

HIV Detection & Response Q&A

What is the purpose of the Oregon Health Authority (OHA) HIV Data and Analysis Program?

Like other conditions such as foodborne illnesses, pertussis and sexually transmitted infections, HIV is reportable to the Oregon Health Authority. OHA's HIV Data and Analysis Program is responsible for *the continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice*. The information collected is used to compile statistics on the number of people newly diagnosed with HIV and the number of people living with HIV. It also helps to determine how well the healthcare system is serving people with HIV and where to direct our resources to improve HIV prevention, care, and treatment across the state.

What is molecular sequence data?

Molecular sequence reporting is the collection and analysis of HIV genetic data generated through HIV drug resistance testing. HIV genetic data is information about the makeup of the virus itself, *unrelated to an individual's personal genetic makeup*. Molecular sequence data has been used for many years to track other conditions such as foodborne infections and tuberculosis. Molecular sequence data helps identify a group of related infections that would not otherwise be recognized as related and focuses public health efforts where they are needed most.

Molecular sequence analysis *examines the genetics of the virus, not the person*.

When is it collected?

HIV genetic data is collected through HIV drug resistance testing. This testing is routinely done when someone starts care for HIV to determine which medications will be most effective or when a provider is considering switching a patient's medication regimen if resistance to a prescribed drug is suspected. Providers use this information to choose the best HIV regimen for their patient. The HIV genetic data, like all reportable lab data, is reported to OHA by laboratories who process the sequence test, not by the ordering provider.

How is this information being used to end the HIV epidemic?

The federal government introduced a pledge to end HIV transmissions by 2030. The plan includes detecting and rapidly responding to growing HIV clusters to prevent new infections. On January 1, 2018, the Centers for Disease Control and Prevention (CDC) required CDC-funded HIV programs to develop plans to use molecular sequence data to detect and respond to HIV clusters and outbreaks.

Who receives this information?

Oregon law requires that HIV-related lab data be reported to the state Public Health Division, HIV data and analysis program per Oregon Revised Statute (ORS) 433.004 and Oregon Administrative Rule (OAR) Chapter 333, Division 018. Molecular sequence data has been reported to OHA's HIV data and analysis program since 2007 but OHA only began reviewing this data to detect and respond to HIV clusters and outbreaks starting in 2018.

OHA's guide to HIV Rules and Statutes can be found at:

www.oregon.gov/oha/PH/DiseasesConditions/HIVSTDViralHepatitis/HIVCareTreatment/Documents/HIVLaws.pdf

Can I opt out of having my HIV's genetic code collected and reported?

It is possible for patients to decline resistance testing, which would prevent the collection of this data; however, that should be a conversation between a patient and their doctor as the decision could impact treatment.

What is a molecular cluster?

A molecular cluster is a group of people living with HIV whose viruses share similar genetic data. A cluster may include people who acquired HIV very recently or sometime in the past.

What do molecular clusters tell us?

When the people in a molecular cluster have acquired HIV recently, a molecular cluster may indicate current and ongoing HIV transmission. Because HIV is constantly evolving, people whose viruses are genetically similar may be closely linked – directly or indirectly – by transmission. Prompt detection of rapidly growing clusters makes it possible to quickly offer prevention and care resources that can improve the health of persons with HIV and reduce new infections.

What are the limitations of molecular sequence data?

These data do not provide a complete picture. First, clusters may only represent a small part of a larger transmission network because not everyone in a cluster has been diagnosed and not everyone with an HIV diagnosis has an HIV genetic sequence available. Second, it is not possible to determine who infected whom. Third, clusters can include people who acquired HIV recently and others who were infected sometime in the past, so the relationships of people in time are not clear.

If a cluster or outbreak is detected, what will OHA do with this information?

Currently, this information is only being used by OHA to identify clusters and outbreaks. OHA may report limited information to a local public health authority with the goal of helping people get tested and linked to medical care and other services. OHA will never contact people directly.

Has this information already been used in Oregon?

Yes, OHA's HIV data and analysis staff monitor this data closely. This data was recently analyzed to identify molecular connections associated with an increase in HIV cases among persons who inject drugs in Multnomah County.

How is this information secured?

OHA's HIV Program complies with comprehensive security and confidentiality protocols approved by the state Information and Security Office that adheres to state and federal law and CDC requirements. A very small group of authorized OHA employees have access to this information for HIV related data and analysis.

What information is reported to the CDC and for what purpose?

CDC-funded grantees are required to report de-identified data to the CDC. This data is exported via a secure system. Names and other identifying information are never included in reports to the CDC.

More information about CDC HIV data collection and analysis can be found at:

<https://www.cdc.gov/hiv/statistics/surveillance/index.html>

Questions?

Please contact Lea Bush at 971-673-0183.