

Attachment 4b

MMP Recruitment Guidance, Project Area Staff Make Initial Contact

Medical Monitoring Project

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Recruitment Guidance and Model Scripts

MMP Staff Make Initial Contact

This document describes issues to consider when developing local procedures and scripts for interview recruitment. To minimize the chance of an adverse impact on sampled persons, MMP staff must confirm the sampled person's identity and address the potential for contacting a person unaware of his/her HIV status. These issues apply equally to both face-to-face and telephone recruitment. Logistical issues of particular relevance to telephone interview are also discussed.

This document specifically addresses the scenario in which MMP staff makes initial contact with the participant. The alternative scenario in which HIV facility staff makes initial contact is described in a separate document. Please note that scripts are provided as examples. Scripts and procedures should be modified according to the project area's local situation.

Participant Identification

MMP staff making initial contact with potential participants should follow their project area standard procedures when contacting potential participants and explaining MMP. Maintaining confidentiality is essential. Mention of HIV/AIDS should not occur until the sampled person's identity can be confirmed. MMP staff should be sensitive to the risk of inadvertently disclosing the sampled person's HIV status.

Before providing a thorough explanation of MMP, staff will need to verify the potential participant's identity. To confirm a participant's identity over the phone, MMP staff members should obtain the following information prior to calling the participant. When the participant is contacted, he/she will be required to provide the matching information. Two or more methods of confirming identity should be used. Examples include:

1. What is your full name (including middle name and/or suffix)?
2. What is your date of birth?
3. Do you have a regular place or person that you go to for medical care? If yes, what is the name of that place or person (persons receiving care only)?
4. I have in my records another phone number for John Doe that begins with (404) 639. Can you tell me the last four digits of that phone number?
5. I have in my records an old address for John Doe with the street number 1437. Can you tell me what street goes with that number?
6. Would you please show me an ID card or a driver's license so that I can make sure I am speaking with the right person (face-to-face recruitment only)?

The option to ask about the person's HIV care facility should only be used if the person is receiving HIV care, and the fact that he or she receives care at a given clinic has been confirmed with that facility. If the person is able to answer these questions correctly, the interviewer may move on to the recruitment portion of the interview. If the person cannot answer the questions correctly by telephone, the interviewer should schedule a face-to-

face interview so that the participant's identity can be confirmed in person by asking to view an identification card. In the less common situation in which a facility staff member is the first to approach patients about MMP, project areas may choose to ask facility staff to give the patient a code number or code word at that time. This code can be later used to confirm the person's identity in place of confirmatory questions.

Sample Script

MMP Staff: *Hello, may I speak with John Doe?*

If asked to identify yourself, respond that you are conducting a health survey. If a letter introducing the survey has been sent in advance, then mention the letter at this time. If the person indicates that he is John Doe, or you are put in touch with John Doe, keep in mind that there could be a Jr. and Sr. with the same name and say:

MMP Staff:

I am getting in touch with you about a health survey for John Doe. This is a chance for Mr. Doe to help out his community, and he will receive _____ as a token of appreciation. For confidentiality reasons I need to make sure that I am talking to the right person. May I ask you a few questions to make sure I'm speaking with the right John Doe?

If yes, continue.
If no, emphasize the importance of confidentiality saying something like, "For the sake of Mr. Doe's privacy, it's very important that I confirm I'm speaking with the right person. Once I've confirmed that you're the right John Doe, I'll explain more about the survey, and I'm sure you'll agree." Other options that may be useful in explaining the need for identity confirmation are: "The reasons I'm asking you to confirm that you are Mr. Doe is because he is the person we randomly chose to participate in this survey." "With your cooperation we can keep this matter confidential," or "Once I confirm I'm speaking with the right person, I will do my best to answer all of the questions that you have."

MMP Staff: *What is your full name including your middle name?*

Participant: *John Alexander Doe.*

MMP Staff: *Great! May I ask your date of birth?*

Participant: *February, 10th, 1974.*

MMP Staff: *Excellent! Just one more question to make sure I'm talking to the right person. Do you have a regular place you go for medical care? If so, what is the name of that place?*

Participant: *The Emory Clinic on Clifton Road.*

MMP Staff: *Thank you, Mr. Doe. Is there a different name that you would prefer me to call you?*

- If answers are correct, go on to introduce the project.
- If not correct, and the initial recruitment attempt was by phone, interviewers should schedule a face-to-face meeting to view an ID card. Interviewers may explain that they would like to meet in person to explain more about the survey and request that the person bring a photo ID.

Project Introduction

MMP staff should also be aware that there is a small but real possibility that a sampled person 1) is not HIV positive (e.g., the case was reported to HIV surveillance in error); or 2) is HIV positive but not aware of his or her diagnosis; or 3) has received positive HIV test results but does not believe them. If a person approached for recruitment meets the description in 1), 2), or 3) above, the recruitment is to be discontinued, because the more pressing need is to confirm or address the person's HIV status. MMP is designed as a data collection activity involving HIV-infected people who know their HIV status, so ideally, MMP staff would identify and exclude sampled persons in these categories before attempting recruitment. This is especially important given that presuming awareness of status might cause distress among individuals who are HIV-negative and or unaware and unprepared to know their HIV status. In practice, though, ascertaining awareness of status--and if unaware, whether description 1), 2), or 3) fits best-- may not be possible without talking with the individual, especially for situation 3), but also for situations 1) and 2) in the absence of additional information.

