

Data Institute: Improving ADR Data Quality and Accuracy

Ellie Coombs

The DART Team

Disclosures

Presenter(s) has no financial interest to disclose.

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Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. Understand the requirements of the ADAP Data Report (ADR)
2. Understand how the Health Resources and Services Administration, HIV/AIDS Bureau uses ADR data and the importance of high-quality data
3. Identify common data quality issues and solutions
4. Troubleshoot and address data quality issues for the 2018 ADR

Obtaining CME/CE Credit

If you would like to receive continuing education credit for this activity, please visit:

<http://ryanwhite.cds.pesgce.com>

Presenters

Paul Mandsager: Health Resources and Services Administration, HIV/AIDS Bureau

Ellie Coombs: The DART Team, Provides technical assistance regarding the ADR

- Organizes and presents ADR-related webinars
- Conducts data quality outreach
- Works with system vendors to improve reporting
- Provides one-on-one technical assistance: Data.TA@caiglobal.org
- Provides content for TargetHIV: <https://targethiv.org/library/topics/adr>

Samantha Penn and M. Thomas Blissett, Nevada Department of Health and Human Services

Ann Nakamura and Luna Woo, California Department of Public Health

Presentation Outline

Overview and Progression of the ADR

Remaining Opportunities to Improve Data Quality

Tips and Solutions: Voices from the Field

- Nevada Department of Health and Human Services
- California Department of Public Health

Data Quality Exercise on Using the Upload Completeness Report (UCR)

30,000 Ft. Overview of the ADR

| | Recipient Report | Client-level data file |
|----------------------|--|--|
| Who does it? | ADAPs | ADAPs |
| What is it? | Organizational information | Demographic, ADAP enrollment, medication and insurance services, and clinical information for enrolled clients |
| How is it submitted? | Online form in the Electronic Handbooks (EHBs), prepopulated with data in the Grantee Contract Management System | XML file uploaded under the Recipient Report |

Systems Used to Create Client-Level Data

ADR-Ready Systems (*also RSR Ready*)

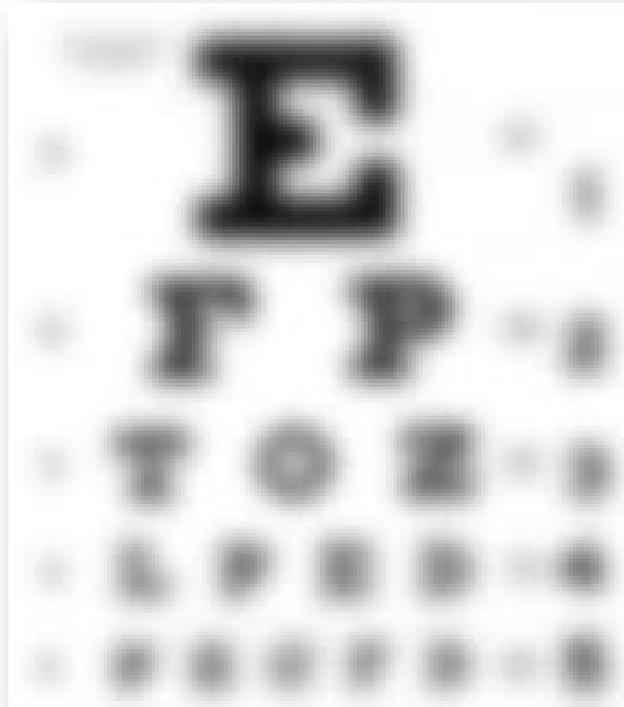
- CAREWare
- Provide Enterprise
- eCOMPAS

TRAX: Free tool developed by HAB that converts data in .CSV files into the XML file

- TRAX application and manual: <https://targethiv.org/library/trax-adr>
- Webinar: <https://targethiv.org/library/adr-trax>

