that their overall communication with providers was good, however a number of those participants also imparted negative aspects about their communication with providers. One aspect that was mentioned several times that hampered the level of communication between patients

and providers was time. Participants noted that they do not have a sufficient amount of time to spend with their providers to ask all of the questions that they might have.

- “I think it’s good, but I always feel like there’s just -- everybody is so rushed. You’re like -- boy, you’ve got to get in and out. I don’t think that you have enough time. [MOD: And how does that affect the communication with your doctor?] Well, I think there isn’t much communication with my doctor. Because I sense that there is just not enough time.” (Group 17; Hispanic/Latino; San Francisco, CA)
- “I think a lot of times, particularly with the HMOs and all these healthy maintenance programs, doctors in general don’t allow a sufficient amount of time for each patient.” (Group 4; African American; Miami, FL)
- “It seems like their time is so limited with you. And a lot of times, I’ll have a lot more time with the med tech who is sitting -- they sit there and take down my information on what is wrong with me. And then the doctor comes whizzing in and reads what the med tech wrote. But I have a lot more time with the med tech. But I’ll ask them a question, and they’ll say “I don’t know; you’ll have to ask the doctor.” And then you’ll ask the doctor and it’s like -- doesn’t speak my language. Or they tend to be a little evasive or beat around it. They don’t give it direct. Like for example, if you have a certain disease they tell you that this is the disease you have and this is how we treat that disease. But the question is, I’m not asking how you treat the disease; how are you going to treat me? Because I’m the one who has the disease. So we know how the disease is treated, but how am I going to be treated. Because what works for one person isn’t going to work for me.” (Group 18; Hispanic/Latino; San Francisco, CA)
- “I feel like I actually get to see my doctor for a very brief time. And I see the billing people the longest, ha, ha. They want to make sure they get your money. And then I see like the med tech, and then I see afterwards a person that prescribes or takes care of prescribing the medicine. And the doctor comes in and whizzes in so fast or whizzes out, that I’m trying to think of all these questions I need to ask him because he’s in and out so quick, and then I’m like “Oh, that question!” And then I say “Can I ask the doctor another question?” And they’re like “Sorry, he’s with another patient.” (Group 18; Hispanic/Latino; San Francisco, CA)

The following excerpt comes from Group 7; Asian, Chicago, IL.

- FS: I think they normally just limit the number of minutes you can be there. Because like, they have patients in different rooms waiting for them. Ten minutes for you, 10 minutes for that person, you know.
- MS: I never let them go away. (laughter) I don’t.
- MOD: Sounds like you force them to communicate with you.

MS: Absolutely. I mean, I'm there to see a doctor, I want some answers and I want to know what's going on. I mean, they're not going to rush me out. If they do then I go to another doctor. That's exactly what I do. I did have a doctor that did that. Used to rush me out just like that and come in, never used to sit down with me, now I have a doctor that sits down with me and tells me everything that I want to know.

- "I think a lot of it depends on the doctor itself. I've had, I've moved several times in the last few years so I've had several different primary care physicians. And I had one that was fabulous, he was in the city and he was great and I could talk to him about anything and ask him anything and he would spend as much time as needed to answer the questions. But I have a doctor now for example, that I can ask him anything, but he just doesn't take the time to explain it the way I need to understand what's going on. He gives me a little answer, for him that's sufficient. For me, I may still need some more clarification. Even though I may ask for it, I may not receive it. So I don't have a problem asking the questions but I, for some reason, certain doctors have a problem getting an answer, so that's frustrating. (Group 20; Caucasian; San Francisco, CA)

### **Tell Me What's Wrong With Me! – Asking Questions**

The previous excerpt speaks to an emerging trend in health care, that is, the need for participants to be fully informed and knowledgeable about what is happening to their bodies and their health. Many participants commented about this need and noted difficulty in obtaining information about what is happening to them when communicating with their providers.

- "I have an infection right now, and the...I went back to the...it is a clinic that you can go to, and this particular doctor that I had, he just took one look at my eyes and says, well, you don't have glaucoma or you don't have any...what they call a thin film something over their eyes? He just gave me a eye drop to put in. So now all I do is just use that eye drop. I don't have to even have to go back to the doctor. I mean, he didn't tell me what was wrong with me, why I break out with it. So, I mean, I just want to go get some glasses and call it a day." (Group 11; African American; Chicago, IL)
- "I'm a person that asks a lot of questions whenever I go visit the doctor. I want to know what this is for, why, what's that do for me? But sometimes doctors make you feel uncomfortable. They think, they make me feel like I'm asking too many questions. If I get that reaction I just go to another doctor." (Group 7; Asian; Chicago, IL)
- "I have a good relationship with my doctor, but not with the eye doctor because the eye doctors don't really tell you nothing, they just do the vision and examine your



eyes and stuff. But most times they don't hardly talk to you to tell you what's really going on with your eyes." (Group 4; African American; Miami, FL)

- "I changed doctors for my daughter when she became diabetic because she...this man made me feel like I was not important in my daughter's life when he was trying to take care of her diabetes and I had questions and I started to ask the questions, he stopped me and he said not now. I need to talk to your daughter and I said, I have questions, so from that point on, I went home and I said I don't want this man to be your doctor and I made sure that I called him the next time. I said I'm not coming to your office. I don't want you taking care of my daughter because of the way you made me feel in your office in front of my daughter. You stopped me from asking questions. I know nothing about diabetes, I want to learn and you...and so he said is there anything that I can do to improve myself, and I said you have to learn to treat people like human." (Group 9; Hispanic/Latino, Chicago, IL)

The following excerpt comes from Group 4; African American, Miami, FL.

- MOD: What do others think about the level of communication or the level of comfort in that communication?  
FS: My doctor's ... well, both of my doctors are good. The only thing is my ophthalmologist or optometrist or whatever it is, I have to ask him what's going on. I mean, he dilates my eyes and does all that stuff. And then he'll just prescribe me a prescription for this thing or that thing, you know to put eye drops or something. What's going on? What are you looking for? Tell me what you're looking for?  
MOD: Does he respond?  
FS: Kind of, sort of. Yeah, he pretty near responds. He don't tell me everything.  
MOD: How do you know he's not telling you everything?  
FS: Because ... well, I'm not comfortable with what he tells me.  
MOD: Okay. So the level of comfort's not that great.  
FS: Right.

## Sharing Information

On the other hand, positive attitudes about receiving eye and/or health care services are witnessed when the participants report that their providers communicate with them and share information with them about their health in a way that they can understand and take the time to answer any questions that they might have.

- “My optometrist takes his time and sometimes it’s like why are we sitting here so long. The whole time he’s there he’s asking questions, answering questions but he’s asking questions I never even think to ask. So I think he’s pretty thorough.” (Group 20; Caucasian, San Francisco, CA)
- “In my case since I go for a comprehensive checkup, I have no complaints. It’s great. They do a battery of tests. And I pretty much I’m very satisfied with their response. And any questions that I ask, they’re always ready to. I feel comfortable with the answers that they give me. I’m happy with that.” (Group 1; Hispanic; Miami, FL)
- “My doctor is great. I can learn anything; I’m very comfortable talking with her. She always answers my questions and she gives me information.” (Group 20; Caucasian, San Francisco, CA)

The following excerpt comes from Group 17; Hispanic/Latino, San Francisco, CA.

- MOD: How is your level of communication with your doctor?  
FS: I’d say a nine, something like that.  
MOD: So what does a nine mean for you?  
MS: Everything I’ve ever asked has been answered. She’s provided a lot of information. Nothing on eyes though -- I’ve never brought that up. Maybe I should have. Next time I go, I’m going to ask.  
MS: I’d say a ten, because I ask a lot of questions.

### **Explaining Health Information**

When doctors do share health information, the majority of participants felt good about the way their medical care provider explained that health information to them. A few participants did report that they have difficulty understanding medical terminology. These participants were of minority racial and ethnic decent, but primarily from African American and Hispanic/Latino backgrounds. In those cases, participants reported that they ask more questions to seek clarity on the health information that was provided to them. However, the ability to clarify and understand medical terminology is hindered because, as stated before, many participants are not afforded the time to have all of their questions answered. The following excerpt comes from Group 3; African American, Miami, FL.

- MOD: How well do you understand your medical care provider?  
MS: These doctors, man, they don’t speak the same language as the layman does.  
MOD: What do you mean?

- MS: I mean, how many of us at this table understand medical terminology?
- FS: That's where you get your books? They have medical books.
- MS: I know that when you walk in the door. (chattering)
- MOD: Hold on, let's make sure we keep one at a time, because otherwise we get garbled on the tape.
- MS: I'm just saying, if the doctor has any sensitivity, he's going to understand that you have not been to Harvard School of Medicine. He's going to speak to you in a way that you can understand what he's trying to tell you. Even though, even though you are supposed to ask the questions that's entirely right. But now listen, if you don't have a doctor that's coming forth, with that, at least that, that's minimum consideration, then you are probably in the wrong place.
- MS: I know, for me, if I ask a doctor a question, he answers me and I don't understand it, I mean, it was Spanish to me, I'm going to ask him again. I'm going to ask him until he tells me how I can understand. After two or three times. Let me put it to you like this.
- FS: And that's breaking it down to the lowest terms. Don't give me these huge medical words. I didn't get a degree in medical [care]. Break it down to me one, two, and three. What is this? What is the problem? I want to know.
- MOD: Okay. Any other thoughts on that?
- MS: Well, some people don't like to seem I don't want to say, dumb. They don't like to seem like they don't know. But that goes both ways, if I ask my doctor something and he tells me in those terms and I don't understand, I need to know so that's why I ask. Because in my field of occupation, he can ask me some question and I can say something to him and he won't understand.
- "Me, sometimes I don't understand the doctor['s] language." (Group 8; Asian, Chicago, IL)
  - "And you have to ask questions, because the terminology they use sometimes is just -- over your head. They have to simplify these things." (Group 17; Hispanic/Latino, San Francisco, CA)
  - "Sometimes I understand it and sometimes I don't. And then sometimes you tell me things I don't wanna hear." (Group 14; African American, San Francisco, CA)
  - "You have to ask questions. You have to ask "Well, can you put that in layman's language?" You have to ask questions. Because if you don't, they're busy themselves. I'm not taking that away. They are busy, but you have to ask questions." (Group 17; Hispanic/Latino, San Francisco, CA)

## Language

Another aspect of communication that impacts the level of understanding that patients and participants have about their health is language. Language is a major aspect of communication that influences the receipt of eye and/or health care services. Language was reported to be an issue primarily among Hispanic/Latino and Asian groups, but moreso among Hispanics/Latino groups. Participants also mentioned that for people who do not speak English well, the quality of care received is also impacted. Using children as interpreters to alleviate communication gaps was noted to be an imperfect solution with negative consequences.

- [MOD: Okay, okay. And what about, say, the older generations? Do they have any fears or beliefs that stop them from going to see the doctor?] “Yeah, since they can’t speak English.” (Group 15; Asian; San Francisco, CA)
- [MOD: Do you perceive the healthcare system to be culturally insensitive at all?] “In the language.” (Group 9; Hispanic/Latino; Chicago, IL)

The following excerpt comes from Group 17; Hispanic/Latino, San Francisco, CA.

- MOD: Okay. Do you perceive doctors to be culturally insensitive or discriminating in terms of their attitudes or perceptions?  
FS: Some of them.  
MOD: In what way?  
FS: If a person doesn’t speak the language, a lot of times they don’t really take the time to let me come in. I can tell you from my experience with my husband, I ask if I can be in the room and she says, “No, I want you to stay out.” I said, “Well, I want to explain what his ailments are.” So after I heard him say “ouch” a couple of times, they called me back in. So it’s like a lot of times, they don’t really care -- it’s certain people. And I don’t feel that it’s prejudice either, okay? Because I never felt that anybody had been down on me. But on my husband, because he looks very Spanish and very dark, it’s like he wasn’t getting the proper treatment, I thought.

The following excerpt comes from Group 9; Hispanic/Latino; Chicago, IL.

- FS: You see it all over the place.  
MOD: You see what all over the place?

FS: Hispanic people that do not speak English and they always have to have some kind of interpreter or they just can't...sometimes they can speak, but they can't...

MOD: ...express themselves.

FS: ...express themselves. Thank you.

MOD: But do you think that affects the type of treatment that you would receive? I mean you said that the doctor may have perceived her...if she may have been someone who may have been new to the country and may not speak English fluently that the doctor may have treated her differently?

FS: I think so.

- "They need [an] interpreter for the simple reason when some people don't have anyone to go with them or else they'll take their minors...their children. The children translate incorrectly and not knowing medical terms it could be very confusing and very dangerous by telling the person that doesn't speak English, giving them the wrong diagnosis or telling the wrong thing that the doctor has not said. [MOD:Okay.] You know there has been a lot of misinterpretations to that effect." (Group 9; Hispanic/Latino; Chicago, IL)
- "I saw before...in doctor's office I saw people try to contact with the physician, but the physician sometimes they don't speak Spanish, so and then, sometime the people...the Hispanic people don't take some interpreter and they confusing because once in a while the physician don't have an interpreter, either. So then they confuse and then the physician try to explain in Spanish, but it's not really going well and I think that the patient can't really understand really well. So I think physicians once in a while need to have an interpreter in the office." (Group 9; Hispanic/Latino; Chicago, IL)

#### **4. Culture**

Issues related to culture were noted in fewer groups relative to attitudes and knowledge. Several aspects of culture were found to influence attitudes, and culture did have some degree of influence over whether participants received eye care or not. In the majority of discussions when asked, "Are there any cultural or family values that get in the way of your going to the eye doctor?" or "Are there any folk beliefs, religious beliefs, beliefs in fatalism, or gender roles that affect your receiving medical care?" the majority of participants said, "No." However, several themes with cultural implications did arise relating to the use of preventive medicine and the use of alternative remedies that influence the receipt of eye care services.

## Traditional, Folk, and Home Remedies

Although general concepts about culture did not seem to influence the receipt of eye care services, many traditional, folk, or home remedies were reported by participants, which they use first when they experience problems with their eyes. In the majority of cases, this is all the care that they receive as they have found that these remedies cure any ailments they are experiencing with their eyes. In other examples of home remedies, particularly among the Asian groups, participants noted that their parent's generation primarily used the remedies that they described and that they have stopped passing them down; although they do believe in home remedies. The majority of the remedies were discussed in the Miami, FL, and Chicago, IL, African American focus groups, although Hispanic/Latino, Asian, and Caucasian groups did offer remedies, as well. The following excerpt comes from Group 11; African American, Chicago, IL.

- MOD: Are there any home remedies that you've heard of for different eye things, different eye conditions or diseases?  
MS: I heard somebody say cucumber.  
FS: I heard to use warm milk in the eyes.  
MOD: Warm milk. For what?  
FS: Warm milk in your eyes, relaxes the eyes. That is a remedy from way back.  
MOD: And for what kind of problems?  
FS: You know before they had all this research and new technologies when they had cataracts a lot of the people back in the day used drops of warm milk to help relax the eyes. And maybe people thought that it would take that skin, that covering from over the eyes. Because as you hear people take milk baths and things that like. It tenderizes the skin? Well, a lot of people felt that that tenderizing, that feeling that was over the eyes because the feeling was just like the skin on sausage or something, in essence, and they felt that that would tenderize that as, you know, that would break it up, that's the way they felt with the warm milk.  
MOD: Any other kind of remedies like that?  
MS: Tea bags.  
MOD: Tea bags for what?  
MS: A lot of people get sties on their eyelid. And warm teabags on the eye reduces the swelling or something.  
FS: A white potato.

MOD: White potato? For what?

FS: Well, my father-in-law told me that he gets boils I think on his eyes, he always has. And he takes the white potato, cuts it in half and he puts it in a white cloth, and he puts it on there and it takes it away, draws the poison in.

- “I take my glasses off. Sometimes to rest my eyes. Or I use a technique called palming where you lay your palms, your hands, on your eyes. And it’s supposed to help your eyes rest, relax and heal.” (Group 6; Caucasian; Chicago, IL)

The following excerpt comes from Group 4; African American; Miami, FL, and was not mentioned by any other African American or other racial/ethnic groups. The following remedy was used to cure pink eye.

- MOD: Now I heard something over here that I had never heard before.

FS: It’s true.

MOD: Well, tell me again.

FS: Yeah, I’ve heard that.

MOD: Hold on, hold on, one person at a time. I’m going to let William go first because he brought it up.

MS: I tried it and it worked for me.

MOD: Well, tell me. What worked for you?

MS: I pissed in the cup and I got my hand on it and put it on my eye and I started kind of seeing a little bit. So I didn’t go to the doctor.

MOD: Who else has heard that?

FS: I heard it.

FS: I heard it for babies.

FS: That’s true.

MOD: What’s true?

FS: That you use the urine. Actually they say the first urine after you get up in the morning you use it and wash your eyes with it. You can do it for babies too. You can use their pampers, the diapers, and wipe their eyes. Like they have cold in their eyes or something like that, it clears it up.

MS: I heard, but I didn’t know that people actually did that.

FS: I’ve done it to my kids.

MOD: Now I’m hearing people say that they’ve done it and it works.

FS: Yes, I did it for my kids.

MOD: Okay. Reginald?

MS: I've heard it. I believe in it. I heard about it, you know. Like they said, that's a tradition for black people. You know what I mean? It goes back.

FS: You couldn't even have a doctor.

MS: You really had to hurt before you'd go.

MS: Yeah, yeah.

MOD: When you say really got to hurt, what do you mean, William?

MS: Like you can't see. It just hurt. Time to go to the doctor.

FS: It hurts real bad.

The following excerpt comes from Group 8; Asian, Chicago, IL; and was not mentioned by any other Asian or other racial/ethnic groups.

