

HIV Data in Action:

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

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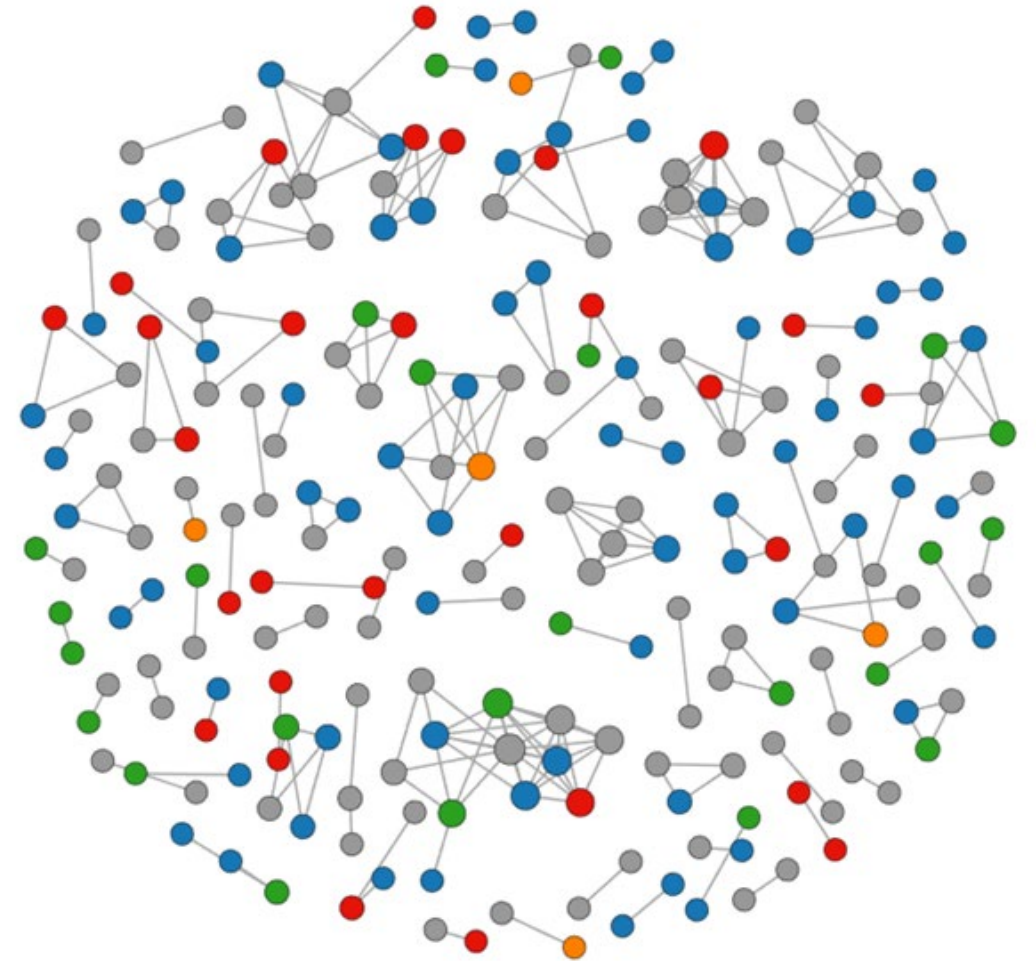
A Regional Response to End the HIV Epidemic in California

Overview

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

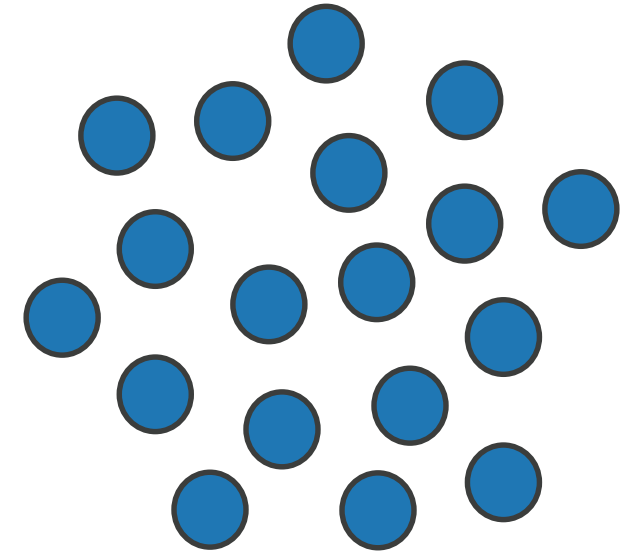
What is HIV molecular data and how is it used?

