Welcome!



Learning Series for HIV Prevention-Surveillance Integration – Effectively Using Data to Support Programs (August 22, 2019)

- We'll get started in a few minutes
- Please:
 - Complete the survey
 - Mute your phone
 - Enter your name(s)/jurisdiction in the Group Chat
- Having IT issues? Use the Q&A box to submit a question. HealthHIV staff will follow-up with you individually.

CSTE/HealthHIV Learning Series for Prevention-Surveillance Integration

Effectively using data to support programs

August 22, 2019



Welcome!



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- Please remember to
 - Complete the survey
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Representatives from



- Arkansas
- California
- Idaho
- Philadelphia
- Mississippi
- Guam
- Illinois

- New Hampshire
- Washington
- Missouri
- Pennsylvania
- Tennessee
- Nevada

Agenda

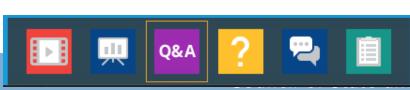
HealthHIV CSTE

- Orientation to On24
- Icebreaker
- HIV Data Privacy & Confidentiality: Laws and Policies That Protect HIV Data: Amy Killelea, JD
 - Q&A and discussion
- Utilizing Enhanced Surveillance Data to Improve Prevention Outcomes: Auntré Hamp, MEd, MPH
 - Q&A and discussion
- Adapting Data Systems to Support Integrated STD/HIV Field Investigations at the Local Level: Will Wheeler, MPH PhD and Ryan Murphy, MPH PhD
 - Q&A and discussion
- Closing

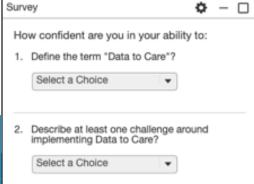
Using On24

HealthHIV CSTE

- Webinar PPT/Recording
 - · Links sent after webinar
- Q&A
 - Technical issues and content/speaker questions
- Group Chat
 - Chat with peers, comments
- Survey
 - Submit before webinar starts







Icebreaker



- Only do icebreaker with the prevention/surveillance colleagues from your health department
 - If not there in person, share by email
- Share the funniest or most fun situation you have ever experienced at work.
- 5 min

You also can share on Group Chat if you'd like!

HIV Data Privacy & Confidentiality: Laws and Policies That Protect HIV Data

Amy Killelea, JD
Senior Director, Health Systems & Policy
NASTAD
CSTE/Health HIV Learning Series



Presentation Road Map

- Review of the existing foundation of HIV data privacy laws and regulations, with a focus on HIV surveillance data
- Trends/findings from NASTAD's legal research project
- Applying existing privacy protections to cluster detection data

Statutory Structure of HIV Data Privacy Protections

Based on NASTAD's review of laws and regulations in ~20 states...

HIV Confidentiality
Statutes: Prohibit
Release of HIV Data
without Consent



- To carry out the public health functions of the health department
- To respond to a public health emergency
- For statistical and research purposes (de-identified)
- To enforce control measures
- In response to a court order or subpoena

Some state statutes explicitly prohibit the release of any data for law enforcement purposes, which is the most protective approach. However, most state statutes compel the release for law enforcement in some circumstances

Where to Find State Laws on HIV Data Release

Communicable Disease Code

- Confidentiality requirements and exceptions governing multiple communicable diseases
- Confidentiality requirements and exceptions that are HIV specific (and more specific)

Public Health Code Enforcement

 Some public health codes prohibit transmission of or exposure to HIV or other communicable diseases with exceptions to HIV data confidentiality for health departments to share data to enforce control measures

Criminal Code

 There are exceptions to HIV confidentiality that compel health department data release found in HIV criminalization statutes themselves

NASTAD Legal Research Project

- For the past year, NASTAD has been assessing state laws governing health department HIV data release
 - Phase one: ten-state analysis of data release laws governing Medicaid data sharing, data-to-care, research data sharing, and law enforcement (completed in 2018)
 - Phase two: deeper dive into law enforcement data release and HIV criminalization laws and policies, with a focus on legal counsel practices (ongoing)
- Limitations
 - Findings are not based on a national sample
 - State laws and policies vary as do health department structures, making it difficult to identify replicable policies and procedures

