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Black Americans' Perspectives of Barriers and Facilitators of Community Screening for Kidney Disease

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Supplemental Material: Focus Group Interview Guide

Study Script and Question Manual

Introduction script

Hello everyone. I would like to thank all of you for being here and helping us out with our focus group. My name is _____ and I will be moderating the discussion today. This is _____ who will be helping out with the recorder and taking notes.

What we would like to talk about today is what motivates or discourages you from participating in free community programs aimed at early detection of kidney disease. We will also discuss what you know and do not know about kidney disease and how a community program could better inform you about kidney disease. Please realize that you do not need to talk about anything you do not want to talk about. The discussion will take about 1 hour.

I just wanted to quickly go over some of the ground rules for today's discussion and some of the parts about it that are important to protecting your rights and feelings.

First, you will only need to use your assigned identification letter, or you can make up a name to use. In front of you are some name cards and pens. Please write whatever name you would like all of us to use when we talk with you today on that name card. We will be recording the discussion and will then type it up. Your name will not be connected to anything you say. No one hearing the recording or reading what is typed will know who you are. Also, the recording will be erased after the discussion is typed up, and all typed copies of the discussion will be kept in a safe, locked place.

The only information about you will be collected on a separate form that does not include your name. This information will only be used to describe the different people who participate in the discussion. It will not be used to link you to your comments in any way. If you have not yet filled out this form, you may do so now.

To make sure that we respect and protect everyone's privacy, I ask each of you to promise not to reveal any information you have learned about the other people participating in this focus group. Please know that you can leave the group at any time.

Also, there may be times when you disagree with what another person may say. We think that disagreements are normal because everyone is different. While you should feel free to discuss any disagreements, let us all do so respectfully and kindly. We are interested in hearing all points of view—there are no right or wrong answers. Also, you do not need to raise your hand to speak. Speak right up, but please respect others when they are talking. Try not to interrupt them. We will try to make sure everyone has a turn to speak.

Everyone has an identification tag, so let's refer to each other by those names during the session. We will not be taking any formal breaks, so if you need to get up to refill your drink or use the rest room, please go ahead and do so quietly.

We want to stress that your participation in this focus group is entirely your choice. Are there any questions? Do each of you agree to participate in this study? Do we all agree to follow the guidelines for this discussion?

Questions for focus group participants

As I mentioned earlier, we are all here today to talk about kidney disease. We want to learn more about what you already know about the kidney, diseases that affect the kidney, and where you like to get health information. In addition, a local organization holds screening events for kidney disease with the hope that we may help people find out if they have kidney disease. We want to better understand what motivates and discourages you from going to a health screening.

Lets start about discuss what you know about the kidney.

1. General knowledge of kidney disease

- a. *What do you know about the kidney?*
 - i. *What is the kidney and what does it do?*
 - ii. *What causes kidney disease?*
 - iii. *What factors may increase your risk for having kidney disease?*
 - iv. *If you have a primary care provider, what has he or she told you about kidney disease?*
 - v. *If you have a primary care provider, does he or she check your kidneys and if so, how?*
- b. *What symptoms would make you concerned about kidney disease?*
- c. *When you think about people who have kidney disease, what concerns you the most?*
- d. *What do you think you can do to protect yourself from having kidney disease?*

We would like to now discuss your feelings about health screening events. To place this discussion in context, a local organization holds free screening events to help in the early detection of kidney disease. The health screening involves a check of your blood pressure, urine, and a review of your health history by a kidney specialist. This organization also provides free education about kidney disease. Lets first talk about health fairs in general.

2. Barriers to participation in community screenings

- a. *How do you feel about health fairs and events that screen for disease?*
- b. *Are health fairs useful to you? In what ways do health fairs help you?*
- c. *What type of health fairs and screening events have you attended in the past? Tell us about your experience.*
- d. *What factors would make it more likely for you to attend a screening event specifically for kidney disease?*
 - i. *What location would you be most likely to participate in a screening event (ie, church, school, at work, at a mall, at a large store)?*
 - ii. *On what day of the week and at what time (morning, afternoon, evening) would you be most likely to attend a screening event?*
 - iii. *How would you like to find out about health screenings?*

- iv. *What impact does your faith have in your likelihood to attend a health screening?*
- v. *What personnel would you like to see or speak with at the health fair? Do you trust the volunteers at health fairs to respect you and your health?*
- vi. *When people at health fairs talk to you about your health, is the setting private enough? Is this a concern?*
- e. *What factors would make you not want to attend a screening for kidney disease?*
 - i. *Would you rather not know if you have a problem?*
 - ii. *Does the prospect of having a kidney problem scare you?*
- f. *If you had to decide right now, would you participate in a free health screening for kidney disease? Why or why not?*
 - i. *The current kidney screening asks you to provide a urine sample. How do you feel about this?*
 - ii. *The current kidney screening does not currently collect a blood sample. If in the future our kidney screening offered free blood testing, would this make it more or less likely for you to participate? Why or why not?*

Lets finish our session talking about how you get information about your health. This will help develop new materials that teach screening participants about kidney disease.

3. Education

- a. *From what sources do you prefer to get your health information?*
 - i. *Are some sources easier to get to than others?*
 - ii. *What role does your primary care doctor have in giving you health information?*
- b. *If you wanted to learn about kidney disease, where would you get it?*
- c. *Do you like to use the internet to get your health information? From what sources?*
- d. *How would you prefer to learn about kidney disease at a kidney-screening event? Why?*
 - i. *Do you pick up pamphlets and are they useful to you?*
 - ii. *What makes a pamphlet more or less useful to you?*
 - iii. *Other than pamphlets, what other ways would you prefer to get information about kidney disease?*
 - iv. *How important is it to interact with a doctor during a community-screening event?*