- 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

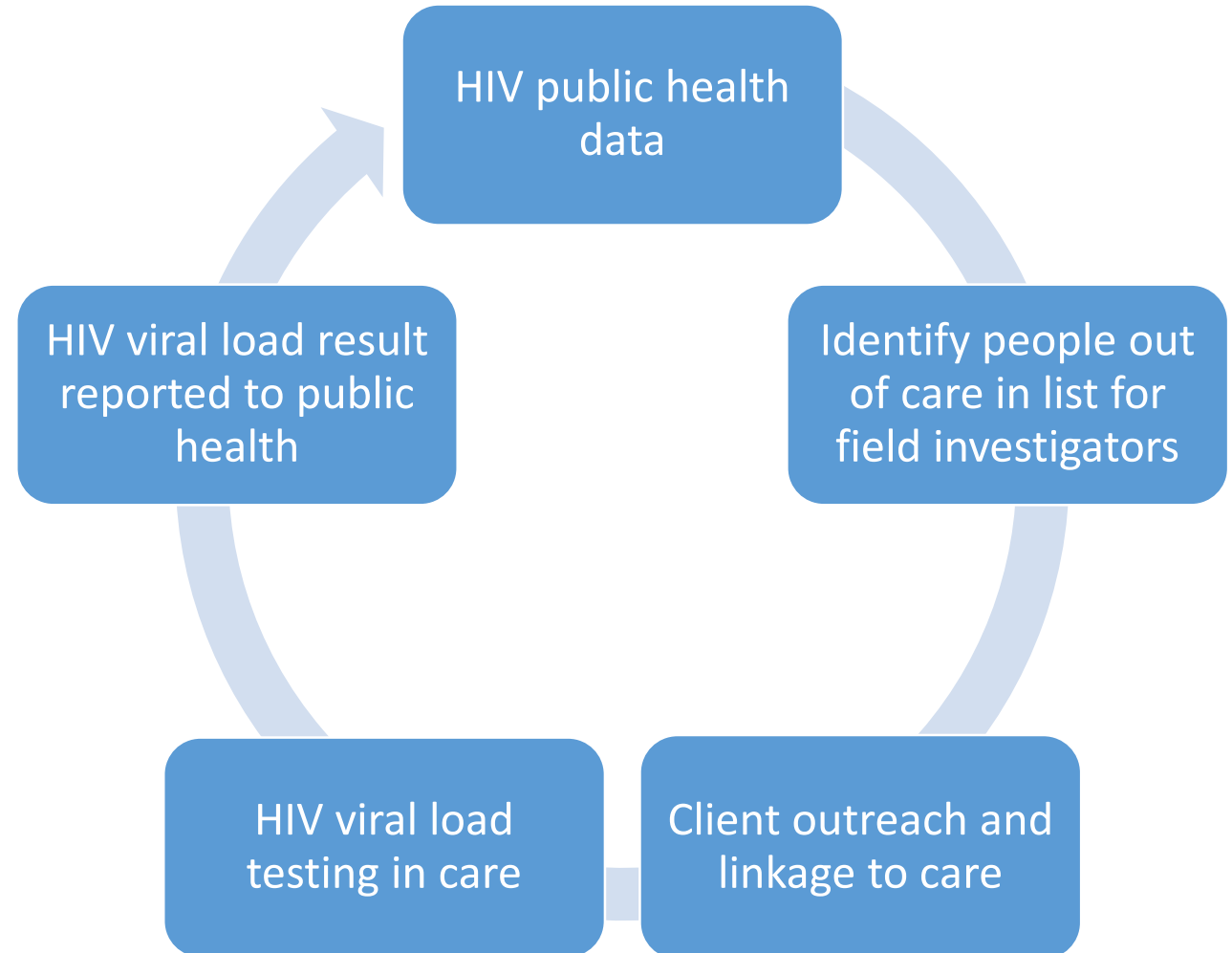
Community Questions and Concerns Raised

- 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



