

LEANING ON CULTURE...

COLLIDING WITH FAITH:

CURBING THE DIABETES EPIDEMIC IN THE LATINO AND

AFRICAN-AMERICAN COMMUNITY

DIABETES FOCUS GROUP STUDY REPORT

BUILDING BRIDGES BUILDING KNOWLEDGE BUILDING HEALTH

(BBKH) COALITION

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NMPP's Social Health Marketing Group

Background:

Northern Manhattan Perinatal Partnership (NMPP) is the lead agency of partnering organizations of the **Building Bridges-Building Knowledge-Building Health Coalition (BBKH)**. The coalition has a thriving Community-Based Participatory Research Network (CBPR) with four faith-based organizations (FBOs), four community-based organizations (CBOs), a public hospital system, an academic medical center, and two universities. The overall mission of the coalition is to create a public health social movement where diabetic patients and their family members who live in the communities of northern Manhattan understand and utilize preventive health interventions associated with diabetes and obesity, adhere to evidence-based treatment regimens, adopt appropriate life-style changes and implement system change public policy initiatives to reduce ethnic disparities in diabetes in the region by 5% by March 31, 2011.¹

Needs Assessment:

Diabetes is of significant concern in ethnic populations. Currently, an estimated 18.2 million Americans have Type I Diabetes or Type II Diabetes mellitus. Of these, African American and Latino adults are 1.6 and 1.9 times respectively more likely to have diabetes than are White adults. In addition to higher prevalence rates, Latinos and African Americans bear a greater burden of diabetes-related complications. Recent New York City epidemiological surveillance data indicate that diabetes has reached epidemic proportions. Over the past decade, the incidence of adult diabetes in New York City has doubled, rising from under 4% to almost 8%, with Latinos (12%) showing the highest rate of all other groups. It is estimated that 30% of all diabetes is undiagnosed, suggesting another 225,000 New Yorkers have diabetes that has not been diagnosed.²

Specific Aims of Focus Group Project:

¹ BBKH Work Plan for April 1, 2006- March 31, 2011; Pg. 4

² Carrillo & Drummonds; 2006; Minority Health Community Partnerships Proposal: Building Bridges, Building Knowledge, Building Health Coalition. Pg. 6

Conducting the diabetes focus groups was one of the first steps to developing BBKH's coalition's poster and radio diabetes social marketing campaign for Northern Manhattan and South Bronx residents. The information obtained from the focus group will be used to guide the creative development of campaign messages and poster concepts. The focus group addressed the issues surrounding perceptions about diabetes prevention, and management.

Specifically the focus groups probed what it would take for the African-American and Latino communities of Northern Manhattan and the South Bronx to arrest the development of diabetes. For individuals who are not diabetic and those who are considered pre-diabetic, the probes attempted to explore issues around pre-emptive prevention and issues related to necessary changes that would prevent the onset of full-blown diabetes. For those who are already diabetic, the focus groups hoped to ascertain key factors that lead to successful management of the disease or further complications including lifestyle changes, medication adherence, health provider involvement, and the role of family and faith. The exploration of beliefs about diabetes, along with the perceived enabling and reinforcing factors needed to prevent and manage the disease, would allow for the BBKH to develop effective messages for the target community. Focus group participants were also asked to share their thoughts about preventive messages that might be well received and effective in their community, as well as venues for disseminating the messages. Having recognized the differences in these communities, in addition to the need to remove the language barrier, the Latino group will be facilitated by a Spanish speaking facilitator.

Limitations of Research:

The focus group interview seeks to develop insight and direction rather than quantitatively precise or absolute measures. Due to the limited number of respondents involved and the special recruitment methods employed, this research must be viewed as exploratory in nature, and should be considered a qualitative frame of reference.

Methods:

Marketing & outreach to obtain focus group participants:

The charge of the marketing and outreach team was to recruit a minimum of **24** participants for the diabetes focus group. Twelve participants would be African American men and women 18 years of age and older from the Harlem community, and the other 12 would be Hispanic Americans living in East Harlem, West Harlem, Washington Heights, or the South Bronx. Individuals who were targeted will include:

- ❖ Persons who have been diagnosed with diabetes.
- ❖ Persons who have been told by a doctor they are pre-diabetic and given a treatment regimen.
- ❖ Persons who do not have diabetes
- ❖ Persons who had family members living with the disease.

