

**Bronx REACH 2010
Door-to-Door Diabetes Survey
in the South Bronx
(Zip Codes: 10452, 10453, 10456, 10457)**

Interviewer Training Manual



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This training manual was adapted from other manuals used for surveyor training at New York University, Columbia University and John Hopkins University.

1. Information about Bronx REACH 2010

The Bronx REACH 2010 Coalition was formed in the fall of 1999, with a grant from the U.S. Centers for Disease Control and Prevention. REACH, which stands for *Racial and Ethnic Approaches to Community Health*, is the first federal program designed to reduce racial disparities in health outcomes. It grew out of the growing awareness that while the prevalence and severity of many illnesses has been reduced over the years, the gap between whites and people of color has not budged.

For example:

- A black baby born today will live seven years less than a white baby born today, resulting in an average life span of 74 years for white males, and 66 years for black males. For females, the average is 80 for whites, 74 for blacks;
- Hispanics are 1.8 times as likely to have diabetes as non-Hispanic whites, and 1.7 times as likely to die from it. African- Americans are twice as likely to have diabetes, and 2.5 times as likely to die from it as whites;
- Women in the Southwest Bronx have rates of death from diabetes roughly twenty times higher than women on the Upper East Side;
- Hispanics in the South Bronx experience death rates for cardiovascular disease that are 17.4% higher than for Hispanics in New York City as a whole;
- African-Americans diabetics are 20% more likely to lose a limb to diabetes than other diabetics, and twice as likely as white diabetics to develop terminal kidney disease.

These things are true, in part, because people of color are far more likely than whites to be uninsured, are more likely to use hospital clinics and emergency rooms instead of office based practices, and are more likely to get referred to institutional clinics for specialty care. In addition, they are far less likely to receive aggressive interventions like cardiac catheterization and other procedures than whites with similar symptoms. In New York City, specialty clinics often provide health care in different settings based on insurance. Due to the disproportionate numbers of Blacks and Hispanics who are uninsured and publicly insured, this results in de facto racial discrimination.

The Bronx REACH 2010 Coalition is committed to reducing the prevalence of diabetes and cardiovascular disease in the southwest Bronx, as well as improving health outcomes among those at risk for these diseases. The project targets zip-code areas 10452, 10453, 10456, and 10457, where the population is more than 95% Black and Hispanic. Last year, the Coalition conducted a literature review and a series of focus groups to understand the causes of racial disparities in health.

The Coalition developed a Community Action Plan to achieve the following goals through the establishment of working committees and projects:

Outreach and Education

- Increase the number of eligible individuals enrolled in insurance programs;
- Disseminate targeted health messages;
- Develop a faith based outreach initiative;

Primary Prevention

- Expand community involvement in primary prevention activities;

Assist People Who are Ill or at Risk

- Identify people living with diabetes and heart disease who are not receiving care;
- Educate the community about health maintenance and appropriate standards of care;

Make the Health Care System Work Better

- Develop and monitor standards of respectful and responsive care;
- Enhance the quality of clinical care and service delivery;
- Improve trust by addressing institutional racism and cultural bias in health care delivery to increase appropriate utilization of the system;

Promote Legislative and Regulatory Change

- Advocate legislative and regulatory changes to guarantee equal access and quality of care for all.

To date, twelve groups have committed to participate in specific projects outlined in the Community Action Plan. These groups include the Institute for Urban Family Health, which serves as the project leader and the Center for Health and Public Service Research of New York University, which is responsible for the research and evaluation aspects of the project. The other organizations are the Mount Hope Housing Company, the Women's Housing and Economic Development Corporation (WHEDCO), St. Edmund's Episcopal Church, the Highbridge Community Life Center, the Cosmopolitan Church of the Lord Jesus, St. Barnabas Hospital, Montefiore Medical Center, HealthForce, the Mid Bronx Senior Citizens Council, and the MARC After School Program.

For more information about this project, or to find out how your organization can play a part, call Charmaine Ruddock, Project Director, at 212-633-0800 ext.291, or send her an email at cruddock@institute2000.org.

2. Purpose of the Door-to-Door Survey

The survey has four goals:

- 1) To help us understand the problems that people who have diabetes face in managing their illness so that we can design programs to meet their needs.
- 2) To give us information so that we can design programs to help prevent diabetes.
- 3) To see if the programs that we have in place will have an impact on people's knowledge and behavior and their ability to get the health care that they need.
- 4) To reach out to people who need help managing their diabetes and link them to places that can help them.