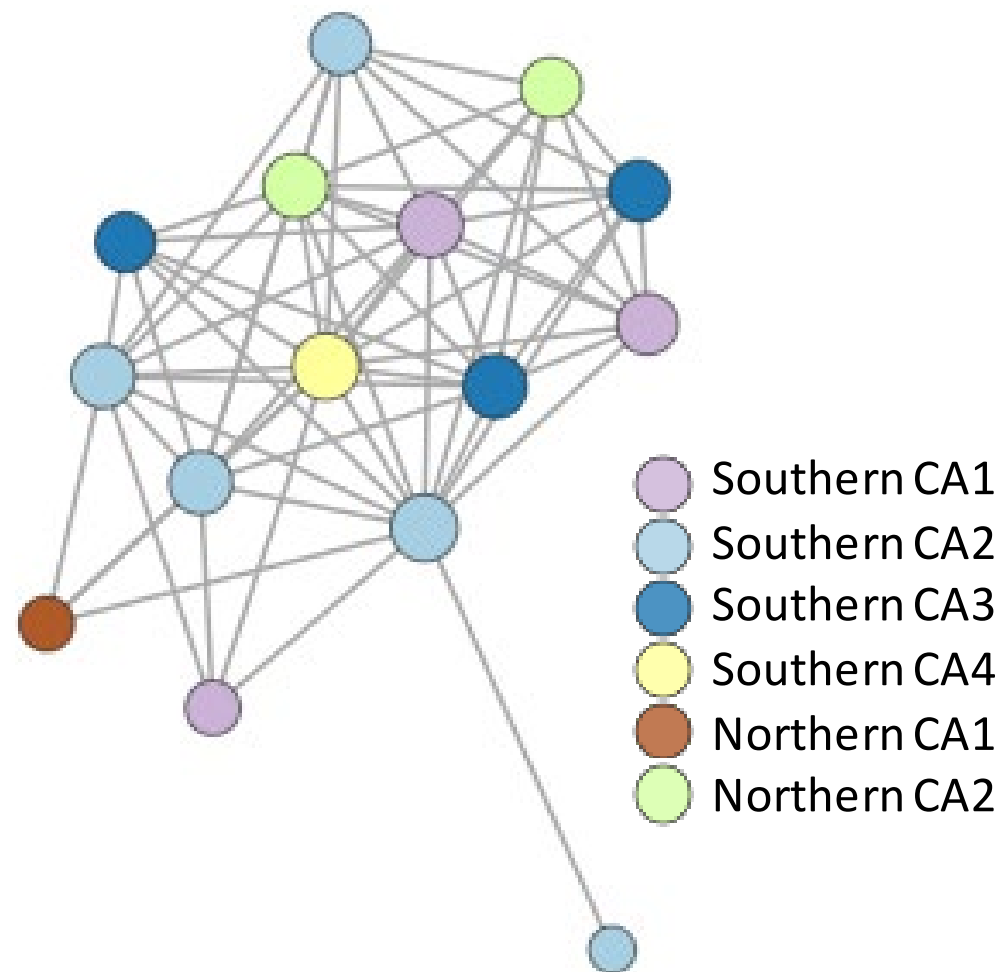
Molecular analysis:

- **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



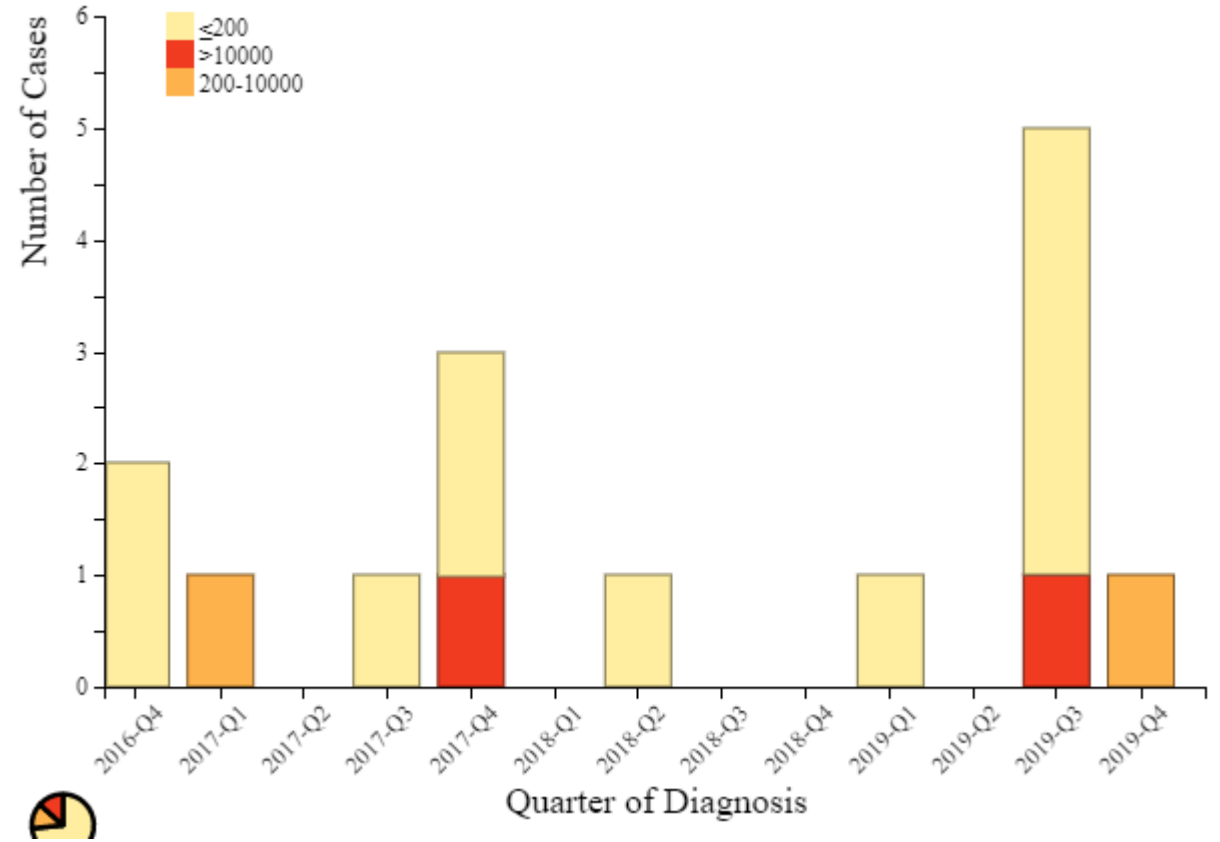
HIV Transmission not Limited by County Boundaries