- MOD: Are there any home remedies that you've heard of for different eye things, different eye conditions or diseases?
- FS: I mean, green stuff is good for eyesight.
- MOD: When you say green stuff, what do you mean?
- FS: Trees and grasses, sometimes go out to the park.
- MOD: So you say look at a lot of live green stuff, it sounds, like trees, grass.
- FS: Sometimes for 15 minute[s], 20 minute[s].
- MS: Who told you that?
- FS: My teacher.
- MOD: Has anybody else ever heard that?
- MS: (Agreement in the group.)
- FS: When we are young we have the eye exercise.
- FS: Yeah. I do it.
- FS: In China it's called... we drink some medicine [to] care for eyes.
- MOD: And what is that medicine, do you know?
- FS: I don't know. Just that the doctor knows that he give you that.
- MOD: Okay, you said in China, what about here in America? Have you done that in America?
- FS: No, I just relax.
- "We try to use the natural stuff. Like using coffee when you got pink eye... [MOD: Wait a minute! Coffee?"] Coffee. Yeah. They say that when you get either...not pink



eye, but when you...that's what it is. When your eye gets stuck together, when you wake up in the morning, you have all that yellow stuff there...you take black coffee and...cold black coffee and wipe it down and little by little it goes away. [MOD: Now are you talking about the coffee grinds or actual brewed coffee?] All brewed...yeah." (Group 10; Hispanic/Latino; Chicago, IL)

- "The only thing that they do is like for sties in Puerto Rico, they take a ring and they do this friction really really hard and it's kind of warm and they put it on the eye. [MOD: Take a ring? What kind of ring?] Any ring. Rub it on you. Make it hot." (Group 10; Hispanic/Latino; Chicago, IL)
- "Things start to degenerate unless you make specific efforts to help improve sight. I take these tablets for strengthening your eyes. [MOD: What is that?] Bilberry." (Group 20; Caucasian; San Francisco, CA)

### **Lack of Preventive Medicine**

Among some of the Hispanic/Latino focus groups, it was noted that within the Hispanic/Latino community, preventive medicine is not practiced as it should be. Participants also mentioned that Hispanics/Latinos and African Americans will not go to the doctor unless their condition is really bad. This, in turn, has great influence on whether preventive eye care is received or not. Also mentioned to be a factor that influences whether care is sought by Hispanic/Latino groups is being too proud to let others around you know that your health is ailing.

- "I think that's a bad thing about I think with the Hispanic communities. Like we don't use preventive medicine. We just...when we have a problem, then we run to the doctor for the doctor to try to do something for us." (Group 10; Hispanic/Latino; Chicago, IL)
- "You have to be in really, really bad condition, then maybe you are going to go out and see the doctor." (Group 10; Hispanic/Latino; Chicago, IL)
- "You really had to hurt before you'd go. Yeah, yeah. [MOD: When you say really got to hurt, what do you mean, William?] Like you can't see. It just hurt. Time to go to the doctor. It hurts real bad." (Group 4; African American; Miami, FL)
- "You will be really proud. There are people that have eye problems, but they don't go to their doctor because they want to keep showing people that I don't need glasses." (Group 10; Hispanic/Latino; Chicago, IL)
- "If they are feeling okay, people feel, why should I go to a doctor? I'm alright! But once they feel something...if they are not scared they will go, but if they are scared, they will also, you know...not want to go." (Group 10; Hispanic/Latino; Chicago, IL)

The following excerpt comes from Group 9; Hispanic/Latino, Chicago, IL.

- FS: A lot of Spanish people won't go to an eye doctor, not unless it's really bad.
- MOD: And why is that? That kind of goes against the grain because everybody in here says they go all the time.
- FS: It's true. They are stubborn.
- MOD: Hold up. Hold up. So this is important for me to hear; I need to understand this part of it, so what were you saying, Diane?
- FS: Oh, I'm just saying it's true. A lot of old Hispanic people are stubborn and they don't need a doctor. They don't have to see a doctor, so yes.
- MOD: Why do they say that though? Why do they feel they don't need to see a doctor?
- FS: Because they feel they are their own doctor.
- MOD: Okay.
- FS: Nobody knows better than what they know.
- MS: You got the home remedies.
- FS: I can fix this.
- MOD: Oh really. When you say home remedies, what do you mean?
- FS: Tears.
- MS: Kind of weeds and stuff...they smoke 'em or do something with them.
- MS: Voodoo...
- FS: ... we are talking about the generation before me. They were older...like they probably could...they drink some kind of...you know there is a lot of remedies.
- FS: ...herbal medicine that you like drink your blood or something like that, ya know?

### **Wash Your Eye Out/ Wait and See**

In one of the African American focus groups in Miami, it was noted that a lot of people would just wash their eye out and hope for the best when experiencing problems with their eyesight, as opposed to visiting an eye care professional. It was also mentioned among some of the African American participants in Miami that they would just wait and see if their eye problems cleared up before contacting their primary care physician or eye doctor. This waiting also seemed to influence the receipt of eye care as many of

these participants found that acting in this manner was beneficial. The following excerpt comes from Group 4; African American, Miami, and highlights discussion about washing the eye out.

- FS: I think culturally you might find a lot of people that just wash their eye out and hope for the best.  
MOD: Now when you say culturally, what do you mean, Vincent?  
MS: Black folks.  
MOD: Talk to me about that a little bit. What do you mean by that?  
MS: That's what you hear from your mother, your aunt, the elderly "doctors" in the family. Wash it out. With any injury you wash it and then hope for the best. Then maybe upgrade with eye drops or something if it still doesn't go away. But immediately go in and seek professional care, no, that's not important.  
MOD: Now when you say culturally is that something that ... I mean, where does that come from? First of all, does anybody else agree with that?  
MS: Yes.  
FS: Yes.
- [MOD: What would you do if you had problems with your sight? Would you cope?] "Sometimes you just have to roll with things, you can't go over to the doctor every time something happens, so sometimes you gotta man up. You know, just take it. I live usually by the theory, the theory of threes with me, you know. It's like, you get one thing wrong, you're fine. You get something else, you're having a bad day. You get a third thing, now you're hurtin'. You know?" (Group 14; African American, San Francisco, CA)

The following excerpt also comes from Group 4; African American, Miami, FL.; and highlights discussion about waiting to see what happens before seeing an eye care professional.

- MOD: You mentioned something earlier. What was it you said earlier about people going to the eye doctor?  
MS: Your prior generation would tell you to wash it and see what happens.  
MS: I think also along with that is a lot of times growing up, I know me when I was a kid, I had so many falls and accidents and all that. You always wait to see what's going to happen, for a period of time, before you go to the doctor. The eye, if we got hit in the eye, when there were fights and all that other stuff, or falling out of a tree, you wait a while to see what's going to happen. That's what we were ...  
MOD: When you say we, who do you mean we?

MS: In my family. Neighborhood kids. We would wait and see what's going to happen.

MOD: Would anybody else agree with that?

MS: Yes.

MS: Yeah, I agree.

FS: Yes.

MOD: Are there other things along that line that affect you going to the eye doctor?

FS: Sometimes they'll be red and you put the eye medicine in it. By the next day it be cleared up, so ...

FS: You don't go.

MOD: When you say put the medicine in, what kind of medicine are you talking about?

FS: Eye drops.

FS: Visine.

## Gender

In one of the African American focus groups in Miami, it was noted that many people do not go to the doctor because they're afraid of hearing bad news. It was also noted that this sentiment is more prevalent among African American males, although it was present in other cultures studied. Participants stated that it is difficult to receive negative information about one's health because it leads one to be dependent on others to do things if one has always been the "strong black male." Denial about health conditions by males was also discussed in one of the Caucasian groups in San Francisco. The following excerpt comes from Group 4; African American, Miami, FL.

- MOD: Are there any other barriers to people going to... We heard people talk about economics, access to doctors.
- MS: Some people, they don't go because they might hear some bad news. And they don't want to hear it.
- MOD: So that's another one of those myths. What do you mean by that, Vincent?
- FS: What I don't hear won't hurt me.
- MS: If I go for a pain in my right side you may say it's liver cancer. I don't want to hear it. I just stay home.
- MOD: How prevalent is that belief?

MS: A lot. (Cross talk)

MOD: Who's heard that?

FS: It's probably more prevalent with men.

MS: I do it myself to some degree. I think most males.

FS: Yes. (Cross talk)

FS: My husband is like that. (Cross talk)

MS: A man isn't going to go.

MOD: Why is that? (Cross talk) Like I said I'm from the North. You guys help me understand this.

MS: A lot of men are scared because they don't want no woman to examine them and stuff like that. Then if they have a male doctor they don't want the male doctor examining them. So they're just not comfortable with nobody touching them.

MOD: But that's different than from what William and Reginald are saying. What Vincent said was that people would not go to the doctors because they're afraid of hearing something, some bad news. That goes back to the question that I asked you about if you knew that your doctor was going to tell you that you are going blind or your sight was getting worse, would you go? Everybody said that they would go. Now you're telling me something different. So which is it? (Cross talk)

MS: The black males, older black males particularly that I know and I know what happened with them with prostate cancer and whatever happened, when the doctor tells you or gives you a bad diagnosis. All of a sudden, you must be dependent on others to do things for you when you were always the strong black male in the family...Now you must depend on other people.

MOD: Hold on for a minute. But help me understand how not going to the doctor makes that any different.

MS: You are avoiding the issue. You don't have to deal with it.

MOD: Clarify that for me. I'm just playing devil's advocate. I want you to clarify that for me. I'm not quite understanding how not going to the doctor makes that situation any different.

MS: The doctor when he gives you the diagnosis he's making it official. You know that something is wrong with you. You can feel that pain, you are secretly taking some medicine or something like that. You know if the pain won't go away, it's chronic, so they are avoiding it. If I go to the doctor, he's going to make it official. He's going to tell me what it is. The lab report is going to come in, whatever, X-rays. He's going to make it official. Then he's

going to have a consultation with the family and now they're going to come around you and not going to let you do this and not going to let you do that.

MS: People just hate to hear bad news. That's all.

MS: I think also in terms of when you mentioned earlier that a lot of us, when you said if you knew that you were going blind, would you go? I think that as a male, you go only because you think he can resolve the issue. If he can't do nothing to help me, if you can't stop me from going blind, then I don't need to go. I'm not going to sit up there if you can't do anything for me. Now if I'm going there, I'm expecting you to put me back to where I was. Once it's determined that you can't do that, and having to face the fact, then it's like a total destruction of who you are as a person.

The following excerpt comes from Group 4; Hispanic/Latino, San Francisco, CA.

- MS: Most men won't go to the doctor.
- MOD: What do you mean that most men won't go to a doctor?
- MS: They just don't. I know several guys -- they just don't want to.
- FS: They are afraid.
- MS: They are afraid, and it's not macho, whatever. You always have these things. And if you have an illness, you're a disabled person and nobody wants that.
- MOD: Why would they be afraid?
- FS: Because they are afraid -- they want to be the head of the family -- this is what I think. They are afraid that if they are sick and if they are told to stay home, then who is going to bring in the money?
- MS: I think it's more than that.
- MOD: Let her --
- FS: I think that's my opinion. They want to be like the ones that are the leader of the gang. And if they are sick and if they are in bed and if the doctor says they have to rest, have to do this and have to do that, they feel that they're going to die once they are in bed. So at least that's what I see from my experience. They don't want you to be out. And also, they are big babies.
- MS: Hey, hey.

## Discrimination, Bias, and Insensitivity

Typically, one factor that would influence the receipt of care, particularly by racial and ethnic minorities, are perceptions of discrimination and insensitivity by doctors and/or the health care system. Many participants reported that they do not find doctors or the health care system to be culturally insensitive or discriminating, although undertones of discrimination and bias are present in several of the included statements made by participants. This stance was particularly true among Caucasian and most Asian participants. It also should be noted that although most participants did not find doctors and the health care system to be racially insensitive and discriminating, they did find doctors and the health care system to be insensitive and discriminating in other areas, which will be discussed later.

- “I think cultural insensitivity is something that’s part and parcel of what the doctor has already had before medical school. I don’t really believe that a doctor is culturally insensitive because of his experiences. I believe that they carry that same baggage from their childhood and in a population, you take 100 people and 50 of them were doctors and 50 of them were just regular folks, I think you would find that same degree of cultural insensitivity between the two.” (Group 19; Caucasian; San Francisco, CA)
- [MOD: Okay. Do you perceive doctors to be culturally insensitive or discriminating in terms of their attitudes or perceptions?] “Some of them. [MOD: In what way?] If a person doesn't speak the language, a lot of times they don't really take the time to let me come in. I can tell you from my experience with my husband, I ask if I can be in the room and she says, "No, I want you to stay out." I said, "Well, I want to explain what his ailments are." So after I heard him say "ouch" a couple of times, they called me back in. So it's like a lot of times, they don't really care -- it's certain people. And I don't feel that it's prejudice either, okay? Because I never felt that anybody had been down on me. But on my husband, because he looks very Spanish and very dark, it's like he wasn't getting the proper treatment, I thought.” (Group 17; Hispanic/Latino; San Francisco, CA.)
- “That could be something very subtle times. And it also depends, you know, how long you have been in this country, I’m an immigrant, so and sometimes when you are new to this country and you don’t understand exactly and so then it is much more difficult. And you feel that way that the doctor is actually in his own culture and does not communicate with you the way you’re used to. And that of course as the years go by, things change because you get used to the culture. So comes also it can be something very subtle. The doctor is in a culture that you’re not always completely aware but you sense a bit of something.” (Group 20; Caucasian; San Francisco, CA.)

- [MOD: Do you perceive the health care system to be culturally insensitive or discriminating?] “Not from my own experience I don’t see it. No.” [Okay.] “Me neither.” (Group 10; Hispanic/Latino; Chicago, IL)
- [MOD: Do you perceive the health care system to be culturally insensitive or discriminating?] “My doctor is Chinese.” “My doctor is Asian, also.” “Mine is Japanese.” [MOD: Okay. But for doctors overall?] “No.” (Group 15; Asian; San Francisco, CA)

The following excerpt comes from Group 4; African American, Miami, FL.

- MOD: Okay. Were you going to say something, Samuel?
- MS: I just wondered how much of this is culture, because one of the things that I look at is how many Black optometrists or ophthalmologists do we know of? We can always find a Black doctor or we can always find an old Black midwife or someone in the community who can help us with our physical part of it. But when it comes to our eyes how many of us really know those types of Black doctors? Even now we go and most of them are some White guy or young White female and that’s just one of those things that we just have not had access to on a regular basis [Black doctors], especially in our communities.
- FS: But it really shouldn’t matter who looks at your eyes, regardless of the color of the person, it doesn’t matter as long as you go.
- MOD: How does that affect the willingness to go to the doctor?
- MS: It’s a Southern tradition, okay. In a Southern tradition, you look and a lot of times you just didn’t trust what they were actually doing to us. So we don’t know what their motivation may have been. So there may have always been someone who looked similar to us or someone who had a proven track record in our community and they did all the health caring. But when it comes to the eyes, that has not always been the case. And I think that’s one of the reasons why we may be more adamant about basic health care and not about eye care, due to those type of situations.
- FS: My eye doctor, she’s an African American.



The following excerpt comes from Group 11; African American, Miami, FL.

- MOD: Do you perceive doctors to be culturally insensitive or discriminating?  
MS: Not where I go.  
MOD: What were you saying, Harry?  
MS: Sometimes.  
MOD: And what do you mean sometimes?  
MS: Sometimes there are doctors and hospitals who don't approach individuals as patients but as people who they are prejudiced, for lack of a better word I'll say prejudiced. You can go into a hospital and a certain doctor or some doctors will give you the short end of what's one over there for. And it's bad. When you go to a hospital and you get a doctor for whatever reason who has a prejudice against you, and you're in for a medical reason, this is bad.

## 5. Other Factors

### Cost

A major factor not related to the Theory of Reasoned Action, but of great concern and reported to be a major influence in the receipt of eye care, is cost. In every focus group, cost was reported to be a factor that got in the way of participants receiving eye care services, as well as required followup services, such as prescriptions. Many participants spoke of how expensive it is to receive many eye care services. Cost was reported to influence the receipt of eye care by participants from each of the four racial/ethnic groups and three cities. The following excerpt comes from Group 4; African American, Miami, FL.

- MOD: What gets in the way of you receiving eye care services? Don't get quiet on me now.  
MS: First thing is going to be economics.  
MOD: When you say economics, what do you mean?  
MS: Most insurances don't provide anything but a 10 or 15 dollar discount on your prescription lenses or whatever you do. It's not like a health plan where you can go in and know what your co-payment or your deductible is up front. With the eyes, you go in there, you don't know what type of cost it's

going to be. So it's frustrating to go in there and all of a sudden you got a \$400 bill that you can't even pay. And then you walk out of there with no medical ... you had the attention, but you don't have the equipment now to get the needs.

MOD: And how does that affect your attitudes or beliefs about eye care?

FS: If you don't know that you have a problem, you don't have to worry about it. But if you go and get the exam and don't have the ability to pay for the exam or the glasses it's a very demeaning...it can be a very demeaning feeling.

MS: And you compound that with other economic things that you may be already facing, now you got another bill on your mind.

FS: Right.

MS: Nobody needs that stress.

- [MOD: What gets in the way of receiving eye care services?] "Well, for me it's money. [MOD: In what way?] Well, I don't have a lot of money. So I'm just going to a doctor just for a general checkup." (Group 6; Caucasian; Chicago, IL)
- "I teach special education and I have like 10 kids...they have a lot of problems with their eyes and there is no way those poor kids...and I tried to see if I can find somebody to provide glasses for those kids and I can't. And those kids are sitting in the front of the blackboard like this [squinting] because they cannot see and it's not a light issue or anything. The parents cannot afford it and it's no way you can go and say okay can these kids get glasses you know because it cost a lot of money. They have an eye and vision lady who go and do screening, but the problem is when they need glasses, who is going to pay for the glasses? Some of those parents cannot afford \$75 for a pair of glasses. So, yeah, they say you need glasses, but where you going to get it? Are you going to buy? I mean it got to the point that I bought glasses for a couple of my students. (Group 10; Hispanic/Latino; Chicago, IL)
- "You know there are people who actually cannot get any kind of care whether eye care or not, because of their financial situation... and even people in HMOs, I mean the prices keep going up so that's a major issue and poor people are suffering because they've got naught." (Group 3; African American; Miami, FL)
- "Today, I know various people in Chinatown still. There are a lot of people that are not aware of certain services. They're afraid and says, "I don't have any money. I'm a poor immigrant." They won't go and see something when, unless somebody says, "oh, there's this free clinic," or the Chinese health care services or whatever it is "will see you because you're a senior citizen and they won't charge you." Because they're terrified that it's gonna cost them something." (Group 15; Asian; San Francisco, CA)

## Insurance Coverage

Another factor related to cost that influences the receipt of eye care reported by focus group participants was insurance coverage. Many participants discussed difficulty in receiving eye care services because such services typically are not covered by most general health insurance plans. This lack of coverage also appeared to influence participants to think about eye care separately and not as a part of their general health. Many participants, particularly those in Miami and San Francisco, also said a referral was needed to seek eye care services. This referral, in many instances, meant that additional time was required now that an appointment was needed to see their primary care physician for a referral and then an additional appointment to see an eye care professional. Receiving eye care services was also made more difficult because participants were left paying two co-payments when their primary intention was to see just an eye care professional.