Our plan is to survey 500 adults with diabetes.

3. How to Interview

The Role of the Interviewer

You are the key to the success of this survey!

You have three very important roles:

- 1) Getting people to participate
- 2) Getting people to do a good job answering the interview questions
- 3) Writing down their responses clearly and accurately

Here is some advice about how you can do each one of these things well.

Getting people to participate:

Some people will agree to participate and be interviewed right away. But there will also be people who are suspicious or who, at first, do not want to participate. Getting them to participate can be difficult, but is one of the most important jobs of the interviewer. Here are some techniques that have worked with other surveys:

Be positive and upbeat, and act confident. Act like you are certain that they will want to participate. Be friendly and neighborly.

Know why this project and this survey are so important. The more you know, the more convincing you can be.

Getting people to do a good job answering the interview questions:

You set the tone of the interview, and you can affect the quality of the answers you receive.

For example, if you rush through the questions, the people you are interviewing may rush through their answers.

If you seem bored, the person answering the questions may not want to spend the time thinking through how they respond.

If you are confused, the person answering will be confused.

Make sure you understand the survey and always feel free to ask the trainers questions.

Writing down the answers clearly and accurately:

You may do a great job interviewing, but if you don't write down the answers clearly and accurately, we will never know that. For us to use the interviews (and for you to get credit for your work), you need to keep track of everything clearly and accurately.

Be sure that you mark down an answer for every question, unless it is missed through a skip pattern. Some questions have a list of possible answers that you are supposed to read to the person you are interviewing. Follow the directions for each of these questions.

In some cases, people will give an answer that is not on the list. Write down what they say in the margin as clearly as possible. We will review these answers.

If you think the person you are interviewing is not telling the truth, please write this down next to the question **after** the interview is over.

3. How to Interview

Guidelines for Interviewing

You will be asking people questions that have a lot of detail and are somewhat personal. Here is some advice about how you can keep control of the interview and collect good information.

Practice:

Be very familiar with the questionnaire, skip patterns, and the entire interview process before doing the first interview.

If you don't understand a question, the person you are interviewing will also be confused. Practice asking the difficult questions until you can ask them in a simple, matter-of-fact way.

Asking the Questions:

a. Don't Show Your Own Feelings or Give Away the "Correct" Answer

It is important not to influence how people reply to the questions. Be careful not to show any personal feelings and judgments.

Do **not** show surprise, approval, or disapproval.

(We'll talk more later about what to do is someone gives an incomplete or confusing answer.)

b. Ask the Questions in the Exact Order that they Appear

In writing the questionnaire, we purposely put the questions in a certain order. Some questions are placed after others on purpose. For example, we didn't want someone to try to "give us the right answer" based on a question they heard before.

So please **don't change the order of the questions** when you are interviewing people.

c. Ask All of the Questions (Unless You Are Told Not To)

Sometimes in answering one question, the person you are interviewing may also give an answer to a later question that you haven't asked yet. **Do not fill in that answer.** Wait until you get to that question and then ask it exactly as it is written on the form.

If the person becomes annoyed at being asked a question again (and may say something like "I just told you that"), respond pleasantly with phrases like:

"You may have already told me this, but let me ask the question to be sure I have the correct answer."

"I have to make sure that I have your full answer to that."

"I need to ask all of these questions in the exact order to make sure we have complete information."

Always feel free to blame the researchers for requiring you to ask repetitive questions or to be very clear about the answers. You can say:

"I know it may sound like I'm being repetitive, but I have to follow the instructions I have from the researchers."

d. Ask Each Question Exactly as it is Worded

Each interviewer needs to ask the questions in **exactly** the same way.

Any change, even of one or two words, can change the meaning of the question.

After all of the interviews are complete, all of the answers will be combined and studied as a group. Therefore, **all of the questions need to be asked in exactly the same way by all of the interviewers.**

e. Keep the Focus on the Interview Questions

The person you are interviewing may describe things from the past or tell a long story. If they ramble or discuss irrelevant topics, you should politely interrupt and get them back on track. This is a very important part of your job.

It can be hard to keep the person focused on the questions without being rude.

Here are some suggestions. Try saying:

“I see” or “O.K.” and then repeating the question.

“That sounds very interesting, but what I need to ask is...”

“I see what you mean, but let me repeat the last question...”

f. What if the Person Says Things That Don't Make Sense or Are Inconsistent?

People often have opinions that may not be accurate or may not make sense. We are interested in learning about those views – even if they are incorrect.

