

ATTACHMENT 4

DATA COLLECTION INSTRUMENTS

HIV PARTNER SERVICES

Exploratory Research

In-Depth Interview Guide

Task Purpose: To explore the knowledge, awareness, attitudes, beliefs and behaviors regarding the main categories in the PS guidelines.

Data Collection

Setting: The in-depth interviews (IDIs) will take up to 1 hour. A trained interviewer will meet with the participant. A note taker will take notes from behind the one-way mirror.

Consenting: Informed consent will be obtained by the interviewer at the beginning of the interview session.

Process: The interview will comprise the following steps:

1. **Welcome:**
 - a. **Welcome**—the interviewer will welcome the participant and explain the purpose of the interview session.
 - b. **Informed Consent**—the interviewer will briefly review the consent form and obtain the participant’s informed consent.
2. **Actions Upon Diagnosing a Patient with HIV.**
3. **Awareness and Knowledge of Former PCRS Guidelines.**
4. **Partner Services.**
5. **Closing.**

Statement of burden for in-depth interviews

Public reporting burden of this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-XXXX)

Welcome

Thank you for coming today. Your participation is very important. I'm _____ and I'm from RTI, a non-profit research organization. I am conducting these interviews for the Centers for Disease Control and Prevention (CDC). The purpose of this interview is to get your feedback on CDC's current partner counseling and referral services (PCRS) guidelines and the new draft partner services (PS) guidelines. Your insights are very important to us in this process, and your time today is appreciated. This interview will last about one hour.

[Interviewer gives participant consent form] Here is an informed consent form. Take a moment to review it and if you agree to it, please sign it.

[Interviewer gives participant 5 minutes to review and sign consent form]

- The consent form states that you have agreed to be part of a study about partner counseling and referral services.
- Your participation is voluntary and you have the right to withdraw from the study at any time.
- You have probably noticed the microphones in the room. They are here because I am audio taping. At the end of today's discussion, I have to write a report. I want to give you my full attention and not have to take a lot of notes.
- Behind me is a one-way mirror. Some of the people working on this project may be observing this discussion so that they can hear your opinions directly from you.
- Your identity and anything you personally say here will remain confidential. Your name, address, and phone number will not be given to anyone, and no one will contact you after this interview is over. When I write my report, I will not refer to you by name.
- Most importantly, there are no right or wrong answers. We want to know your opinions and what you think about the materials we will be discussing. I do not work for the people sponsoring this research and I did not develop any of these materials, so don't hold back on giving me your honest opinions.
- Do you have any questions before we begin?

I. Warm-Up

1. Please tell me a little about you and your medical practice.
 - Number of years in practice (post residency)
 - Description of practice

2. How about your patients?

[Probe as needed for:]

 - age
 - race
 - ethnicity
 - gender
 - sexual orientation
 - socioeconomic status
 - type of insurance (Medicaid/Medicare or private insurance or self pay)
 - number of HIV positive patients
 - number of HIV positive patients diagnosed a year

II. Actions Upon Diagnosing a Patient with HIV

3. When you have a patient test positive for HIV, what do you do?
 - Do you refer them to another organization for services (e.g. prevention counseling, partner notification, medical care)? Why/why not?
 - If yes: What services do you refer them for?
 - Where do you refer them? (e.g. health department, community-based organization)
 - Please tell us what's involved when referring someone for services. In other words, walk us through the process that you go through.
 - What could be done to make this referral process easier?

4. When you have a patient test positive for HIV, what kind of assistance do you offer them with notifying their partners?
 - What is involved in the process of helping them notify their partners? When does this typically happen?
 - Do you refer them to another organization for assistance with notifying their partners? Why/Why not?
 - Where do you refer them? (Probe for health department, CBOs, if not mentioned)

5. Once your office has referred a patient to outside services, does any additional follow up with the patient take place?
 - If yes, please tell me what is involved in the follow-up process.

6. How important do you think it is for physicians to assist patients who test positive for HIV in notifying their partners that they may have been exposed to HIV? Why/why not?

7. Do you ask your HIV-positive patients about the HIV status of their partners? Why/Why not?
 - How comfortable are you inquiring about the HIV status of your patients' partners?

8. Who else in your practice talks to newly diagnosed patients about their partner(s), referrals, treatment, and care?
9. For HIV-positive patients who you treat on an ongoing basis, do you periodically re-introduce questions about their partners? Why/Why not? How often do you ask them about their partners?
10. What [local] resources would be available to you if you needed to address partner notification with an HIV-positive patient? Are you aware of local organizations where you could refer a patient for these services or assistance?
 - Community-based organization? Health department?
11. Do you have a dedicated person in your office responsible for ensuring that newly diagnosed patients are linked to the Health Department or other services for follow up?
 - What is the relationship of your office with the Health Department (or other services)?
 - How does the HD make your office aware of the services they offer?

III. Awareness and knowledge of former PCRS (1998) guidelines

12. Before today, had you heard of Partner Counseling and Referral Services, also known as “PCRS”?
 - If **YES**: Please tell me what you know about PCRS. [GO TO 13]
 - Are there any components of PCRS beyond the partner notification? What are they?
 - If **NO, or incomplete** understanding: Partner Counseling and Referral Services is also known as *partner notification* and was formerly called *contact tracing*. It is a voluntary service which means that no one is forced to use it. It is a set of services usually provided by health departments. The services are for HIV-positive persons and their sex or needle-sharing partners. The idea is to notify partners that they may have been exposed to HIV. The HIV-positive person willingly contacts his/her partners. Sometimes, people are uncomfortable contacting their partners, so they can ask the health department to do it for them. If the health department contacts the partners, they will never use the patient’s name (it’s completely confidential). The partners can then be tested for HIV. Counseling services and referrals for medical services are also offered for anyone who tests HIV-positive. [GO TO 15 if totally unaware]
13. [IF aware of PCRS] Based on what you know, how effective do you think PCRS is as a way to reach people who have been exposed to HIV and may be infected, but not know their status?
14. [IF aware of PCRS] What impact has PCRS had upon your practice? That is, what are some of the current practices you follow because of PCRS?
 - What are some of the positive aspects?
 - What are some of the negative aspects?
 - What would you change about PCRS to better fit your practice?