- “I don’t have eye insurance. So making a decision to go to an optometrist or an ophthalmologist is something I wouldn’t do unless I needed to do it.” (Group 20; Caucasian; San Francisco, CA)
- “I’m very resentful that places of employment do not take care of eye care. Particularly since most, you know, work nowadays involves computer work and you are sitting in front of those damn things for 12 hours a day and sorry, we’re not going to pay for glasses, or that’s something you got to do it on your own. That doesn’t make sense. And I’m very resentful.” (Group 20; Caucasian; San Francisco, CA)
- “I totally agree with you because the cost is very high and they pay for my pap smears, all you do is just pay the \$20...\$15-\$20.00 office visit and the rest of it is covered. For the eye care it should be the same.” (Group 9; Hispanic/Latino; Chicago, IL)
- “A long time ago, we could go to any doctor we wanted and your co-payment was five dollars, ten dollars, and it’s went up to fifteen dollars, thirty dollars, a hundred dollars for emergency room. These guys are money hungry. They are killing us.” (Group 3; African American; Miami, FL)
- [MOD: For those of you who haven’t been in two years or more, why haven’t you gone (to an eye doctor)?] “I felt I didn’t need to see one, no symptoms, no deterioration of vision, and lack of insurance coverage.” (Group 20; Caucasian; San Francisco, CA)
- “I should go every year ‘cause it’s [my vision] changing so much these days. In fact, I’m due but until I get on a health plan somewhere, it’s gonna have to wait.” (Group 15; Asian; San Francisco, CA)

- [MOD: If there is one thing that the National Eye Institute could do to address barriers to receiving eye care, what would it be?] “Make eye care a part of health care in terms of being supported by HMOs. Make it more of an inclusive package.” (Group 20; Caucasian; San Francisco, CA)

### **Get It At the Drug Store**

Another factor related to cost that influences the receipt of eye care, particularly by an eye care professional, is that in many places one can find discounted eye wear at the local drug store or other stores. Many participants stated that obtaining eye wear in this manner was an economically viable option to receiving necessary eye care and professionally prescribed lenses. This situation, in many cases, meant that participants were self diagnosing their eye problems and attempting to gauge and find adequate prescription lenses on their own.

- “My dad has always had a problem with his eyesight and I remember he used to...I don’t know if you guys remember the store called Woolworth’s? Anyway, when I was old enough to drive; I was like 17 and he would say hey, go get me some glasses. And I’m like dad, you can’t go to the store and get glasses, you have to make an appointment at the doctor’s, and he was like, no, go to Woolworth’s and get me some glasses. And I’m like Woolworth’s? And that was just like really strange for me. But those were the glasses that he needed to use, so he’d be able to read the paper, which is what I have now.” (Group 5; African American; Chicago, IL)
- “Because it’s costs. My youngest sister, she buys her reading glasses from Costco. It costs 10 dollars, why go and pay \$150 for a pair of reading glasses...I know what my prescription is so I just go and I buy glasses from Costco. (Group 9; Hispanic/Latino; Chicago, IL)
- “No, I was just saying my primary care physician always refers me to somebody. I don’t have insurance so I have to pay as I go, so I go through the Sam’s Club, and they do a thorough exam before they release [me], and plus I wear contacts.” (Group 11; African American; Chicago, IL)
- “I don’t know what it is, but it works all of the time. When it comes testing time and kids trying to get into high school, a lot of times, students need glasses but their parents can’t afford it and they tell them in a heartbeat go to the jolly Walgreen’s and get yourself something to put on. Because I used to have [a] collection in my drawer and I gave them out because the kids cannot see.” (Group 5; African American; Chicago, IL)

## Class Discrimination and Bias

As previously stated, most participants did not find the health care system or doctors to be racially discriminating or biased, although undertones of perceived discrimination and bias are present in several of the statements made by participants. However, a number of participants in all race/ethnicities found doctors or the health care system to be insensitive and discriminating based on economic status and ability to pay for health care services/type of insurance and not on race and ethnicity. This so-called “class” discrimination and bias emerged in several of the discussion groups, including some of the Caucasian groups. Although this issue was not cited to always directly influence the receipt of eye care, the comments and the issue as a whole are noteworthy as they can adversely impact participant beliefs and attitudes about doctors and the health care system, and ultimately impact whether eye and/or health care services are received.

- “If I could say again, I just think the breach is more... it’s almost like blue collar, white collar, than it is, like black, white, or stuff like that. That would be my thoughts on it.” (Group 14; African American; San Francisco, CA)
- [MOD: Do you perceive the health care system to be culturally insensitive or discriminating?] “Insensitive about the patient, about all the steps that we have to go through to see a specialist. And also the high cost of everything, including medicine and prescriptions. Because they don’t know we pay for insurance, but we have to pay for prescriptions also. Have to pay for the drugs.” (Group 1; Hispanic/Latino; Miami, FL)
- [MOD: Do you perceive doctors to be culturally insensitive or discriminating?] “Are we just talking about the eye doctor, or primary care?” [MOD: Just doctors. Any doctors.] If they are any different? Culturally insensitive did you say? I don’t think so. I think for them it’s, they have to get you in and out right away. It’s all money.” (Group 7; Asian; Chicago, IL)
- [MOD: Okay. Do you perceive doctors to be culturally insensitive or discriminating in terms of their attitudes or perceptions?] “I think there's discrimination against people who are obviously poor. [MOD: Economic discrimination.] Yes!” (Group 17; Hispanic/Latino; San Francisco, CA)

The following excerpt also comes from Group 4; African American, Miami, FL.

- MOD: Do you perceive doctors to be culturally insensitive or discriminating?  
FS: I’ve never had that experience.  
MOD: That kind of goes back to what Samuel was talking about.

MS: I don't know if it's so much cultural now, but I'm just saying in terms of how we have developed sort of this ... I see it as a generational group. But in terms of now, I think if there is any type of bias, it's based on class.

MOD: What do you mean by that?

MS: If you got the money to pay for my services I'll take the best care of you. If you don't have the money, I'll give you a rush job and get you out of here so I can get the quantities in to make my bills.

MOD: Okay, what do other people think?

FS: Some of them do rush you in and rush you out.

FS: Yes, some doctors do. Rush you in and rush you out.

MOD: What did you say, Mildred?

FS: I said that I haven't had that experience.

MOD: Okay, which experience?

FS: They rush you in and rush you out. My doctor is pretty good. They take the time. If I want to ask questions he's there or she's there. And they take as much time as I need. Not as much time as I need, but sufficient time.

MS: I haven't had the actual experience, but I've heard some black doctors, who were trained in white institutions, say that the treatment of their colleagues to minorities is not as aggressive as it is with white males, white females.

MOD: Now say it again for me, Vincent.

MS: The treatment of blacks, Hispanics, Asians is not as aggressive as it is with white males and white females.

FS: There are studies that show that.

MOD: That show what?

FS: I think that it's in certain medical conditions, whether it's heart, a number of different medical conditions that the study revealed that minorities were not aggressively being treated as Anglos. Heart attacks, and a number of others, cancer.

MS: Particularly black women.

FS: There are studies to show that.

MOD: Okay. Does that affect your willingness to go to a doctor?

FS: No.

The following excerpt comes from Group 3; African American, Miami, FL.

- MOD: Okay, now why, is there something cultural or discriminating in there? I mean you are saying what you feel because you are getting a different kind of care.
- MS: Okay, okay.
- MOD: Just break it down here for me, it's just me and you talking.
- MS: If I've, I've actually been to private doctors and they see me come in alone, I get shunned. But when I bring my patient in there, big books, Jewish man I'm welcomed in there with open arms. Without the money bags I'm sitting there for hours, ignored.
- MOD: Okay, Michelle?
- FS: He has a point there. For example, we get right back to the HMO and the PPO. I've seen it happen. I have a PPO, which means that doctors automatically getting paid then and there. People that got HMO, they don't. So, and I've seen it and I go in there if it's not me or whoever, you got PPO, the doctor will see you right away, no problem. Hello Miss Robinson, Hello Miss so-and-so. Have HMO, oh sit down we'll get to you. You know, I mean it's wrong, because right now you have some doctors, not all of them, don't get me wrong. I know they have to survive too, but it's, back in the day, about helping people, now it's about how much you got in your account or whatever. But like I said everybody's different, but I mean it plays a major role with insurance now. I mean this is what's killing us now.
- MS: Before you answer your name they going to find out do you have insurance. Blue Cross or not.
- MOD: Do you feel that the type and level of insurance is more of a discriminating factor than race, or sex or whatever the case may be? Do you think the type of insurance is more influence of the type of care you receive as opposed to your race or sex or class?

FS: Of course, you can come in there from planet Mars, but if you got a good insurance, all stuffy about it. You could be green; they don't care.

MOD: Okay.

The following excerpt comes from Group 11; African American, Miami, FL.

- MOD: Why are you shaking your head, do you agree or disagree [discussion about insensitivity, discrimination and bias in the health care system]?

FS: Oh, I have seen a lot of prejudice in the medical field and it's been... the medical field is really going down at this particular time, you know, in a lot of different areas. But basically a lot of it ... I've been up on general areas of the levels, I've been on public aid, I've been with the greatest health care. I've got the greatest health care now, and then I have that bad health care. And my experiences with HMOs and PPOs have been awful so I just paid the doctor, because I couldn't deal with HMOs and PPOs, because you are generalized, you are grouped. And you're on an assembly line, in many cases, in many cases. The insurance that I carry now is great insurance. When they look on the back of that insurance card, I can have six doctors standing in the room with me in five seconds, because they see that insurance card. But at the same time, I've had doctors that truly, truly cared, even when I was on public aid. They loved their job. You have prejudices and racism; that's a vast area; you know, it's just a matter of what door you walk in, you know, pretty much. What doctor you really see that determines whether you're going to be subjected to a prejudice or whether you'll get the best of health care. It's not generalized across the board because you're a doctor now that you're going to treat every patient the same way, and if you look into some of the insurances and the way the doctors get paid, sometimes you can side with the doctors.

MOD: Let me ask you this, are you saying that doctors discriminate based on the type [of] insurance that you have, or are they discriminating for a different kind of reason?

FS: There are times that they discriminate on insurance, there's times they discriminate on racism, there's times that they discriminate, because they're really just not into it.



## **B. Factors That Differ by Race/Ethnicity**

As previously introduced, a number of factors were identified by the participants in Miami, Chicago, and San Francisco, which influence their receipt of eye care. Several of those factors predominantly influenced the receipt of eye care for certain racial and ethnic groups and not others. There did not appear to be many differences in reported factors influencing the receipt of eye care by location of the three focus groups with the exception that referrals were cited to be problematic slightly more in San Francisco and Miami than in Chicago and a few others, as reported below.

### **1. Attitudes**

Participants in each of the 20 focus groups shared various attitudes about eyes, eye examinations, the health care system, and their relationships with their primary care physician or eye care professional. One attitude reported to influence the receipt of general health care services and the receipt of eye care is that many of the participants found the health care system to be a hassle and a negative experience overall. In general when participants were discussing experiences with the health care system and health care providers or doctors, their attitudes did not seem to vary based on race/ethnicity or location of the focus group. However, comments revealing negative attitudes about the health care system were stated more frequently in the San Francisco, CA, focus groups. Distrust of the health care system was a belief that was prevalent in each racial/ethnic group. In Chicago, Caucasian participants reported distrust of the health care system more than other racial and ethnic groups.

Participants also discussed attitudes about their eye health, the importance of eyesight, and related beliefs that were found to influence the receipt of eye care. An overwhelming majority of participants stated they value their eyesight and healthy vision. However, a number of participants also stated a competing belief that they take their eyesight for granted. In general, when participants were discussing attitudes about their eyesight and eye health, their responses did not vary based on race/ethnicity or location of the focus group.

A number of participants, including those participants who have not seen an eye care professional in the past two years, have the attitude that seeing an eye care professional is not a necessity. This attitude was stated to be driven primarily by fear and denial, the belief that participants' vision has not changed, or that one primarily visits an eye care professional to get their prescriptions changed. The attitude that seeing an eye care professional is not a necessity appeared to be consistent across each of the three cities

and each of the four ethnicities with the exception of one variable. Although some of the more pronounced examples came from the African American focus groups. Fear was not reported by any of the Asian groups.

Table IV-1 details specific factors related to attitude that influence the receipt of eye care and the racial and ethnic groups that factor was reported to be an issue among.

**Table IV-1: Factors Reported To Influence the Receipt of Eye Care by Racial/Ethnic Group - Attitude**

Factors Reported To Influence the Receipt of Eye Care	Racial/Ethnic Group Reported By:
<b>Attitude</b>	
<b>Health Care System</b>	
▪ Receiving eye and/or health care services is time consuming	All Racial/Ethnic Groups
▪ Insufficient time provided to have a pleasing physician–patient encounter	All Racial/Ethnic Groups
▪ Stifled relationships with their providers	All Racial/Ethnic Groups
▪ Health care system is highly disorganized and complicated	All Racial/Ethnic Groups
▪ Health care providers are heavily influenced by the pharmaceutical and health insurance industries	All Racial/Ethnic Groups
▪ Distrust of the health care system	All Racial/Ethnic Groups
<b>Eyesight</b>	
▪ Eyesight and healthy vision are very important	All Racial/Ethnic Groups
▪ Eyesight is taken for granted	All Racial/Ethnic Groups
<b>Eye Examinations</b>	
▪ My vision has not changed	All Racial/Ethnic Groups
▪ The primary reason for visiting an eye care professional is to check or change one’s eyeglass or contact prescription	All Racial/Ethnic Groups
▪ Fear and denial	Hispanic/Latino; African American; Caucasian

## 2. Knowledge

Knowledge appeared to have an influence over whether one receives eye care or not. As mentioned before, it seemed evident that participants form intentions to take action based on whether information is provided to them. Generally speaking, participants in the three locations and in each racial/ethnic group were not very knowledgeable about eye health. Several of the Hispanic/Latino, African American, and Asian participants in Chicago and San Francisco stated they knew nothing about preventive eye care and that they did not think one could prevent loss of eyesight.

A major theme that emerged from this research was that when participants visit their primary care physicians, their physician does not share information with them about their eyesight. The majority of participants also reported that their primary care physician does not conduct a basic eye screening during general physical examinations. This theme was reported to influence the receipt of eye care services and did not seem to vary based on race/ethnicity or location of the focus group.

It was also noted by the majority of participants that they do not seek out information about their eyes. A majority of focus group participants are not knowledgeable about eye diseases and conditions. In general, themes about seeking eye health information and knowledge about eye disease and conditions did not vary based on race/ethnicity or location of the focus group.

Lastly, several participants noted that in the media, there is a lack of information provided about the importance of eye health and an increased awareness of eye disease and visual impairments in comparison to other diseases such as breast cancer. This finding was reported to affect their prioritization of receiving eye care services and did not vary based on race/ethnicity or location of the focus group.

Table IV-2 details specific factors related to knowledge that influence the receipt of eye care and the racial and ethnic groups that factor was reported to be an issue among.

**Table IV-2: Factors Reported To Influence the Receipt of Eye Care by Racial/Ethnic Group - Knowledge**

Factors Reported To Influence the Receipt of Eye Care	Racial/Ethnic Group Reported By:
<b>Knowledge</b>	
<b>Sharing Eye Health Information</b>	
<ul style="list-style-type: none"> <li>▪ Primary care physician does not share information with them about their eyesight</li> </ul>	All Racial/Ethnic Groups
<ul style="list-style-type: none"> <li>▪ Primary care physician does not conduct a basic eye screening</li> </ul>	All Racial/Ethnic Groups
<b>Participants Do Not Look for Eye Health Information</b>	
<ul style="list-style-type: none"> <li>▪ Participants do not seek out information about their eyes</li> </ul>	All Racial/Ethnic Groups
<ul style="list-style-type: none"> <li>▪ Participants are not knowledgeable about eye diseases and conditions</li> </ul>	All Racial/Ethnic Groups
<b>Lack of Publicized Eye Health Information</b>	
<ul style="list-style-type: none"> <li>▪ There is a lack of publicized information emphasizing the importance of eye health and awareness of eye disease and visual impairments</li> </ul>	All Racial/Ethnic Groups

### 3. Communication

As previously stated, communication was reported to be a very important component of doctor and patient interactions. The majority of participants said that they had a good level of comfort in communicating with their primary care physician or eye doctor. Despite the overall high level of comfort in communicating with providers, many participants shared examples of poor or hampered communication with their providers. In general, discussions about communication did not seem to vary based on location and were not predominated by one racial or ethnic group over another. However, regarding understanding medical terminology and language, differences were noted as described below.

Several participants stated that the level of communication was hampered due to insufficient amounts of time spent with providers. Many participants noted difficulty in obtaining information about what is happening to them when communicating with their providers. These findings were reported to influence the receipt of eye care services and did not seem to vary based on race/ethnicity or location of the focus group.

The majority of participants felt good about the way their medical care provider explained health information to them. However, a few participants did report that they

have difficulty understanding medical terminology. These participants were of minority racial and ethnic decent, but primarily from African American and Hispanic/Latino backgrounds.

Another aspect of communication reported to impact the level of understanding that patients and participants have about their health is language. Language was reported to be an issue primarily among Hispanic/Latino and Asian groups, but moreso among Hispanics/Latino groups.

Table IV-3 details specific factors related to communication that influence the receipt of eye care and the racial and ethnic groups that factor was reported to be an issue among.

**Table IV-3: Factors Reported To Influence the Receipt of Eye Care by Racial/Ethnic Group - Communication**

Factors Reported To Influence the Receipt of Eye Care	Racial/Ethnic Group Reported By:
<b>Communication</b>	
<b>Comfort</b>	
<ul style="list-style-type: none"> <li>▪ I have a good level of comfort communicating with my primary care physician and eye doctor</li> </ul>	All Racial/Ethnic Groups
<b>Time</b>	
<ul style="list-style-type: none"> <li>▪ Communication with my primary care provider is hampered by the short time spent with my provider</li> </ul>	All Racial/Ethnic Groups
<b>Asking Questions</b>	
<ul style="list-style-type: none"> <li>▪ It is difficult obtaining information about what is ailing me when I visit with my primary care provider</li> </ul>	All Racial/Ethnic Groups
<b>Explaining Health Information</b>	
<ul style="list-style-type: none"> <li>▪ Difficulty understanding medical terminology and health information given by their primary care provider</li> </ul>	Hispanic/Latino; African American
<b>Language</b>	
<ul style="list-style-type: none"> <li>▪ Language impacts the level of understanding information that participants have about their health</li> </ul>	Hispanic/Latino; Asian

#### 4. Culture

Many of the descriptions related to culture that influence the receipt of eye and/or health care services come from participants of racial and ethnic minority backgrounds. A number of traditional, folk, or home remedies were reported by participants, which

they use first when they experience problems with their eyes. The majority of traditional, folk, or home remedies were discussed in Miami, FL, and Chicago, IL. Descriptions about use of traditional, folk, or home remedies were mostly reported by African American participants. However, Hispanic/Latino and Asian participants provided descriptions of traditional, folk, or home remedies use, as well.