The flyers were in English and Spanish, included a phone number to call if interested, and the date of the focus group. The incentives for participation were on the flyer, including the \$25 cash incentive. In addition to circulating the flyers through programs affiliated with the BBKH coalition, general street outreach was done in East Harlem, West Harlem, Washington Heights, and the South Bronx. Flyers were given out in subway stations and on the trains in these areas as well. (*Please see appendix 1 for Outreach Flyers*).

Stratification of the Groups:

Due to the fact that the budget only allowed for 2 focus groups, one for African Americans and one for Spanish-speaking Latinos, it was important that the groups were stratified appropriately to render quality data regarding the issues. Each group of 12 consisted of the following:

- 4 Individuals diagnosed with diabetes → 2 between ages 18-35
→ 2 ages 36 and older

- 4 Individuals diagnosed with pre-diabetes → 2 between ages 18-35
→ 2 ages 36 and older

- 4 Individuals who **do not** have diabetes
 - at least 2 w/ immediate family member w/ diabetes
 - 1 between ages 18-35
 - 1 age 36 and older
 - 2 free of diabetes
 - 1 between ages 18-35
 - 1 age 36 and older

Screening Process for Focus Groups:

Each potential participant engaged in a pre-screening phone interview in order to verify eligibility for participation and group placement. The pre-screening phone number and the focus group date was the only information given on the flyers. The time and location of the focus group was given once that individual was selected for participation. The screening was broken into groups such as area of residence, age (18 to 35; 36 and up), and diabetes status (i.e. whether they had been diagnosed with diabetes, were pre-diabetic, or no diabetes at all).

The questionnaire was developed by the project coordinator with guidance from: Mario Drummonds, CEO of NMPP, the project director; Joanne Casado, Executive Director of Bronx Health Link; and Lori Wheaton-Holmes, BBKH Program Manager.

Originally, it was thought that the pre-diabetic participants would have been individuals who had received a medical diagnosis from their physician and place on a treatment regimen. However, this group was very difficult to identify. Therefore, the pre-screener was revised to select individuals who

may be in a pre-diabetic state, even though a physician has not yet diagnosed them. (*Please see appendix 2 for the pre-screening questionnaire*).

Following the phone questionnaire, the caller was told if he or she was selected for a focus group or that they would be called back. If selected, he or she will be given the additional details.

Development of the Discussion Guide Focus Group Facilitation:

The discussion guide was developed after extensive literature review and field research by the focus group project coordinator contracted specifically for this project.

The guide was reviewed and revised based on supervisory meetings with the project director. The probes were organized to target prevention issues for the non-diabetic group members and gradually moved to management issues of participants who were living with diabetes.

The major probes for the focus groups were as follows:

- Awareness and perceptions about diabetes
- Ideology and perceptions about prevention
- Knowledge and perceptions about lifestyle changes & medication
- Circumstances that separate those who manage diabetes well from those who do not.
- Perceptions about existing public health messages relating to diabetes as well as messages and venues that would be effective.

*****See appendix 3 for Focus Group Discussion Guide *****

A Spanish-speaking facilitator was contracted to conduct the Latino focus group. She also reviewed all materials for the project to ensure that they were relevant and appropriate for the Spanish-speaking target population and assisted in the translation of all materials.

Focus Group findings to Probes for African American Group:

Awareness & Perceptions about Diabetes

In general all the participants in the focus group were well aware of diabetes, including the two types, some causes, signs and symptoms, and complications. They all acknowledged the disease as a problem in the general population, as well as being prevalent within the African American community. In fact every participant (those with the disease, as well as those without) spoke of family members who suffered from complications or death as a result of diabetes.

The participants who were not already diagnosed with diabetes, not only saw themselves at risk, but they also saw their children, grandchildren, and other loved ones at risk. They blamed cultural eating habits, the prevalence of processed and refined foods in the food chain and the inaccessibility to nutritious food choices. Few cited genetics and for those that did, they acknowledged that predisposition could be overcome with the correct lifestyle.