Why Data Quality Matters

Your program through the lens of poor data quality

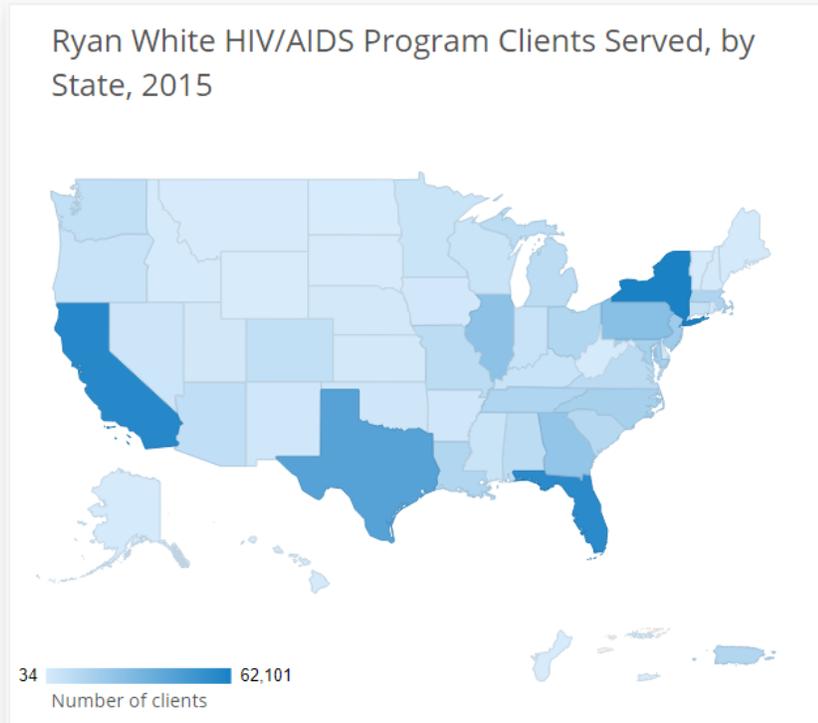


Why Data Quality Matters

Good data provide a clear image of the good work you do



Data Help RWHAP Funders and Stakeholders Learn More about the Program



Learn how AIDS Drug Assistance Program (ADAP) Funds were administered in the United States in 2015

The HIV/AIDS Bureau administers the AIDS Drug Assistance Program (ADAP), which is a state- and territory-administered program that provides medications and access to health care coverage to those who lack coverage and resources.

In 2015, an estimated 259,531 clients were served by ADAP in the United States. A total of 34,265 new clients were served.

Toggle "Data Tables" in the left navigation to view the data for all charts.

State Profiles: <https://hab.hrsa.gov/stateprofiles2015/#/>

ADR Data Help Your Project Officer (PO) Learn More About Your Program

Data Quality Summary Report:

- Compares summaries of ADR data with the previous year
- Calls with DART, ADAPs and POs help POs understand program trends and data management issues

ADAP Data Report (ADR) Data Quality Summary Report

State
2016 Data

SNAPSHOT OF SUBMITTED DATA

Total Number of Clients Submitted: 11,307

Table 1: Client Characteristics as a Percent of Total Clients Submitted

| | 2015 State | | 2016 State | | National Percent |
|---|------------|---------|------------|---------|------------------|
| | Count | Percent | Count | Percent | |
| Services Received | | | | | |
| Only Insurance Services Received (#20) | 2,235 | 21% | 2,726 | 24% | 32% |
| Only Medication Services Received (#25) | 3,996 | 38% | 3,244 | 29% | 38% |
| Both Services Received (#20 and #25) | 1,476 | 14% | 1,448 | 13% | 10% |
| No Services Received (Not #20 or #25) | 2,815 | 27% | 3,889 | 34% | 20% |
| Total Number of Clients Submitted | 10,522 | 100% | 11,307 | 100% | 100% |
| New Clients (#14) | 1,604 | 15% | 1,630 | 14% | 13% |
| Dis-enrolled Clients (#18) | 3,362 | 32% | 2,631 | 23% | 21% |
| No Services Requested (#18) | 1,483 | 14% | 2,569 | 23% | 7% |

Metrics related to services received are broken down differently than the metrics in the Confirmation Report.

