Planning for Molecular Surveillance and Cluster Work: Engaging the Community in Iowa

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In 2018, there were 2,872 people living with HIV in Iowa who were diagnosed. Approximately 73% resided in the ten most populous counties, with 29% in Polk County alone. The remaining 27% resided in more rural areas.

For more information, visit https://idph.iowa.gov/ivsiddhp/hiv.

May 2019
Iowa 2018 HIV Care Continuum

- PLWH: 3,208
- Diagnosed: 2,759 (86%)
- Linked Within 1 month: 2,379
- Retained in Care: 2,223
- Virally Suppressed: 2,223 (81%)

Number of Persons
Community Engagement Efforts

• Fact Sheets

• Presentations, Webinars & Interactive Activities
  • Community Planning Group
  • Ryan White Part B Sub-recipients
  • HIV Prevention Sub-recipients
  • Community Groups – Positive Iowan’s Taking Charge (PITCH)

• Future Plans
  • Statewide HIV strategic planning
  • Engage more PLWH
Frequently Asked Questions About Molecular HIV Surveillance

What is Molecular Surveillance?
Molecular HIV surveillance (MHS) is a technique that uses HIV genotype data from genetic resistance testing to look at how the virus is spreading in a community. This involves the collection and analysis of HIV sequence data. It is important to emphasize that MHS focuses exclusively on HIV genetic material and not genetic material of the person who is diagnosed with the disease. Within the field of public health, molecular surveillance data are also used to track foodborne illnesses and tuberculosis.

How does it work? How are molecular HIV data collected?
When someone living with HIV attends an HIV medical appointment for the first time, the provider may order a drug resistance test to help determine the best medication regimen. This drug resistance testing is done by analyzing the genetic sequence of the virus. This information gets sent to the medical provider and to the Iowa Department of Public Health (IDPH). IDPH compares these data to the nucleotide sequence data of HIV from other Iowans living with HIV to determine commonalities. This helps figure out where HIV is rapidly spreading and interventions may be needed.
How can molecular HIV information be used?

Molecular surveillance data can be used to:

- Describe HIV transmission patterns (i.e., how HIV is spreading) to guide public health strategies;
- Detect rapid increases in HIV (sometimes called “clusters” or “outbreaks” in a given area or population;
- Learn more about HIV in a geographic area or within groups.
Frequently Asked Questions About Molecular HIV Surveillance

This information helps the health department to guide HIV prevention efforts and figure out where funding and resources should be increased. It also assists with identifying a fast-growing network of people being newly diagnosed with HIV to help interrupt transmission.

How is molecular HIV information NOT useful?
Molecular HIV information CANNOT be used to establish whether one person transmitted to another person. The information only tells us if the virus is similar, but not who gave the virus to whom. IDPH is not interested in knowing who gave the virus to whom. In Iowa, molecular HIV information CANNOT be released from the IDPH to law enforcement, prosecutors, or courts for any reason.

What are specific activities IDPH may implement using these data?
IDPH believes the information could be used as a tool to enhance the effectiveness of Partner Services and re-engagement of Iowans living with HIV who are out of medical care. Discretion and sensitivity will continue to be of utmost importance in the implementation of these programs. The information could also alert us to rapid transmission among a population or in a region.

How does it benefit the community?
IDPH hopes that use of this information will assist in reducing transmission of HIV, ensuring Iowans living with HIV have access to medical care, and assist with achieving viral suppression. Also, IDPH hopes use of this information will help reduce HIV disparities (both in diagnosis and viral suppression). Overall, this information may help allocate resources to the areas and populations that need them most.
Frequently Asked Questions About Molecular HIV Surveillance

Can molecular HIV sequence data be released by IDPH or providers to the public, law enforcement, or courts?
No. Molecular HIV sequence data cannot be released to the public, law enforcement, or courts. However, once these data are stripped of all identifiers, they are sent to CDC. Iowa Code section 141A.9 states that “HIV-related test results” (which means a diagnostic test) can be released with a court order (from a judge). HIV-related test means a test that determines the presence of HIV or antibodies to HIV. An HIV-related test does NOT include viral loads; CD4+ cell counts; molecular/sequence data; partner services; or case management data.