Lack of preventive medicine was also reported to be a factor that influences the receipt of eye care. Primarily among some of the Hispanic/Latino participants, it was noted that within the Hispanic/Latino community, preventive medicine is not practiced as it should be. Hispanics/Latino and African American participants also mentioned that they are unlikely to go to the doctor unless their condition is really bad. Hispanic/Latino participants also mentioned that health care services are often not sought among people in that culture due to pride about letting others know that one's health is failing.

Another factor mentioned that influenced the receipt of eye care was washing one's eye out and hoping for the best when experiencing problems with eyesight. This treatment was reported by participants in one of the African American focus groups in Miami. Some of the African American participants in Miami said that they would just wait and see if their eye problems cleared up before contacting their primary care physician or eye doctor.

Gender issues were also noted to influence the receipt of eye care. The finding that males tend to not like going to the doctor was reported to be a factor influencing the receipt of eye care services, particularly among African Americans. This finding was mentioned by Hispanic/Latino and some Caucasian participants, and did not seem to vary by location of the focus group.

Many participants reported that they do not find doctors or the health care system to be culturally insensitive or discriminating. At the same time, undertones of perceived racial and ethnic discrimination and bias are present in several of the statements made by participants. Caucasian and most Asian participants said they did not find doctors or the health care system to be culturally insensitive or discriminating. African American and Hispanic/Latino participants were found to report perceived undertones of cultural insensitivity or discrimination within the health care system. This finding did not seem to vary based on location of the focus group.

Table IV-4 details specific factors related to culture that influence the receipt of eye care and the racial and ethnic groups that factor was reported to be an issue among.

**Table IV-4: Factors Reported To Influence the Receipt of Eye Care by Racial/Ethnic Group - Culture**

Factors Reported To Influence the Receipt of Eye Care	Racial/Ethnic Group Reported By:
<b>Culture</b>	
<b>Traditional, Folk and Home Remedies</b>	
<ul style="list-style-type: none"> <li>▪ Use of traditional, folk, and home remedies to cure health problems before seeking care from doctor</li> </ul>	African American; Hispanic/Latino; Asian
<b>Lack of Preventive Medicine</b>	
<ul style="list-style-type: none"> <li>▪ Preventive medicine is not practiced</li> </ul>	Hispanic/Latino
<ul style="list-style-type: none"> <li>▪ Only go to the doctor if your condition hurts really bad</li> </ul>	African American; Hispanic/Latino
<ul style="list-style-type: none"> <li>▪ Too proud to go to the doctor</li> </ul>	Hispanic/Latino
<b>Wash Your Eye Out/Wait and See</b>	
<ul style="list-style-type: none"> <li>▪ Wash your eye out and hope for the best when experiencing problems with eyesight</li> </ul>	African American
<ul style="list-style-type: none"> <li>▪ Wait to see if eye problems clear up before contacting a primary care physician or eye doctor</li> </ul>	African American
<b>Gender</b>	
<ul style="list-style-type: none"> <li>▪ Males tend to not like going to seek health care services</li> </ul>	African American; Hispanic/Latino; Caucasian
<b>Discrimination, Bias and Insensitivity</b>	
<ul style="list-style-type: none"> <li>▪ Found the health care system to not be culturally insensitive or discriminating</li> </ul>	Caucasian; Asian
<ul style="list-style-type: none"> <li>▪ Found the health care system to be culturally insensitive or discriminating</li> </ul>	African American; Hispanic/Latino

## 5. Other Factors

As previously mentioned, several factors not related to the Theory of Reasoned Action, but of great concern and reported to be a major influence in the receipt of eye care, were discussed in the various groups. In each focus group, cost was reported to be a factor that served as a barrier to participants receiving eye care services. Cost was reported to influence the receipt of eye care by participants from each of the four ethnic groups and three cities.

Many participants discussed the difficulty in receiving eye care services because such services typically are not covered by most general health insurance plans. This finding did not seem to vary based on race/ethnicity or location of the focus group. Many

participants, particularly those in Miami and San Francisco, also said a referral was needed to seek eye care services. That finding did not vary based on race/ethnicity.

Also reported to influence the receipt of eye care was the purchase of discounted eye wear or other eye care products at the local drug store or other stores. This finding did not seem to vary based on race/ethnicity or location of the focus group.

A number of participants found doctors and/or the health care system to be insensitive and discriminating based on economic status and ability to pay for health care services/type of insurance. This finding was mostly mentioned by participants with racial and ethnic minority backgrounds, although a few Caucasian participants reported similar beliefs. This finding was consistent across each of the three focus group locations.

Table IV-5 details specific factors related to other variables that influence the receipt of eye care and the racial and ethnic groups that factor was reported to be an issue among.

**Table IV-5: Factors Reported To Influence the Receipt of Eye Care by Racial/Ethnic Group – Other Factors**

Factors Reported To Influence the Receipt of Eye Care	Racial/Ethnic Group Reported By:
<b>Other Factors</b>	
<b>Cost</b>	
<ul style="list-style-type: none"> <li>▪ It is expensive to receive many eye care services</li> </ul>	All Racial/Ethnic Groups
<b>Insurance Coverage</b>	
<ul style="list-style-type: none"> <li>▪ It is difficult obtaining eye care services because typically they are not covered by most general health insurance plans</li> </ul>	All Racial/Ethnic Groups
<ul style="list-style-type: none"> <li>▪ Obtaining eye care services is made more difficult because of the necessity to obtain a referral before doing so</li> </ul>	All Racial/Ethnic Groups
<b>Get It at the Drug Store</b>	
<ul style="list-style-type: none"> <li>▪ Discounted eye wear and other eye care products can be purchased at the local drug store</li> </ul>	All Racial/Ethnic Groups
<b>Class Discrimination and Bias</b>	
<ul style="list-style-type: none"> <li>▪ The health care system was reported to be insensitive and discriminating based on ability to pay and type of insurance</li> </ul>	African American; Hispanic/Latino; Asian



## C. Additional Information

Participants were also asked additional questions not related to the model or to factors that influence the receipt of eye care in order to help the National Eye Institute ascertain sources of health information, beliefs about loss of eyesight, and knowledge about preventive eye care.

### 1. Sources of Health Information

In general, participants stated that they get information pertaining to health issues from a number of places. Most participants report receiving information on health issues from television, radio, their job, journals, or their primary care physicians. Family members and friends, the Internet, magazines, newspapers, weekly newsletters, pamphlets in doctor's offices, mailings, and the American Association of Retired Persons were also mentioned as sources of information.

- [MOD: Where do you get information for health issues?] "Primarily from my health care provider. They send us a monthly magazine with articles." (Group 4; African American; Miami, FL)
- "TV gives you a lot of information if you pay attention. And the TV always has some sort of a health issue that they talk about." (Group 9; Hispanic/Latino; Chicago, IL)
- "My company provides an enormous amount of information on health issues. We have a gym. We have online information that they send us. There are newsletters. There is a wealth of information." (Group 4; African American; Miami, FL)

Caucasians in San Francisco reported receiving health information from journals and books more than other participants.

- "I have many books and I subscribe to about four health letters that come to me. Plus Kaiser gives you a health book of general symptoms." (Group 20; Caucasian; San Francisco, CA)
- "I have a couple of medical books myself, one published by the AMA. And some wellness books that have been put out by some organizations. But a lot of material I get right from the doctor's office, pamphlets which are lying there. (Group 20; Caucasian; San Francisco, CA)
- [MOD: Where do you get information for health issues?] "Certain journals that are specialized, just staying on top of what's going on." [MOD: Any particular journals,

Susanna?] “There’s one called Well Being Journal. The one I use is Prevention.” [MOD: Prevention Magazine? Okay.] (Group 19; Caucasian; San Francisco, CA)

- “I have three journals. I get Health After 50. The University of California has one called Wellness and there’s another one for heart disease. Also I use Prevention as my main guide.” (Group 19; Caucasian; San Francisco, CA)

In Miami, some participants said that they do not seek health information. For example, one participant stated that he was not that curious. Another mentioned that he doesn’t get any health information besides that offered by his doctor.

## Internet

In general, most participants report using the Internet to gather health information. In Miami, approximately half of all the participants in each focus group said that they use the Internet to gather health information. In terms of the types of health information retrieved from the Internet, the majority of all participants said that they use the Internet to research specific diseases. Participants also reported using the Internet to locate information about alternative therapies and medicine, co-payment fees, prescribed medicines and side effects, cheaper prescriptions, diet information, symptoms, and dietary supplements. They also use the Internet to conduct research prior to seeing a doctor.

In Chicago, Caucasian and African American participants were most likely to use the Internet to gather health information. In both of the Asian groups, less than half of the participants said they used the Internet to find health information. In one of the Hispanic/Latino groups, none of the participants said they used the Internet to find health information; they all reported that they did not have computers.

In San Francisco, Caucasian and Asian participants were most likely to use the Internet to gather health information. In both of the African American groups, half of the participants said they used the Internet to find health information. In one of the Hispanic/Latino groups, less than half of the participants said they used the Internet to find health information.

- [MOD: Okay. Anybody here use the Internet for health information? Anybody?] “We’re from the old school. I don’t have a computer. I don’t like the computer. I’d rather read it or search my own information.” “I don’t even know how to turn one on.” “I don’t, either.” (Group 9; Hispanic/Latino; Chicago, IL)

- “I go to certain Websites to order herbs and vitamins.” (Group 19; Caucasian; San Francisco, CA)
- [MOD: And what type of health information do you look for on the Internet?] “I use it for drugs, for prescriptions. To try to better understand what I’m putting in my body, you know, how it could affect me.” (Group 4; African American; Miami, FL)
- “I look up whatever needs I might have at the time for my family or for myself.” (Group 17; Hispanic/Latino; Miami, FL)
- “Yeah. I look up [prescriptions] and see what are the side effects and what do they cure, what do they do. I also look up interactions. [MOD: Interactions of medications?] Medications. I wanted to know which of my medications affects diabetes because my sugar was going up so I looked. (Group 19; Caucasian; San Francisco, CA)

## 2. Knowledge and Prevention

### Loss of Eyesight

In each of the focus groups, disease and accidents were mentioned the most as reasons people lose their eyesight. Neglect, heredity, lack of medical care or early detection, improper lighting, diabetes, straining your eyes, age, poor nutrition, cataracts, watching too much television, and not protecting your eyes when working were also mentioned as reasons people lose their eyesight.

- “There are certain characteristics that may be carried in a family, like glaucoma and other issues that people may not be aware of or seek attention early enough for. So there may be hereditary factors that people may not be aware of so, therefore, they’re not getting the proper attention, but it still comes back down to basic eye care. Or it may be from an accident also.” (Group 4; African American; Miami, FL)
- “To answer your question, just lack of getting your eyes checked. You know, some people walk around and they don’t take good care of themselves.” (Group 14; African American; San Francisco, CA.)
- [MOD: Why do people lose their eyesight?] “Accidents. Not taking proper care. [MOD: What do you mean, not taking proper care?] Like someone said, if you needed to wear glasses and you don’t. Or you eat the wrong things, it might affect your vision.” (Group 17; Hispanic/Latino; San Francisco, CA)

## Preventive Eye Care

A variety of responses was given when the participants were asked what they knew about preventive eye care. In most of the groups, participants noted wearing sunglasses, getting regular check ups, having proper eyeglass prescriptions, and wearing protective eye wear were steps you could take to prevent eye problems. Participants also reported performing yoga, getting enough sleep, ensuring proper lighting, taking vitamins and anti-oxidants, having good nutrition, maintaining good hygiene (keeping hands away from eyes), watching T.V. from a proper distance, and eating carrots were key to preventive eye care. Eye exercises were also noted by several participants as something they do to improve or protect their eye health.

- “There was a woman written up in the Chronicle, she kept her eyesight in terrific shape. She died. And the way she did it, when she was younger, she would start exercising her eyes, roll them around and all that. Never had to use glasses for reading. Sounds like it probably does work.” (Group 17; Hispanic/Latino; San Francisco, CA)
- “I found out when I was looking at things for the macular degeneration, there’s vitamins and supplements. Lutein is one that they recommend.” (Group 6; Caucasian; Chicago, IL)
- [MOD: How can people prevent eye loss?] “Eye checks. Don’t read in low light; don’t sit too close to the TV. Don’t play with bb guns; they will put your eye out. Wear protective goggles. Control your diabetes. (Group 20; Caucasian; San Francisco, CA)
- “I’d watch my nutrition and I’d try to eat things that I think help my overall health. Take nutritional supplements. I take Centrum Silver and Vitamin A, D. And when I’m out in the bright sun, I wear wrap around sunglasses.” (Group 6; Caucasian; Chicago, IL)
- “Basically, have a regular eye exam. Healthy diet. Back in the olden days they used to tell us eat plenty of carrots, it’s good for your eyes. And...even more so today.” (Group 3; African American; Miami, FL)
- [MOD: What do you know about preventive eye care?] “When you’re working around with tools, you put on goggles, safety goggles. And sunglasses.” (Group 15; Asian; San Francisco, CA)

Several of the minority participants stated they did not know of any preventive steps they could take to preserve their eyesight and that they did not think you could prevent loss of eyesight. In San Francisco, among one of the African American groups, several of the participants stated that they have never heard of preventive eye care.

- [MOD: How can people prevent eye loss?] “In some cases I don't think you can. [MOD: What do you mean you don't think you can?] Well, just like we were all saying, if it's genetic, if it's something that's going to happen to you, maybe you can do something to prolong it maybe if you started getting [vision loss] at an early age, but then, I mean, it might be something that's going to happen to you anyways.” (Group 11; African American; Chicago, IL)
- [MOD: What do you know about preventive eye care?] Nothing other than safety issues with glasses. (Group 11; African American; Chicago, IL)
- [MOD: Okay. What do you know about preventive eye care?] “Nothing. I don't.” (Group 13; African American; San Francisco, CA)

Despite this finding, in Chicago, among both of the Asian focus groups, an overwhelming majority of the participants stated that looking at green things, such as trees and grass, improves your eye health. However, in San Francisco the overwhelming majority of Asian participants had never heard of such a connection. Another Asian participant added that in China he learned that you should not read on the bus, as it will affect your eyes and cause you to become lightheaded. Yoga and eye exercises were also noted by the Asian and Hispanic/Latino participants to be helpful in preventing loss of eyesight.

- [MOD: How can people prevent eye loss?] “I mean, green stuff is good for eyesight. [MOD: When you say green stuff, what do you mean?] Tree and grasses, sometimes go out to the park. [MOD: So you say look at a lot of live green stuff, it sounds, like trees, grass.] Yes, sometimes for 15 minute, 20 minute.” (Group 8; Asian; Chicago, IL)

## **Eye Problems**

The majority of participants stated that they would go to their primary care physician or eye doctor if they were experiencing problems with their eyesight. Many participants, particularly in Miami and San Francisco, mentioned that this process was difficult due to the necessity of obtaining a referral to see an eye care professional. However, a number of participants said seeing an eye care professional would depend on how severe they thought their eye problems were. Other participants stated that they would call a pharmacist, tell family and friends, go to an emergency room, or “wait and see.” The issue of cost arose as a major factor when deciding what to do when experiencing problems with eyesight. One participant said he/she would go to Walgreens and self-medicate.

- “Well, I used to work during the late shift and I used to get off in the morning and it was like one block away [and] the stop sign was blurry. I’ve never ever had problems with my eyes. So when that all happened I said, hey, I need to go see somebody. He told me I had diabetes and it was pretty bad at the time because I wasn’t taking care of it and that was the reason why my eyesight was blurry.” (Group 3; African American; Miami, FL)
- “I had, maybe two years ago, it was about 1 o’clock in the morning. I was in the bathroom and I felt strange and for about 30 seconds, I could not see. And I screamed for my son to call 911, I can’t see. And they came out, I called 911. And they checked everything and they said it was maybe something that just happened for a couple of seconds. But after that, it never happened, it didn’t happen again.” (Group 14; African American; San Francisco, CA)
- I had a problem last year with my right eye. And what I did was I called my eye doctor for a referral to go to the specialist. (Group 1; Hispanic/Latino; Miami, FL)
- [MOD: What do you do when you have problems with your eyesight?] “Go to the drugstore, Walgreens or whatever and look for things that...ask the pharmacist first; you know what would he recommend about eye pain or maybe your eyes are dripping, maybe they're dry, and you need something like a re-wet drop or something like that.” (Group 11; African American; Chicago, IL)
- [MOD: What do you do when you have problems with your eyesight?] “Go to the doctor.” “I think it depends on how serious a problem it is.” [MOD: For instance?] “Like I have dry eyes. Sometimes they’re worse than others. I don’t always call a doctor. I just use the artificial tears. That kind of helps it. I take my glasses off. Sometimes to rest my eyes. Or I use a technique called palming where you lay your palms, your hands, on your eyes. And it’s supposed to help your eyes rest, relax, and heal.” (Group 6; Caucasian; Chicago, IL)
- “Well, like when I was starting...my vision would get blurry when I was reading and automatically I knew that something was wrong, so I just went to the doctor at Sears and had it checked out and sure enough I needed glasses. But you know that’s about it.” (Group 9; Hispanic/Latino; Chicago, IL)

A common theme that came forth, particularly among the African American groups in Miami was to do nothing or just wait and see when you are having eye problems. In one instance, a participant stated that he would wash his eye, go to sleep, and hope for the best.

- “Some people do nothing because of fear. Some people don’t want to know.” (Group 4; African American; Miami, FL)

- [MOD: What would you do if you were having problems with your eyes?] “I think culturally you might find a lot of people that just wash their eye out and hope for the best.” (Group 4; African American; Miami, FL)
- “It depends on what the symptoms are. If it’s just dry eye I can take care of that unless if I don’t feel anything more symptomatic or more serious. But I will bring it up in my next exam. [MOD: How long would you let it go before you went to the eye doctor?] “Would go two or three weeks.” [MOD: Anyone else?] “It depends on the severity of it. If it is a stabbing pain, my God, you go straight away. If something is just uncomfortable then it just may go away by itself as with any kind of illness.” (Group 20; Caucasian; San Francisco, CA)
- “I just cope with it.” [MOD: And what does that mean for you, Gary?] “Well, I cope with it, when it happens I just wait until it passed. And when it passes I go on and function like it was before.” (Group 3; African American; Miami, FL)
- “Put cold water on it.” (Group 8; Asian; Chicago, IL)
- “One time...Christmas time, I went to Arizona and I have eye infection, so I took some eye drop and I said oh it goes away.” [MOD: How long before it went away?] “Well, as far as I know it went away because it doesn’t bother me anymore.” [MOD: Okay. So how long was it before it didn’t bother you anymore?] “Three month.” (Group 9; Hispanic/Latino; Chicago, IL.)