+

Table 2: Insurance Assistance

| | 2015 State | | 2016 State | | National Percent |
|--|------------|---------|------------|---------|------------------|
| | Count | Percent | Count | Percent | |
| Insurance Assistance Received (#20) | 3,711 | - | 4,174 | - | - |
| Any Type of Insurance Assistance Received (#67) | 3,711 | - | 4,174 | - | - |
| Full Premium Payment | 2,376 | 64% | 2,893 | 69% | 41% |
| Partial Premium Payment | 76 | 2% | 138 | 3% | 8% |
| Co-pay/Deductible | 2,983 | 80% | 3,105 | 74% | 85% |
| Insurance Assistance Type Missing (#20 Reported but Missing #67) | 0 | 0% | 0 | 0% | 0% |

Table 3: Insurance Amounts

| | 2015 State | | 2016 State | | National Percent |
|--|------------|---------|------------|---------|------------------|
| | Count | Percent | Count | Percent | |
| Of Clients with Full or Partial Premium (#67) | 2,405 | - | 2,933 | - | - |
| Clients with Premium Amount Paid Reported (#21) | 2,405 | 100% | 2,933 | 100% | 100% |
| Clients with Months Coverage Reported (#22) | 2,405 | 100% | 2,933 | 100% | 100% |
| Of Clients with Co-pay/Deductible (#67) | 2,983 | - | 3,105 | - | - |
| Clients with Amount Paid for Co-pay/Deductibles Reported (#23) | 2,983 | 100% | 3,105 | 100% | 99% |

Table 4: Medication Assistance

| | 2015 State | | 2016 State | | National Percent |
|--------------------------------------|------------|---------|------------|---------|------------------|
| | Count | Percent | Count | Percent | |
| Medication Services Received (#25) | 5,472 | - | 4,692 | - | - |
| Clients with a D-Code Reported (#26) | 5,472 | 100% | 4,692 | 100% | 100% |
| Clients Missing D-Code (#26) | 0 | 0% | 0 | 0% | 0% |
| Number of Unique D-Codes Reported | 50 | - | 51 | - | - |