How do I get involved?
If you’re interested in learning more about how molecular HIV surveillance data are used, or providing your feedback to IDPH on how these data should be used, please contact Randy Mayer, Bureau Chief of HIV, STD, and Hepatitis, at randall.mayer@idph.iowa.gov or (515) 242-5150.
Presentation Outline

• What is Surveillance and what is reportable in Iowa
• Security of Data (physical, policy, Iowa Code)
• Purpose of cluster and outbreak detection and response
• What is molecular HIV surveillance (MHS)
  • MHS does not tell us whether one person transmitted to another person (no directionality)
Presentation Outline Continued

• How are HIV genotype data collected
• Cluster network example
• Additional methods to identify clusters
  • Time-space analyses
  • Information from DIS, testing sites, or case managers
• Examples from other states
  • Massachusetts
• Interactive activity & discussion
• Potential Interventions
Interactive Activity

Using realistic examples (with fake data) of what IDPH examines when detecting potential fast-growing networks of HIV within Iowa.

**Example A: Molecular HIV Data Example**

<table>
<thead>
<tr>
<th>Cluster ID</th>
<th>eHARS ID</th>
<th>Diagnosed within past 12 months</th>
<th>Date of Most Recent Viral Load</th>
<th>Viral Load</th>
<th>Transmission Category</th>
<th>Sex</th>
<th>Age at Diagnosis</th>
<th>Race</th>
<th>Diagnosis Year</th>
<th>County of Residence</th>
<th>Facility Name</th>
<th>Facility City</th>
<th>Facility County</th>
<th>Year of Birth</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>No</td>
<td>1/15/2019</td>
<td>20</td>
<td>Heterosexual Contact</td>
<td>Female</td>
<td>30-39</td>
<td>White</td>
<td>2016</td>
<td>County X</td>
<td>Facility P</td>
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<td>County X</td>
<td>1965</td>
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<tr>
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<td>Female</td>
<td>30-29</td>
<td>Black</td>
<td>2016</td>
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<tr>
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**Example B: Molecular HIV Data Example**

<table>
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<th>Date of Most Recent Viral Load</th>
<th>Viral Load</th>
<th>Transmission Category</th>
<th>Sex</th>
<th>Age at Diagnosis</th>
<th>Race</th>
<th>Diagnosis Year</th>
<th>County of Residence</th>
<th>Facility Name</th>
<th>Facility City</th>
<th>Facility County</th>
<th>Year of Birth</th>
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<tbody>
<tr>
<td>2</td>
<td>12</td>
<td>No</td>
<td>9/1/2017</td>
<td>10500</td>
<td>MSM</td>
<td>Male</td>
<td>30-39</td>
<td>Latino</td>
<td>1995</td>
<td>County A</td>
<td>Facility C</td>
<td>City M</td>
<td>County C</td>
<td>1965</td>
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<tr>
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<td>30-29</td>
<td>Black</td>
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<tr>
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<td>16</td>
<td>Yes</td>
<td>3/1/2019</td>
<td>20</td>
<td>MSM &amp; PWID</td>
<td>Male</td>
<td>40-49</td>
<td>White</td>
<td>2018</td>
<td>County A</td>
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<tr>
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<td>Male</td>
<td>20-29</td>
<td>White</td>
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<td>18</td>
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<td>Female</td>
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<td>White</td>
<td>2016</td>
<td>County C</td>
<td>Facility C</td>
<td>City M</td>
<td>County C</td>
<td>1962</td>
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</table>

