

ATTACHMENT 3

Moderator's Guide for Consumer Focus Groups Latino Discrimination in Health Care and Civil Rights to Non-Discrimination in Certain Health Care and Social Service Programs

Need in the room: Pencils for all participants.

Introduction [10 minutes]

Welcome and thank you for joining us. My name is [moderator's name] and I will be your moderator for this focus group session, which is about discrimination against Latino's in health care. We will also talk about certain civil rights laws that prohibit discrimination in certain health care and social service programs. I'd like to hear your views about issues related to this topic, and I'm also interested in your thoughts on some messages and materials written about these topics.

I am not an expert on these topics: rather I am an independent moderator trained to facilitate our discussion.

Our client for this research is the U.S. Department of Health and Human Services Office for Civil Rights, located in Washington, D.C. Our discussion should last about an hour and a half.

Disclosure

- Observation: There is a one-way mirror in this room, with observers on the other side who are interested in hearing your views on these topics, but don't want to interrupt the conversation.
- Audio taping and video recording: This session will be recorded by audio and video tape to enable us to capture everything being said today. We will use the tape to assist us in writing our report to our client.
- Confidentiality assured: Your name or any other personal information will not appear in the report.
- 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 we have written a report about all the opinions we have heard here and in other locations, all tapes and notes will be destroyed.

Ground rules

- We want to hear from everyone, so we ask that everyone speaks but that only one person speaks at a time. Because we want to hear your opinion, if you're being quite I might call on you.
- There is no right or wrong answers, to these questions; we are interested in a variety of experiences, viewpoints and personal opinions.

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is XXXX-XXX. The time required to complete this information collection is estimated to average two hours per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: U.S. Department of Health & Human Services, OS/OCIO/PRA, 200 Independence Ave., S.W., Suite 336-E, Washington D.C. 20201, Attention: PRA Reports Clearance Officer

- As the Moderator here, I am neutral on these topics. Please feel free to be candid and honest – tell us how you really feel and not what you think we want to hear.
- It's okay to disagree; if you disagree with something you hear please be respectful of other's right to their opinion, and be willing to offer your own views and opinions.
- If anyone needs to use the restrooms, they are located [specify]. Please feel free to get up and use them. There is no need to stop the discussion. I do ask that only one person leave at a time for the restrooms.
- As we need your full attention, please turn off all cell phones

Do you have any questions before we get started?

Participant introductions

- Brief introductions around the table
 - o Share your first name and tell us what you like to do in your free time.

Health Care Experience (25 minutes)

- We are now going to spend some time talking about your experience with health care providers (such as doctors, nurses, clinic intake staff) and the medical care you receive.
- Now let me see a show of hands, how many of you are the person in your household primarily responsible for your family's medical care?
 - o [PROBE IF NECESSARY] What I mean is things like scheduling doctor appointments, taking kids or elderly relatives to the doctors, picking up prescriptions from the pharmacy, things like that?
- Generally, where do you go, or where do you take your family, when someone needs medical care?
 - o [PROBE IF NECESSARY] Do you have a doctor or clinic you visit regularly or do you end up going to the Emergency Room, urgent care clinic or somewhere else?
 - o For those who said they wait to seek medical care, why do you tend to wait?
- How did you choose your doctor or provider?
 - o Did you feel like you had a variety of good provider options to choose from?
 - o If not, what do you feel limited your choice of options?
 - o Did you find it difficult to find a doctor or provider that could communicate with you in the language you feel most comfortable speaking?
- Tell me about your typical health care experience.
 - o Do you feel you experiences with the health care system have been positive?
 - o For those who said no, why do you say that?
 - o Overall how would you rate the quality of care you and your family received?
 - o What parts of the health care experience did you like?
 - o What parts did you not like, or what would you change?
 - o Wherever you go for care, does your provider have someone on staff who can speak

Spanish?

- o Do you know?
 - o Would you feel comfortable asking if there was someone on staff who speaks Spanish, available to assist you in communicating?
 - o When choosing a provider, how important is it that someone on their staff speaks Spanish?
 - o Is it important to you that the doctor speaks Spanish?
 - o When speaking with your provider, do you prefer to communicate in a language other than English?

 - o [FOR THOSE THAT SAID PROVIDER HAS SPANISH SPEAKING STAFF]
 - o Do you generally talk with your care provider in Spanish or English?
 - o What positions do those individuals who speak Spanish usually have? (i.e. nurse, receptionist, doctor).
 - o Do those staff people speak Spanish well enough to communicate with patients about medical information?
 - o When choosing a doctor or choosing where to get care, do you check to make sure that the provider has someone on staff who can communicate in Spanish?

 - o [FOR THOSE THAT SAID PROVIDER DOES NOT HAVE SPANISH SPEAKING STAFF]
 - o Do you ever wish you could talk with your provider in Spanish?
 - o Would that allow you to communicate with them more effectively to receive better care?