Ideology & Perceptions about Prevention

All the participants who did not have diabetes saw the ability to prevent the onset of the disease in their hands. They were aware of the risks, the habits and the complications of the disease, but admitted that they are complacent when it came to prevention. Those in the group agreed that usually nothing is done to arrest the development of the disease. They have observed their family, friends, and neighbors doing nothing until the onset of complications of the disease. Pre-diabetic and diabetic participants confirmed this culture of complacency in relation to the disease.

Although the participants owned their ability to prevent the disease, they adamantly identified many of the socio-political issues that render their environment less conducive to eating right and maintaining the type of lifestyles necessary to ward off the disease especially when symptoms are not visible. These issues include the abundance of fast food restaurants, junk food and soft drinks at convenience stores, and limited and unappealing fresh foods in local grocery stores. The high costs of healthy foods, compared to processed and refined products, were also cited as an obstacle to maintaining

preventive behaviors. They also discussed the inability to obtain enough physical activity as a result of crime (in neighborhood parks, stairwells in buildings, etc.) sitting in front of computers all day at work, and not having the time or money to spend at the gym. Routine stress and hectic schedules was also cited as a major obstacle to preventive behaviors. The participants said stress undermined their resolutions to make lifestyle changes because comfort foods were often used as a coping mechanism. In addition, some participants said they often ate fast food because there was not enough time to eat well-balanced meals.

Some participants stated that they would have been more likely to follow the advice of their physicians to make lifestyle changes had they been given some resources and support along with this advice. They discussed the need for referrals to nutritionists, recipes, free or low cost venues for physical activities, and more time with their doctors to plan a reasonable course of action. Group participants came to the consensus that the current medical model, where doctors see patients for approximately 15 minutes, was not conducive to offering the level of guidance and support needed to properly manage the disease. Therefore, one has to take charge of his or her health.

Knowledge & Perceptions about Lifestyle Changes & Medication

The discussion highlighted many issues with regard to the extent of knowledge that needs to be acquired to make a significant lifestyle changes in order to reverse the course that could result in full-blown diabetes. A significant skill that participants discussed was knowledge about exactly what the foods they consume regularly contains. The group discussed the importance of reading food labels and understanding how different ingredients affect their bodies and specifically their blood sugar. They also spoke of understanding serving sizes, portion control, and methods of food preparation.

Participants also called for a gradual change in many of the eating practices that are culturally embedded within their communities. They discussed the expectation of eating everything that is on one's plate, and they talked about many foods that are known to be unhealthy, but cannot be abandoned because of their cultural and historical significance. Some participants suggested the need for sharing

healthier means of preparation as an alternative to abandoning these foods altogether. The group agreed that it is possible to transform cultural norms to incorporate practices that will enable and reinforce those who are on the track to diabetes to acquire and maintain healthier lifestyles so they do not acquire the disease.

The focus group participants shared their dislike of taking medications and discussed physicians being much too willing to write prescriptions and sending patients away. They also discussed the fears regarding the long-term effect of the medication.

When asked about the role of prayer and their spiritual beliefs in relation to their general ideology of the group was that their creator would help them if they helped themselves. They related spiritual fables that conveyed that particular message. All the participants saw their faith as a means of gathering strength, discipline, and support so that they themselves could succeed in the measures they needed to prevent the onset of diabetes or reverse their status.

Circumstances that separate those who manage diabetes well from those who do not.

Unfortunately, the participants in the group agreed that far too many in the community wait until the onset of complications to do something about their disease. There were individuals present who had not managed their disease properly from the beginning and were undergoing procedures and enduring pain as a result.

The discussion highlighted the need for diabetic individuals to be in an environment that includes supportive family and friends who empathize with their situation and support their much-needed lifestyle modifications. Examples about the types of support needed included but were not limited to:

- Appropriate food and beverage choices at gatherings and events
- Family members eating better as a show of support and as a means of improving their own health.
- Family members not contributing to stress that may drive unhealthy habits as a means of coping.

