

“Proxy” Needs Assessment Questions for PLWH/A Now in Care Who Have Been Out of Care

Approach: Hopefully, your State or EMA is trying to assess unmet need by finding people not in care, learning about their service gaps and barriers to care – and helping them enter care. Because this is challenging, and you want a broad understanding of barriers to care, you may want to add questions to your PLWH/A study to identify PLWH/A who are currently in care using the Unmet Need Framework definition, but were out of care for at least a year during the past 3-5 years. Once you identify such individuals, you can ask them about service gaps and barriers to care during the time they were out of care. *If you are targeting people who are currently out of care as well as people who were previously out of care, you will probably want to ask both groups very similar questions about service gaps and barriers to care.* Following are some sample questions for people previously out of care.

1. During the past 12 months, have you had at least one of the following: a CD4 count, a viral load test, or a prescription for anti-retroviral therapy?
 Yes No

2. If you said Yes to question #1, has there been a period of at least 12 months over the past five years when you were *not* receiving HIV-related primary medical care, using that same definition?
 Yes No
If yes, when were you out of care? From about [month and year]_____ to about [month and year]_____.

3. What best describes your situation during that period? Check the response that best fits your situation.
 I had recently been diagnosed with HIV, and had not entered primary care.
 I had been receiving medical care for HIV, but I dropped out of care.
 Other (specify _____)

4. What zip code or neighborhood did you live in during the period when you were out of care? _____
What zip code or neighborhood do you live in now? _____

5. Why were you not receiving primary medical care during that period? Please identify up to three reasons that you consider the most important in explaining why you were not in care.
 I couldn't afford care and didn't know I could get it without paying.
 I didn't know where to go to get care.
 I was not ready to deal with my HIV status.
 I was afraid of being identified as HIV-positive.
 I had heard bad things about the medications and their side effects.
 I was in jail or prison and didn't want to ask for care there.
 There wasn't a medical facility near where I lived.

- It was too hard to get services (for example, long waits, inconvenient hours, no child care).
- I had too many other things to worry about in my life.
- I was homeless.
- I was using drugs or alcohol.
- I had mental health problems.
- I had a bad experience with a doctor or other medical staff.
- The medical facility wasn't a good "fit" for my needs.
- I had a bad experience with my medications and didn't want to continue taking them.
- Other (please explain _____)

6. Tell us more about your situation – explain what caused you to be out of care.

7. While you were out of care, what services other than medical care and medications did you need – what were your other service gaps?

- Substance abuse treatment
- Mental health services
- Dental care
- Case management
- Transportation
- [Add others as desired]

8. What caused you to get back into care? Please identify up to three main reasons.

- I got sick and knew I needed care.
- I was ready to deal with my illness.
- I got the information I needed to get into care.
- I found a doctor or medical facility I liked.
- A family member or friend helped me get into care.
- Someone else with HIV/AIDS reached out to me.
- An outreach worker found me and helped me get into care.
- Someone who had been involved in my care followed up, and got me to return to care.
- I was able to get access to care (for example, I got transportation, the facility started having evening or weekend hours, I moved)
- I got out of jail or prison.
- I was able to deal with other problems in my life that had been keeping me out of care.
- Other (explain _____)

9. Tell us more about how you got back into care.

10. What is the most important reason why people with HIV or AIDS in this [community/metropolitan area/state] sometimes don't get HIV-related primary medical care?