- ~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



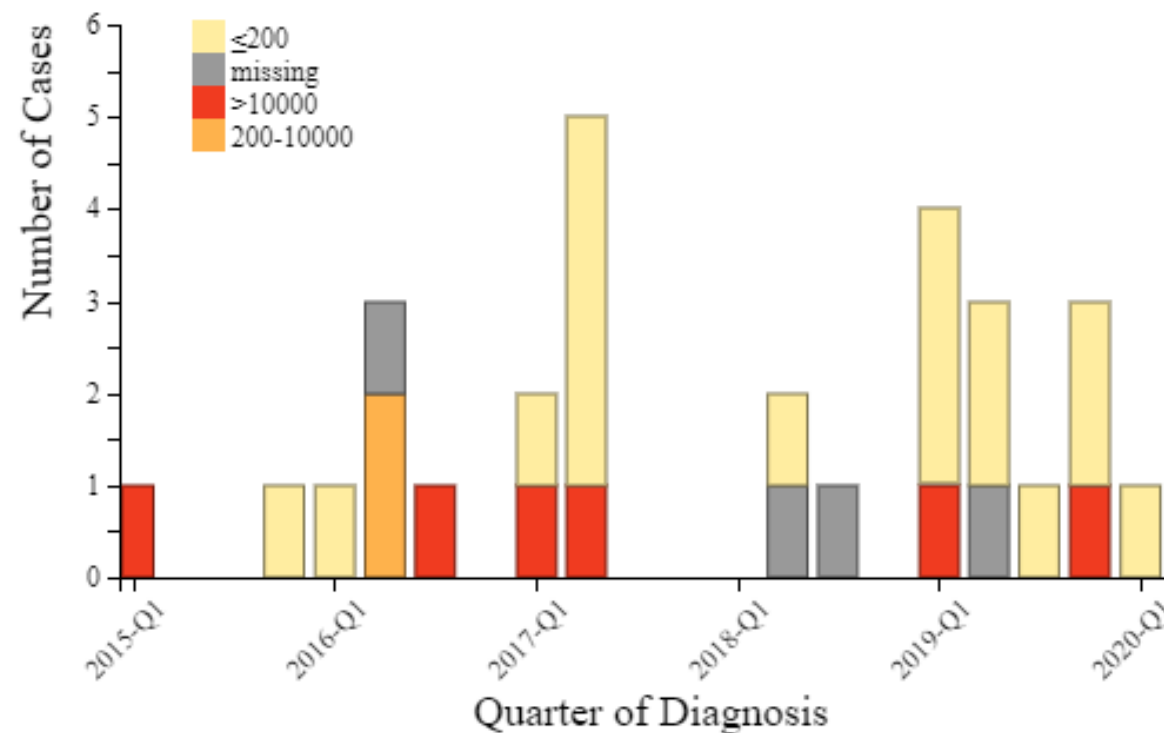
Understanding Data Delays and Underreporting

- 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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