The focus group participants who were winning the fight against the disease and those who were not doing so well agreed that in general, family and friends seeing their challenge to manage the disease as a collective effort made all the difference.

Group participants who were successfully managing their diabetes also had physicians who gave them a great deal of guidance and support. One individual spoke about his physician helping him to set goals and the physician challenging and encouraging him to establish and sustain behaviors that were intended to reverse his diabetic status.

All the focus group participants had fears about the complications of the disease. No one wanted to lose limbs, lose their eyesight, to suffer stroke or kidney failure. What separated those who actively prevented and managed the disease from those who did not appear to be varying levels of self-efficacy. In the focus group discussion the managers illustrated their commitment to reversing their status with statements like:

“Losing a limb was not an option.”

“Blindness was non negotiable.”

“I would do everything in my power to make sure I am there for my grandchildren.”

Those participants who had already suffered complications did not have such strong statements. Their statements were based on wants rather than action.

“I want to be healthy for my children and grandchildren”

“I don’t want to have to go to the hospital every other day for....”

“I know I need to make better choices.”

The entire group was very fearful of what they could foresee in terms of the diabetes status of generations to come. Participants with children spoke about not wanting their children to suffer, but found their surroundings would make it almost inevitable. They discussed foods served in schools, choices in their neighborhoods, the marketing of unhealthy foods to young children, computer and video games socializing them for a sedentary lifestyle, and the examples that they set as parents. The group

agreed that children and young adults must be targeted aggressively to insure that they do not develop diabetes.

Ideas about social marketing campaign

When asked where they obtained their information about diabetes, the focus group participants said most of what they knew about the disease came from family, friends, and neighbors, who had first hand experience with the disease. They all agreed that the educational material created about diabetes was often too clinical. They felt this material would be more effective if it highlighted behaviors that put individuals at risk, possible complications, and preventive measures in very simple terms. None of the participants could recall any ads that alerted or educated the community about diabetes. The only ads they saw were those that were intended to market the blood sugar test strips. Participants felt that if the spokespersons for these ads shared their personal stories in relation to the disease such as the changes they made, the challenges they faced, and the importance of managing or preventing the disease, the message would be far reaching. They also felt that candid and shocking illustrations of the complications of diabetes would raise awareness for those who need it.

Very young children were seen as a very important aspect of any social marketing campaign related to diabetes. Some participants paralleled the impact of teaching children about the dangers of smoking cigarettes to the possible impact of teaching them about the dangers of diabetes. First, they felt that children could convince the adults in their lives to make the appropriate lifestyle changes. Second, they thought that children were a great preventive target population because their lifestyle habits are still being established. They even felt that pre-schoolers and their parents ought to be a primary target group for any diabetes campaign where prevention was concerned.

Discipline, consistency, and patience were said to be key weapons in winning the fight against diabetes. Most of the group members discussed the inability for individuals in the community to sustain lifestyle change efforts. One participant made the point that many abandon their efforts right before they would begin to see changes that would boost their moral and give them more incentive to continue

on the path to healthier lives. Therefore, one has to be extremely patient throughout the process of making these gradual life-altering changes in their daily routines. Participants felt that a media campaign should use these words and convey the message that this was a step-by-step, day-to-day process and not something that would happen over night. They felt messages of encouragements for those who were on the path already would be effective.

There was a great deal of ideas about ways to market diabetes prevention and management messages. Participants spoke about school projects that would involve parents, educational sessions through churches, a catchy jingle and/or phrase that branded diabetes management and prevention. Some discussed replicating some of the techniques the private industry uses to market unhealthy products. However, having recognized the limited resources public health has to do this work in comparison, the group members concluded that a campaign, no matter how simple, had to be multi-faceted, it should saturate the community, and it had to be sustained.

Findings to Probes for Spanish-Speaking Group:

Awareness & Perceptions about Diabetes

The participants in this focus group knew the most important facts about diabetes. They defined the condition, they distinguished between the two types, stated different forms of treatment, and they knew of the possible complications. They all admitted that diabetes is a very big problem in their communities. Almost everyone felt their own children were at risk because they were overweight and not physically active. They blamed themselves and cafeteria food as the cause.