**Example C: Molecular HIV Data Example**

<table>
<thead>
<tr>
<th>Cluster ID</th>
<th>eHARS ID</th>
<th>Diagnosed within past 12 months</th>
<th>Date of Most Recent Viral Load</th>
<th>Viral Load</th>
<th>Transmission Category</th>
<th>Sex</th>
<th>Age at Diagnosis</th>
<th>Race</th>
<th>Diagnosis Year</th>
<th>County of Residence</th>
<th>Facility Name</th>
<th>Facility City</th>
<th>Facility County</th>
<th>Year of Birth</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Yes</td>
<td>4/5/2019</td>
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<td>County J</td>
<td>Facility E</td>
<td>City L</td>
<td>County J</td>
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</tr>
<tr>
<td>3</td>
<td>20</td>
<td>Yes</td>
<td>2/15/2018</td>
<td>98000</td>
<td>PWID</td>
<td>Male</td>
<td>13-19</td>
<td>White</td>
<td>2016</td>
<td>County J</td>
<td>Facility F</td>
<td>City O</td>
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<td>2002</td>
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<td>3</td>
<td>21</td>
<td>Yes</td>
<td>12/20/2016</td>
<td>125000</td>
<td>MSM &amp; PWID</td>
<td>Male</td>
<td>20-29</td>
<td>Black</td>
<td>2016</td>
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<td>Facility E</td>
<td>City L</td>
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<td>20-29</td>
<td>White</td>
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<tr>
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<td>11/20/2019</td>
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<td>20-29</td>
<td>White</td>
<td>2016</td>
<td>County J</td>
<td>Facility F</td>
<td>City O</td>
<td>County J</td>
<td>1966</td>
</tr>
</tbody>
</table>
Interactive Activity

Using realistic examples (with fake data) of what IDPH examines when detecting potential fast-growing networks of HIV within Iowa.

**Example D: Statistical Analysis (Time-Space Analysis) Example**

<table>
<thead>
<tr>
<th>County</th>
<th># Persons Newly Diagnosed by Year</th>
<th>Average</th>
<th># Persons Newly Diagnosed in Most Recent 3 Months</th>
<th>Alert</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>11/01/2016 - 12/31/2016</td>
<td>6.5</td>
<td>3</td>
<td>N</td>
</tr>
<tr>
<td>B</td>
<td>6/1/2017 - 12/31/2017</td>
<td>2.5</td>
<td>2</td>
<td>N</td>
</tr>
<tr>
<td>C</td>
<td>11/01/2018 - 12/31/2018</td>
<td>2</td>
<td>2</td>
<td>N</td>
</tr>
<tr>
<td>D</td>
<td>15/16/17</td>
<td>1.5</td>
<td>1</td>
<td>Y</td>
</tr>
<tr>
<td>E</td>
<td>28/30/32</td>
<td>2</td>
<td>2</td>
<td>N</td>
</tr>
<tr>
<td>F</td>
<td>1/1/2018</td>
<td>0</td>
<td>1</td>
<td>N</td>
</tr>
</tbody>
</table>

**Questions to consider:**
- What do you think may be going on in Examples A and B?
- Does this information warrant public health action? If so, what strategies should be used?
- Within a potential cluster, how would you decide who in the cluster you should focus on?
- If all of these examples of potential increases in HIV happened at the same time, how would you decide which to respond to first?
- What does IDPH need to consider when developing activities to respond to clusters?

**What these data show:**
- Examples A, B, and C are three potential clusters or networks of persons with HIV (persons whose virus is genetically similar) identified through molecular surveillance.
- Note that there are demographics, most recent viral load and date, transmission category, county of residence, facility information, and year of birth presented. When IDPH analyzes these data to identify potential clusters, names are not used.
- Example A shows four people. All are female, born between 1986 and 1998, all residing in the same county. Diagnosis occurred between 2016 and 2018. No males were identified as part of this network using molecular HIV data.
- Example B includes seven people. Six are male and one is female, born between 1954 and 1996, residing within three counties. One person was diagnosed in 1993, and the rest were diagnosed in 2017-2018. One person in this network has a high viral load.
- Example C includes five people. Four out of five are male, and four out of five were under age 30 at diagnosis. Note that all persons in this cluster were diagnosed within the past year, and were not virally suppressed at most recent viral load.
- Example D is another way to identify a potential rapid increase in HIV. It shows that County C had a large increase in the number of persons newly diagnosed with HIV from 2017 to 2018 (2 persons newly diagnosed to 7 persons newly diagnosed).
Interactive Activity

Using realistic examples (with fake data) of what IDPH examines when detecting potential fast-growing networks of HIV within Iowa.