It may be possible to identify persons who are aware that they are HIV-positive before attempting to recruit them by determining whether they have had CD4 and viral load results reported to HIV surveillance and performed after the date of the HIV diagnostic test. CD4 and viral load tests may constitute evidence of care, and someone who has had a post-test care visit should have received their HIV test results, so CD4 and VL tests reported to surveillance might indicate that a sampled person is aware of his/her HIV diagnosis. (Keep in mind that a single CD4 or VL test may not be a perfect proxy for knowledge of HIV status, because it may represent a test ordered on blood drawn for diagnostic testing, rather than during a care visit). Conversely, the absence of reported CD4 or VL test result does not always indicate that a person has not had a care visit and has not received their HIV test results—results may not have been reported or may be delayed, or the person may have received care outside the jurisdiction.

CD4 and VL tests can be used to guide the recruitment approach. However, given that even CD4 and VL results are not perfect indicators of awareness of status, MMP staff should be conservative in tailoring their approach, i.e., deferring to the individuals approached.

In introducing MMP, it is important to quickly put the sampled person at ease, establish the project's legitimacy, develop rapport, and convey the reasons they might choose to participate. The script below is proposed as a model to accomplish these objectives.

Sample Script

MMP Staff: *Hi, my name is _____, and I'm getting in touch with you to see if you would be interested in participating in a project funded by the US Centers for Disease Control and Prevention and conducted by the [insert health department].*

We're collecting information to improve health services for people with your specific health care needs. If you choose to participate, you will complete a one-time 45-minute interview and your medical record will be reviewed. You will be given _____ as a token of appreciation.

➤ For those with evidence of having received HIV care:

You and 400 other participants were randomly chosen from among people who have had a positive HIV test, because the health needs of people living with HIV are so important to our community. We take your privacy very seriously. This project is completely confidential. We will not use your name or medical record number in any of the reports from this project. Would you be interested in participating?

If yes, go on to scheduling the interview.

➤ For those without evidence of having received HIV care:

You and 400 other participants were randomly chosen from among people who have had an HIV test, because the health needs of people living with HIV are so important to our community. According to our records, you had an HIV test on [insert date of test]. Did you receive the results of that test?

If yes, continue with recruitment script.

If no, follow local procedures that have been approved by CDC for delivering positive HIV test results, post-test counseling, and linking persons to HIV care. Do not proceed with recruitment for MMP; the focus should be on helping the person process the test results and linkage to care. Provide contact information so that the person can contact MMP staff if he/she wants to participate at a later date. Report to your CDC project officer the fact that you have contacted a person unaware of his/her HIV status and consider whether the event meets the criteria for adverse event reporting.

Only those who have had a positive HIV test are eligible for this health survey. According to our records, your HIV test on [insert date of test] was positive, meaning that it showed evidence of HIV infection. Is that the same test result that you were given?

If yes, continue with recruitment script.
If no, it is possible that either the sampled person is mistaken or that surveillance data are incorrect. Do not proceed with recruitment. Provide contact information so that the person can contact MMP staff if he/she wants to participate at a later date. Follow local procedures that have been approved by CDC for confirming HIV test results and linking persons to HIV care. If the investigation concludes that the person is HIV positive, the focus should be linkage to HIV care. Report to your CDC project officer the fact that you have contacted a person unaware of his/her HIV status and consider whether the event meets the criteria for adverse event reporting.

This project is completely confidential. We will not use your name or medical record number in any of the reports from this project. Would you be interested in participating?

If yes, go schedule the interview.

Telephone Interview Logistics

Scheduling the Interview

❖ Scenario 1: Telephone Interview Selected

MMP Staff: *Great! I'd like to offer you the opportunity to complete the interview either over the phone or in person. Please keep in mind that the interview may take up to 45 minutes and may cover sensitive information. If you choose to complete the interview over the phone, you'll need to have a phone and a private space that you can use to complete the interview. Would you like to complete the interview by phone or in person?*

Participant: *Well, I work during the day. Could we do it over the phone after work?*

MMP Staff: *Yes, that's no problem. Like I said, some of the questions can be sensitive. Will you have a private place to do the interview?*

Participant: *Yes, at my sister's house.*

MMP Staff: *Do you have a landline or a cell phone?*

Participant: *I'll use my cell phone.*

MMP Staff: *Okay. The interview will take 45 minutes to complete and we won't be able to reimburse you specifically for the cell phone minutes used. We will only be able to provide you with \$___ as a token of appreciation. Is that okay?*

Participant: *Yes, I have unlimited minutes.*

Interviewer can proceed to schedule the telephone interview.