- And when your provider or someone else gives you information about your health care, or anything related to health care, how important is it that they give you that information in Spanish?
 - o If they give you the information in English, do you feel as if you can understand it?
 - o Do you find it at all helpful to be given information in English?
 - o What do you do if you are given information in English but cannot understand it or are not sure exactly what it means?
 - o [PROBE IF NECESSARY] Do you ask them to explain the information, or have someone on their staff translate and explain the information for you?
 - o Or do you have someone you know (i.e. friend, family member, co-worker) translate and explain the information for you?
 - o How often do you do this?
 - o What types of documents do you normally ask to be translated or explained for you? (i.e. patient forms, after-care instructions, medication directions).

- In your opinion, are there health/healthcare issues unique to Latinos?
 - o What would those be?
 - o Do you feel as if your health care provider understands these issues?
 - o [PROBE FOR BOTH YES/NO] Why do you say that? Can you give me an example of why you think they do or do not understand health care issues unique to you as a Latino?

- o Do you think being able to communicate and receive health care information in a language other than English (such as Spanish) is an issue unique to Latino's or do you think other cultures experience the same issue?
- How much do you rely on your provider as a source of information about health care, generally?
 - o What other sources do you use/rely on to obtain health care information?
 - o [PROBE IF NECESSRY] Do you rely on friends, family, social workers, teachers, someone else to tell you about important information relevant to you and your family's health care?

Discrimination in Health Care (25 minutes)

- Now let me ask you about something we touched on a bit earlier. In recent years, has anyone here received medical care they feel was inadequate or of low quality?
 - o [TO THOSE THAT SAY YES] Can you briefly tell me what happened?
 - o [IF NO SAYS YES] Well does anyone know of a friend or family member that did?
 - o [IF THEY KNOW SOMEONE WHO DID] Why do you think they received inadequate or low quality care?
 - o [PROBE IF IT DOESN'T COME UP] Do you feel it had anything to do with the fact that they were receiving free or reduced cost care?
 - o [PROBE IF IT DOESN'T COME UP] Do you think that ethnicity played a role in this?
 - o Do you feel a possible accent or limited ability to speak or understand English played a role in their receiving inadequate or low quality care?
- Do you think discrimination in health care is a problem for Latinos?
 - o [IF THEY SEEM CONFUSED ABOUT WHAT "DISCRIMINATION" IN HEALTHCARE IS] An example of discrimination in healthcare might be being treated differently because of your race or the language that you speak.
 - o [TO THOSE THAT SAID YES] Why do you say that?
 - o [TO THOSE THAT SAID NO] Why do you say that?
 - o How do you think you would know if Latino's faced discrimination in health care?
 - o Do you feel as if your family and friends receive the same level of care as non-Latino or non-Spanish speaking people?
 - o If not, can you explain what you feel is different about the care those people receive?
- How would you know if you faced discrimination in health care or in a health care setting?
 - o Can you give me an example of some behavior by a provider that made you think you were being subjected to discrimination?
 - o [IF THEY SEEM CONFUSED ABOUT BEING SUBJECTED TO "DISCRIMINATION" IN HEALTHCARE] For example, some Latinos say they feel they received lower quality

care because of their race or because of the language they speak. These would be examples of experiencing discrimination in health care.

- What else has anyone experienced or witnessed in terms of discrimination against Latinos in health care?
 - What happened?
 - Why do you think that was discrimination?
 - How did that experience make you feel?
 - [PROBE IF NECESSARY] Did that experience make you feel: Angry? Misunderstood? Intimidated? Scared?
 - Did the experience scare or upset you so much that you felt intimidated about seeking care in the future?
 - Do you have family or friends who feel this way?

- What other things would you characterize as discrimination against Latinos in health care? Not necessarily things you've experienced or witnessed yourself; just tell me anything that comes to mind that would make you think you were being discriminated against in receiving healthcare.
 - [PROBE – IF IT DOES NOT COME UP IN CONVERSATION, ALLOW SOME DISCUSSION ABOUT WHETHER THEY CONSIDER THE FOLLOWING TO BE FORMS OF DISCRIMINATION]
 - Not having anyone on staff that speaks Spanish?
 - Not having anyone on staff to translate?
 - A provider not offering to have someone on their staff to translate for you?
 - Being told to have a family member or friend explain medical information to you?
 - Not having materials or forms in Spanish?

- What would you do/have you done, if you experienced discrimination in any of the ways we're discussing?
 - Did/would you tell anyone?
 - [IF YES] Who did/would you tell?
 - Why would you tell that person?
 - Did/would anything happen as a result of you telling that person?
 - What did/would you expect to happen as a result of you telling that person?
 - Ideally, what would you want to happen?
 - Did you or the person you told know that you had a legal right to file a complaint about the experience?