Potential Interventions in Cluster Response: Individual-level

<table>
<thead>
<tr>
<th>People Living with HIV, diagnosed, in care</th>
<th>People Living with HIV, diagnosed, but of care</th>
<th>People Living with HIV, not diagnosed</th>
<th>Not living with HIV, potential for exposure to HIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Offer referral to RW case management</td>
<td>• Offer referral to care</td>
<td>• Offer HIV testing</td>
<td>• Offer HIV testing</td>
</tr>
<tr>
<td>• Re-interview for new partner, if needed</td>
<td>• Offer referral to case management</td>
<td>• Offer linkage to care help</td>
<td>• Offer PrEP referral and condoms</td>
</tr>
<tr>
<td></td>
<td>• Re-interview for new partners, if needed</td>
<td>• Offer referral for RW case management</td>
<td>• Offer harm/risk reduction counseling</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Interview for partners</td>
<td>“Who else do you think would benefit from a test?”</td>
</tr>
</tbody>
</table>
**Interactive Activity**

Using realistic examples (with fake data) of what IDPH examines when detecting potential fast-growing networks of HIV within Iowa.

**Potential Interventions in Cluster Response: Localized by region, or at state level**

<table>
<thead>
<tr>
<th>Medical providers – Local Area</th>
<th>Testing Sites - Region</th>
<th>IDPH – Statewide</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Provide opt-out HIV testing in healthcare settings</td>
<td>• Provide testing events in outreach settings</td>
<td>• Promote opt-out HIV testing</td>
</tr>
<tr>
<td>• Complete sexual health histories with patients</td>
<td>• Distribute condoms</td>
<td>• Promote PrEP</td>
</tr>
<tr>
<td>• Educate on and prescribe PrEP</td>
<td>• Utilize Social Network Strategy as a testing intervention</td>
<td>• Distribute condoms</td>
</tr>
<tr>
<td>• Provide education to reduce stigma</td>
<td>• Provide referrals to Ryan White program for patients newly diagnosed</td>
<td>• Increase awareness of Ryan White program</td>
</tr>
<tr>
<td>• Use people-first language</td>
<td></td>
<td>• Increase robustness of re-engagement program</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Maintain StopHIViowa.org</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Use people-first language in all publications</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Provide Partner Services for persons identified as part of a cluster</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Maintain HIV-related marketing to increase testing, raise awareness of RW services, and reduce stigma</td>
</tr>
</tbody>
</table>
Engaging People Living with HIV

• PITCH Wellness Summit – annual event hosted for PLWH by PLWH
• Community Planning Group
• Community Planning Group (Plus)
  • Expanding invitation to all PLWH in Iowa and provided support to attend
  • Recruited through PITCH and Ryan White service providers
• Meetings with HD Staff and PLWH

So thrilled to have Randy and Nicole with the Iowa Dept of Health, come to the PITCH Wellness Summit to discuss with PLHIV about HIV Molecular Surveillance policies and hear community concerns
Next Steps

• Create a sub-committee of our Stop HIV Iowa planning committee to engage the community, stakeholders, providers, and PLWH when developing strategies related to molecular surveillance and cluster outbreak detection and response

• Attend Ryan White Part C and Part B Consumer Advisory Board meetings
Lessons Learned

• Language! Language! Language!
  • Network of HIV vs. Cluster
  • Rapid increase in diagnoses of HIV vs. Outbreak
  • Molecular HIV data example vs. Case study

• Keep showing up

• Share information in a variety of ways
  • Presentations, discussions, webinars, activities

• Leadership participate in engagement activities

• Anticipate negative feedback

• Demonstrate as much transparency as possible

• Think carefully about the messenger

• Ask the community what they need
Thank you!

Iowa Department of Public Health
Bureau of HIV, STD, and Hepatitis
Biz McChesney, HIV and Hepatitis Prevention Program Manager
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