So **do not try to correct people** or point out their mistakes.

If you know something about the person you are interviewing and you think they have answered a question incorrectly, do not correct them or change the answer

g. Make the Person You are Interviewing Feel Comfortable

Your goal should be to make the person you are interviewing feel as comfortable as possible. Be friendly and calm.

If the person seems nervous or says that they feel uncomfortable answering a question, remind them that all of their answers will be kept confidential.

Also remind them that there are no right or wrong answers to these questions. We are interested in their opinions.

But remember that the person you are interviewing **does** have the right to refuse to answer a question. (We'll discuss this more when we talk about the Consent Form.)

h. Getting a Clear Answer (“Probing”)

One of the hardest and most important parts of your job will be getting the person you are interviewing to answer the question the way it was asked. People may give only part of an answer or they may misunderstand the question or go off on another topic. Sometimes they will be difficult to understand.

It is your job to get them back on track and to “probe” for a clear answer to the question.

When should you probe?

Probe when the person misunderstands the question:

This usually happens when the person you are interviewing didn’t hear or missed a key word or phrase in a question. Here is an example:

Question: Do you smoke cigarettes on a daily basis?

Response: “I usually smoke about a pack a week.”

In this example, the person did not hear that the interviewer asked him about his **daily** smoking habits.

The interviewer should probe by saying something like, “I see. Well, do you smoke cigarettes on a **daily** basis.”

If you stress the key words the second time, the person will understand and give you the answer you need.

Probe when the person finds it hard to remember something:

Some questions require the person you are interviewing to remember events that took place some time ago. If they have a hard time remembering, ask them for their best guess.

Sometimes it helps to ask if it occurred before or after a holiday or other date.

Probe when the person says they don't know:

Sometimes when a person says that they don't know, they may really mean that they don't understand the question or that they need some time to think about it.

Some people may say that they don't know because they are afraid of giving the wrong answer or because the question seems too personal.

So if the person answers "I don't know," **do not be in too big of a rush to settle for the "Don't Know" response.**

If you just wait quietly as if you are expecting an answer, they will usually think of something to say. This is usually the best approach for a "Don't Know" response.

How do you probe?

Here is what **not** to do:

- Don't change anything about the question. If you think that the question is confusing, make a note in the margin and go to the next question. Discuss this with the trainers, if possible, before conducting the next interview.
- Don't show that you expect a certain answer or that one answer is better than another.
- Don't assume anything. Here is an example of what can go wrong if you assume something:

Question:

“In general, would you say that your health is excellent, very good, good, fair, or poor?”

Response:

“I already told you I have diabetes.”

Improper Probe:

“Then would you say your health is fair or poor?”

That probe forces the person who is being interviewed to decide between two choices (fair or poor). But she may feel that despite her diabetes, her health is excellent.

The interviewer should have just said, “Yes, I know,” and then simply repeated the question.

Here is what you **should** do:

- Wait as if you are expecting an answer and want the person you are interviewing to continue.
- Show your interest and understanding by saying thing like “Uh-huh” or “I see” or “Yes.”
- Repeat the question or the possible answers. Many people hearing the question for a second time realize what kind of answer is needed. They may not have heard the question fully the first time or they might have missed the point of the question.

- If the person’s answer is confusing you can use questions like these:

“What do you mean exactly?”

“What do you mean by...?”

“Could you please explain that a little? I don’t think I quite understand.”

- Sometimes you will need to ask them to be more specific. You can use questions like these:

“Could you be more specific about that?”

“Tell me more about that. What/who/how/why...?”

- Sometimes people will be vague about numbers. If they give a range of numbers (for example, five to ten), you can probe by saying “I can only put down one number. Can you tell me what the best answer is?” If they refuse to choose a number, you should select the number in the middle.
- Sometimes you will need to need to pull them back on track. You can use phrases like these:

“Generally... (and then repeat the exact question)”

“Usually...(and then repeat the exact question)”

“What is your best guess?”

“Which choice comes closest to how you feel?”

“I see. Well, let me ask you again...(and then repeat the exact question)”

- Some questions are open-ended. This means that there is no set of answers to choose from or to circle. Instead, you are asked to write down the person’s words exactly.

For these kinds of questions, you can probe for more information simply by repeating what the person has already said.

You can also say, “Is there anything else you would like to add?”

4. Guidelines for Diabetes Survey

Step-By-Step Review of Consent Form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

You have been invited to take part in a research project aimed at helping people with diabetes and heart disease in the South Bronx. What we learn from you and others will help us improve health care in your community.