The participants felt that there is plenty of information on diabetes but not enough education on it. They felt that only college students, individuals with a good doctor, or those who work in the health field are well informed about the disease. The group members agreed that the Internet is a great tool for

research purposes but not everyone has access or knows how to use it. Also, they felt someone has to have a really strong desire to know about the disease to actually research it.

Ideology & Perceptions about Prevention

The group discussed the ways in which culture can be a problem when it comes to trying to establish a better diet. They spoke about different cultures having different foods and the many Hispanic dishes that are high in fat being a challenge. Most of the women in the group complained about not having enough money to buy healthy foods, and for those who had the money, their grocery stores don't sell much of it. The group discussed how richer neighborhoods have better options like fresher produce and organic goods.

The group blamed doctors as part of the reason there is such a lack of knowledge on diabetes prevention and management. Everyone complained that doctors did not devote enough time or interest into their patients. They said their doctors are normally bombarded with too many appointments, often have to rush patients through their visits, and ultimately fail to discuss certain things.

The group felt everyone should take control of their own life and protect themselves from diabetes. No one person mentioned religion or faith as a means of protection or way of dealing with sickness. The link between their faith and health was lacking even when probed. Everyone acknowledged the importance of having routine exams and following a healthy diet.

Obtaining adequate exercise seemed to be an inconvenience. Age was one of the reasons some participant gave for not getting enough exercise. Weather was another reason participants cited for not maintaining exercise routines. They found the gym to be a good alternative when the weather was bad or unpredictable. However, the group felt that gyms were often too expensive. Home equipment was another option but they said was just as pricey and space consuming. Some of the women felt that running in the street was too dangerous. The only alternative the group determined had no complications

was running up and down the stairs. This was the only form of exercise they found did not involve money, contracts, or danger.

Knowledge & Perceptions about Lifestyle Changes & Medication

When the topic of medication came up; everyone felt it was beneficial, affordable, and easy to manage. There were no complaints other than the idea that all diabetic medication should be free because it is so necessary. One of the participants told the group she had problems when she went to pick up her prescription from the pharmacy but her insurance no longer covered it.

The focus group discussed ways of incorporating fitness and better eating into their daily routines as a great way to prevent the onset of diabetes and manage it. Some of these suggestions included limiting their use of transportation and walking more, taking two days out the week to cook healthy dinners, adding vegetables to more dishes, and using low fat ingredients. They felt these changes were affordable, accessible, and entailed actions they were confident that they could accomplish.

Circumstances that separate those who manage diabetes well from those who do not.

Group members discussed how gender plays a role in family health. They described that it was more common for women to be more involved with each other whenever one is sick as opposed to men who generally take care of themselves if there isn't a caring woman around. When the men in the group discussed taking care, a few considered this care to entail the drinking of alcohol and a nap. This illustrated the gender differences regarding home health care when illness occurs.

There was a participant whose entire family is diabetic except her. The problem in her case is that she allowed her sons to neglect their condition thus making it worst. Some participants admitted to having a very passive attitude about their own health status and the health status of their loved ones. They were not pushing either themselves or their loved ones to manage their diabetes. Another participant shared that one of her sons made jokes about his legs being cut off and laughed about ants running to his urine. Meaning, his urine was so full of sugar it attracted ants.

In addition to complacency, the group cited lack of knowledge, depression, denial, or act of rebellion as reasons they felt they themselves and fellow community members submitted to the disease. Participants highlighted the importance of addressing diabetes in a manner that people would not feel ashamed. They need to be encouraged so that they can accept their situation be more eager to take control.

Ideas about social marketing campaign

When attempting to reach this community on this topic, it is crucial to do so in a way that easily grabs their attention. The group shared many ideas on different ways the government or organizations can promote diabetes prevention and management. Participants believe people in general are somewhat lazy or tired due to work, family, and other responsibilities. They believe the best way to capture this group of people is to strategically place messages and materials to be read in their way as part of commuting, chores, and activity related routines. The group felt if individuals have to go out of their way to get the information, many would not make the effort. One of the venues included giving subway riders diabetes educational material to read during their daily commute to work. The group felt this would most likely put the topics in people's heads.