History of the ADR Data Quality Efforts

Focus on submission

Focus on completeness

Focus on accuracy

2012

2018

Efforts to Improve Completeness and Accuracy

Tools available in the ADR Web System

- Upload Completeness Report (UCR)
- Validation warnings

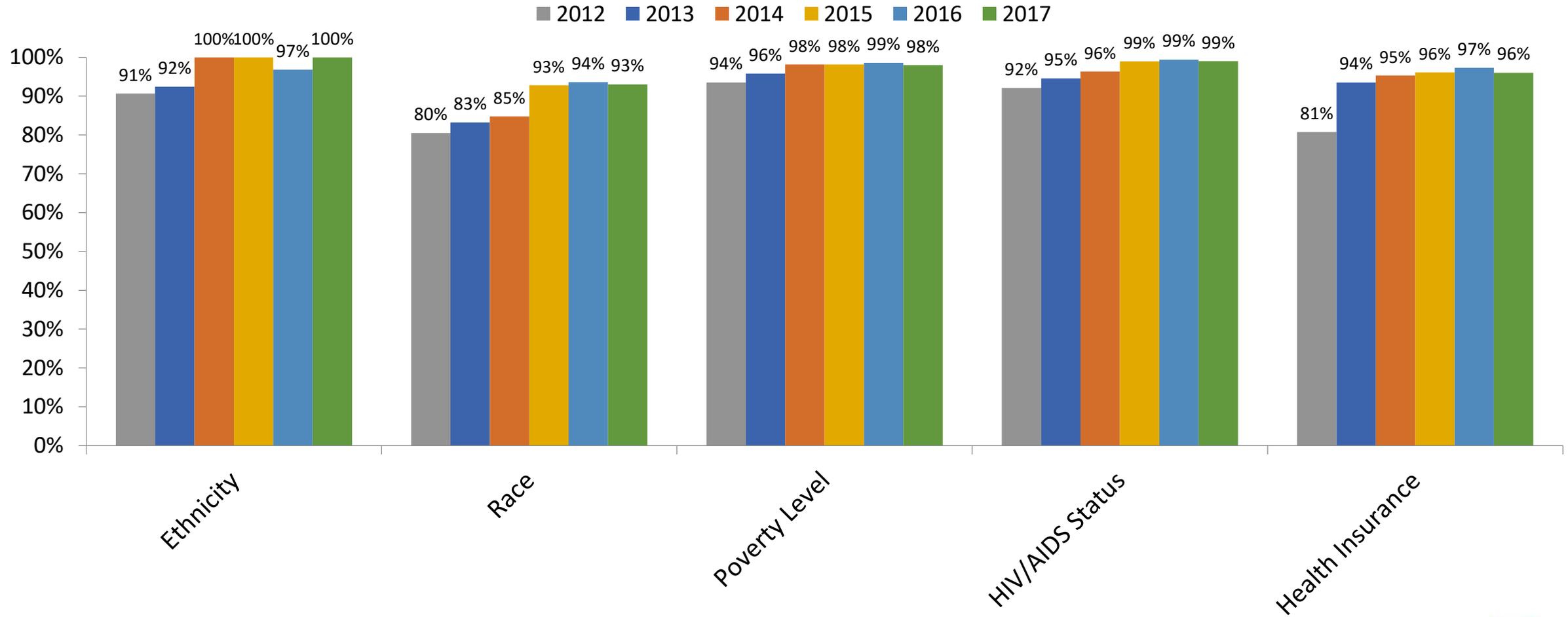
Data Quality Summary Reports

Annual calls with ADAPs to discuss data management and quality improvement strategies