General Findings

- Patient consent/notification provisions with regard to HIV surveillance data are limited
- Most statutes and regulations do not explicitly address emerging data-sharing practices (e.g., data-to-care, Medicaid data sharing, and molecular HIV surveillance use)
- Majority of statutory schemes provide broad discretion to health department and/or legal counsel to make data-sharing decisions
- As a result of statutory/regulatory breadth, health department data-sharing practices varied based on legal counsel and/or health department interpretation

1) Data-to-Care Data Sharing

- Themes and variations
 - Data sharing among HIV programs is almost always possible without a data sharing agreement
 - Most jurisdictions limit the extent to which surveillance data is shared for the purpose of linkage-to-care
 - Only share out-of-care lists
 - Share viral load information with treating provider only
 - Restricted access to HIV data to health department staff or "designees" (could include local health departments and/or contracted agencies)

Only health department may access Care and Surveillance data

Health department may share limited information with specified entities

Health department may share surveillance data, including VL, with providers

2) Medicaid Data Sharing

- Themes and variations
 - Formal data-sharing agreement required in all cases
 - Jurisdiction-specific limitations on what type of data can be shared with Medicaid:
 - Share PII on HIV viral load directly with Medicaid agency who is allowed to re-share with Medicaid MCOs
 - Share aggregate data (viral load and/or diagnosis) as a result of surveillance/Medicaid match with state Medicaid agency
 - Share aggregate data (viral load and/or diagnosis) as a result of surveillance/Medicaid match with individual MCOs

Health department may not share surveillance data with Medicaid

Health department may share limited/aggregate information with Medicaid

Health department may share
PII surveillance data, including
VL and diagnosis, with
Medicaid and MCOs

3) Research Data Sharing

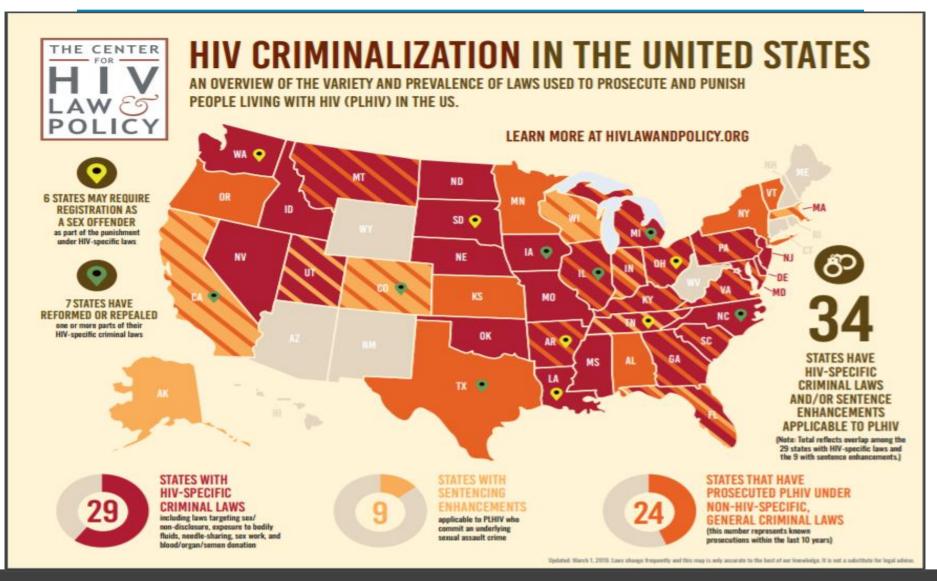
Data request submitted to health department

Data requests are reviewed by health department staff, data governance entity, or IRB

If research is approved, a data- use agreement is executed

Health department staff are typically involved in the research process

4) Law Enforcement Data Sharing



Breaking Down the Statutes

In what manner must the data be requested?

Court order (signed by a judge)

Subpoena (not signed by a judge)

Law enforcement officer request

What types of data can be released?

"All records and information"

"HIV test"

"Medical or epidemiological information"

At what point can data be requested?

During an investigation

During a prosecution

For the purposes of sentence enhancement

Are there protections for the data once released?