- Who do you think is responsible for preventing discrimination in a health care setting?
 - Is it the responsibility of a state agency, like a state Attorney General's Office?
 - Is it the responsibility of a Federal Government Agency? Which one[s]?
 - Is it the responsibility of community groups? Which ones?
 - To what extent do you think these agencies or groups have been successful in helping to prevent discrimination in health care settings? Why do you say that?

- o To what extent do you feel that they have been unsuccessful? Why do you say that?

Office for Civil Rights (10 minutes)

Now we are going to change gears slightly and shift our focus to a specific office within a government agency.

- Has anyone here heard of a federal government agency called the U.S. Department of Health and Human Services; sometimes referred to as HHS?
 - o What about the U.S. Department of Health and Human Services Office for Civil Rights?
 - o [IF ANYONE SAYS THEY KNOW OF THE OFFICE] How do you know about the HHS Office for Civil Rights?
 - o [IF UPON DISCUSSION IT IS CLEAR THEY ARE SPEAKING ABOUT ANOTHER AGENCY] You are talking about the Department of (Justice/Education/Labor, etc.) Office for Civil Rights. Did you know HHS has an Office for Civil Rights?
- What is the first thing that comes to mind when you hear Office for Civil Rights, within the Department of Health and Human Services?
 - o [PROBE] It's ok if you have never heard of them before. Hearing the name of the office, what do you think the office does?
- Let me tell you a little about the HHS Office for Civil Rights (OCR for short):

OCR makes certain that people have equal access and opportunity to participate in certain health care and human services programs without facing unlawful discrimination. OCR serves a number of functions including: investigating complaints, enforcing rights, and providing public education and information.

The Civil Rights Division of OCR enforces Federal laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age and, in certain circumstances, sex and religion. These laws and regulations apply to programs and activities that receive financial assistance from HHS. This division also enforces a Federal law and regulation that prohibit discrimination on the basis of disability in health care and social service programs of state and local governments.

OCR has ten regional offices throughout the country. These offices serve a number of functions including providing information, receiving discrimination complaints against health care providers and social service agencies, and when appropriate conducting investigations into those complaints. If you feel a health care provider, or state or local government agency, has discriminated against you (or someone else) based on race, national origin, disability, or age, you may file a civil rights complaint with OCR. To assist you in doing this, complaint forms are provided in both English and Spanish.

- After hearing a little about the HHS Office for Civil Rights, would you consider filing a complaint with them if you ever experienced or witnessed what you believed to be discrimination in a health care or social service program?

- o If yes, why would you consider doing so?
- o Do you think it would be difficult to file a complaint with OCR?
- o What do you think would be the result of filing a complaint with the office?
- o If not, is there any particular reason you would hesitate filing a complaint with them?
 [PROBE IF NECESSARY: ARE YOU AFRAID OF HAVING TO GIVE PERSONAL INFORMATION TO A GOVERNMENT AGENCY? DO YOU WORRY THAT DOING SO COULD LEAD TO INFORMATION BEING SHARED WITH LAW ENFORCEMENT? DO YOU FEAR SOME TYPE OF RETALIATION AGAINST YOU FOR DOING SO?]
- I am now going to read you a few statements about civil rights and the HHS Office for Civil Rights; and after each I would like you to tell me if that statement makes you feel more comfortable reporting a case of discrimination to OCR and why?
 - o Civil rights are personal rights guaranteed and protected by the U.S. Constitution and federal laws enacted by Congress. Under these laws, all persons in the United States have a right to receive health care and human services in a nondiscriminatory manner.
 - o OCR enforces civil rights laws that prohibit discrimination on a number of bases, including race, color and national origin. OCR has jurisdiction over health care and social services agencies receiving federal financial assistance from HHS. Such agencies include such things as hospitals, clinics and nursing homes.
 - o If you believe you have been discriminated against because of such things as race, color, or national origin, you or someone else may file a complaint with OCR. Complaints may be filed by mail, fax, or even online.
 - o In OCR investigations the name of the person complaining usually is kept confidential. If OCR determines that release of your name is necessary for the investigation of a complaint, you will be asked to sign a release. You have the right to choose not to sign a release; however the investigation into the complaint may be held back or stopped by making this choice.
- Now I'm going to read you a few statements about civil rights relating to "LEP" individuals. LEP means Limited English Proficient. LEP individuals are people who do not speak English as their primary language and who have a limited ability to read, speak, write, or understand English.
 - o Receivers of federal funds and all federal agencies are required by law to take reasonable steps to provide meaningful access to Limited English Proficient persons.
 - o These individuals may be entitled to language assistance with respect to a particular type of service, benefit, or encounter.
 - o Vital documents may need to be translated when a significant number or percentage of the population eligible to be served, or likely to be directly affected by the program/activity, needs services or information in a language other than English to communicate effectively.