- What about PCRS has made it difficult to implement?
[GO TO 16]

15. [IF NOT aware of PCRS] Based on what I have told you about PCRS, what impact do you think it would have on your practice?

- Do you think it is something you would implement? Why/Why not?

IV. Introduction to Partner Services (PS) and Its Impact

Until now, we have talked about the PCRS system which was developed in 1998. The CDC is currently working on updating and replacing PCRS with the *HIV Partner Services* program or simply “PS”. The old PCRS guidelines primarily focused on patients diagnosed in a public sector settings such as STD/HIV counseling and testing locations and Health Department clinics. The new PS guidelines encourage *all* patients diagnosed HIV positive to receive PS whether in a private health care setting or public health care setting. We would like to find out your thoughts on the new guidelines and the role you may play in implementing these guidelines. The new guidelines have not been published. Like PCRS, PS is free, voluntary and confidential.

There are two primary goals of HIV Partner Services:

1. To help provide services to all HIV-infected persons, link them to medical care and treatment, and counsel them to avoid transmission to others;
2. To ensure sex and drug-injection partners are notified of their potential exposure and gain early access to individualized counseling, HIV (and other STDs) testing, medical evaluation, and treatment.

MODERATOR: Provide handout of PS overview. Give physician time to review and then discuss.

16. [If not familiar with PCRS, skip to #17] What do you see as the main differences between the old PCRS guidelines and the new PS guidelines?

17. How do you think the new guidelines will impact your practice?

18. As a physician, what do you see as the most important thing you can do to make PS successful?

(Logic for question 19: Draft guidelines state that where data is available, only 22% of newly infected HIV patients are interviewed to trace partners. The most critical first step for a physician is to refer this newly diagnosed patient to PS.)

19. Traditionally, newly infected patients have been interviewed by health department PS specialists (often called Disease Intervention Specialists). However, as part of PS, training may be provided to physicians so that they could do this interviewing. How do you feel about doing these interviews?

- Comfort level?
- Time constraints?

- Reimbursement?
- Other factors?

(Logic for question: Line 516 of draft PS guidelines brings up the possibility to expand index patient interviews beyond public health staff to physicians)

- Who do you think is the best person to interview newly diagnosed patients?
 - Self
 - PAs?
 - Nurses?
 - Social workers?
 - Counselors?
 - Disease Intervention Specialists from the health department?
 - Others?
- Do you think a physician could be more effective than a PS specialist at eliciting partner information? Why/why not?

20. After a newly diagnosed patient identifies their partners, they can either contact their partners themselves, called “self notification”, or they can request someone make the notifications for them which is termed “provider notification” (here ‘provider’ refers typically to a PS specialist at the health department.)

- What do you see as the strengths and weakness of the *self* notification approach?
- What do you see as the strengths and weakness of the *provider* notification approach?
- Which strategy do you think would be most successful in notifying partners?
- Which strategy would you recommend to your patients and why?

(Line 965 states preferred strategy is provider notification)

- In this context, “provider” refers to a PS specialist at a health department. However, the definition may expand to physicians, nurses and PAs. How comfortable would you and/or your staff be with conducting partner notification?
 - What do you see as the benefits of having physicians, nurses and/or PAs conducting partner notification?
 - What do you see as the barriers or challenges?
 - Time constraints?
 - Reimbursement?
 - Others?

21. Are you and other health care provider staff in your office familiar with local, state and federal laws regarding HIV and HIV testing?

IV. Implementing Partner Services (PS) into Health Care Settings

The new guidelines are recommending fully integrating HIV PS as part of a comprehensive HIV prevention system throughout the prevention and care continuum for HIV-infected persons.

22. How easy or hard would it be for your practice to fully integrate HIV PS as part of a comprehensive HIV prevention system?
23. What do you see as some of the barriers to implementing PS in your practice?
 - What could be done to remove those barriers?
24. How could the health department facilitate the process of referring your patients to PS?
 - What would you need from the health department to streamline getting patients into PS?
 - Tools
 - Forms (paper or electronic)
 - Designated disease intervention specialists “on-call” when needs arise or “on-site” at your practice
25. How would you need to change the way you currently interact with your HIV positive patients in order to implement PS?
 - When would you implement PS? (Prior to the HIV test; when HIV test results are provided; some time after results are provided?)
26. Do you feel that your practice would benefit from training on PS? Why/Why not?
27. What follow up procedures would your practice implement with patients and/or partners once referred out for services after HIV diagnosis?
28. What procedures would your practice implement to ensure partners of newly diagnosed patients are tested for HIV?
29. Do you and/or your staff receive training on providing services similar to PS once a person is diagnosed with HIV?
 - If yes, who provides this training, what does the training content consist of, and how often does this training occur?

V. Closing

Okay, we are pretty much out of time. Do you have any last thoughts?

[Moderator will check with observers for additional questions or comments.]

I would like to thank you for coming today and working hard on this. This has been very useful in helping us to learn your perspective on the new PS guidelines that are being developed.