In camera hearing

Notice to subject of data request

Limited use to matter at hand

The Role of Public Health Legal Counsel

- Most states route requests for HIV data for law enforcement purposes to legal counsel
 - Could be different process for states where local health departments have access to surveillance data
- Legal counsel review the request to ensure it complies with state law and either reject the request or work with the health department to comply with the request
 - Usually release of requested records; sometimes testimony from health department staff
- Even where statutes are broad as to data that may be released, legal counsel and health departments generally operate under a principle of limited release

Implications for Cluster Detection Data

Limiting Principles of Data Release

Statutory

 "HIV test" has been interpreted to include ONLY the HIV diagnosis data and prohibit release of any other data, including viral load, partner services, and genetic sequencing

Relevance

- Current limitations of cluster detection data make it irrelevant for criminal exposure and transmission elements
- Even if cluster detection data is relevant for exculpatory purposes, the health department is not likely or best source of that data

Policy and Procedural

 Data release can and should be structured in a limited way

Considerations to Protect HIV Data

- Review statutes and regulations in your jurisdictions to assess how protective they are
- Work with public health legal counsel to encourage narrow interpretation
- Ensure that public health legal counsel understand the changing surveillance technology and the limits of genetic sequencing data
- Communicate existing legal protections to communities impacted by HIV

Resources

- Amy Killelea (<u>akillelea@nastad.org</u>)
- NASTAD HIV Data Privacy and Confidentiality Paper, <u>https://www.nastad.org/sites/default/files/Uploads/</u> <u>2018/nastad-hiv-data-privacy-06062018.pdf</u>.
- NASTAD Health Systems Integration Data Sharing Resources, https://www.nastad.org/domestic/health-systems-data.

Questions/Discussion





Polling question



Utilizing Enhanced Surveillance Data to Improve Prevention Outcomes



Auntré Hamp, MEd, MPH
Director, Health Data Analytics Program
Georgetown University
Office of the Senior Vice President
for Research

GEORGETOWN UNIVERSITY

Overview



ATra Black Box System provides a secure and private mechanism to exchange and link data across data owners (HIV surveillance units)



Current/previous projects include: NIH ATra Black Box Pilot (2015), CDC ATra Black Box Contract Project (2017), ORNL 5J (2017), CDC PS18-1808 (2018)



Over 1.6 million case records across 26 HIV surveillance jurisdictions have been processed in the ATra Black Box



Public Health jurisdictions use data to de-duplicate case records across jurisdictions but additionally update important care markers that enhance D2C efforts

Improving Health Outcomes



Improved HIV Surveillance Data Quality --> Improved Capacity for Data to Care Goals for the use of the ATra Black Box include:

- Improving our understanding of the overlap of persons living with HIV across jurisdictions
- Facilitate tracking in/out migration across the jurisdictions for services
- Increasing the timeliness of surveillance information sharing across jurisdictions
- Enhancing data quality in support of data-to-care activities



Prevention and Data-to-Care Implications

Benefits of data exchanges include:

- Improving care markers information for PLWH and Treatment as Prevention Strategies
- Reducing the time to re-engage individuals in the care and ultimately reach viral suppression
- Identify persons who may be eligible for PrEP services
- Identify gaps in HIV surveillance data to assist in rapidly responding to new acute HIV infections

Future of the HIV Data Sharing and Linkages



Expansion of PS18-1805

We are continuously onboarding new participants to the PS18-1805 project. There are currently 26 jurisdictions participating with 5 additional jurisdictions aiming to participate by the end of the year.



Increase capacity to assess persons at risk for HIV via STI surveillance data

Georgetown is in the process of launching a new project with DC, Maryland and Virginia to conduct similar linkages with STI surveillance data. These linkages will assist in identifying candidates for PrEP, persons who have not received STI treatment and persons with repeat STI infections



HRSA 19-039

Georgetown will serve as a Technical Assistance Provider (TAP) to assist in the assessment and implementation of data linkages between STI and HIV databases for the purposes of improving care outcomes especially amongst the Ryan White (RW) population.



