Building Bridges: Data Sharing Agreements

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NASTAD
Overview

- Role of data sharing agreements in the National HIV/AIDS Strategy
- Types of agreements
- Data sharing agreement partners
- NASTAD’s data sharing agreement resource bank
NHAS and Data Sharing

Data sharing agreements help achieve these goals by:

- **Identifying** people living with HIV who are not in care
- **Linking or re-engaging** people who are not in care to HIV care and treatment services
- **Monitoring** the viral suppression and other health outcomes while people are engaged in care and treatment
Key Agreement Elements

- Timeline of Use
- Scope of Work
- Data Strategy
- Systems and staff members
# Types of Data

<table>
<thead>
<tr>
<th>Defined Individuals</th>
<th>Aggregate Data</th>
<th>Access Considerations</th>
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<tr>
<td>CD4 of 500</td>
<td>To track service utilization by individuals or research treatment effectiveness for subpopulations.</td>
<td>To identify trends across the state for clients and people engaged with the state health department in any capacity.</td>
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<tr>
<td>HIV (+)</td>
<td>To identify people not linked or retained in care. Case managers can provide necessary support based on the client's information.</td>
<td>To detect gaps in surveillance efforts by payers, providers, and hospitals.</td>
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<td>PrEP User</td>
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- **Enrolled in ADAP**
  - Name
  - Medical ID #12345
  - Age
  - Race and ethnicity
  - SSN
  - Address

- **Enrolled in ADAP**
  - Age
  - Race and ethnicity
  - CD4 count and viral load
  - Prescription
Types of Agreements

- Memorandum of Understanding (MOU)
- State Law
- Health Department Policy
- Interagency Agreement
- Database User Agreement
- Client Consent Form
Possible Partners

- Prevention and Surveillance
- Ryan White Parts A and B
- Medicaid
- STD Agency and Family Planning Agency
- Department of Corrections
- Centers for Medicare and Medicaid Services (CMS) and Medicare Part D
- Pharmacies and Pharmacy Benefits Manager (PBM)
Surveillance & Ryan White

Ryan White Programs
Submit a list of RW clients from their jurisdiction for whom they would like to receive lab results entered into eHARS.

Surveillance
Within 30 days of the deadline, they will return the requested lab data for the specified RW clients.

Ryan White Database
The information is entered into their client tracking database, which is used by case managers to monitor the health status of their clients.
CA Medicaid & Ryan White

Established a data sharing agreement, which authorized 30 staff to use the Medi-Cal (Medicaid) Eligibility Data System (MEDS)

Office of AIDS pulls a monthly match of Ryan White client data and MEDS client data

Office of AIDS pays an annual fee for access to the databases and use of data

Both the Department of Health Care Services and Office of AIDS are responsible for securing the data and abiding by California’s disclosure laws
ADAP & PBM

Data Confidentiality
- Limit access to confidential information to the fewest number of people, for the least among of time
- Confidentiality breaches must be reported within 1 calendar day

Statement of Work
- Outlines specific steps of each party involved in the agreement
- Authorizes the DOH to request data on clients
- Requires a computerized data system

IT Policies
- Safeguards must meet state standards and guidelines
- Computers must be kept in secure location and updated for security. Information must be encrypted
- Breaches must be reported within 2 calendar days
PBM Reporting Requirements

**Brief Narrative**
- Insurance market trends
- Enrollment Issues
- Coordination activities
- Program issues affecting clients

**Program Statistics**
- Total number of current enrollees
- New enrollees
- Current enrollees divided into various types of plans including: COBRA, Medicare, Individual Plans, etc

**Client Enrollment**
- Client information must be submitted to the DOH every month
- The information will be used to maintain current data systems
- Includes: client ID, client DOB, and specific data about insurance plan
NASTAD’s Resource Bank

- Surveillance
- Ryan White Parts A and B
- Medicaid
- Department of Corrections
- Centers for Medicare and Medicaid Services (CMS)
- Pharmacy Benefits Manager (PBM)
onTAP

- NASTAD.blackboard.com
  - Username
  - Password
- Various Communities of Practice, Courses, and Modules
- DSA resource bank is a module within the Data to Care course
My onTAP
Resources
Prevention with HIV Positive Persons
Data to Care
### Agreement Bank

![Image of NASTAD Content: Data Sharing Agreements](image)

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Questions and Discussion

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HIV Data Sharing Agreements in Illinois

Presenter: Curt Hicks, MS
HIV Prevention Administrator,
Illinois Department of Public Health
Presented July 28, 2016 at the
2016 NASTAD Prevention & Care Technical Assistance Meeting
To describe the array of Data Sharing Agreements (DSAs)

- Intra-Sectional – between Units of the HIV Section
- Intra-Departmental – between HIV Section and other the Departmental Sections
- External – between the Department and other entities

To describe the role of an Integrated HIV Data System in facilitating and regulating data sharing by agreements
Intra-Sectional Agreements

Provide Enterprise

Surveillance

Prevention

Care

ADAP & CHIC
Statewide electronic HIV database used by Illinois HIV Care, ADAP/CHIC, Prevention, and Surveillance
- Complies with CDC Data Security & Confidentiality requirements
- Secure sectors for each Data Set
- Access to a sector is individually authorized on a need-to-know basis per Data-Sharing Agreements
- All users must complete Confidentiality & Security Training, pass a quiz, and sign an oath annually
With the shared Data system, DSA’s can support:

* User-directed data access within a Sector
* Automated data exchanges between Sectors
Intra-Sectional Agreements
Prevention-Surveillance DSA

Gives Surveillance access to:

* Testing Data
  * Positive Test result case Information
  * VL and CD4 Labs scanned into the Testing record as evidence of Treatment Engagement with non-RW Medical Care Providers
  * Electronic HIV Surveillance Case Report (planned)
* Surveillance-Based Services Documentation
  * Case Updates (patient or provider information)
  * VL and CD4 Labs from non-RW Providers
Prevention-Surveillance DSA

Gives Prevention access to:

* Dates of first diagnosis for previously reported cases
* PE offers a built-in **look up** for Prevention to check whether a positive case has already been reported to Surveillance
* Surveillance Case Numbers for clients testing newly positive
* Adding the Surveillance Case Number into Prevention Testing record triggers **automated** ongoing checks for labs in all the sectors: Surveillance, Care & ADAP/CHIC, updating the Test

* eHARS cases needing Surveillance-Based Services (SBS)
* Newly Diagnosed PWH
* Not In Care
* Recently STI-Coinfected PWH
* PWH with high VL (Planned)
Intra-Sectional Agreements

Provide Enterprise

Surveillance

Prevention

ADAP & CHIC

Care
Prevention-Care DSA

Gives Care access to:

* HIV-Positive Testing Clients referred to RWCM
  * Client contact information & contact preferences
  * Scanned Client-signed Care Referral Authorization
  * Test results- Preliminary and possibly confirmatory
  * Scanned lab results from any confirmatory tests

* SBS Clients referred to RWCM
  * Client contact information & contact preferences
Prevention-Care DSA

Gives Prevention automated feedback access to:

* Dates of first RW medical appointments attended
* Confirmation of RW Case Management enrollment
* To track care engagement & retention, adding the Surveillance Case Number into Test Record triggers ongoing updating of the Test Record with labs from the Care record
* To help distinguish Linkage from Reengagement, any Care lab dates and values prior to the Test
Intra-Sectional Agreements

Provide Enterprise

Surveillance

Prevention

Care

ADAP & CHIC
Surveillance-Care DSA

Gives Care access to:
* Updated Viral Load & CD4 Labs for entire RW Care client enrollment list (~23,000) each month

Gives Surveillance access to:
* Any Care-enrolled Clients not yet reported to eHARS so that Case Reports can be requested
* CD4 and VLs in Care records not yet in eHARS
Intra-Sectional Agreements

Provide Enterprise

Surveillance

Prevention

ADAP & CHIC

Care
ADAP/CHIC-Care DSA

Gives Care access to:
* RW Case Managers can view ADAP applications
* RWCM’s receive automated emails re: ADAP enrollments or insufficient applications
* Updated Viral Load & CD4 Labs for entire RW Care client enrollment list

Gives ADAP/CHIC access to:
* RWCM records to support locating clients not responding to requests, locate needed documentation
Intradepartmental Agreements
Intradepartmental Agreements

HIV-STD DSA allows:

- Cross-referencing of HIV cases with GC, CT, Syphilis records for SBS Co-infection referrals
- Providing HIV Prevention’s Integrated GC, CT and Syphilis testing results to the STI Section
- Providing STD Routine HIV Testing data to the HIV Prevention Unit
Intradepartmental Agreements

HIV-CD DSA allows:

* Cross-referencing of HIV cases with HBV and HCV records for SBS Co-infection referrals
* Providing HIV Prevention’s Integrated HBV & HCV testing results by to the CD Section

HIV-TB DSA allows:

* Cross-referencing of HIV cases with TB records for the HIV Epidemiologic Profile
* ReportingTB’s Routine HIV Testing to HIV Surveillance
External Agreements

- Client
- IDPH
- Designated SBS Providers
- LHDs
- Lead Agencies
- Providers
External Agreements

Client Agreements:

* Risk-Targeted Testing Consent authorizes:
  * Testing record to be entered into Provide
  * Regional Lead Agency to review record for QA
  * Surveillance to release to Testing agency eHARS evidence of prior diagnosis and care
    * To ensure appropriate supports for a first diagnosis linkage vs. previously diagnosed with care retention support needs
    * To provide Testing agencies with accurate new positivity rates by site
Client Agreements:

* Client Referral to RWCM Authorization allows:
  * Prevention to send to RWCM client contact information and contact initiation preferences
  * RWCM to confirm RWCM enrollments & First Medical Appointments
External Agreements

Client Agreements:

* Client RWCM Enrollment Agreement allows:
  * Sharing CM record with ADAP for coordination

* Client ADAP Enrollment Agreement allows:
  * Sharing of ADAP records (except for drug pricing information) with RW Case Management
External Agreements

IDPH

Client

Designated SBS Providers

LHDs

Lead Agencies

Providers
External Agreements

Local Health Departments:
* Illinois Law authorizes Local Health Departments to conduct Surveillance-Based Disease Investigation Services **within** their jurisdictions, allowing IDPH to refer HIV Surveillance cases to them

Designated Surveillance-Based Service Providers:
* Grant agreements designate:
  * Local Health Departments to provide SBS outside their jurisdictions
  * CBO’s with specialized cultural competencies to conduct SBS, permitting surveillance case referrals
Local Health Departments:

* Illinois Law authorizes Local Health Departments to conduct Surveillance-Based Disease Investigation Services within their jurisdictions, allowing IDPH to refer HIV Surveillance cases to them
External Agreements

Designated Surveillance-Based Service Providers:

* Grant agreements designate:
  * Local Health Departments to provide SBS outside their jurisdictions to otherwise unserved counties
  * CBO’s with specialized cultural competencies to conduct SBS, permitting surveillance case referrals
  * Lead Agencies to access Positive Testing Records and SBS records of the Providers within their Regions in order to coordinate and conduct Quality Assurance within their regions.
Acknowledgements

* Cheryl Ward, IDPH HIV Surveillance Administrator
* Dr. Jeffrey Maras, IDPH HIV Care Administrator
* Bryan Walsh, IDPH HIV Data Administrator
Questions

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