- o Health care providers must provide language assistance services at no cost to a patient and cannot require a person to provide an interpreter of their own.
- Was this information new to you?
 - o Knowing this information, would you now be more inclined to convey you need for language assistance to your health care or social service provider?
 - o [PROBE IF NECESSARY] Why or why not?
 - o Do these statements make you feel more comfortable reporting a case of discrimination to OCR?
 - o Why or why not?

Collateral Materials Testing (assuming 5 pieces: 3 radio ad scripts and 2 pieces of print material) (40 minutes)

Some materials have been developed to explain information concerning civil rights laws against discrimination, enforced by the HHS Office for Civil Rights. The radio commercials would play in local radio markets and the print material would be made available through a variety of sources. I'd like to get your reactions to these materials. We'll go through each one separately.

- Radio Ads #1,2 & #3
(Allow 7 minutes for each)

[PLAY RADIO COMMERCIAL OR IF NOT COMPLETED READ SCRIPT]
[FOR EACH COMMERCIAL ASK THE FOLLOWING:]

- o What is your first impression of the radio spot? [TRY TO HEAR FROM EVERYONE]
- o Would the radio commercial catch you attention if you heard it? Why or why not?
- o What stands out most to you from the commercial? If you had to say the commercial was about one thing, what would you say was the main point of the commercial?
- o Was any of the information in the commercial new to you? [WAIT FOR RESPONSE, PROBE IF NECESSARY] What information was new to you?
- o Was there anything you did not like about the commercial? Any information you did not find helpful or that you already knew?
- o Where there any words or phrases that you found confusing, unclear or hard to understand?
- o Is there anything you would change about the commercial? Any information you think should be added to it?
- o Does this information make you feel empowered? Does it make you feel more informed about your civil rights?
- o Would the information change how you would react if you felt a health care provider or state or local government agency had discriminated against you (or someone else)?

Now I am going to hand out some print material. I would like everyone to take a few minutes to read the material so that I can get your reaction.

- Print Material – Two Pieces
(Allow 8 minutes for each)

[HAND OUT PRINT MATERIAL]

[FOR EACH PIECE OF PRINT MATERIAL ASK THE FOLLOWING:]

- What is your first impression of this material? [TRY TO HEAR FROM EVERYONE]
- Would the material catch your attention if you saw it? Why or why not?
- What stands out most to you from the material? If you had to say the material was about one thing, what would you say was the main point it was trying to get across?
- Was any of the information in the material new to you? [WAIT FOR RESPONSE, PROBE IF NECESSARY] What information was new to you?
- Was there anything you did not like about the material? Any information you did not find helpful or that you already knew?
- Were there any words or phrases that you found confusing, unclear or hard to understand?
- Is there anything you would change about the material? Any information you think should be added to it?
- Does this information make you feel empowered? Does it make you feel more informed about your civil rights?
- Would the information change how you would react if you felt a health care provider or state or local government agency had discriminated against you (or someone else)?
- What other sources would you trust receiving this information from?
- Are there specific media outlets, such as newspapers, magazines, TV stations, online sites (web sites, blogs, and chat rooms) or organizations you would trust?

Wrap Up (2 minutes)

- Compared to when you started this session, are you more interested in learning about your civil rights and the laws that prohibit discrimination?
- After hearing and reading the previous materials, do you feel better prepared to take action to uphold your civil rights and report an act that you believe may be discrimination against you or someone else in health care or human services programs?
 - [IF YES] Why do you say that? What about those materials make you feel better prepared? [PROBE] Is it because of the facts those materials provided you; like having the right to file a complaint and how to do so? Do those facts make you feel more knowledgeable about your rights?
 - Did the materials make you feel more comfortable about reporting a possible case of discrimination against you or someone else?
 - [IF NO] Why not?
 - [PROBE] Was the information not helpful? [IF THEY SAY INFORMATION WAS NOT HELPFUL] Was the information not presented in a clear way that made the information easy to understand?

- Earlier I mentioned the Department of Health and Human Services Office for Civil Rights. Do you now feel you have a better understanding of what that office does? [TRY TO HEAR FROM EVERYONE]
 - In your own words, what would you say the HHS Office for Civil Rights does?
 - Are you interested in learning more about the HHS Office for Civil Rights?
 - Do you think you will share with family and friends the information you heard today about the Office for Civil Rights and your rights to nondiscrimination and right to file a complaint if you feel those rights have been violated?
- After everything we talked about today, do you think you would ever file a complaint with the HHS Office for Civil Rights if you or someone else experienced an act that you believe could be discrimination in a health or human services program?
 - [PROBE] Why/Why not?

Dismissal

That completes our conversation.

- On behalf of HHS Office for Civil Rights, I want to thank all of you for your valuable time and input here today.
- Moderator - Check with clients for any additional information.