Collective/Collaborative Benefits

Our Health Data Analytics Program has assisted in creating "Communities of Practice" which serve to promote best practices for data linkages as well as discussions around surveillance, prevention and D2C

Contact Information

Auntré D. Hamp, MEd, MPH auntre.hamp@georgetown.edu (202) 487-3013

Questions/Discussion



Polling question



Polling question



Adapting Data Systems to Support Integrated STD/HIV Field Investigations at the Local Level

Integrating HIV Surveillance & Prevention Learning Series 8/21/2019

Ryan Murphy, PhD MPH (CDPH STD Control Branch)
Will Wheeler, PhD MPH (CDPH Office of AIDS)



Overview

- Background
- CalREDIE STD/HIV Field Investigation Incident (SHFII)
- Local Interventional Surveillance Access (LISA)

Background: Public Health Activities on Reported Cases of HIV/STD

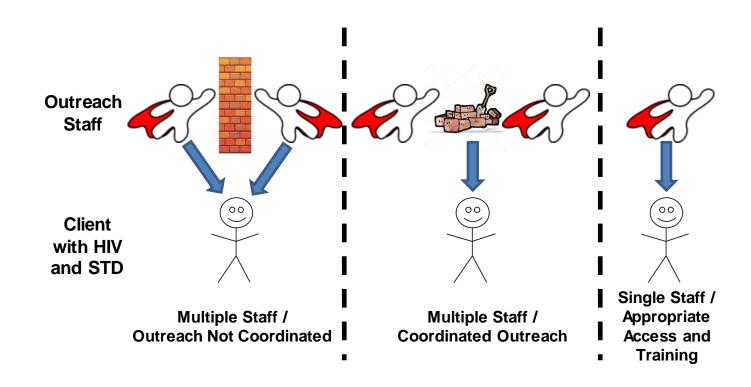
- Linkage/re-engagement in HIV care
- Tx verification or referral (STD)
- HIV/STD/HCV testing
- HIV pre-exposure prophylaxis (PrEP)
- Referral to other services
- Contact tracing (+ above, as appropriate)

Background: Data Collection — Prior Approach

- Contact Tracing:
 - 1) HIV only \rightarrow LEO
 - HIV Testing Encounter
 - Risk Reduction Activities Encounter
 - Stand Alone Partner Information Form
 - 2) Ryan White funded \rightarrow ARIES
 - 1) STD only or STD + HIV → CalREDIE

- <u>Linkage/Re-engagement in care:</u>
 - 1) HIV only \rightarrow LEO
 - HIV Counseling Information From (CIF)
 - Health Care HIV Test From (HTF)
 - Risk Reduction Activities (RRA) Form
 - 2) Ryan White funded \rightarrow ARIES
 - 3) If co-infected with STD → CalREDIE (duplicate data entry)

Variation among LHJs in level of Integration for HIV/STD Field Investigations





STD/HIV Field Investigation Incident (SHFII)

STD/HIV Field Investigation Incident (SHFII)

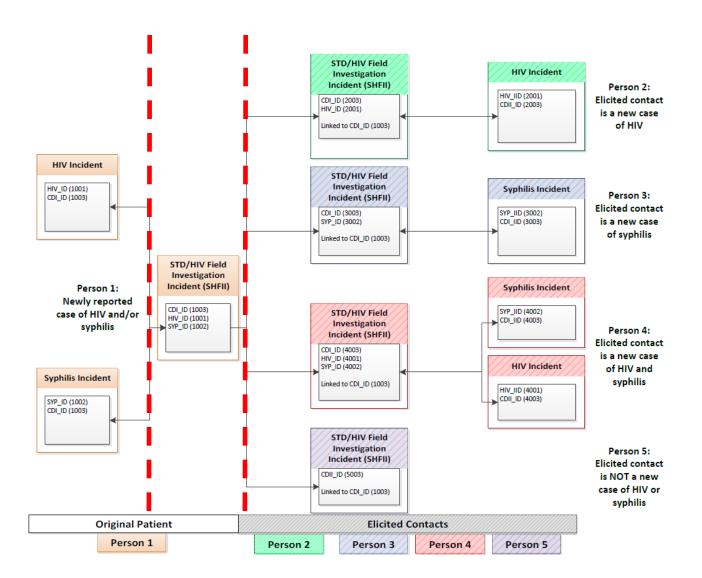
 A recently developed incident in CalREDIE that will be used to document health department follow-up activities for reported cases of STD and HIV