The group also felt that most people prefer information and messages of this nature to come to them in creative forms. An example that was given was posting basic diabetes facts on milk cartons. The group discussed the need to compartmentalize the information in groups. Some examples include listing symptoms, important health exams, and possible complications. Participants did emphasize the need for simple and more straightforward messages that is easy to understand. They said anything lengthy would be destined for the garbage cans.

The group also discussed the need for visuals that get people's attention. They felt that image is important, so instead of using an old boring white doctor in a commercial or pamphlet, they should use young attractive people. The participants were strongly apposed to the use of fear to deliver the diabetes

prevention and management messages. They thought it be best for the campaign to focus on positive messages so that people who do have diabetes can face their condition positively and more confidently.

Conclusion:

The two focus groups rendered some very valuable information that can be used to launch an effective diabetes prevention and management campaign. There were a few similarities between the African-American and Latino groups such as the role of culture and family relating to food choices and lifestyle changes. The groups were also very different in terms of what was emphasized, and types of messages they wanted to see and hear. Unfortunately, these two groups were only a small sample of the communities they represent. The BBKH coalition will continue to collect more qualitative data as opportunities and venues arise relating to the probes of this study.

After the review of this report, a creative team will develop poster concepts and radio drafts. This team will consist of members of the BBKH coalition, NMPPs Social Health Marketing Group, and a few of the focus group participants. Final campaign products will be disseminated in schools, housing projects, churches, bodegas, supermarkets, MCH providers and consumers, and check cashing places to name a few. This diabetes social marketing campaign will seek to develop new partnerships and utilize existing partnerships with health advocacy organizations, local/state health departments, and corporations to assist in social marketing. The results of this campaign will then be evaluated in terms of short-term response and the overall impact on the target community of Northern Manhattan and the South Bronx in the fight to reverse the development of diabetes in our community.

Appendix 1—Focus Group Recruitment Flyers

Building Bridges, Building Knowledge, Building Health (BBKH) Coalition

control exercise

weight diet

facts low fat

health fresh

myths heredity

**Food for
Thought**

Focus Group Discussion about Diabetes Prevention and Management

Wednesday, April 4, 2007 @ 6:00 pm

You get **DINNER, \$25 CASH**, and a **METROCARD** for your time

Call 646 410-6020 or 212 289-2400 for more information

Space is Limited!

Creative Services by NMPP's Social Health Marketing Group, Inc. 212 665-2600 x308/Black Cat Design 718 753-0244

Building Bridges, Building Knowledge, Building Health (BBKH) Coalition

control

ejercicio

peso

dieta

hechos

bajas calorías

salud

fresco

mito

herencia

Materia en que
Pensar

Vamos hablar Sobre la Diabetes como se Presenta y como Prevenirlo

Miercoles, Abril 4, 2007 a las 6:00 pm

Habra comida **Gratis, \$25 en Efectivo, y un Metrocard**

Puedes llamar para mas informacion al 646 410-6020 or 212 289-2400

¡Espacio Limitado!

Creative Services by NMPP's Social Health Marketing Group, Inc. 212 665-2600 x308/Black Cat Design 718 753-0244

Appendix 2— Pre Screening Telephone Questionnaire

PRE-SCREENING QUESTIONNAIRE

++THANK THE RESPONDANT FOR CALLING AND EXPLAIN THAT THE GROUPS WILL CONSIST OF PEOPLE WITH VARYING CHARACTERISTICS RELATING TO AGE, RESIDENCE, AND THEIR DIABETES STATUS. ASK IF THEY WOULD BE WILLING TO ANSWER A FEW QUESTIONS TO SEE WHERE THEY WOULD FIT IN.

