

Form
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The Data to Care (D2C) Public Health Strategy: Successes, Challenges, and Lessons Learned in Identifying, Linking, and Reengaging Persons Diagnosed with HIV to Medical Care

Attachment 3b: D2C Client Interview Guide

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: OMB-PRA (0920-New)

Data to Care (D2C) Client Interview Guide

Date: _____

Respondent ID: _____

Interviewer Three Digit Initials: _____

Start Time: __:__AM/PM

INTRODUCTION AND PURPOSE OF THE INTERVIEW

[INTERVIEWER NOTE: INTERVIEWER INSTRUCTIONS APPEAR IN ALL CAPS AND SHOULD NOT BE READ VERBATIM]

INTERVIEWER READ INTRODUCTION: "Thank you for agreeing to speak with me today. My name is [Interviewer name], and I am part of a study team that is speaking with people living with HIV in your state in order to learn more about experiences connecting with medical care.

First, here is a form that explains the study in more detail. Would you like to read it yourself, or would you prefer for me to read it to you?"

ACCORDING TO RESPONDENT'S ANSWER, LET RESPONDENT READ IT OR READ IT TO RESPONDENT.

"We would like to record the interview today. The recording will ensure that our notes of today's conversation are complete and accurate. We will destroy the recording at the end of the study. Do you have any questions before you sign?"

ANSWER ANY QUESTIONS, AND WITNESS RESPONDENT SIGNING.

"Thank you. Here is a copy of the consent form for you to keep. As a reminder, your participation is voluntary. If there are any questions that you prefer not to answer, please tell me, and I'll move on to the next question."

HAND COPY TO RESPONDENT.

TURN ON TAPE RECORDERS AND SAY: "Now that I have the recorders on, may I also have your verbal permission to record our interview?"

Section A: BACKGROUND

INTERVIEWER READ INTRODUCTION: "I am going to begin by asking you several short questions to better understand your background and your situation. Please answer openly and to the best of your ability. Remember that you can refuse or skip any question you do not want to answer."

1. What is your age in years? |____|____|

2. Do you consider yourself Hispanic or Latino(a)?

Yes..... 1

No..... 2

3. What racial group or groups do you consider yourself to be? (PROVIDE SHOW CARD AND MARK ALL THAT APPLY)

- American Indian or Alaska Native..... 1
- Asian..... 2
- Black or African-American..... 3
- Native Hawaiian or other Pacific Islander..... 4
- White..... 5

4. Which of the following best represents how you think of yourself?

- Gay (lesbian or gay)..... 1
- Straight, this is not gay (or lesbian or gay)..... 2
- Bisexual..... 3
- Something else..... 4
- I don't know the answer..... 5

5. What sex were you assigned at birth, on your original birth certificate?

- Male..... 1
- Female..... 2
- Refused..... 3
- Don't know..... 4

6. Do you currently describe yourself as male, female, or transgender?

- Male 1
- Female..... 2
- Transgender..... 3

7. Just to confirm, you were assigned {_FILL based on Question_5} at birth and now describe yourself as {FILL based on Question 6}. Is that correct?

- Yes 1
- No..... 2
- Refused..... 3
- Don't know..... 4

8. What is the highest level of education you have completed?

- Less than a high school degree 1
- High School graduate/GED..... 2
- Some college / Associate's Degree..... 3
- Bachelor's degree 4
- Master's degree..... 5
- Professional school degree (MD/JD) or doctorate (Ph.D.)..... 6

9. In the past 12 months have you stayed on the street, in a shelter, or temporarily in someone's home because you had no regular place to live or stay?

- Yes..... 1 Ask 8.1
- No..... 2 Skip to Q 9
- Don't know 3
- Refused..... 4

8.1 Do you consider yourself currently homeless?

- Yes..... 1
- No..... 2
- Don't know 3
- Refused..... 4

10. In approximately what month and year were you diagnosed with HIV?

Month |__|__|

Year |__|__||__|__|

11. How soon after your diagnosis did you first begin to take HIV medications?

a. Do you remember the month and year when you first took HIV medications?