SHFII: Sections in CaIREDIE

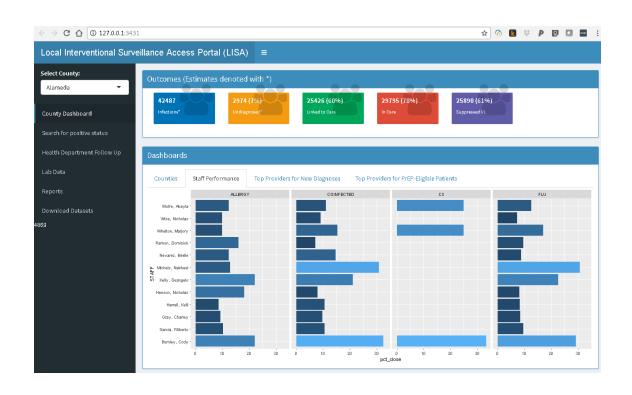
6 Sections:

- 1. Patient (system)
- 2. Investigation Tracking
- 3. Linkage to Care (HIV, STD, HCV, PrEP, other services)
- 4. Client Risk Information
- 5. Contacts
- 6. Case Investigation (system)

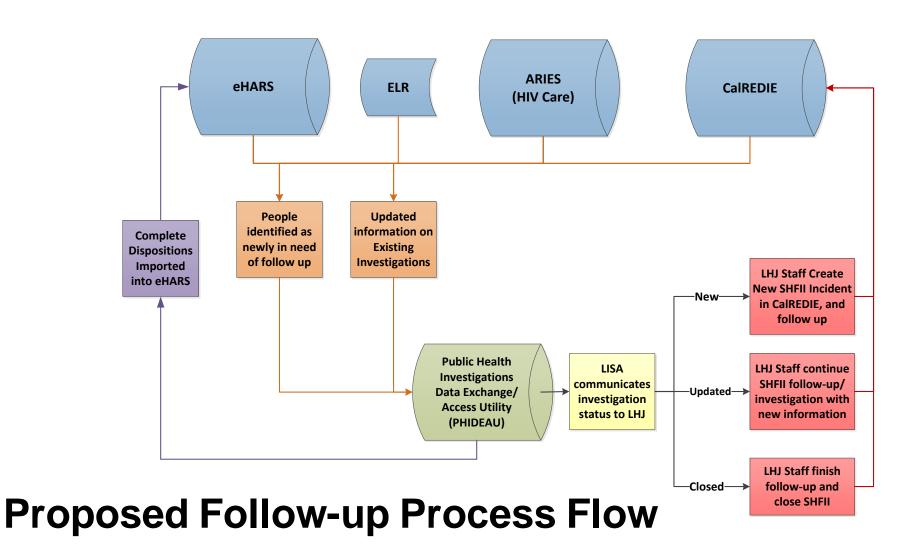
Proposed Record Flow in CalREDIE



- Nimble solution for two-way Local/State data exchange
 - Disseminate client-level and agency level actionable information
- Overcome technical and statutory barriers
 - Provide LHJs access to eHARS
 - Integrated data from relevant OA/STD data systems
 - Cross-jurisdictional data sharing
- Create routine tasks and reports



New Di	agnoses Not Lin	ked to Care	Prevalent Cases Out of C	are Lost to Follow	v Up Recent Detec	table Viral Load PrEP Eligible	
how 10	▼ entries						Search:
	LName	♦ FName	♦ ВОВ	DxDT	♦ COUNTY	PROVIDER	
1	Rodgers	Elisabeth	2000-01-21	2017-08-13	Sacramento	Sutter	Javier Gomez
2	Baker	Dakota	1968-12-12	2017-11-22	Sacramento	County PH Clinic	Michael Jones (DIS)
3	Price	Christian	1983-04-04	2017-09-10	Sacramento	HIV Specialist Org	Javier Gomez
4	Dixon	Aaron	1960-10-28	2017-11-22	Sacramento	Other HIV Specialist Org	Sarah Morton (DIS)
5	Chambers	Garrett	1995-01-20	2017-08-25	Sacramento	Kaiser	Javier Gomez
5	Vasquez	Alexía	1986-02-04	2017-03-18	Sacramento	Kaiser	Michael Jones (DIS)
7	Gardner	Mustaba	2000-11-30	2017-01-09	Sacramento	Other	Michael Jones (DIS)
3	Arneson	Brendon	1994-02-14	2017-09-17	Sacramento	Other HIV Specialist Org	Michael Jones (DIS)
9	Taylor	Eric	1988-11-04	2017-04-27	Sacramento	Small PMD	Sarah Morton (DIS)
LO	Sandoval	Martin	1988-05-28	2017-11-22	Sacramento	County PH Clinic	Unassigned



THANK YOU!