1. *How did you hear about the group?*
2. *Do you live in that area....*Probe neighborhood or residence.
3.
 - a. *Are you Hispanic?* If yes go on to #4
 - b. If no, *are you African American?*
4. *What year were you born?*
5. *Have you been diagnosed by a medical professional to have Diabetes?*
 - a. If yes, *have you been prescribed any medication?* → Obtain name, number they can be reached and best time to call.
 - b. If no, continue to 5.
6. *Have you been diagnosed with being in a pre-diabetic state by a health professional?*
 - a. If yes, *have you been prescribed any medication?* → Obtain name, number they can be reached and best time to call.
 - i. If no to a., What *has your doctor recommended?* → Obtain name, number they can be reached and best time to call.
 - b. If no to # 6, continue to #7
7. *Would you consider yourself at risk for diabetes?*
 - a. If Yes, Why? Probe:

Family History Diet (Fast food vs. veggies), Weight, Inactivity

8. *Do you have any immediate family that currently has diabetes?*
(Immediate Family = anyone who lives in the same household with, or spend a lot of your time with)

→ Obtain name, number they can be reached and best time to call.

End the call by informing the potential participants that they will be called and invited to attend the group based on their responses. Let them know they will be contacted by March 30th and humbly ask them not to call again.

Notes:

Invited participants should be asked respectfully not to bring children or babies because their presence will interfere with the focus group proceedings and childcare is not available.

Participant will be asked to arrive at least 15 minutes early so the group can start and finish on time and give them the address, date, and time of the group.

Appendix 3 — Focus Group Discussion Guide

DISCUSSION GUIDE

INTRODUCTION

(10 MINUTES)

-Moderator Introduction – name, independence, no affiliation with research sponsor

-Purpose of the Interview

- To understand the issues, obstacles, and successes around preventing diabetes and diabetes management.
- Explain group composition (i.e. some general population, pre-diabetics, living with diabetes, some have concurred it).
- Encourage participants to speak freely. Explain that some questions may apply to them and some may not. Encourage sharing not only their experiences and views but also those of family and friends not present.

-Logistics and Security

- Recording - audio taping for analysis purposes
- Confidentiality – anonymous interview strictly for research purposes, not related to sales or marketing efforts, etc
- Candid response appreciated – no right or wrong answers, spontaneous and honest reactions to questions and stimuli.
- Location of restrooms; Cell phones off or vibrate, can get refreshments or excuse self quietly if need to.

→ TURN TAPE ON NOW

Participant Introductions – Name, diabetes status/reason interested in the group. **Modeling Moment!! Be very brief!!!**

FAMILY – Ice Breaker

(15 minutes)

“How would you describe your family?” In addition to your general description, please speak about: your specific family composition and its defining characteristics.

-Probe: culture, social support, living environment, degree of interaction.

“What are some of the things that you like most about your family?”

“What would you change?”

-Probe if not mentioned: Role of family in health related issues and concerns.

“How do these issues impact you and / or your family? Why?”

GENERAL POPULATION QUESTIONS (mainly for Non-Diabetics) (20 minutes)

C. AWARENESS & PERCEPTIONS ABOUT DIABETES

(MODERATOR: WRITE THE WORD “DIABETES” IN THE MIDDLE OF THE FLIP CHART AND CIRCLE IT)

1. “For those who don’t have it at all, what do you know about this word?” (Person’s name-->Why do you say that?)

-Probe other names for the disease.

-Probe basic knowledge about complications and available treatments. (E.g. insulin injections → what are some other methods of treatment?

Type 1 & Type 2 → What’s the difference. etc..)

-Probe the source of this information

How much from health professionals, media, family & friends)

2. “Do you see this disease as a problem in your community?

Why? Why not?”

-Probe perceived prevalence

-Probe perception about pre-disposition and heredity.

D. IDEOLOGY & PERCEPTIONS ABOUT PREVENTION

3. “Do you think you should be doing anything now to prevent yourself from getting the disease?” If so what?”

- Probe perceived ideology (i.e. do they control own destiny or a higher power).
- Probe attitudes about prevention as well as specific preventive measures.

Note: Once you hear from those without diabetes, ask the others to think back to what they thought before diabetes was introduced or became a part of their lives.