Analysis of 2017 medication data

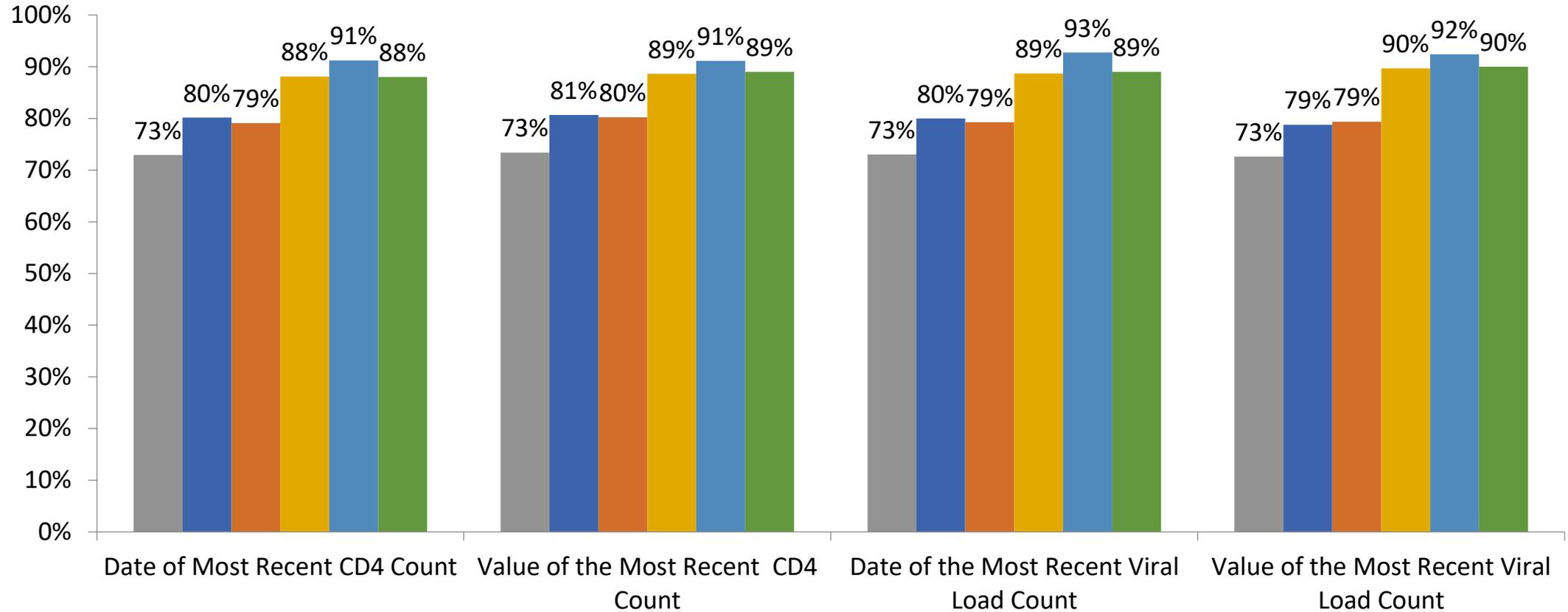
Ongoing technical assistance

Completeness Rates for Client Demographics



Completeness Rates for Clinical Information

■ 2012 ■ 2013 ■ 2014 ■ 2015 ■ 2016 ■ 2017



Presentation Outline

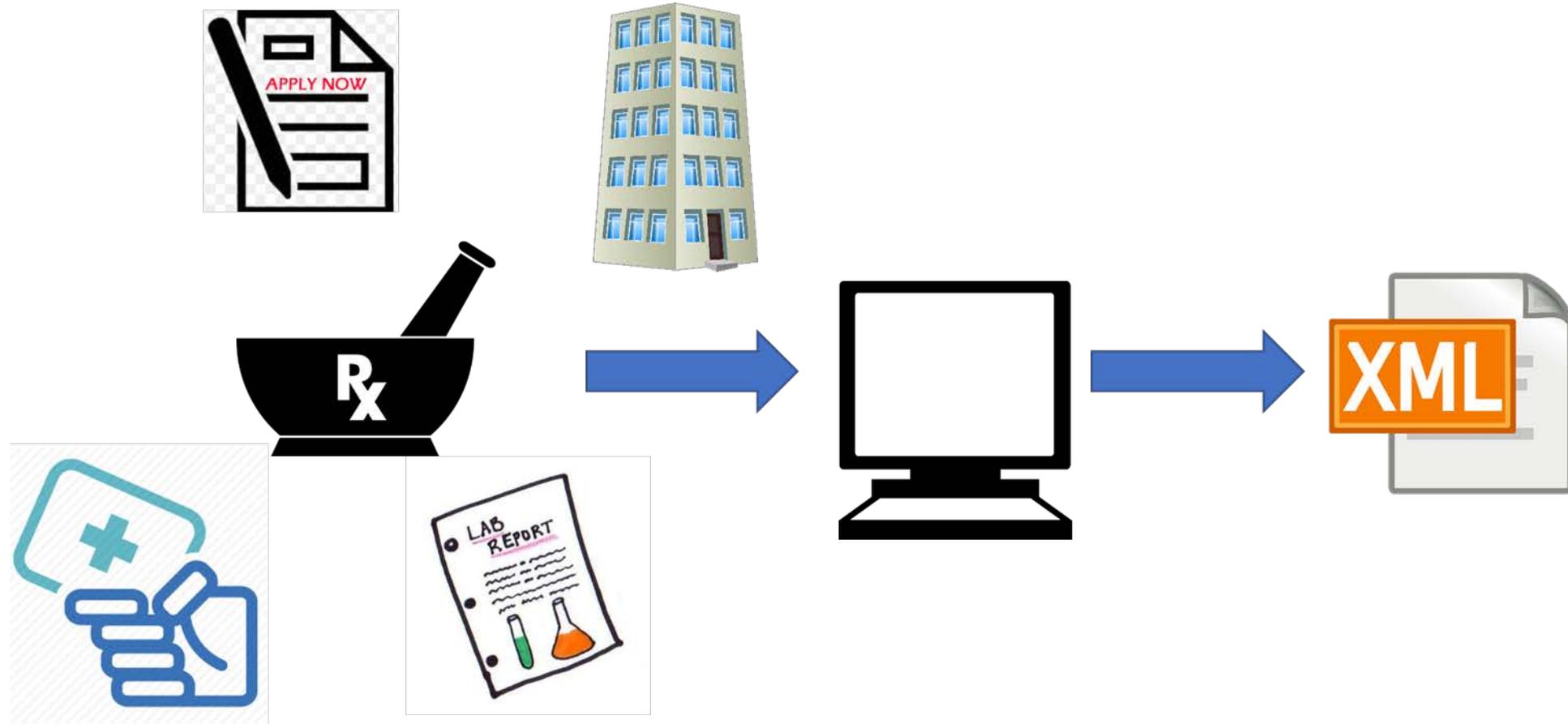
Overview and Progression of the ADR

Remaining Opportunities to Improve Data Quality

Tips and Solutions: Voices from the Field

Data Quality Exercise on Using the Upload Completeness Report (UCR)

Complex Data Management Systems



Complex Data Management Systems

Most ADAPs only consolidate data annually for ADR submission, so they miss out on using their data outside the reporting period

