Protocol – Medicaid MCO Outreach to People with HIV Who May Not Know Their Status

AIDS Foundation Chicago, April 2022

Background: In 2022, the Illinois Department of Public Health (IDPH) began sharing viral suppression data with the Illinois Department of Healthcare and Family Services (HFS), which then sends that data to Medicaid managed care plans (MCOs), as directed by Governor Pritzker’s Executive Order 2019-08. The purpose of the data sharing is to monitor and improve the quality of HIV care provided to Medicaid members and improve engagement and retention in HIV care.

This protocol was developed by AIDS Foundation Chicago and Illinois Public Health Association with input from all Medicaid MCOs as part of the collaboration between IDPH, HFS and advocates to implement the executive order. For more information or for questions, contact John Peller, President & CEO, AIDS Foundation Chicago, jpeller@aidschicago.org.

It outlines actions MCO care coordinators can take if IDPH data and MCO data disagree on a member’s HIV status. In some situations, IDPH data will indicate that a member has HIV but the MCO does not have diagnosis or claims information that corroborates the IDPH data. IDPH data indicates if a member has a suppressed or unsuppressed viral load and the date of the last test.

1) Review of MCO diagnosis and claims data before reaching out to a member

Before reaching out to a member who is believed to be living with HIV, care coordinators should review diagnosis and claims information. For each member with HIV, care coordinators should:

- Review IDPH data indicating if the member is virally suppressed or not.
- In MCO data, look for a diagnosis code indicating that the member is diagnosed with HIV.
- In MCO data, look at claims to see if the person: 1) has had a lab test for HIV (viral load test and/or CD4 test), 2) saw a provider for HIV-related care, and/or 3) is taking antiretroviral medications. It’s possible that some members will not have all three, since they may not be fully engaged in HIV care. For example, a member could have gotten their labs done and seen a doctor for HIV care, but never picked up medications or stopped taking them. If they have one or more of these indications in claims, contact the member and work to fully engage them in HIV-related health care.

If the Medicaid member 1) does not have a diagnosis code or claims indicating they have HIV, and 2) IDPH data indicates that they have a suppressed or unsuppressed viral load, there are three possible explanations, with recommended actions for care coordinators:

**Scenario 1 - Member does have HIV but is not getting HIV-related medical care:** This is likely to be the most common reason that a member does not have an HIV diagnosis or claim. In 2019, 32% of people diagnosed with HIV in Illinois did not get HIV-related care
There are many reasons a person may have stopped getting HIV care such as HIV stigma, substance use, homelessness, mental health challenges, or criminal justice involvement.

**Recommendations for care coordinators:** Be understanding. Don’t judge the member for not getting HIV care. Tell the member that it happens to many people and it’s OK. Ask why the member has not gotten HIV care. What are the barriers? What resources can the MCO provide? Listen actively. Discuss the importance of taking HIV medications for their individual health and to protect their partners. Remind the member that people who take HIV medications can be very healthy. Offer to help the member find a provider in their community who can help them. A provider funded by the Ryan White program can offer expert medical care and supportive services, including case management (in partnership with the MCO care coordinator) (see resources below).

**Scenario 2 - Member does not know that they have HIV:** This is likely to be uncommon. A member may have been tested for HIV but was never informed about their results. This could occur because the provider did not have correct contact information for the member or it’s possible that there’s a mistake in the data (a provider may have checked the wrong box on a form used to report HIV status to IDPH).

**Recommendations for care coordinators:** Be understanding and patient. Members may be upset and concerned. Tell the member that there may be a mistake in the data. Ask the member what their concerns are and how you can support them. Help them make an appointment with a provider in their community that can give them another HIV test and help them get into medical care, if needed. Inform the member that people who have HIV can have normal lives and few health complications if they take HIV medications as directed. Inform the member that they should not have condomless sex with any partners until they have gotten tested for HIV and gotten their results. Discuss the best time to follow up with the member to support them.

**Scenario 3 - Member was incorrectly diagnosed with HIV (member says they do not have HIV, but IDPH data indicates they do):** This is likely to be uncommon. Some HIV tests can deliver incorrect results. This is called a “false positive” and can happen with rapid HIV tests. Providers typically order a different HIV test to confirm the HIV diagnosis, and if this test comes back negative, the provider would inform the patient that they do not in fact have HIV. However, not all providers are able to contact their patients (again, often because of incorrect contact information).

**Recommendations for care coordinators:** Apologize to the member. Inform the member that you will make a note in their records that they report that they do not have HIV. Explain that the data came from IDPH as part of an initiative to improve care for people with HIV. Contact Jamie Gates, IDPH HIV Surveillance Program Coordinator, Jamie.Gates@illinois.gov, to inform them that the member says they do not have HIV. IDPH will contact the client through alternative means.
Additional resources

- Illinois HIV Resources - How to Find Local HIV Providers Funded by the Ryan White HIV Program
  - Statewide
    - www.HIVCareConnect.com
  - Chicago-area
    - HIV Resource Hub: 1-844-HUB(482)-4040 or www.HIVHUB.org
    - HIV Case Management: AFC Hotline: 312-690-8860 or www.aidschicago.org/i-need/casemangement

- HIV Treatment Guidelines
  - https://www.cdc.gov/hiv/guidelines/index.html

- How Antiretroviral Medications Work
  - https://www.youtube.com/watch?v=9aDNwlRaJqw

- How to Explain What Undetectable Means to Your Patients:

- Illinois AIDS Confidentiality Act

- Health Insurance Portability and Accountability Act
  - https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html

- HIV Stigma and Discrimination – Centers for Disease Control and Prevention

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