Month |__|__|

Year |__|__||__|__|

b. If respondent doesn't remember the date, ask: Did you take these medications right away after you found out you were HIV positive?

- Yes.... 1
- No.... 2

12. How soon after your diagnosis did you first get your HIV labs done?

a. Do you remember the month and year after your diagnosis when you first had your HIV labs done?

Month |__|__|

Year |__|__||__|__|

b. If respondent doesn't remember the date, ask: Did you first get your HIV labs done right away after you found out you were HIV positive?

- Yes... 1
- No 2

13. Do you currently have health insurance coverage?

- Yes..... 1
- No..... 2 → SKIP TO Q15
- Don't know 3
- Refused..... 4

13. What is your **primary** type of health insurance coverage? [CODE ONE]

- Insurance through a current or former employer or union (of this person or another family member) 1
 - Insurance purchased directly through an insurance company (by this person or another family member) 2
 - Medicare (for people 65 and older or people with certain disabilities) 3
 - Medicaid, Medical Assistance, or any kind of government assistance plan for those with low incomes or disability (includes Ryan White?) 4
 - Tricare or other military healthcare 6
 - VA (including those who have ever enrolled or used VA healthcare) 7
 - Student plan 8
 - No insurance coverage 9
 - Other 10
 - Don't know 11
 - Refused 12
- If NO coverage, → SKIP TO Q15

14. Since you first were diagnosed with HIV, was there a time that you didn't have any health insurance coverage?

- Yes..... 1
- No..... 2
- Don't know 3
- Refused..... 4

15. Are you currently working at a job that pays money? (IF YES, PROBE FOR FULL- OR PART-TIME)

- Yes, full-time..... 1
- Yes, part-time..... 2
- No 3
- Refused..... 4

SECTION B: HIV Care Experiences

INTERVIEWER READ: "Thank you for all the information you've provided so far. Now we are going to switch gears. I am going to ask you about your care experience. Let me start by asking you about your history of treatment for HIV."

1. Have there been times in your past when you were not receiving regular HIV care or stopped taking your HIV medications?

IF YES, ask: "Why was that? Tell me more about it."

PROBE AS NEEDED:

- HOW MANY TIMES SINCE DIAGNOSIS HAVE YOU STOPPED RECEIVING HIV CARE?
- WHAT WERE YOUR REASONS FOR FALLING OUT OF CARE?
- WHAT WERE YOUR REASONS FOR NOT TAKING MEDICATIONS?

If NO, confirm that the respondent has been in care since diagnosis.

INTERVIEWER READ: "Now, let's discuss your current treatment."

2. Are you currently taking your HIV medication as prescribed?

Yes..... 1
No..... 2

3. Are you currently in treatment and seeing a provider for your HIV care?

IF YES, ask: "Tell me about being in treatment now. Tell me about your visits to a provider, and what the treatment is like."

PROBE AS NEEDED:

- ARE YOU ATTENDING REGULAR VISITS? HOW OFTEN?
- WHEN DID YOU START GETTING HIV CARE FROM THIS PROVIDER?
- HAVE YOU BEEN PRESCRIBED ANTIRETROVIRAL THERAPY (ART)?
IF YES, HOW ARE YOU TAKING THEM?

- WHAT DO YOU LIKE AND NOT LIKE ABOUT THE PROVIDER?
- ARE THERE THINGS IN YOUR LIFE RIGHT NOW THAT MAKE IT HARD TO STAY IN CARE?

INTERVIEWER READ: "Now I'd like to ask you about being contacted to get (back) in HIV care and treatment."

4. Someone contacted you about getting into HIV Medical Care. What can you tell me about that experience?

PROBE AS NEEDED:

- DO YOU KNOW WHY YOU WERE CONTACTED?
- HOW WERE YOU CONTACTED? HOW DID THEY REACH YOU? WHO CONTACTED YOU?
- WHAT DID THEY SAY?
- HOW DID YOU FEEL ABOUT BEING CONTACTED?