## Dilated Eye Exam

When asked, “What is a dilated eye examination?” about half of all the participants had a good understanding of what the examination was. There were many participants in several groups who weren’t very knowledgeable about what a dilated examination was. Some comments from those who were less knowledgeable about what a dilated examination was included, “It is a deep cleaning of the eye, and it is conducted by your primary care physician.” Each group was eventually able to indicate that drops were placed in your eyes to widen the pupils so the eye doctor could look at the back of the eye. Other responses offered by the participants are below.

- “I know he dilated mine, but I forgot what it was.” (Group 10; Hispanic/Latino; Chicago, IL)
- “When your eyes are dilated, they have a better chance to see everything they want to see. [MOD: And what is it that they are looking for?] “Glaucoma.” “Macular degeneration, probably. Anything going on with the cornea. You can see it better, I believe.” (Group 17; Hispanic/Latino; San Francisco, CA)

- [MOD: Okay. What is a dilated eye examination?] “That’s when the doctor wants to look further back into your eye. So he’ll add I think two types of drops they’ll put into your eye. And you’ll wait. Either you’ll sit in the examining room or go outside in the waiting room and then wait. And then your eyes become all blurry and hazy. And then he’s able to look into your eye with more high-powered lights. So it’s a more detailed examination. It opens the iris up.” [MOD: For what reason?] “Basically, it’s to get a visual access into the eyeball.” (Group 6; Caucasian; Chicago, IL)
- “I can’t answer that because I’ve never had my eyes dilated.”(Group 11; African American; Chicago, IL)
- “They take a really bright light and look inside and make sure everything’s good in there. [MOD: When you say everything’s good in there, what do you mean?] Well, that your blood vessels are good. I guess, everything’s attached or, you know, nothing’s gone wrong. The rods and cones are in place.” (Group 15; Asian; San Francisco, CA)
- “That’s, yeah, when they put the drops in and it actually opens up your pupils so they can see more directly past your retina.” (Group 14; African American; San Francisco, CA)
- [MOD: Okay. What is a dilated eye examination?] “Put drops in your eyes.” [MOD: What happened? Why did they put drops in your eyes?] “To see how it dilates. It opens the pupil.” [MOD: Okay and then what? What’s the purpose of that?] “I’m not sure what it is, but I know...I mean...I can’t tell whether it’s to check diabetes or...but it’s to check something inside of your...some other disease other than your eyes.” (Group 10; Hispanic/Latino; Chicago, IL)

### 3. Frequency of Eye Care

The overwhelming majority of participants stated that people should have their eyes examined one to two times per year.

In Miami, an overwhelming majority of both African American and Hispanic/Latino participants saw an eye doctor and had their eyes examined within the past year. One African American participant, who had been diagnosed with strabismus in 1980, stated that he had not been back to an eye doctor since. Another African American participant stated that he had never been to an eye doctor, but does have diabetes. When Miami participants did report seeing an eye care professional, they reported visiting an optometrist or ophthalmologist in approximately equal proportions to have their vision checked. For those who had not seen an eye doctor in several years, when asked, “Under what circumstances would you go to an eye doctor?” participants said they



would go if their vision got bad enough, if they couldn't see anything, if they had redness of the eye, or if their time permitted.

In Chicago, among the Caucasian and African American groups, all of the participants had seen an eye doctor in the past one to two years. Among the Hispanic/Latino and Asian groups, most participants had seen an eye doctor in the past three years, however several participants had never seen an eye doctor or had their eyes examined. When Chicago participants did see an eye care professional, they reported visiting optometrists more frequently than ophthalmologists for vision screenings or examinations.

Procrastination was cited as the major reason why Chicago participants had never seen an eye doctor or had not seen an eye doctor in a long while. When asked, "Under what circumstances would you go to an eye doctor?" a majority of Chicago participants said they would go if they needed to get their prescription changed. Others said they would go if they could not read street signs, if their vision was blurry, if their eyes hurt, or if they kept getting headaches.

In San Francisco, the majority of the Caucasian participants had seen an eye doctor in the past year. Many African American, Hispanic/Latino, and Asian participants reported that it had been two years since they last made a visit to an eye doctor. There were several instances where it had been longer than four years since certain African American, Hispanic/Latino, and Asian participants had seen an eye doctor. When San Francisco participants did report seeing an eye care professional, they reported visiting optometrists and ophthalmologists for vision screenings or examinations in approximately equal proportions.

When asked, "Why have you not gone to an eye doctor?" San Francisco participants said that they didn't feel it was necessary, they were too busy, they just buy new glasses at the drug store, the prescription in the glasses they currently have is just fine, and they have no symptoms. Insurance reasons were also cited. A majority of these participants said they would go if they needed to get their prescription changed, if they had experienced a change in their vision, if their glasses broke, if they lost one of their contact lenses, or if they kept getting headaches.

## 4. What Can Be Done

### What Is Needed To Overcome Barriers to Eye Care?

The majority of participants spoke of the need for better education about various eye diseases, eye health, and preventive steps to preserve healthy vision to help overcome the obstacles to receiving eye care that were mentioned in the focus group discussions. Others mentioned the need to address educating children about proper health and eye care. Related to better education about eye health was a request brought forth in many of the discussion groups to continue advertising health care issues. Specifically for eye health, there is a need for more advertisements in the form of PSAs and better education about various eye diseases.

Several others mentioned that addressing aspects of the health care system are needed, as they are major obstacles to receiving care. Some suggestions were to make health care more affordable and to treat people like human beings, to examine different forms of entitlements, and to take profit margins out of health care to make our system more like the Canadian system. A national health care system was also said to be needed to overcome some of the obstacles mentioned as the people who need health care the most are the ones who can't receive it. Participants also mentioned that some of their own prejudices need to be overcome, as they serve as barriers to receiving care.

### What Would You Like To Know About Eye Health?

As the groups came to a close, the participants were asked what other things they would like to know about eye health. A wide range of responses followed:

- "I'd like to know and have a clear definition of the two functions of the optometrist ... and I have a general idea...and the ophthalmologist. But it seems that they overlap. And when I visit one, especially the optometrist, I get some information that perhaps should be coming from the ophthalmologist rather than the optometrist. There's like a grey area. They overlap. And I'm not sure what information I should trust from an optometrist. Who I understand measures your eyesight. Maybe I'm wrong. I'm not familiar with." (Group 1; Hispanic/Latino; Miami, FL)
- "Retinitis and all of those other things, I think there needs to be more information put out there and make it broader, and get people more familiar with certain diseases. Most people don't know anything about anything but glaucoma and cataracts. When you talk about retinitis and things like that, it's like, oh, well that happens to

somebody else, so we need to know, we need that information, so we know it can happen to anybody.” (Group 11; African American; Chicago, IL)

- “You know, actually, you know, I don’t see anything about preventive eye care. You see a lot about no smoking or how bad secondhand smoke is but nothing on the eyes. Nothing about the eyes. And heart disease. They talk about that.” (Group 15; Asian; San Francisco, CA)
- “I would like to know more preventive measures endorsed by the Eye Institute. What can we do? Is the bilberry a good thing?” (Group 20; Caucasian; San Francisco, CA)

Participant responses fell into the following categories:

- How to prevent eye problems
- How to improve night vision, particularly when driving at night
- A better understanding of the differences between an ophthalmologist and an optometrist
- Information about how to take care of one’s eyes (preventive eye care)
- Preventive steps to preserve eyesight, particularly with children
- Over-the-counter medicines to treat eye conditions
- How often different age groups should receive an eye exam
- Long-term effects of laser surgery
- Warning signs of potential eye problems
- Information about vitamins that can improve eye health
- The impact of hygiene on eye health
- Whether any miracle drugs exist to treat eye disease
- Information about corrective surgery and its effectiveness
- Information about lighting and its effect on one’s eyes
- How nutrition and exercise can affect eye health
- Cures for blurry vision and dry eyes
- The latest advances in eye treatments and medicine
- Eye diseases and how to prevent them
- Information on floaters

### **Where Would You Like To Receive Eye Health Information?**

Most participants stated that they would like to receive eye health information in the mail, via e-mail and the Internet, public education on television, and from their doctor. They also mentioned that the schools should be more involved in disseminating eye health information through teachers, counselors, and health coordinators. Two San

Francisco participants mentioned that they would like to attend a free lecture on eye health. Below is a complete list of places participants reportedly would like to receive eye health information:

- Radio
- Magazine
- E-mail
- Internet
- Health Fairs
- Television
- Signs on Public Transportation
- Cereal boxes
- Cartoons for children
- Brochures
- Pamphlets
- Pharmacies
- Billboards
- Postal Mail
- Doctors' offices
- Libraries
- Lectures

### **How Would You Like To Receive Eye Health Information (format)?**

The overwhelming majority of participants stated that they have never seen a public service announcement about eye health. The overwhelming majority of all participants also said they would like to receive eye health information via PSAs. One Chicago participant noted that it would be great if a segment on eye health were to be aired on the Oprah Winfrey show. It was also noted that segments about eye health should be aired on news shows, 20/20, 60 minutes, and the Armed Forces Network. Other requested formats to receive eye health information included videos, CDs, DVDs, the written word, T.V. commercials, pamphlets, books, brochures, and game formats for children. The following excerpt comes from Group 20; Caucasian; San Francisco, CA, and highlights the benefits of videos in communicating information about a particular eye disease.

- "I was diagnosed with glaucoma and I looked that up in a couple of my books just to read about it. Also, one of the most helpful things that the doctor gave me, a video which he doesn't have time to go through all that's happening and the diagrams. It made more of an impression on me than him telling me [what] I have and what's going on in two seconds. It's like, when I go to doctors, like taking a test. I'm on really high alert stress, being in a hospital is stress. And I don't hear everything he says. Or you don't remember everything he says. So I got to taking a pad with questions and writing them down. Nonetheless, the video is great." (Group 20; Caucasian; San Francisco, CA)
- "I think the information is available, a plethora of different conditions. But how the information is delivered. And I guess it's a marketing thing. It needs to be delivered in a way where people, they're learning while at the same time it's fun, particularly

with the young children. I think the delivery of that information, that some work can be done in that area.” (Group 4; African American; Miami, FL)

- “Anything you hear and see, visualize, at least with me I understand it a lot more than if, because a lot of times sometimes there’s things you read you just don’t understand what you are reading anyway. What the terminology, what they use, or the way they put it because this is an area where that we’re not familiar with at all, unless you’re specialized in that field. So if you have visual as well as hearing, I think that would help a lot.” (Group 8; Asian; Chicago, IL)
- [MOD: Where would you like to receive eye health information?] “Mostly for TV, not the Internet, but the bus, like commercial vehicles and something like that.” (Group 10; Hispanic/Latino; Chicago, IL)

### **“One Thing the NEI Could Do” To Address Barriers**

Lastly, the participants were asked, “If there was one thing the National Eye Institute could do to address some of the barriers to receiving eye care that were mentioned, what would it be?” In Miami, the overwhelming majority of participants mentioned addressing the cost of eye care services. Many of the participants said that it is too expensive to receive eye care in America. Participants also mentioned that eye care services are not typically covered in most insurance plans, and that needed to be addressed. An overwhelming majority of participants mentioned a need for a more concerted focus on preventive eye care and screening. Participants stated that providing eye screenings through mobile vans and in shopping malls would be beneficial, and that recognizing cultural differences is one thing the NEI could do to address barriers to receiving eye care.

In Chicago, when asked, “If there was one thing the National Eye Institute could do to address some of the barriers to receiving eye care that were mentioned, what would it be?” the majority of participants mentioned a need to make eye care more of a health priority and increase awareness that with regular eye exams, one can prevent many eye disorders. Many of the participants also said that it is too expensive to receive eye care in America. Several suggested that free eye exams should be given, that exams should take place in schools, and that outreach programs should be directed at children. Participants also mentioned that eye care services are not typically covered in most insurance plans and it should be a covered service. Lastly, it was mentioned that more money should be spent on advertising the importance of eye health and that a spokesperson should be used to communicate eye health messages.

Finally, in San Francisco, when participants were asked, “If there was one thing the National Eye Institute could do to address some of the barriers to receiving eye care that were mentioned, what would it be?” the majority of participants also mentioned making eye care more of a health priority and increasing awareness that regular eye exams can prevent many eye disorders. The use of a spokesperson was mentioned as likely being helpful in communicating eye health messages. Many of the participants, as in the previous two cities, said that it is too expensive to receive eye care in America. Several participants also said that free eye exams should be given to the public, and that eye care should be a part of general health insurance packages. Participants also suggested that exams and screenings be made more accessible through mobile vans and offered at malls and shopping centers. Directing messages at youth was also mentioned as something to do to address barriers to receiving eye care. Lastly, participants in San Francisco suggested that primary care physicians be required to perform eye screenings on patients during office visits.

## **VI. SUMMARY AND RECOMMENDATIONS**

### **A. Summary and Conclusions**

The purpose of this research was to determine why people are not receiving timely eye care. A recent study notes that people at risk for vision loss are not receiving optimal eye care, although eye diseases are treatable (Hartnett, Key, Loyacano, Horswell, and DeSalvo, 2005).

Research indicates that several diseases and disorders of the eye are prevalent in certain racial and ethnic minority communities, and disproportionately affect minority populations more than Whites (Friedman, West, Munoz, Park, Deremeik, Massof, et al., 2004; Varma, Ying-Lai, Klein, and Azen, 2004; Kempen, O'Colmain, Leske, Haffner, Klein, Moss, et al., 2004; Higginbotham, Gordon, Beiser, Drake, Bennett, Wilson, et al., 2004) This study also sought to identify how factors such as attitudes, knowledge, communication, and culture influence the receipt of eye care and whether those factors vary by race and ethnicity.

In March and April 2005, 20 focus groups were conducted to assess medical knowledge, health beliefs, and attitudes that might influence the receipt of eye care. One hundred eighty people over the age of 40 in Miami, FL; Chicago, IL; and San Francisco, CA, participated in the discussions. Of the 180 people, 54 participants were African American, 54 Hispanic/Latino, 36 White, and 36 Asian.

Focus group discussions were guided by a moderator's discussion guide, which was developed using the Theory of Reasoned Action. As outlined in the TRA, a behavior is the result of an intention to perform that behavior. Intentions are formed by a combination of attitudes and subjective norms, which are formed by beliefs people have about themselves and their environment (Ajzen & Fishbein, 1980). The TRA was useful in developing discussions that reveal beliefs that might influence the receipt of eye care.

The overarching themes that emerged from this research are:

- **Several attitudes influence the receipt of eye care.**
  - Health care system is a hassle
  - Poor relationships or lack thereof with providers
  - Eyesight is important
  - Eyesight is taken for granted.
- **There is a lack of knowledge about preventive eye care and the importance of eye examinations.**
  - People are not knowledgeable about eye diseases and disorders.
  - Physicians do not share eye health information, which may explain why participants are not knowledgeable about eye diseases.
  - People do not seek eye health information – related to not having eye problems.
  - There is a lack of publicized information and awareness about eye health.
- **Communication influences the receipt of eye care.**
  - Poor communication with providers negatively impacts beliefs and attitudes about receiving eye and/or health care services.
  - An insufficient amount of time is spent with patients for them to ask questions and communicate with their providers.
  - Good communication with providers increases participants' knowledge about eye health and preventive measures to ensure healthy vision.
  - A few participants found medical terminology difficult to understand, which stifled communication between patients and providers.
  - Language barriers exist that lead to a misunderstanding of health messages and perceived mistreatment on the part of certain participants.
- **Culture influences the receipt of eye care primarily for African American and Hispanic/Latino racial/ethnic groups.**

- For many African American and Hispanic/Latino racial/ethnic groups, traditional, folk, and home remedies are used to cure eye problems before going to see an eye care professional.
- There is a lack of preventive medicine practices embedded in the culture of certain minority racial and ethnic groups, particularly among Hispanics/Latinos.
- A tradition practiced among African Americans is a wait-and-see approach.
- Males are less likely to receive care, particularly among African American racial groups.
- Undertones of perceived racial and ethnic discrimination and bias exist on behalf of African American and Hispanic/Latino participants in the receipt of care.
- **Other factors (not related to research questions) that influence the receipt of eye care:**
  - Cost of eye care services is prohibitive.
  - Eye care is not a standard part of most general health care plans.
  - San Francisco and Miami participants, in particular, stated the referral process influences the receipt of eye care.
  - The drug store offers eye care services.
  - Participants perceive discrimination and bias by class, ability to pay for services, and insurance type.
- **Several factors found to influence the receipt of eye care differ by race/ethnicity**
  - Fear and denial about receiving eye examinations are issues reported by Hispanic/Latinos, African Americans, and Caucasians.
  - Difficulty understanding medical terminology is an issue reported by Hispanics/Latinos and African Americans.
  - Language was reported as a barrier to eye care services by Hispanics/Latinos and Asians.
  - Several cultural factors were reported to influence the receipt of eye care for racial and ethnic minority participants
  - Discrimination and bias by class, ability to pay for services, and insurance type is perceived to exist in the health care system from African American, Hispanic/Latino, and Asian participants.



## 1. What Are the Attitudes That Influence the Receipt of Eye Care?

The role of patients' perception is a phenomenon that is gaining much attention within the health care system. Similarly, within this study, participants' beliefs and attitudes appear to be the primary factor influencing the receipt of eye care. Perhaps attitude is a major prohibitory factor in the receipt of eye care because a number of the other variables ultimately impact participants' belief systems, which, in turn, impact their attitudes.

Many participants found the health care system to be a hassle to deal with and a negative experience overall. Participants thought the health care system was problematic in terms of scheduling appointments and having long wait times. Participants also reported that they have stifled relationships with their providers where they feel that their health care providers and the health care system do not adequately address their health care needs. A majority of participants distrusted the health care system. Others found it to be disorganized and complicated.

A majority of participants, primarily in Miami and San Francisco, reported that in order to see an eye care professional, they must obtain a referral. Thus, given some of the negative attitudes and beliefs about the health care system, some participants are unlikely to receive eye care services unless there is an emergency. A number of participants discussed their frustrations with having to obtain a referral to seek care from an eye care professional. This added step requires time and finances in terms of co-payments. These additional requirements are likely to negatively influence the receipt of preventive eye care services.

In addition to participants' attitudes about the health care system, many participants reported conflicting beliefs about their eyesight. Generally speaking, the overwhelming majority of participants value their eyesight and healthy vision. At the same time, many participants revealed a competing belief that they take their eyesight for granted. Both of these beliefs were shown to have influence on whether eye care services were received or not.