You will be interviewed about what you know about diabetes or heart disease, how you have managed the disease, where you get care, and what services you have received. Everything you say will be confidential and will not be part of your medical record or affect your care in any way.

The interview is in two parts. The first part will take about 5 minutes. If you have certain kinds of health problems, there is a second interview, which will take about 45 minutes. If you complete this second interview, we will give you a \$6 Metro Card as a thank you for taking the time to talk to us.

Taking part in this survey is up to you. It is totally voluntary. You can stop at any time or skip any question you don't want to answer. There are no risks or direct benefits to you, although we hope that the study will lead to improvements in diabetes and heart disease services in the area.

The study has been explained to you and your questions have been answered. If you have questions later or wish to report a research-related problem, or if you wish to learn about the results of the survey, you may contact the principal investigator, John Billings at (212) 998-7554 or john.billings@nyu.edu. For questions about your rights as a research participant, you may contact the University Committee on Activities Involving Human Subjects, Office of Sponsored Programs, New York University, (212) 998-2121.

You have received a copy of this consent document to keep.

Agreement to Participate

Subject's Signature

Date

**Step-By-Step Review of the Screener
to See if the Person has Diabetes**

(See attached survey form)

Step-By-Step Review of the Diabetes Survey

(See attached survey form)

5. Interview Procedures

Preparing for the Interview

Before each interview, check to be sure you have the following materials

1. The questionnaire (make sure that you have versions in English and in Spanish!)
2. Consent forms
3. Response cards
4. Blue Pens
5. Watch or clock
6. Note pad for additional comments (optional)
7. Tracking form (will be supplied after testing)
8. Identification badge

Note: Identification badges must be obtained at the Institute for Urban Family Health at 16 East 16th Street – 4th floor on Tuesday, November 6th at 8:30 am. Ask for Norma Ayala.

Asking for the Interview

Interviews will take place in people's homes. Working with Mt Hope, Highbridge, and Mid-Bronx Seniors, we will select the apartment buildings where interviews should take place. Interviewers will approach people by knocking on apartment doors and identifying themselves. Start with:

“Hello. I am an interviewer with the Bronx REACH 2010 project. This is a project that is helping to reduce the problem of diabetes and heart disease in this neighborhood. Do you have a few minutes to answer a survey?”

Make sure that you hold the questionnaire so that the person you are interviewing cannot read the questions. There are questions where “refused” or “don't know” are acceptable answers. We prefer that people give us more information, so we do not want them to see these answers.

Ending the Interview

Before you leave the interview, take time to review the questionnaire. While the person you interviewed is still there, quickly make sure all questions are answered. No question should have missing answers unless it was part of a skip pattern.

Also, make sure all your answers are clearly marked and all your writing is legible!!!! Check for missing or unclear answers, and ask any additional questions you need to fill in.

Make sure to thank the person you have interviewed. If they have completed the full diabetes questionnaire, make sure to give them the Metro Card.

Give everyone the flyer that describes the Bronx REACH 2010 Coalition. Ask people to fill in the tear sheet if they are interested in receiving any help or volunteering. Collect these forms but keep them separate from the survey.

Safety Issues

Go in pairs.

Do not conduct the interview if in your opinion, the person is unable or unwilling to answer the questions, or if he or she seems upset or angry.

Also do not attempt to interview someone who seems to be drunk or on drugs.

If you ever feel unsafe, politely end the interview. Give the person the Metro Card if you have already started the diabetes survey, and leave.

Submitting Your Questionnaires

Before you hand in your questionnaire check to make sure that you have done the following things:

Make sure the entire introductory box is completed, including your ID number and the date of the interview

Make sure you have entered the beginning and end times of the interview

6. Keeping Track of Your Work

We will add this information at a later date.

7. Interviewer Performance Goals and Guidelines

Expectations:

- Attend all training sessions
- Obtain identification badge
- Complete two or three pilot questionnaires
- Work a minimum of 20 hours per week
- Be a polite and careful and thorough surveyor
- Be a professional representative of the Bronx REACH 2010 Coalition

Compensation

Interviewers will be paid \$15 per completed diabetes survey and \$3 per screening survey if no diabetes survey is done. Payment will be made if the survey is legible and fully complete.

As compensation for time spent in training and in testing the questionnaire, interviewers who complete the training and testing will be paid an additional \$120 after they submit their first two completed diabetes surveys.