❖ Scenario 2: Telephone Interview Selected: On the Spot

Participant: *Can I take the interview right now?*

MMP Staff: *During the interview, there are some questions that have multiple answers, and seeing the answers in front of you may help you pick the best one. Also, some questions ask about specific dates, so it is helpful to have a calendar. We have response cards to help with these questions. If you want to complete the interview right now, I can help you get the response cards off the internet. Do you have internet access right now?*

If yes, MMP staff will direct the respondent to a website to retrieve the response cards (4mmp.cdc.gov). If the sampled person does not have web access, the interviewer may still conduct the interview on the spot, if it is his/her judgment that delaying the interview is likely to lead to failure to interview the participant. In that case, proceed with script.

MMP Staff: *Okay, since we don't have the response cards, I'll be extra careful about reading the answer choices slowly. Please feel free to stop me at any time to ask me to repeat something you may not have heard or understood.*

If the MMP staff member feels that waiting to mail the response cards will not interfere with recruitment, he or she may say:

MMP Staff: *Okay. It's really important that you have the response cards with you when taking the interview. Let's schedule the interview for a few days from now. That will give me a chance to mail the cards to you. The cards will have HIV-related information on them. Is it okay to send them to you through the mail?*

If no, MMP staff should then follow the protocol currently used to set up face-to-face interviews.

➤ **Scenario 3: In-person Interview Selected**

MMP Staff: *Great! I'd like to offer you the opportunity to complete the interview either over the phone or in person. Please keep in mind that the interview may take up to 45 minutes and may cover sensitive information. If you choose to complete the interview over the phone, you'll need to have a phone and a private space that you can use for the interview. Would you like to complete the interview by phone or in person?*

Participant: *I'd rather do it in person.*

Interviewer should schedule a face-to-face interview. If the identity confirmation was by phone, the interviewer should reconfirm identity when meeting face-to-face.

Informed Consent

Depending on what is permitted locally, verbal or written consent for participation must be obtained before conducting the interview. To obtain verbal consent, interviewers must read the informed consent form to the participant. To obtain written consent, interviewers can either mail the consent form (for an interview by telephone or videoconference) or obtain consent in person, for example when recruiting at an HIV clinic or the person's residence. If obtaining consent through the mail, interviewers should read the consent form to the participant again prior to starting the interview.

❖ Verbal Consent

MMP Staff: *Before we begin the interview, I want to be sure I have your consent to participate. In order to do that, I have to read what is called an "Informed Consent" form. After I have read the form and answered your questions, you will have the chance to agree or disagree.*

Do you have any questions?

❖ Written Consent via Mail

MMP Staff: *Before we can schedule the interview, I need to be sure I have your consent to participate. I'll ask you to sign a form saying that you agree to participate. I will mail you the form, called an Informed Consent form, and ask you to read it over. If you have questions about the form, please call me. If you agree to participate, please send the signed form back to*

me in the self-addressed envelope. After I receive your signed form, I will contact you to schedule your appointment. The consent form will have HIV-related information on it. Is it okay to send it to you through the mail?

If no, interviewer should schedule a face-to-face interview.

❖ **Written Consent in Person**

MMP staff members may obtain written consent if they recruit participants in person at an HIV clinic or at the person's residence.

Response Cards

Ideally, participants should obtain the response cards prior to participating in the interview. MMP staff will either mail the response card set to the participant prior to the interview, provide the response cards to the participant in person at the time of recruitment, or the cards may be accessed via CDC or local MMP websites. However, administering the interview without response cards is preferable to not administering it at all.

❖ **Mail**

MMP Staff: *During the interview, there are some questions that have multiple choices or options to select more than one answer. I will mail you a set of response cards before the interview that list the possible answers to these questions to make it easier for you to choose your answer. The cards will have HIV-related information on them. Is it okay to send them to you through the mail?*

If no, interviewer should schedule a face-to-face interview.

❖ **In-Person**

If MMP staff members recruit participants in person, they should provide the response cards to the participant when scheduling the interview.

❖ **Internet**

MMP staff should direct persons who agree to complete the survey during the initial contact to the local MMP external website or the CDC website, accessible at 4mmp.cdc.gov, so they can retrieve the response cards. If the respondent cannot access the cards, the interview may be rescheduled or the interview may be administered without the response cards.

Tokens of appreciation

Interviewers should explain how the participant will receive the token of appreciation for completing the interview. Measures to ensure that the participant received the token of appreciation include certified mail, in-person delivery, and self-addressed stamped reply cards. All of these methods have been used successfully by MMP sites in the past.

❖ Mail

MMP Staff: *As I explained earlier, you will be given \$___ as a token of appreciation today. The \$__ will be in the form of a _____. We will send this out by mail, but will need you to sign for it so that we can be sure you received it. Can I verify your address?*

❖ Medical Facility

MMP Staff: *As I explained earlier, you will be given \$___ as a token of appreciation. The \$__ will be in the form of a _____. You will be able to pick it up at your doctor's office at your next visit. When you pick it up, you will be asked to sign a receipt so that we can confirm that you received it.*