Lastly, a number of participants reportedly have an attitude that seeing an eye care professional or obtaining an eye exam is not a necessity. This attitude appears to primarily be driven by fear, denial, the belief that participants' vision has not changed, that they have never had eye problems to begin with, or that one primarily visits an eye care professional only to get their prescriptions changed. Ironically, in each of the 20 focus groups, visiting an eye care professional was stated to be one way in which people can prevent loss of eyesight and preserve healthy vision. Thus, the attitude that

seeing an eye care professional or obtaining an eye exam is not a necessity is yet another competing attitude that seems to contradict participants' general attitudes and values about the importance of eyesight and healthy vision.

What is clearly implicit in the attitude that there is no necessity to see an eye care professional or that the only time there is a need to see an eye care professional is to change one's prescriptions, is a lack of awareness about preventive eye care. As stated before, participants were asked, "What do you know about preventive eye care?" In each of the discussion groups, participants revealed that getting one's eyes checked by a professional is one form of preventive eye care. Yet many participants stated that their eyesight was fine, and "if it isn't broken, there is no need to fix it." This statement reflects the significance of this attitude and an apparent lack of knowledge about preventive eye care through visits with an eye care professional. Perhaps participants need to be reminded of the asymptomatic nature of many eye diseases and disorders, and informed that the best way to prevent eye disease is through routine eye examinations.

## **2. How Does Knowledge Influence the Receipt of Eye Care?**

Across each of the three locations, participants were not very knowledgeable about eye health. Most participants were somewhat knowledgeable about what a dilated eye exam was. The majority also reported that one should have an eye examination once or twice a year. However, the majority of focus group participants were not knowledgeable about eye diseases and conditions.

The majority of participants reported that their primary care doctor does not share information with them about their eyesight. Participants also stated that the majority of participants do not seek information about their eyes. This attitude is probably due to the fact that many participants are not experiencing problems with their eyesight or eyeglass and contact prescriptions. Nonetheless, if the participants are not inquiring about eye health and their primary care doctors are not sharing information with them, it is very likely that participants will remain ignorant about preventive eye care and the asymptomatic nature of many eye diseases. Without information and education about eye health, participants have nothing to change their beliefs and, ultimately, attitudes about receiving eye care.

Many participants noted that there is a lack of information provided about the importance of eye health, and a lack of awareness of eye disease and low vision in the media, especially in comparison to other diseases such as breast cancer. Participants

also reported not receiving information via other sources such as PSAs; although some did report receiving pamphlets about eye health in their doctor's office. The lack of publicized awareness and information about eye health for several participants was reported to affect their prioritization of receiving eye care services. It is the author's contention that pieces of information build one's knowledge base on which a person forms beliefs. Those beliefs, in turn, form attitudes that go on to influence whether a behavior such as receiving eye care is performed, as illustrated by the Theory of Reasoned Action.

### **3. How Does Communication Influence the Receipt of Eye Care?**

One problem that may contribute to a patient's perception of quality health care and beliefs about the health care system is communication with health care providers (Kaiser Family Foundation, 2004). Participants were more likely to have a positive experience when their providers communicated with them and shared information with them about their health in a way that they could understand and took the time to answer any questions that they had. Thus, communication was found to be a very important component of doctor and patient interactions.

The effect of communication on receipt of care is witnessed through participants' attitude about the health care system. The majority of participants stated their overall level of comfort in communicating with their primary care physician or eye doctor was good, very good, or excellent, although many participants reported poor relationships with providers.

Despite the overall high level of comfort in communicating with providers, many participants stated that the level of communication between providers and themselves was hampered by short amounts of time spent with providers, difficulty in obtaining a complete picture about their health status, difficulty understanding medical terminology, and language barriers. The few participants who reported difficulty understanding medical terminology were from African American, Hispanic/Latino, or Asian racial/ethnic backgrounds. Language was reported to be an issue among the Hispanic/Latino and Asian racial/ethnic groups. Participants also mentioned that for people who do not speak English well, the quality of care received is also impacted.

The examples of poor or hampered communication with providers was found to frustrate participants and, in some cases, left them hesitant about seeking followup care. Many participants stated that they do not see an eye doctor because their primary care physician makes no mention of it. An overwhelming majority of participants across

each of the three cities also reported that their primary care physician no longer conducts a vision screening or asks them to read an eye chart. Doctors' inattention to eye health and their lack of communication about eye health issues are forms of non-verbal communication and convey messages about the perceived unimportance of eyesight.

#### **4. What Are the Cultural Factors That Influence the Receipt of Eye Care?**

The influence of culture on receiving eye care is noteworthy, although cultural factors were not reported by every racial and ethnic group. Nonetheless, several themes with cultural implications were noted to directly influence the receipt of eye care. Cultural issues that influence the receipt of eye care were traditional, folk, and home remedy use, primarily by African Americans; an ideology to not use preventive medicine, embedded primarily within the Hispanic/Latino culture; an ideology to "wait and see" among African Americans; and an ideology that African American males are less likely to receive health care services. Also, undertones of perceived racial and ethnic discrimination and bias were noted in comments, particularly among the African American and Hispanic/Latino participants. These perceptions affect beliefs about the health care system, and in some instances, the receipt of care.

Traditional, folk, and home remedies were reportedly used to cure eye problems before going to see an eye care professional. In the majority of cases, these remedies were all the care received, as participants reported that these remedies cured any ailments they were experiencing with their eyes. Cultural factors, unlike factors such as communication and knowledge, appear to directly serve as barriers to the receipt of eye care.

Perhaps through better education, the influence of some of these cultural factors can be reduced. In many cases, "waiting it out" and not taking a preventive stance related to health care can have devastating consequences. Furthermore, gender issues in the receipt of care need to be addressed. What appears to be driving gender disparities in the receipt of care is that males do not want to seem dependent or weak. In some manner, this attitude must be confronted, such that if care is not received, they will indeed become dependent and weak. What will also pose a difficulty in increasing the receipt of eye care is that many of the traditional, folk, and home remedies were found to work. It is not the author's contention to downplay or dismiss the effectiveness of and trust certain cultures have in traditional therapies, however the consultation of an eye care professional should not be discounted if avenues in which to do so are available (i.e., insurance coverage). Messages should be disseminated that traditional

medicine can and should be used in conjunction with western medicine, but perhaps that will require western medicine to more gainfully accept the significance of traditional medicine.

## **5. Other Factors That Influence the Receipt of Eye Care**

Outside of attitudes, knowledge, communication, and culture, a major factor reported to influence the receipt of eye care was cost. In every focus group, cost was reported as a barrier to receiving eye care services.

Cost was also mentioned as influencing whether followup and recommended services, such as prescriptions, were obtained. The cost of services is prohibitive, particularly when it comes to prescribing followup care. In many instances, followup care, even in the form of getting glasses, can be just as expensive, if not more, than the professional eye care services that were received. Eye drops, glasses, and lenses were reported to be very expensive. In many cases, eye care was just received from the local pharmacy or drug store, which meant that many participants were self diagnosing their eye problems and identifying adequate prescription lenses on their own. This process completely circumvents the possibility of an eye care professional performing an eye exam diagnosing other vision-related problems. The issue of cost also relates to the concerns of class and economic discrimination and bias that were raised by participants among each of the four racial/ethnic groups. Several participants were noted to perceive the health care system and doctors as being insensitive or discriminating, based on economic status and the ability to pay for health care services/type of insurance.

Lastly, the fact that many eye care services are not covered as a standard service in most general health plans was reported to be another factor that influences the receipt of eye care. Many participants discussed difficulty in receiving eye care services because of a lack of such services. Unfortunately, this lack of services also appeared to influence participants to think about eye care separately and not as a part of their general health. Also, many participants, particularly in Miami and San Francisco, stated that a referral was needed to seek eye care services. This referral process meant that additional time was required to make an appointment to see their primary care physician for a referral, and then to get an appointment to see an eye care professional. This process also contributes to additional cost outlays on behalf of the participants, as they have to pay two co-payments when their primary intention was to see just an eye care professional.

## **6. Factors That Influence the Receipt of Eye Care and Differ by Race/Ethnicity**

The majority of the factors identified as influencing the receipt of eye care services for the 180 participants were reported to be factors affecting each of the four racial and ethnic groups studies. Each of the four racial and ethnic groups mentioned attitudes and knowledge as issues that influence the receipt of eye care. No significant differences in factors that influence the receipt of eye care were witnessed by the three focus group locations, with the exception of referrals, which were cited to influence the receipt of eye care slightly more in San Francisco and Miami than in Chicago.

The most differences were according to race and ethnicity when examining how culture and communication influence the receipt of eye care. Although the majority of participants felt good about the way their medical care provider explained health information to them, a few African American and Hispanic/Latino participants reported that they have difficulty understanding medical terminology. Language, primarily among Hispanic/Latino and Asian participants, was also reported to impact communication and the level of understanding that patients and participants have about their health.

Cultural factors also influenced the receipt of eye care by race/ethnicity. African American, Hispanic/Latino, and Asian participants used traditional, folk, or home remedies when they experience problems with their eyes before deciding to go to the doctor. Hispanic/Latino participants noted that within their community, preventive medicine is not practiced as it should be. Also, some of the Hispanic/Latino and African American participants mentioned that they are unlikely to go to the doctor unless their condition is really bad. Washing the eye out and taking a “wait and see” approach were reportedly done by African American participants before contacting their primary care physician or eye doctor. African American, Hispanic/Latino, and some Caucasian participants mentioned that males tend to not like going to the doctor. Lastly, undertones of perceived racial and ethnic discrimination and bias were present in several of the statements made by African American and Hispanic/Latino participants, which may influence the receipt of eye care services.

Other factors that differed by race and ethnicity were fear and denial about receiving eye examinations and class discrimination and bias in the health care system. Fear and denial about receiving eye examinations were reported by all racial/ethnic groups with the exception of Asian participants. A number of participants, primarily those from racial and ethnic minority backgrounds, found doctors or the health care system to be insensitive and discriminating based on economic status and the ability to pay for health care services/type of insurance.

## B. Discussion

Several of the issues that influence the receipt of eye care are cyclical in nature. There is a lack of knowledge about eye diseases and disorders, which may be due to a lack of communication between providers and patients. The lack of communication may, in turn, be due to inadequate relationships reported by participants with providers. Participants are thirsty for knowledge and typically have a number of questions that need to be answered. However, in many cases, their providers do not take the time to answer those questions and better educate the participants about possible conditions, including eye disease. Poor relationships and communication with providers can lead to a lack of education about health conditions and can ultimately translate into a lack of received health care services. If Americans are somehow better informed about eye disease and disorders, either in their doctors' office or via other channels, such as PSAs, pamphlets, and advertisements, patients will be better educated and equipped with information with which they can make health care decisions and take action.

Attempts should be made to incorporate regular eye screenings and the sharing of eye health information into regular check-ups and general physical examinations. Study data indicate that screening for serious eye disease in a primary care setting is an efficient mechanism to use for the identification of patients with undetected ocular disorders that require followup or treatment (Strahlman, Ford, Whelton, and Sommer, 1990) Generally speaking, the majority of focus group participants had seen a doctor in the past 12 months. Basic eye screenings would allow for doctors to examine patients' eyes and initiate conversation about the participant's eyesight. At a minimum, physicians should ask, "How is your eyesight? Have you been experiencing any problems seeing lately?" Many participants noted that they do not pay attention to their eyes because their physician makes no mention of it. Even the process of physicians doing something as simple as taking a light and looking into the patient's eye may spark conversation and raise attention to eye problems that participants may be having.

On the other hand, consumers of eye and/or health care services should be educated directly. An overwhelming majority of participants was reported to value eyesight. Many participants stated that they wanted to see their children, flowers, and the beauty that life offers. Eye health messages need to appeal to these feelings and remind people about how they value their eyesight, particularly in terms of a decreased quality of their life if they were to lose their eyesight. Messages that provide information about the benefits of regular eye examinations and recommended intervals for obtaining eye exams is necessary. Providing statistics about the prevalence of eye diseases and disorders among older Americans will help increase awareness and serve as a

foundation for persuading Americans to take eye care seriously. Educational campaigns need to place these concepts in perspective for Americans so that they will be informed when to make proper decisions about their eye health. People need to be educated about preventive measures they can take to protect their vision and things they should be mindful of that can indicate the onset of vision problems. Effective education may result in an increase of preventive measures and the receipt of eye care to ensure healthy vision.

Study findings reveal that perceptions of disrespect were reported more frequently among racial and ethnic minority participants. Elsewhere, it has been reported that minorities were significantly more likely to report being treated with disrespect or being looked down upon in the patient-provider relationship. Persons who thought that they would have received better treatment if they were of a different race were significantly less likely to receive optimal chronic disease screening and more likely to not follow the doctor's advice or to put off care (Blanchard & Lurie, 2004). Perceptions of racial and ethnic discrimination, bias, and insensitivity should be further investigated as they may impact the receipt of preventive eye screenings and examinations.

Also making an influence on the receipt of eye care are the number of options Americans have in which they can receive eye care services that do not need an eye care professional's prescription or approval to obtain. Many participants obtained eye glasses from their local pharmacy or drug store and other retail locations. Costco and Wal-Mart were also places reported to sell eye wear. Many participants feel that purchasing eye wear is all that is necessary to correct their ailing vision. This occurrence does not allow for an eye care professional to adequately examine one's eyes and possibly diagnose other problems that may be present, such as eye disease.

A number of participants noted denial and that they are fearful of hearing bad news and having to face the consequences. Quigley et al. report that an important barrier to accessing care is denial of the potential seriousness of an eye problem (Quigley, Park, Tracey, and Pollack, 2002). It needs to be communicated to people in this situation that being informed is better than being uninformed. People should be educated that being knowledgeable of possible eye disease is the best way to prevent blindness or advanced stages of the disease. It is important to know that being fearful of bad news and possible consequences of the disease will only lead to worse outcomes.

Many of the identified barriers to the receipt of eye care will take a lot of effort to address. Barriers result from a number of different factors, such as time spent with patients, and access issues like insurance coverage. However, barriers dealing with



attitudes and knowledge should be tackled first. One attitude is that wearing glasses is a sign of getting old, and therefore participants reported that they are more likely to avoid getting glasses. The effects of deteriorating sight and the benefits of obtaining eyewear should be highlighted. Messages about the importance of taking care of one's eyes should mimic other educational campaigns, such as breast, colon, and prostate cancer, cholesterol, and high blood pressure awareness campaigns. An overwhelming majority of participants reported that they have never seen a PSA about eye health. At the same time, many participants had heard of educational campaigns about heart disease and breast cancer, and are taking action to prevent the onset of those diseases.

### **C. Recommendations**

As mentioned earlier, many of the barriers identified to receiving eye care result from a number of different factors and will take a lot of effort to address. However, barriers relating to attitudes and knowledge should be addressed first. To help educate the masses about eye disease and increase healthy vision, the following recommendations should be considered:

- The majority of participants report going to their primary care doctor or eye care professional when experiencing problems with their eyes. Information about eye diseases and disorders, as well as preventive measures they can take to avoid such problems, should be made available in these office settings.
- As most participants report using the Internet to gather health information, the NEI should continue its efforts to provide timely and up-to-date information about eye health on its Website. To bring attention to certain eye diseases and disorders, the NEI should showcase a particular eye disease or disorder each month on its home page with links to obtain more information about that disease or disorder. It would also be worthwhile to establish partnerships with other organizations where the NEI Internet address could be placed on their Websites to link them to the eye health information located on the NEI Website.
- Fear was shown to be a barrier to receiving health and/or eye care services. It is important to educate people with this barrier that not being knowledgeable about their health status will leave them in a worse position to ultimately improve their health status. Eye disease should be caught shortly after, if not before, the onset of the disease. Perhaps implementation of a "Fear is not an

option. Knowing is half the battle” campaign would be an effective way to confront fear as a barrier to receiving eye care services.

- About half of all the participants had a good understanding of what a dilated eye examination was. Efforts should continue to educate the masses about what a dilated eye exam is, the benefits of obtaining such an exam, and the recommended intervals that one should receive dilated eye examinations.
- The majority of participants noted that their primary care physician does not conduct a general eye screening during general physical examinations. Several participants suggested that a screening should be incorporated into general physical examinations to bring attention to eye care. Perhaps if general routine eye screenings were conducted as part of primary care physicians’ examinations, it would heighten awareness of eye problems. The patient could then be further evaluated by their primary care physician or referred to an eye care professional.
- Several participants reported that they do not prioritize the receipt of eye care services or are less apt to receive eye care services because their physician makes no mention of it. Doctors should be encouraged to remember that eye care is part and parcel of total health care. They should also be encouraged to ask the patient about any eye problems during general physical examinations. Additionally, more involvement on behalf of primary care providers in the education of Americans about what they can do to prevent vision loss may positively affect patient prioritization of seeking eye care services.
- An overwhelming majority of participants value their eyesight. Many participants stated that they wanted to see their children, flowers, and the beauty that life offers. Eye health messages should appeal to these feelings and remind people about how they value their eyesight, particularly in terms of demonstrating the significance of what can happen to their quality of life if they were to lose their eyesight.
- The majority of participants spoke of the need for better education about various eye diseases and the need to overcome the obstacles to receiving eye care that were mentioned in the focus group discussions. The NEI should evaluate other health education and awareness campaigns and strategically develop future awareness campaigns for eye care.

- A lack of a perception of need for regular eye examinations was cited as a barrier to the receipt of eye care services. To correct false perceptions of need, published information about the benefits of regular eye examinations and recommended intervals for obtaining eye exams is necessary. Additionally, providing statistics about the prevalence of visual impairments and blindness among older Americans may help increase awareness and serve as a foundation for educating consumers to increase the receipt of eye care services.
- Many participants spoke of the need to receive eye health information via television, radio, and other advertisements. Nominating a spokesperson was mentioned as being a great way to educate people about eye health by several participants. Evaluation of these forms of advertising and education should be considered.
- Formats such as videos, PSAs, and other visual means of communicating information were requested formats by most participants for receiving eye health information. These formats should be widely used to educate and transfer messages about eye health.
- A brief factsheet about eye diseases and risk factors should be developed and made available in doctor's offices and mailed to interested organizations, such as insurance companies and employers.
- The primary purpose of qualitative research is to develop hypotheses that can be tested quantitatively to determine generalizability. It is recommended that the major themes from this research be reviewed for insertion in a major quantitative and nationally representative study.

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## Appendices

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# Appendix A

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**Screener's Guide**  
Miami, FL  
Chicago, IL  
San Francisco, CA

## **Participant Screener: Miami, FL**

### **Recruitment Criteria**

The study sample of the general population will include fluent English-speaking males and females over the age of 40 in San Francisco, CA; Chicago, IL; and Miami, FL. A total of 180 participants will be recruited to take part in a total of 20 discussion groups. Approximately 54 participants will be African American, 54 Hispanic/Latino, 36 White, and 36 Asian.