Office of AIDS

Lauren Nelson, MPH

CalREDIE

Deniz Dominguez, MHS
Sebastian Chavez
Allison Jacobsen, MPH
Larry Imel

SHFII – Screenshots



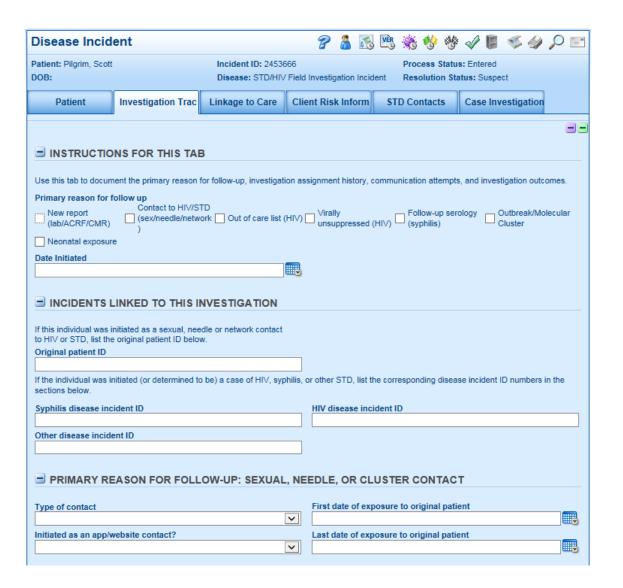
SHFII – Screenshots: Patient Tab

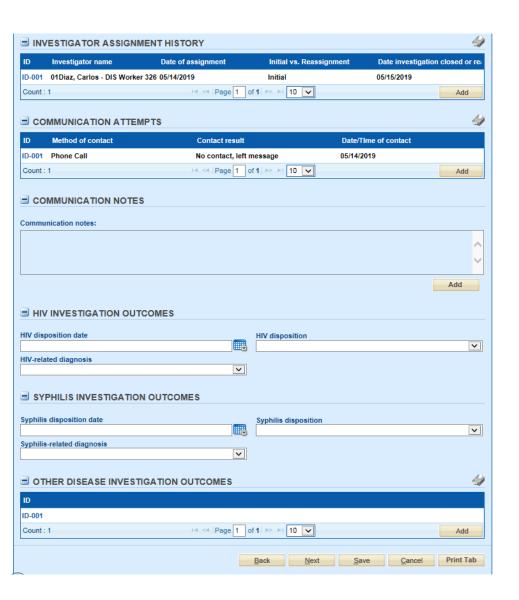




SHFII – Screenshots: Investigation Tracking Tab

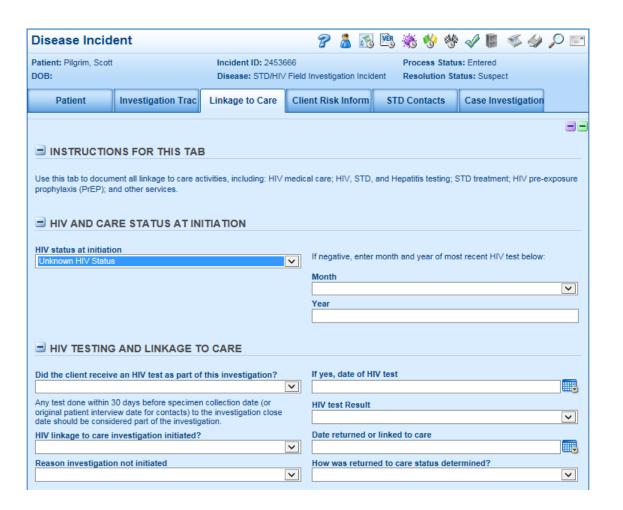


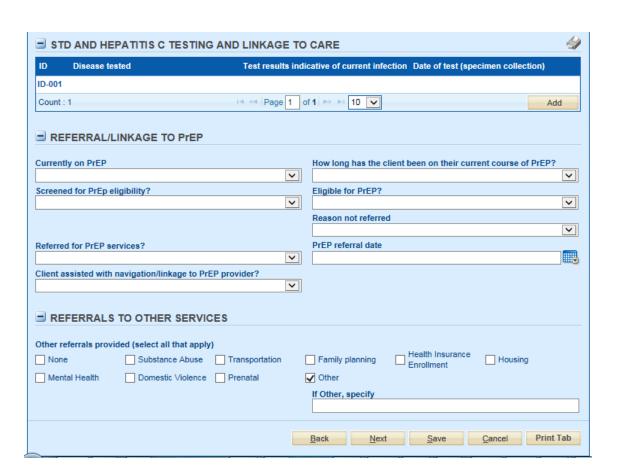




SHFII – Screenshots: Linkage to Care Tab

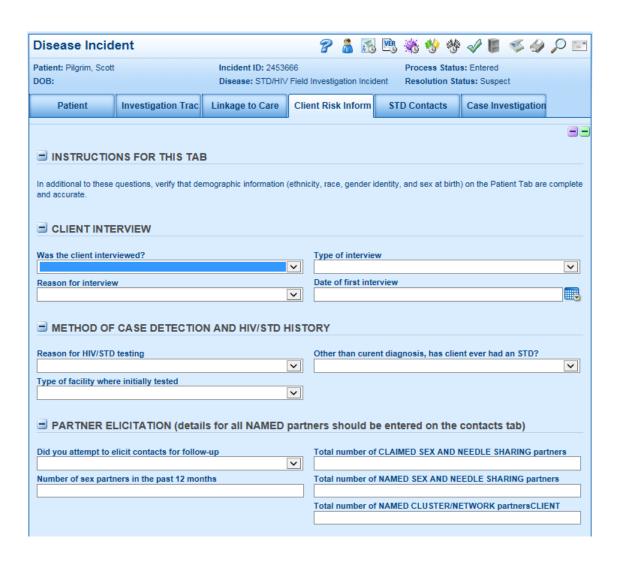




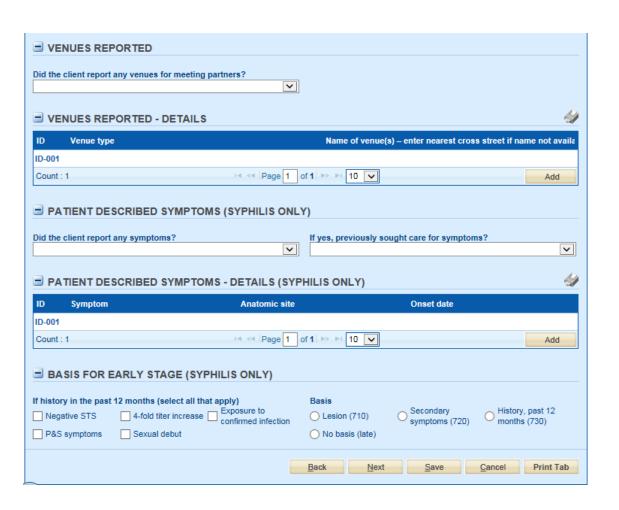


SHFII – Screenshots: Client Risk Information Tab



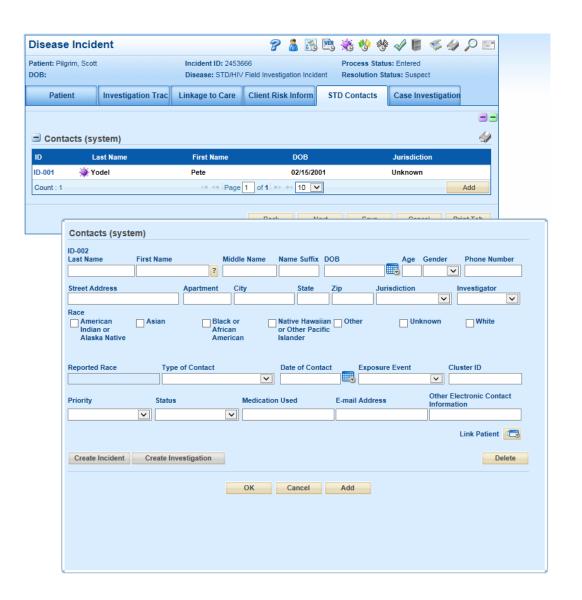


■ SEXUAL RISK INFORMATION							
Vaginal or anal sex in the past 12 months (select all that apply)							
None reported Refused Males Females Transgender/gender							
Other sexual risk behaviors in the past 12 months (select all that apply):							