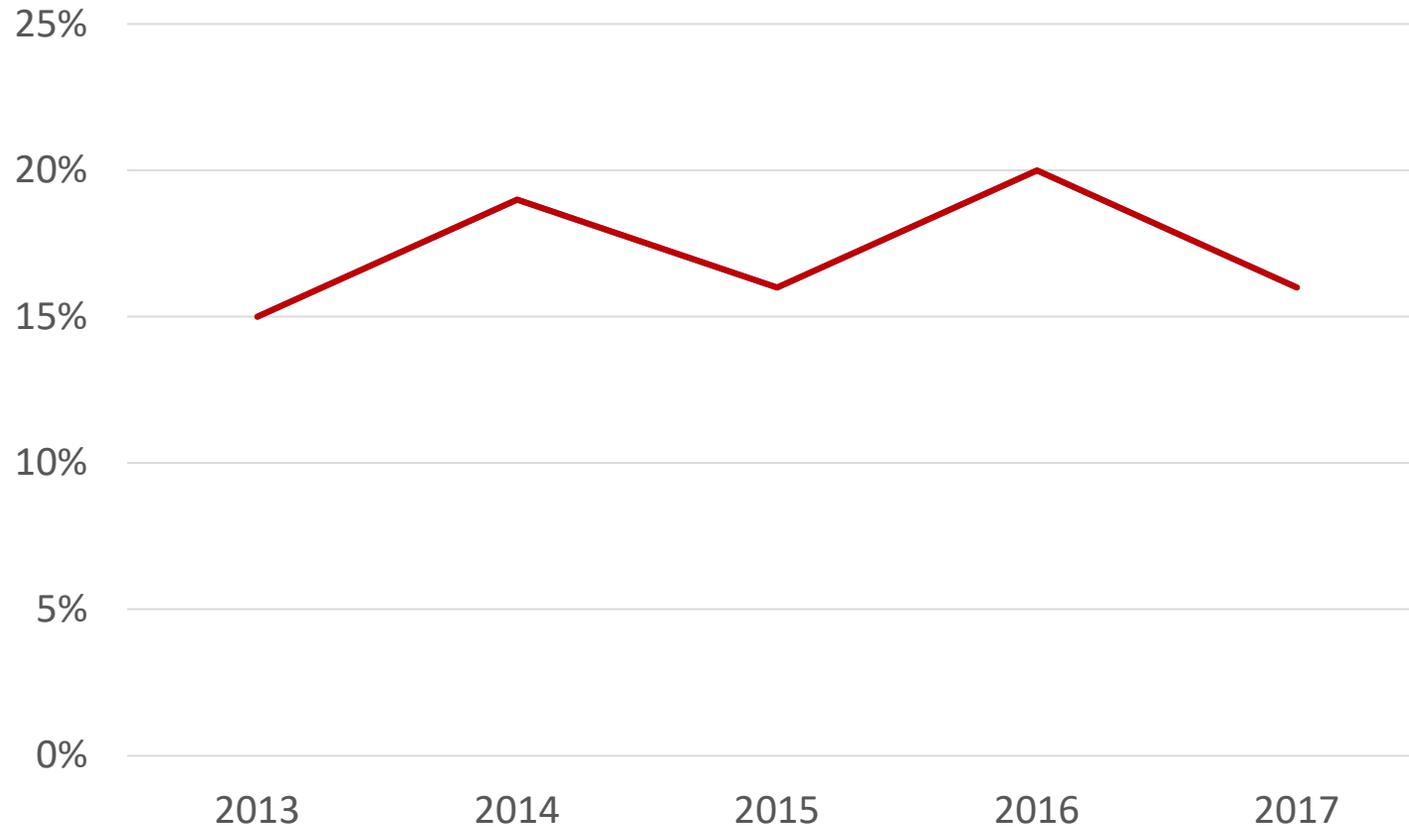
Use your data throughout the year to:

- Identify and resolve data quality issues
- Inform program improvement activities

Ask yourself:

- What information can help us improve the impact of our ADAP?
- What systems and processes do we need to access this information?