#### **Miami, FL**

*Group 1* – Hispanic/Latino

*Group 2* – Hispanic/Latino

*Group 3* – African American

*Group 4* – African American

### **General Notes**

- The participants should be adults 40 years and older.
- Each group should be composed of approximately equal proportions of men and women.
- All participants must be able to read and understand English.
- Persons who work at or have worked at, have an immediate family member who works for the National Eye Institute or any state or local government agency responsible for eye care shall be excluded.
- Persons who work in or have worked in, have an immediate family member who works in the eye care industry (i.e. Lens Crafters, For Eyes, ophthalmologist, optometrists, etc.) or the health care industry in general (i.e. physicians, nurses, health educators, etc.) shall also be excluded.
- Participants shall not have participated in a focus group, discussion group or other qualitative research study during the past year. Participation in telephone surveys is allowable.
- Participants will be paid between \$70 each for their participation.
- Discussion groups will last approximately 2 hours.
- Dinner (deli platter) will be offered to participants in the 5:30 p.m. group. Refreshments (light snacks) will be offered to participants in the 8:00 p.m. group.
- Discussion groups will be audiotaped. The first focus group will be videotaped.
- The identity of the participants will remain confidential.



## Scheduling

The schedule for the discussion groups for Miami, FL, is as follows.

Date	Time	Participants
Mar. 9	5:30 p.m.	Hispanic/Latino
Jan. 9	8:00 p.m.	Hispanic/Latino
Mar. 10	5:30 p.m.	African American
Mar. 10	8:00 p.m.	African American

## Introduction

Good afternoon/evening. My name is [name] and I am calling from [facility name]. We are conducting research to gather information about factors that influence whether you receive care for your eyes. This research is being conducted by ORC Macro International on behalf of the National Eye Institute (NEI) at the National Institutes of Health (NIH). Would you give me 5 minutes of your time to answer a few questions?

## Screening Questions

1. Is there a member of your household who is age 40 or above?
  - Yes                      ► ask to speak with that person and REPEAT introduction
  - No                            ► terminate (thank respondent politely)
2. Gender
  - Male                        (NOTE: Once 50% of one gender is obtained then:
  - Female                    ► terminate (thank respondent politely) and select only for opposite gender)
3. Do you speak English fluently?
  - Yes                        ► continue
  - No                           ► terminate (thank respondent politely)
4. Have you or any member of your immediate family ever worked for the National Eye Institute or any other Federal, state or local agency that is responsible for eye Care?
  - Yes                        ► terminate (thank respondent politely)
  - No                           ► continue

5. What is your occupation? If retired, what was your occupation before you retired?

- Eye care professional (i.e., ophthalmologist, optometrist or optician) ▶ terminate (thank respondent politely)
- Health educator ▶ terminate (thank respondent politely)
- Health care provider ▶ terminate (thank respondent politely)

All others, make note below.

- \_\_\_\_\_ ▶ continue

6. Which ethnic group do you identify with primarily?

- White, not Hispanic or Latino Origin ▶ terminate (thank respondent politely)
- Black or African American ▶ continue, invite to African American group
- Hispanic or Latino Origin ▶ continue, invite to Hispanic/Latino group
- Asian or Pacific Islander ▶ terminate (thank respondent politely)

All others, invite to an alternative group if respondent's appropriate group is not filled.

- American Indian or Alaska Native ▶ terminate (thank respondent politely)
- Other ▶ terminate (thank respondent politely)
- Refused ▶ terminate (thank respondent politely)

7. In the past year, have you participated in any discussion groups, mock juries, or other market research studies? **[Participation in telephone surveys is allowable]**

- Yes ▶ terminate (thank respondent politely)
- No ▶ continue

## Invitation

We would like to invite you to participate in a discussion with one of our researchers to talk about eye care. The discussion will last approximately 2 hours. Your participation and everything you say during the discussion will remain confidential. Your name will not be used in any results from this research.

The discussion group will take place on:

- ▶ Wednesday, March 9, 2005 at [5:30 p.m./ 8:00 p.m.] (for Hispanic/Latino respondents)
- ▶ Thursday, March 10, 2005 at [5:30 p.m./ 8:00 p.m.] (for African American respondents)

at our offices. You will receive \$70 for participating in this group.

Additionally, you will be served [insert type of food served] before the discussion begins. Are you interested in participating in this discussion group?

- Yes                      ► continue
- No                         ► terminate (thank respondent politely)

### **Personal Information**

**I would like to send you a confirmation and informed consent letter and directions to our facility. In order to do so, would you please tell me your name, mailing address, email address (if available) (or fax number) and a phone number where you can be reached:**

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**City:** \_\_\_\_\_ **State:** \_\_\_\_\_ **Zip:** \_\_\_\_\_

**Phone:** \_\_\_\_\_ **Fax:** \_\_\_\_\_

**Email Address:** \_\_\_\_\_ **(optional)**

**Date of discussion group:** \_\_\_\_\_

**Time of discussion group:** \_\_\_\_\_

**We are only inviting a limited number of people, so it is very important that you notify us as soon as possible if for some reason you are unable to attend. Please call [Recruiter Contact] at [telephone number] if this should happen. We look forward to seeing you on March [9 / 10] at [5:30 p.m. / 8:00 p.m.]. If you use reading glasses, please bring them with you to the discussion group. Also be sure to review and sign the informed consent letter and bring it with you to turn in on the day of the discussion. Thank you for your time.**

## Participant Screener: Chicago, IL

### Recruitment Criteria

The study sample of the general population will include fluent English-speaking males and females over the age of 40 in San Francisco, CA; Chicago, IL; and Miami, FL. A total of 180 participants will be recruited to take part in a total of 20 discussion groups. Approximately 54 participants will be African American, 54 Hispanic/Latino, 36 White, and 36 Asian.

#### Chicago, IL

*Group 1 – Caucasian*

*Group 2 – Caucasian*

*Group 3 – Asian*

*Group 4 – Asian*

*Group 5 – Hispanic/Latino*

*Group 6 – Hispanic/Latino*

*Group 7 – African American*

*Group 8 – African American*

### General Notes

- The participants should be adults 40 years and older.
- Each group should be composed of approximately equal proportions of men and women.
- All participants must be able to read and understand English.
- Persons who work at or have worked at, have an immediate family member who works for the National Eye Institute or any state or local government agency responsible for eye care shall be excluded.
- Persons who work in or have worked in, have an immediate family member who works in the eye care industry (i.e. Lens Crafters, For Eyes, ophthalmologist, optometrists, etc.) or the health care industry in general (i.e. physicians, nurses, health educators, etc.) shall also be excluded.
- Participants shall not have participated in a focus group, discussion group or other qualitative research study during the past year. Participation in telephone surveys is allowable.
- Participants will be paid between \$70 each for their participation.
- Discussion groups will last approximately 2 hours.
- Dinner (deli platter) will be offered to participants in the 5:30 p.m. group. Refreshments (light snacks) will be offered to participants in the 8:00 p.m. group.
- Discussion groups will be audiotaped.
- The identity of the participants will remain confidential.

## Scheduling

The schedule for the discussion groups for Chicago, IL is as follows.

Date	Time	Participants
Mar. 21	5:30 p.m.	Caucasian
Mar. 21	8:00 p.m.	Caucasian
Mar. 22	5:30 p.m.	Asian
Mar. 22	8:00 p.m.	Asian
Mar. 23	5:30 p.m.	Hispanic/Latino
Mar. 23	8:00 p.m.	Hispanic/Latino
Mar. 24	5:30 p.m.	African American
Mar. 24	8:00 p.m.	African American

## Introduction

Good afternoon/evening. My name is [name] and I am calling from [facility name]. We are conducting research to gather information about factors that influence whether you receive care for your eyes. This research is being conducted by ORC Macro International on behalf of the National Eye Institute (NEI) at the National Institutes of Health (NIH). Would you give me 5 minutes of your time to answer a few questions?

## Screening Questions

1. Is there a member of your household who is age 40 or above?
  - Yes                      ► ask to speak with that person and REPEAT introduction
  - No                            ► terminate (thank respondent politely)
2. Gender
  - Male                        (NOTE: Once 50% of one gender is obtained then:
  - Female                    ► terminate (thank respondent politely) and select only for opposite gender)
3. Do you speak English fluently?
  - Yes                        ► continue
  - No                         ► terminate (thank respondent politely)



## Invitation

We would like to invite you to participate in a discussion with one of our researchers to talk about eye care. The discussion will last approximately 2 hours. Your participation and everything you say during the discussion will remain confidential. Your name will not be used in any results from this research.

The discussion group will take place on:

- ▶ Monday, March 21, 2005 at [5:30 p.m./ 8:00 p.m.] (for Caucasian respondents)
- ▶ Tuesday, March 22, 2005 at [5:30 p.m./ 8:00 p.m.] (for Asian American respondents)
- ▶ Wednesday, March 23, 2005 at [5:30 p.m./ 8:00 p.m.] (for Hispanic/Latino respondents)
- ▶ Thursday, March 24, 2005 at [5:30 p.m./ 8:00 p.m.] (for African American respondents)

at our offices. You will receive \$70 for participating in this group.

Additionally, you will be served [insert type of food served] before the discussion begins. Are you interested in participating in this discussion group?

- Yes                      ▶ continue
- No                            ▶ terminate (thank respondent politely)

## Personal Information

**I would like to send you a confirmation and informed consent letter and directions to our facility. In order to do so, would you please tell me your name, mailing address, email address (if available) (or fax number) and a phone number where you can be reached:**

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**City:** \_\_\_\_\_ **State:** \_\_\_\_\_ **Zip:** \_\_\_\_\_

**Phone:** \_\_\_\_\_ **Fax:** \_\_\_\_\_

**Email Address:** \_\_\_\_\_ (optional)

**Date of discussion group:** \_\_\_\_\_

**Time of discussion group: \_\_\_\_\_**

**We are only inviting a limited number of people, so it is very important that you notify us as soon as possible if for some reason you are unable to attend. Please call [Recruiter Contact] at [telephone number] if this should happen. We look forward to seeing you on March [21 / 22 / 23 / 24] at [5:30 p.m. / 8:00 p.m.]. If you use reading glasses, please bring them with you to the discussion group. Also be sure to review and sign the informed consent letter and bring it with you to turn in on the day of the discussion. Thank you for your time.**



## Participant Screener: San Francisco, CA

### Recruitment Criteria

The study sample of the general population will include fluent English-speaking males and females over the age of 40 in San Francisco, CA; Chicago, IL; and Miami, FL. A total of 180 participants will be recruited to take part in a total of 20 discussion groups. Approximately 54 participants will be African American, 54 Hispanic/Latino, 36 White, and 36 Asian.

#### **San Francisco, CA**

*Group 1 – Caucasian*

*Group 2 – Caucasian*

*Group 3 – Asian*

*Group 4 – Asian*

*Group 5 – Hispanic/Latino*

*Group 6 – Hispanic/Latino*

*Group 7 – African American*

*Group 8 – African American*

### General Notes

- The participants should be adults 40 years and older.
- Each group should be composed of approximately equal proportions of men and women.
- All participants must be able to read and understand English.
- Persons who work at or have worked at, have an immediate family member who works for the National Eye Institute or any state or local government agency responsible for eye care shall be excluded.
- Persons who work in or have worked in, have an immediate family member who works in the eye care industry (i.e. Lens Crafters, For Eyes, ophthalmologist, optometrists, etc.) or the health care industry in general (i.e. physicians, nurses, health educators, etc.) shall also be excluded.
- Participants shall not have participated in a focus group, discussion group or other qualitative research study during the past year. Participation in telephone surveys is allowable.
- Participants will be paid between \$70 each for their participation.
- Discussion groups will last approximately 2 hours.
- Dinner (deli platter) will be offered to participants in the 5:30 p.m. group. Refreshments (light snacks) will be offered to participants in the 8:00 p.m. group.
- Discussion groups will be audiotaped.
- The identity of the participants will remain confidential.

## Scheduling

The schedule for the discussion groups for San Francisco, CA, is as follows.

Date	Time	Participants
Apr. 4	5:30 p.m.	Caucasian
Apr. 4	8:00 p.m.	Caucasian
Apr. 5	5:30 p.m.	Asian
Apr. 5	8:00 p.m.	Asian
Apr. 6	5:30 p.m.	Hispanic/Latino
Apr. 6	8:00 p.m.	Hispanic/Latino
Apr. 7	5:30 p.m.	African American
Apr. 7	8:00 p.m.	African American

## Introduction

Good afternoon/evening. My name is [name] and I am calling from [facility name]. We are conducting research to gather information about factors that influence whether you receive care for your eyes. This research is being conducted by ORC Macro International on behalf of the National Eye Institute (NEI) at the National Institutes of Health (NIH). Would you give me 5 minutes of your time to answer a few questions?

## Screening Questions

1. Is there a member of your household who is age 40 or above?
  - Yes                      ► ask to speak with that person and REPEAT introduction
  - No                            ► terminate (thank respondent politely)
2. Gender
  - Male                        (NOTE: Once 50% of one gender is obtained then:
  - Female                      ► terminate (thank respondent politely) and select only for opposite gender)
3. Do you speak English fluently?
  - Yes                         ► continue
  - No                            ► terminate (thank respondent politely)

4. Have you or any member of your immediate family ever worked for the National Eye Institute or any other Federal, state or local agency that is responsible for eye Care?

- Yes                   ▶ terminate (thank respondent politely)
- No                       ▶ continue

5. What is your occupation? If retired, what was your occupation before you retired?

- Eye care professional                   ▶ terminate (thank respondent politely)  
(i.e. ophthalmologist, optometrist or optician)
- Health educator                       ▶ terminate (thank respondent politely)
- Health care provider                   ▶ terminate (thank respondent politely)

All others, make note below.

- \_\_\_\_\_ ▶ continue

6. Which ethnic group do you identify with primarily?

- White, not Hispanic or Latino Origin ▶ continue, invite to White American group
- Black or African American           ▶ continue, invite to African American group
- Hispanic or Latino Origin           ▶ continue, invite to Hispanic/Latino group
- Asian or Pacific Islander           ▶ continue, invite to Asian American group

All others, invite to an alternative group if respondent's appropriate group is not filled.

- American Indian or Alaska Native   ▶ terminate (thank respondent politely)
- Other                                   ▶ terminate (thank respondent politely)
- Refused                               ▶ terminate (thank respondent politely)

7. In the past year, have you participated in any discussion groups, mock juries, or other market research studies? [**Participation in telephone surveys is allowable**]

- Yes                       ▶ terminate (thank respondent politely)
- No                       ▶ continue

## Invitation

We would like to invite you to participate in a discussion with one of our researchers to talk about eye care. The discussion will last approximately 2 hours. Your participation and everything you say during the discussion will remain confidential. Your name will not be used in any results from this research.

The discussion group will take place on:

- ▶ Monday, April 4, 2005 at [5:30 p.m./ 8:00 p.m.] (for Caucasian respondents)
- ▶ Tuesday, April 5, 2005 at [5:30 p.m./ 8:00 p.m.] (for Asian American respondents)
- ▶ Wednesday, April 6, 2005 at [5:30 p.m./ 8:00 p.m.] (for Hispanic/Latino respondents)
- ▶ Thursday, April 7, 2005 at [5:30 p.m./ 8:00 p.m.] (for African American respondents)

at our offices. You will receive \$70 for participating in this group.

Additionally, you will be served [insert type of food served] before the discussion begins. Are you interested in participating in this discussion group?

- Yes                      ▶ continue
- No                            ▶ terminate (thank respondent politely)

## Personal Information

**I would like to send you a confirmation and informed consent letter and directions to our facility. In order to do so, would you please tell me your name, mailing address, email address (if available) (or fax number) and a phone number where you can be reached:**

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**City:** \_\_\_\_\_ **State:** \_\_\_\_\_ **Zip:** \_\_\_\_\_

**Phone:** \_\_\_\_\_ **Fax:** \_\_\_\_\_

**Email Address:** \_\_\_\_\_ (optional)

**Date of discussion group:** \_\_\_\_\_

**Time of discussion group:** \_\_\_\_\_

**We are only inviting a limited number of people, so it is very important that you notify us as soon as possible if for some reason you are unable to attend. Please call [Recruiter Contact] at [telephone number] if this should happen. We look forward to seeing you on April [4 / 5 / 6 / 7] at [5:30 p.m. / 8:00 p.m.]. If you use reading glasses, please bring them with you to the discussion group. Also be sure to review and sign the informed consent letter and bring it with you to turn in on the day of the discussion. Thank you for your time.**



# Appendix B

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Informed Consent

## INFORMED CONSENT FOR PARTICIPATION IN RESEARCH ACTIVITIES

### IDENTIFICATION OF VARIABLES THAT INFLUENCE THE RECEIPT OF EYE CARE

- I. **PURPOSE OF THIS RESEARCH STUDY** I have been invited to be in a research study to gather information about what influences me to receive care for my eyes. I was selected as a possible participant because I am an English-speaking adult in the age range the research is studying. I will participate in a focus group discussion that will last almost two hours. I have been asked to read this form and ask any questions that I may have before agreeing to participate in this study.
- II. **WHAT WILL BE DONE/PROCEDURES** The purpose of this study is to learn about what influences people to see an eye doctor. I will be asked to participate in discussions about my general health, my vision, and what may get in the way of me going to an eye doctor. The discussions should last about two hours and will be audiotaped and observed by project staff from the National Eye Institute (NEI) and ORC Macro.
- III. **POSSIBLE BENEFITS** I have been informed that my participation in this research may not benefit me or my health. Potential benefit to others may result from the knowledge gained from my participation in this research study.
- IV. **POSSIBLE RISKS AND DISCOMFORTS** I have been informed that the risks and discomforts of participating in this study are minimal. I have been informed that, depending upon my answers about going to an eye doctor I may feel uncomfortable or possibly embarrassed.
- V. **CONFIDENTIALITY OF RECORDS** Any information learned from this study in which I might be identified will remain confidential and will be disclosed only with my permission, to the extent allowed by law. I have been informed to avoid using my last name during the focus group. All records and tapes will be stored in a locked file cabinet in a locked room. Only the investigator and members of the research team will have access to these records. If information learned from this study is published, I will not be identified by name. By signing this form, however, I allow the research study investigator to make my records available to the University of Maryland Baltimore County (UMBC) Institutional Review Board (IRB) Office and regulatory agencies, as required by law.
- VI. **OFFER TO ANSWER QUESTIONS** The principal investigator Mr. Robert Alexander, has offered to and has answered any and all questions regarding my participation in this research study. If I have any further questions, I can contact Mr. Robert Alexander.