None reported Approximates Received Gave drugs/money Sex partner used Vaginal or anal sex							
Refused Sex while							
ingh/intoxicated							
Had sex with a pregnant partner in past 12 months (males only) Had sex with MSM in past 12 months (females only)							
= SUBSTANCE USE							
Substance use past 12 months (select all that apply):							
None reported Methamphetamine Crack Prescription opiods Excessive alcohol Erectile dysfunction							
Refused Heroin Cocaine Cannabis Nitrates/Poppers Other							
If other, specify							
Injection drug use (12 months)							
No Yes, needle sharing							
HOUSING STATUS							
Did the client experience any of these housing situations in the past 12 months (select all that apply)?							
Transitional/Unstabl							
None reported Refused Homeless housing house							
nouse							
INCARCERATION							
Has the client been to any of the following in the past 12 months							
Institutionalized at diagnosis? (select all that apply) None reported Jail Prison							
None reported ☐ Jail ☐ Prison Refused ☐ Juvenile Hall							



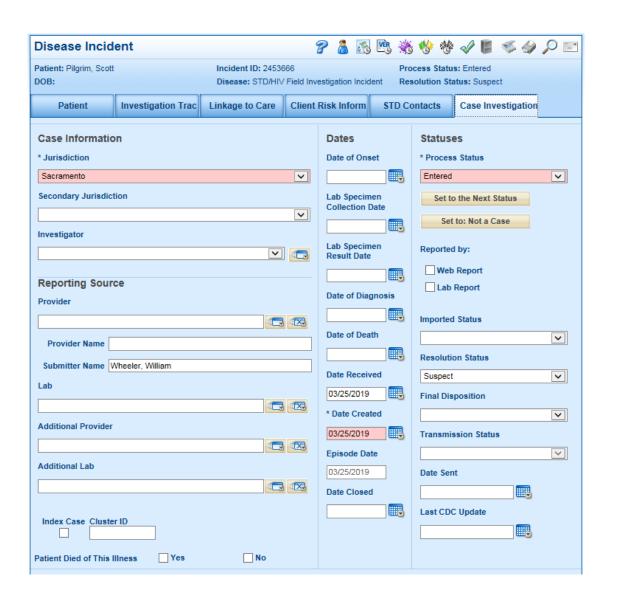
SHFII – Screenshots: Contacts Tab

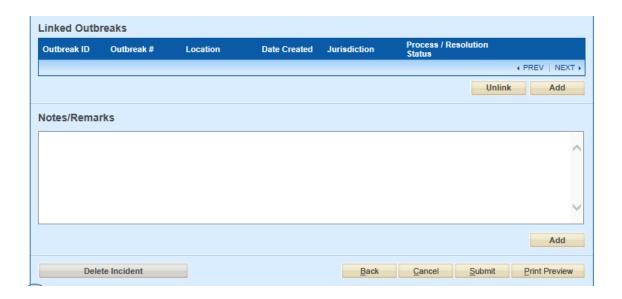




SHFII – Screenshots: Case Investigation Tab







Questions/Discussion



Polling question



Polling question



What's next?

HealthHIV CSTE

- Resource document
- Next webinars
 - HIV clusters: September 17th 12pm PDT/3pm EDT
 - Role of DIS: September 26th 12pm PDT/3pm EDT
- Webinar evaluation
 - https://cste.co1.qualtrics.com/jfe/form/SV_8JoaCcN2t WXp4MZ



Evaluation:

https://cste.co1.qualtrics.com/jfe/form/SV 8JoaCcN2tWXp4MZ

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