INTERVIEWER: IF RESPONDENT DOES NOT REMEMBER BEING CONTACTED AND THINKS THEY ALONE MADE THE DECISION TO SEEK CARE, SKIP TO Q9

5. At the time they first contacted you, were you trying to get in care? Were you looking for a HIV care provider?

IF YES, PROBE AS NEEDED:

- WHY?
- WHAT HAD YOU BEEN DOING IN ORDER TO FIND A CARE PROVIDER?
- WAS ANYTHING PREVENTING YOU FROM FINDING OR VISITING AN HIV PROVIDER? DID YOU HAVE ANY DIFFICULTIES?

IF NO, PROBE AS NEEDED:

- WHY NOT?
- DID YOU THINK YOU DID NOT NEED TO BE IN TREATMENT? WHY?
- DID YOU THINK YOU COULD NOT GET IN TREATMENT? WHY?
- DID YOU HAVE PREVIOUS EXPERIENCES WITH TREATMENT THAT AFFECTED YOU?

6. Did the person who contacted you help you deal with issues that were keeping you out of care?

IF YES, PROBE AS NEEDED

- HOW DID THEY HELP YOU?

- DID YOU HAVE ANY DIFFICULTY IN PAYING FOR CARE?
- DID THE PROGRAM HELP YOU FIND A WAY TO GET COVERAGE FOR HIV CARE? HOW?
- PROBE ABOUT THE BARRIERS ALREADY MENTIONED.

INTERVIEWER READ: "Let's discuss your first appointment with your provider after you were contacted."

7. How soon after someone first contacted you did you have your first appointment for HIV care?

PROBE AS NEEDED:

- DAYS? WEEKS? MONTHS? DID THE PROCESS MOVE QUICKLY?
- DID THE PERSON THAT CONTACTED YOU MAKE THE APPOINTMENT FOR YOU?

- HOW? HOW OFTEN? WHAT WAS GOOD AND BAD ABOUT THE PROCESS OF GETTING YOUR APPOINTMENT?
- DID YOU KEEP THE APPOINTMENT AND SEE THE PROVIDER? WHAT MADE YOU DECIDE TO GO TO THAT INITIAL VISIT AND SEE THIS PROVIDER?
- DID THE PERSON WHO CONTACTED YOU GO WITH YOU TO YOUR FIRST APPOINTMENT? IF YES, WAS THAT HELPFUL?
- DID THE PERSON WHO CONTACTED YOU STAY IN TOUCH WITH YOU AFTER THAT? TELL ME MORE ABOUT THAT.

- WHAT DID YOU LIKE AND DISLIKE ABOUT YOUR FIRST APPOINTMENT?

- DID YOUR EXPERIENCES WITH GETTING CONNECTED TO CARE, OR YOUR EXPERIENCES DURING THEIR FIRST APPOINTMENT, AFFECT HOW LIKELY YOU ARE TO STAY IN CARE?

8. What do you wish the person who helped you get your appointment had done differently?

PROBE AS NEEDED:

- WHAT ABOUT THE WAY THEY INITIALLY CONTACTED YOU?
- WHAT ABOUT THE TYPE OF INFORMATION THEY OFFERED?
- WHAT ABOUT HOW MUCH THEY WORKED TO GET YOU INTO CARE?
- WHAT ABOUT HOW THEY CONNECTED YOU TO A PROVIDER?

INTERVIEWER READ: "As we wrap up the conversation today, I would like to know your ideas about other people who might not be in HIV care."

9. There are other people who are living with HIV in [jurisdiction] who are not in HIV care. Why do you think that is?

IF DON'T KNOW, PROBE

- BARRIERS (TOO BUSY, CLINIC NOT OPEN DURING NON-WORK HOURS, TOO EXPENSIVE, UNINSURED, NO TRANSPORTATION, DON'T LIKE/TRUST DOCTORS, ETC.)

10. Based on your experience, what suggestions do you have to help health workers locate others living with HIV who are not in care?

Section C: Closing

11. Please think about all the things we just discussed. What else do you think is important for me to know about your experience of getting into HIV care?

INTERVIEWER READ: "Thank you so much for your time!"

PROVIDE INCENTIVE. HAVE RESPONDENT SIGN RECEIPT. TURN OFF RECORDERS.

END TIME: ____:____ AM/PM