- VII. SPONSOR OF THE RESEARCH** I have been informed that this research is sponsored by the National Eye Institute.
- VIII. PAYMENT TO SUBJECT FOR PARTICIPATION** I have been informed that I will receive \$70 for my participation in this study, regardless of my completion of the focus group discussion.
- IX. VOLUNTARY PARTICIPATION WITH RIGHT OF REFUSAL** I have been informed that my participation in this study is completely voluntary. I am free to withdraw my consent for participation in the study at any time.
- X. IRB REVIEW AND IMPARTIAL THIRD PARTY** This study has been reviewed and approved by the UMBC Institutional Review Board (IRB) and the ORC Macro IRB. A representative of the UMBC IRB Office is available to discuss the review process or my rights as a research subject. The telephone number of the IRB Office is (410) 455-2737.
- XI. SIGNATURE FOR CONSENT** The above-named investigator has answered my questions and I agree to be a research subject in this study.

Participant's Name: \_\_\_\_\_ Date: \_\_\_\_\_

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Investigator's Signature: \_\_\_\_\_ Date: \_\_\_\_\_





# **Appendix C**

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**Moderator's Guide**

# IDENTIFICATION OF VARIABLES THAT INFLUENCE THE RECEIPT OF EYE CARE

## Moderator's Guide

### Welcome

Good afternoon, my name is (moderator's name) and I will be your moderator for this session. I am employed by a management consulting firm located just outside of Washington, DC. Our client, the National Eye Institute (NEI), one of the 27 institutes and centers at the National Institutes of Health (NIH), is interested in learning information about factors that influence whether you receive care for your eyes. I want to let you know that I am not an expert in eye care, rather I am an independent moderator trained to facilitate our discussion.

### Introductions

Before we begin, let's introduce ourselves. As I mentioned, I am \_\_\_\_\_. My job is to ask you questions and, if needed, to ask you to clarify your response. It is important for you to know that there are no right and wrong answers here. We just want to get a better understanding of why and when you obtain care for your eyesight or what prevents you from getting it at all.

Let's begin on my left and move around the table. Tell me what you would like to be called and how long you have lived here. Thank you.

### Ground Rules

Now I would like to talk a little bit about our ground rules for today's discussion. Ground rules are our guidelines for operating today so that we can complete our task in a manner that is respectful of everyone and provides all of you with the opportunity to express your thoughts safely and confidentially.

- You have been invited here to offer your views and opinions.
- **Everyone's** participation is important.
- Please speak **one** at a time.
- As I said before, there are **no** right or wrong answers.

- It's **okay** to be critical of the topic presented and to disagree but be willing to offer your own views and opinions.
- **For first group in Miami ONLY:** This session will be videotaped and audiotaped. This recording allows us to capture everything that is being said today, which we will need to write our report to the National Eye Institute. (If there is a one-way mirror, mention that there are observers in the next room and mention who the observers are and why they are behind the mirror. Also mention where the audio equipment is located if it is not obvious.) NOTE: Skip the next bullet (first **Miami** group only).
- This session will be audiotaped. This recording allows us to capture everything that is being said today, which we will need to write our report to the National Eye Institute. (If there is a one-way mirror, mention that there are observers in the next room and mention who the observers are and why they are behind the mirror. Also mention where the audio equipment is located if it is not obvious.)
- All of your answers will be **confidential**, so feel free to say exactly what is on your mind. Nothing will be attributed to any particular person in our report.
- After the discussion group is over, stop by the receptionist's desk to pick up your incentive. There will also be some information and materials available from the National Eye Institute.
- If anyone needs to use the rest room, they are located [specify]. There is no need to stop the discussion.
- Lastly, please turn off the ringers on your cellular phones.

Do you have any questions before we get started?

*Special note: Throughout our discussion, I will use the words primary care physician, ophthalmologist and optometrist. A primary care physician is anyone who you see as a usual source for primary medical care and not a specialist, for example a nurse practitioner or a doctor. An ophthalmologist is a medical doctor who provides total eye care, ranging from comprehensive medical eye examinations, diagnosis of eye diseases and disorders to performing medical, surgical, and laser procedures to treat them. An optometrist is a doctor of optometry and is trained in diagnosing eye disease, prescribing eye glasses and contact lenses.*

## Discussion

### I. General Health

*Let's begin by talking about your health.*

1. How do you rate your general health?
2. How often have you seen a doctor in the past year?
  - Probe: If respondent(s) **has seen** a doctor ask:
    - In general, how would you describe your experiences with medical care providers or doctors?
  - Probe: If respondent(s) **has not seen** a doctor, ask a little bit about why he/she has not.
    - Do you see a need for “wellness” exams or screenings?
    - Why have you chosen not to visit your doctor/medical care provider?
3. How often, if at all, does your primary care provider/doctor conduct a vision screening with you during your office visits? When your primary care provider looks into your eyes, what do you think he/she is looking for?
4. Where do you get information for health issues?
  - Probe:
    - e.g., TV, radio, newspapers, magazines, friends/family, and/or Internet.
      - How many of you use a computer or access the Internet for health information?
      - What type of health information do you seek on the Internet?
5. Have you ever sought information regarding your eyesight/vision?
  - Probe:
    - Would you go any place differently if looking for information about eyes?
      - e.g., Lens Crafters, Costco, ophthalmologist/optometrist, Internet, primary care physician, newspaper, magazines, friends.

## II. Vision Perception and Beliefs

*Let's talk some more about your eyes specifically.*

1. Why is your eyesight important to you?
  - Probe:
    - e.g., precious, indispensable, very important, what would it be like without your eyesight?
2. I'm going to read you 5 things that could happen to anyone.
  1. \_\_\_\_ Losing your memory
  2. \_\_\_\_ Losing your hearing
  3. \_\_\_\_ Losing an arm or a leg
  4. \_\_\_\_ Losing your eyesight
  5. \_\_\_\_ Losing your speech

What would be the worst thing that could happen to you....losing your memory, hearing, an arm or leg, your eyesight, or speech? With a show of hands, how many would say the worst thing would be losing their memory. [say number out loud], how many would say losing your hearing [say number out loud], ....continue through losing your speech.

- Probe: Why do you think losing your memory, hearing, a limb or speech is worse than losing your sight?
3. Why do you think people lose their eyesight?
    - Probe:
      - e.g., disease, injury, older age...
  4. What do you know about preventive eye care?
    - Probe:
      - How can people prevent loss of eyesight (i.e., getting their eyes checked, surgery, diet, vitamins, glasses, drops, protective eye wear)?
        - (If getting their eyes checked is mentioned ask, 'What do you mean by getting your eyes checked?')
      - Do you take any of these steps or actions mentioned?
  5. What do you do when you have problems with your eyesight?
    - Probe:
      - Do you seek help if you have a problem with your eyesight? If yes...
        - Do you go to the doctor? If yes, what kind of doctor?
        - Talk to family or friends?

- If no, do you just cope? What does that mean?
- 6. How often do you think you should you have your vision checked or examined?
  - Probe: **MODERATOR NOTE:** Obtain responses from all participants
    - When was the last time you saw an eye doctor and had your eyes examined? (past year, 1-2 years, more than 2 years, never)
    - Whom did you see? (optometrist, ophthalmologist, other)
    - Why did you go or why have you not gone?
    - Under what circumstances would you go to an eye doctor?
- 7. What have been your experiences with family members or friends that have had problems with their eyesight?
  - Probe:
    - Do family members have vision problems (e.g., glaucoma, cataract, AMD)?
    - What types of experiences have they had as a result of these vision problems (disability, isolation, helplessness, hopelessness, etc.)?
    - Has that stopped you from seeing an eye doctor?
    - How has that experience affected your attitude, beliefs, or behaviors regarding your own sight or vision care?
- 8. How might the possibility that an eye examination confirming that your eyesight is deteriorating or that you are going blind influence whether you visit an eye doctor?

### III. Vision Literacy and Communication

1. Has your primary care physician ever shared information with you about your eyesight?
  - If Yes - Probe:
    - What was discussed?
    - What did your primary care physician ask you?
    - What did you ask your primary care physician?
    - Did the information prompt you to see an eye doctor?
2. Let's discuss communication between you and your eye doctor or other medical care providers.
  - Probe:

- How would you describe your level of comfort in communicating with your primary care physician or eye doctor?
  - Have you ever felt that your doctor did not understand you or your illness?
  - How well do you understand your medical care provider? How do you feel about the way they explain health information to you (technical words, descriptions of procedures, etc.)?
3. What is a dilated eye examination?

*Before we move on, a comprehensive dilated eye examination involves placing drops in the eyes to dilate, or widen, the pupils (the round opening in the center of the eye). A comprehensive dilated eye examination is vital to maintaining and protecting healthy eyesight.*

#### **IV. Attitudes and Cultural Barriers to Vision Health**

1. What beliefs, attitudes, myths, or feelings do you have about going to the eye doctor? What gets in the way of you receiving eye care services?
  - Probe:
    - e.g., (attitudes/perceptions - nothing can be done, fear, time, language, knowledge, shame, guilt insurance, cost, etc.) painful, for older aged people...
    - Do you perceive doctors to be culturally insensitive or discriminating (attitudes/perceptions)?
    - Do you feel your medical care provider respects you?
  
2. What feelings do you have about the health care system that get in the way of you going to an eye doctor?
  - Probe:
    - Do you perceive the health care system to be culturally insensitive or discriminating (attitudes/perceptions)?
    - Do you distrust the health care system?
  
3. Where do the feelings you just shared come from?
  
4. For those of you who mentioned [knowledge/beliefs/fears], how has that stopped you from seeing an eye doctor?
  - Probe:

- Are these [knowledge/beliefs/fears] from your childhood or acquired with age?
5. Are there any cultural or family values get in the way of your going to the eye doctor?
    - Probe:
      - Do these folk beliefs, religious beliefs, beliefs in fatalism, or gender roles affect your receipt of eye care?
  6. After hearing what everyone said, what do you need to do to overcome these obstacles (or barriers)?

## V. Additional NEI Questions

**Moderator:** *Before we end our session today, I want to check with my client and see whether there is anything else I need to ask or clarify. I'll be back in a minute or two.*

1. What else would you like to know about eye health?
  - Probe:
    - Where would you like to receive this information? (e.g., primary care provider, eye care professional, home health aid, staff at senior center, nurse)?
    - What format would you like to receive this information? (e.g. public service announcements, videos, pamphlets in doctor's office, other print publications)?
2. If there was one thing that the National Eye Institute could do to address some of the barriers to receiving eye care mentioned today, what would it be?

On behalf of the NEI, I wish to thank all of you for your input today.





# Appendix D

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Demographic Sheet

## DISCUSSION GROUP PARTICIPANT INFORMATION

Date: \_\_\_\_\_

Time: \_\_\_\_\_

Site:  Miami, FL       Chicago, IL       San Francisco, CA

### 1. Gender:

Male       Female

### 2. Age: (years)

\_\_\_\_\_ years old

### 3. Education (years)

Some high school       College graduate  
 High school graduate/GED       Graduate school/Professional degree  
 Some college

### 4. Marital Status/Living Situation:

Single     Married     Divorced     Widowed     Other \_\_\_\_\_

### 5. Household Income:

No Income       \$50,000 - \$74,999 per year  
 Less than \$ 15,000 per year       \$75,000 - \$99,999 per year  
 \$15,000 - \$24,999 per year       \$100,000 or more per year  
 \$25,000 - \$49,999 per year

### 6. Health insurance:

I have it       I don't have it       Don't know

**7. What type of practice does your primary care physician work in:**

- Private Practice                       Health Maintenance Organization (HMO)  
 Other \_\_\_\_\_

**8. Have you ever been told that you have any of the following eye conditions?** (check all that apply) Please ask if you are uncertain about a particular eye condition.

- Cataract                                       Glaucoma                                       Low Vision  
 Diabetic Eye Disease                       Age-Related Macular Degeneration  
 Other (please specify): \_\_\_\_\_



# Appendix E

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Demographic Profiles by Location

**Table 1: Demographic Profile By Location (Age, Marital Status, Gender)<sup>8</sup>**

<b>Race/Ethnicity</b>	<b>Age</b>	<b>Marital Status</b>	<b>Gender</b>
<b>Miami, FL. (n = 33)</b>			
Hispanic/Latino	40-54 (6) 18% 55-69 (5) 15% 70+ (4) 12%	Yes (12) 36% No (3) 10%	Male (9) 27% Female (6) 18%
African American	40-54 (9) 27% 55-69 (8) 24% 70+ (1) 4%	Yes (5) 15% No (13) 39%	Male (8) 24% Female (10) 31%
<b>Chicago, IL. (n = 86)</b>			
Hispanic/Latino	40-54 (13) 15% 55-69 (5) 6% 70+ (3) 4%	Yes (14) 16% No (7) 8%	Male (10) 12% Female (11) 13%
African American	40-54 (15) 18% 55-69 (6) 7% 70+ (1) 1%	Yes (10) 12% No (13) 15%	Male (10) 12% Female (13) 15%
Caucasian	40-54 (12) 14% 55-69 (11) 13% 70+ (0) 0%	Yes (8) 9% No (15) 17%	Male (12) 14% Female (11) 13%
Asian	40-54 (14) 16% 55-69 (5) 6% 70+ (0) 0%	Yes (16) 19% No (3) 4%	Male (9) 11% Female (9) 11%
<b>San Francisco, CA. (n = 76)</b>			
Hispanic/Latino	40-54 (9) 12% 55-69 (7) 9% 70+ (2) 3%	Yes (6) 7% No (12) 16%	Male (9) 12% Female (8) 11%
African American	40-54 (15) 19% 55-69 (4) 5% 70+ (0) 0%	Yes (9) 12% No (10) 13%	Male (8) 11% Female (10) 14%
Caucasian	40-54 (10) 13% 55-69 (9) 12% 70+ (2) 3%	Yes (9) 12% No (12) 16%	Male (11) 15% Female (10) 14%
Asian	40-54 (8) 11% 55-69 (8) 11% 70+ (2) 3%	Yes (9) 12% No (9) 12%	Male (9) 12% Female (9) 12%

<sup>8</sup> Percentages may not total to 100% due to rounding.

**Table 2: Demographic Profile By Location (Household Income, Education, Insurance Status)<sup>9</sup>**

Race/Ethnicity	Household Income (\$)	Education	Insurance Status
<b>Miami, FL. (n = 33)</b>			
Hispanic/Latino	No Inc. (1) 1% < 15 K (0) 0% 15-24,999 (2) 6% 25-49,999 (4) 12% 50-74,999 (5) 15% 75-99,999 (1) 3% 100,000+ (2) 6%	Some HS (2) 6% HS Grad (0) 0% Some college (5) 15% College Grad (6) 18% Grad/Prof (2) 6%	Yes (14) 44% No (1) 3% Don't Know (0) 0%
African American	No Inc. (1) 1% < 15 K (3) 9% 15-24,999 (5) 15% 25-49,999 (4) 12% 50-74,999 (2) 6% 75-99,999 (2) 6% 100,000+ (1) 3%	Some HS (1) 3% HS Grad (6) 18% Some college (6) 18% College Grad (2) 6% Grad/Prof (3) 10%	Yes (13) 41% No (4) 12% Don't Know (0) 0%
<b>Chicago, IL. (n = 86)</b>			
Hispanic/Latino	No Inc. (0) 0% < 15 K (1) 1% 15-24,999 (4) 5% 25-49,999 (11) 13% 50-74,999 (3) 4% 75-99,999 (2) 2% 100,000+ (0) 0%	Some HS (2) 2% HS Grad (10) 12% Some college (5) 6% College Grad (4) 5% Grad/Prof (0) 0%	Yes (17) 20% No (4) 5% Don't Know (0) 0%
African American	No Inc. (2) 2% < 15 K (1) 1% 15-24,999 (3) 4% 25-49,999 (10) 12% 50-74,999 (2) 2% 75-99,999 (5) 6% 100,000+ (0) 0%	Some HS (1) 1% HS Grad (3) 3% Some college (14) 17% College Grad (2) 2% Grad/Prof (3) 3%	Yes (15) 17% No (7) 8% Don't Know (1) 1%
Caucasian	No Inc. (0) 0% < 15 K (2) 2% 15-24,999 (3) 4% 25-49,999 (7) 8% 50-74,999 (3) 4% 75-99,999 (4) 5% 100,000+ (3) 4%	Some HS (0) 0% HS Grad (5) 6% Some college (6) 7% College Grad (10) 12% Grad/Prof (2) 2%	Yes (19) 22% No (3) 3% Don't Know (1) 1%
Asian	No Inc. (0) 0% < 15 K (1) 1% 15-24,999 (4) 5% 25-49,999 (10) 12% 50-74,999 (3) 4% 75-99,999 (1) 1% 100,000+ (0) 0%	Some HS (3) 3% HS Grad (2) 2% Some college (5) 6% College Grad (5) 6% Grad/Prof (4) 5%	Yes (16) 19% No (3) 3% Don't Know (0) 0%

<sup>9</sup> Percentages may not total to 100% due to rounding.

Race/Ethnicity	Household Income (\$)	Education	Insurance Status
<b>San Francisco, CA. (n = 76)</b>			
Hispanic/Latino	No Inc. (0) 0% < 15 K (0) 0% 15-24,999 K (3) 4% 25-49,999 K (7) 10% 50-74,999 K (5) 7% 75-99,999 K (1) 1% 100,000+ K (2) 3%	Some HS (0) 0% HS Grad (2) 3% Some college (3) 4% College Grad (9) 12% Grad/Prof (4) 5%	Yes (17) 23% No (0) 0% Don't Know (1) 1%
African American	No Inc. (0) 0% < 15 K (4) 5% 15-24,999 K (2) 3% 25-49,999 K (5) 7% 50-74,999 K (5) 7% 75-99,999 K (2) 3% 100,000+ K (1) 1%	Some HS (1) 1% HS Grad (3) 4% Some college (11) 14% College Grad (3) 4% Grad/Prof (1) 1%	Yes (17) 23% No (2) 2% Don't Know (0) 0%
Caucasian	No Inc. (0) 0% < 15 K (1) 1% 15-24,999 K (0) 0% 25-49,999 K (4) 5% 50-74,999 K (7) 10% 75-99,999 K (5) 7% 100,000+ K (4) 5%	Some HS (0) 0% HS Grad (1) 1% Some college (7) 9% College Grad (9) 12% Grad/Prof (4) 5%	Yes (20) 26% No (1) 1% Don't Know (0) 0%
Asian	No Inc. (1) 1% < 15 K (0) 0% 15-24,999 K (1) 1% 25-49,999 K (4) 5% 50-74,999 K (4) 5% 75-99,999 K (5) 7% 100,000+ K (1) 1%	Some HS (0) 0% HS Grad (1) 1% Some college (3) 4% College Grad (11) 14% Grad/Prof (3) 4%	Yes (17) 23% No (1) 1% Don't Know (0) 0%