HIV Data in Action:

A regional approach to using molecular HIV data to prevent infections and improve health

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A Regional Response to End the HIV Epidemic in California
Overview

- HIV molecular / sequence data process
- Data sharing
- Assistance and Capacity Building
- Community concerns
- Challenges:
  - multi-jurisdictional
  - data delays
  - best practices/prioritizing
- Future directions
What is HIV molecular data and how is it used?

- Drug resistance testing recommended for all HIV-infected persons
- Testing generates HIV nucleotide sequence data of the virus (molecular HIV data)
- Sequences can be used to identify if there are large groups of similar sequences indicating rapid HIV transmission
- **New process**: We can use this information to focus prevention efforts
Routine molecular analysis to detect large groups that represent recent, rapid transmission

- Secure HIV Trace program analyzes HIV pol sequences
  - Analysis focused on the most recent 3 years
  - Highly related viral sequences (<0.5% different)
  - **Priority**: At least 5 persons with HIV diagnosed within the recent 12 month period

- Monthly data analysis
  - Standardized aggregate data summary and line list
  - Share data (via SAFE) with majority jurisdiction
  - Outreach to other counties (fewer people) by majority jurisdiction or state
  - Data sharing: case-by-case
Assistance and Capacity Building for Molecular Data

- New technology – lessons learned
- Collaboration to develop protocols to:
  - Interpret molecular data – optimal formats / visuals
  - Share data as appropriate
  - Educate field investigators, medical providers, case managers, and community organizations (ongoing process)
  - Prioritize and provide services based on the data at individual and group levels
- California Prevention Training Center (PTC) – capacity building grant related to services in response to molecular data
Community Questions and Concerns Raised

- Data security and privacy
- Criminalization – many states have HIV specific criminal laws
- Consent – information on notifiable conditions including certain infections is automatically reported
- Stigma – especially in small communities
HIV Data-to-Care: Example of using identifiable public health data

- As part of HIV clinical monitoring, HIV viral load testing is performed
- HIV laboratory results are automatically reported to public health
- Benefits of viral suppression to individual health and to preventing HIV transmission (U=U)
- Risk (no individual consent) mandates additional protections and very limited access to the viral load data
Molecular analysis:

- **Does NOT** test a person’s genetics – only the virus is sequenced
- **Does NOT** identify a person
  - Multiple people can have an identical sequence
  - The sequence within a person changes over time
- **Does NOT** determine direct links between people
- **Does NOT** determine directionality of transmission
- **Does NOT** replace partner services or community outreach
HIV Transmission not Limited by County Boundaries

- ~90% priority clusters include people from multiple counties
- Partner networks span similar geographic areas
- Local field investigators most likely to recognize a pattern but limited to data access
- Discussion: Regional data sharing for cluster response
Understanding Data Delays and Underreporting

- Sequence obtained after linkage to HIV care
- Missing sequence if not diagnosed, not linked to care, sequence not obtained, lab not reporting, poor sequence quality
- Recently detected clusters do not always include people with a recent diagnosis
Best Practices and Prioritization

- Best practices and prioritization being developed
- Differences with injection drug use and sexual transmission
- Partner services and three year interval emphasized
- Linkage to care and viral suppression **highest priority**
- Consider social network or snowball sampling approaches
Future directions for Molecular Data

- New technology – lessons learned
- Collaboration to develop protocols
- Implementation of statewide data systems for HIV and partner services data
- Regional approach to secure, protected, and confidential molecular data sharing
- Evaluation of novel approaches to HIV prevention utilizing molecular data
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