PRE-DIABETIC QUESTIONS (Mainly for Non-Diabetics) (20 Minutes)

“Some of you are here because either you or your doctor has decided that you are in a pre-diabetic state, based on your diet, weight, inactivity, and perhaps you have a family history of the disease.”

4. “Do you believe it is in your power to prevent yourself from acquiring this disease?”

E. KNOWLEDGE & PERCEPTIONS ABOUT LIFESTYLE CHANGES & PRE-EMPTIVE MEDICATION.

5. “What measures have you or will you take to accomplish this.”

-Probe knowledge about extent of lifestyle changes and medication adherence needed, doctor’s instructions etc. Including perceptions about food and exercise.

6. “What is your confidence level that you can prevent the progression of this disease?”

-Probe possible obstacles to measures that are identified and instructions from health providers.

-Probe drivers and contexts that would help or have helped them to succeed.

F. PERCEPTIONS ABOUT PREDISPOSING, ENABLING, AND REINFORCING ELEMENTS IN RELATION TO DIABETES MANAGEMENT

- “What messages, either from media, family, or community would reinforce what needs to happen to prevent the full blown disease.

Note: Once you hear from pre-diabetics open to general group and have those who are diabetic recall and answer based on perceptions when they may have been in the pre-diabetic state.

DIABETIC QUESTIONS (Mainly for those with diabetes) (30 minutes)

7. “What circumstances do you think separates people who fight the disease and those who just submit to it and as a result suffer complications of the disease?”
 - Probe obstacles to lifestyle change*** (food choices related to cultural experiences, with family, in neighborhood etc.)
 - Probe what makes it possible to manage the condition successfully*** (role of family support, prayer, and psychological condition).
8. “Are you frightened at the thought of experiencing any of the complications of diabetes”
 - Probe extent of fear and anxiety related to complications*** – (amputations, blindness, kidney failure, heart attacks, strokes, and death.) (E.g. losing a limb, blindness, stroke etc...)
9. What do you think about the medications that are used for diabetes?
 - Probe Perceptions about Diabetes Medications***
 - Do they work? Are they Available? Do people take them when prescribed?
 - Why? Why not?
10. “How do you feel about your ability to schedule and follow through on structured exercise time.” (I.e. gym, walks for purpose of activity, w/ DVDs at home etc...)
11. “What part do you feel your doctor should play in preventing and managing your diabetes status?”
 - Probe nature of current relationships & level of support expectation.***
 - Pill pusher vs. Lifestyle coach

12. “How do you feel about public health and government interventions like recent trans-fat ban laws for restaurants or reducing fast food venues altogether in neighborhoods?”

- Probe perceptions about government and public health mandates

13. “For those of you with small children or who have young relatives, how does their future look to you in terms of their health and diabetes status?”

-Probe awareness of childhood obesity and its relationship to diabetes

-Probe perception about the role of family, schools, faith-based groups and health professionals

Note: After hear from diabetics, open questions to the rest of the group for their input and in relation their experiences as well as those of family members or friends who have diabetes.

IDEAS ABOUT SOCIAL MARKETING CAMPAIGN (15 Minutes)

14. What would be most effective way to communicate messages about diabetes prevention and management to your community?

-Probe: Community seminars – where? Print materials – what kind?

Giveaway items such as T-shirts, stickers, etc.?

15. What are you more likely to read or pay attention to?

-Probe: flyers, billboards, posters, newspaper ads, magazine ads, or TV ads?

16. “What kind of ads do you see in your neighborhood relating to diabetes?”

“Relating to Healthy diet and exercise?”

17. “Would they have a greater impact if the images or language represent your community?”

18. Would they have a greater impact depending on where you see them?

-Probe: places like subway vs. public assistance office or healthcare office etc.

- Is it better if educational materials are supported by commentary and support services?
-Probe: discussion with your doctor, caseworker, health educator, cooking classes etc...

H. WRAP-UP **(5 minutes)**

Thank participants for taking the time to offer their thoughts and experiences on such an important topic. Encourage them to continue to take better care of themselves and their families. Let them know that if they wish to participate in developing the media campaign they should sign the sheet going around. Explain that they will not be paid for that.