Guidelines Issued for Health Departments to Aid in Linkage and Retention

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A think tank has issued recommendations to health surveillance groups to suggest how to properly use reported laboratory data about people with HIV to help keep them from dropping out of care. In November, Project Inform held a gathering in San Francisco of academics and representatives from AIDS service organizations and health departments to create these guidelines, which ultimately received a unanimous vote of approval from the group.

According to current estimates from the Centers for Disease Control and Prevention (CDC), only about 80 percent of the estimated 1.2 million people living with HIV in the United States know they are HIV positive, around 60 to 68 percent are linked into HIV care and between 30 and 41 percent are retained in care. (For more on this topic, see POZ's March 2013 cover story, "Falling Through the Cracks.")

The health departments of several municipalities around the country have recently begun pairing with local health providers to use the surveillance data they receive on people's CD4 and viral load screens to aid in tracking down patients who have been lost to care; similarly, such data sharing can save providers the trouble of tracking down patients if it happens that the individuals are receiving care elsewhere. This think tank was arranged both to encourage such cooperation and to discuss how to best manage important privacy and safety concerns.

"The risks of harm to individuals from improper use of HIV information can indeed be very real, especially in states with punitive laws related to HIV status disclosure," Walt Senterfitt, an HIV activist and public health epidemiologist who attended the think tank, said in a release. "The group decided, however, that there is a potentially much greater harm in not doing everything possible to ensure access to treatment, care and support of those with HIV who are marginalized by the system. The keys to mitigate harms and optimize benefits are careful planning, community engagement and full-throated advocacy to change punitive and non-evidence-based HIV criminal laws."

The report urges health departments to consider beginning such programs in order to improve retention in care for people with HIV, and to reach out to various concerned parties, especially those living with the virus, during their planning process in order to aid development and address

concerns that may arise.

To read the report, visit
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