Percent of Clients with No Services



Medication Analysis

Focus on data quality, not program quality issues

Focus on antiretrovirals (ARVs)

Targeted technical assistance based on findings

Medication Outreach Topic Areas

No medication data

A small share of clients with medication services

Single fills with greater than 365 days supply

\$0 drug cost for a high share of fills

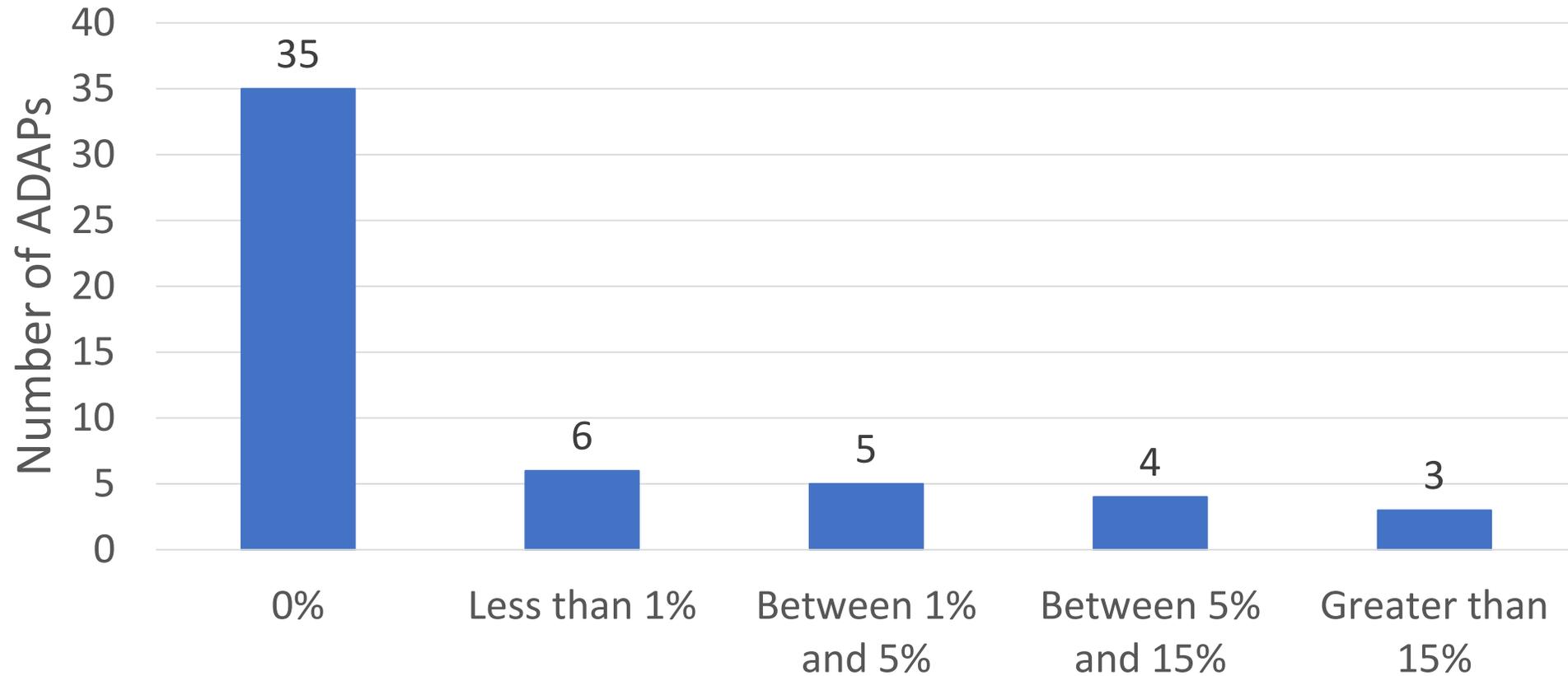
Unusually high or low median daily drug costs

Large fluctuation in daily cost for the same medication

Unusual prescription rates for ARVs

Unusually high or low drug spells per client

Percent of Fills with \$0 Drug Cost



Differences in Median Daily Drug Cost

Stribild, Genvoya: Over 200,000 fills across all ADAPs

Median drug price ranged from \$0.97 to \$99.30 across ADAPs

Number of ADAPs within the median cost range:

- Less than \$5: 3 ADAPs
- Between \$20-\$35: 23 ADAPs
- Between \$48-\$66: 5 ADAPs
- Greater than \$88: 19 ADAPs

Fluctuation in Daily Cost for the Same ARV

Measure:

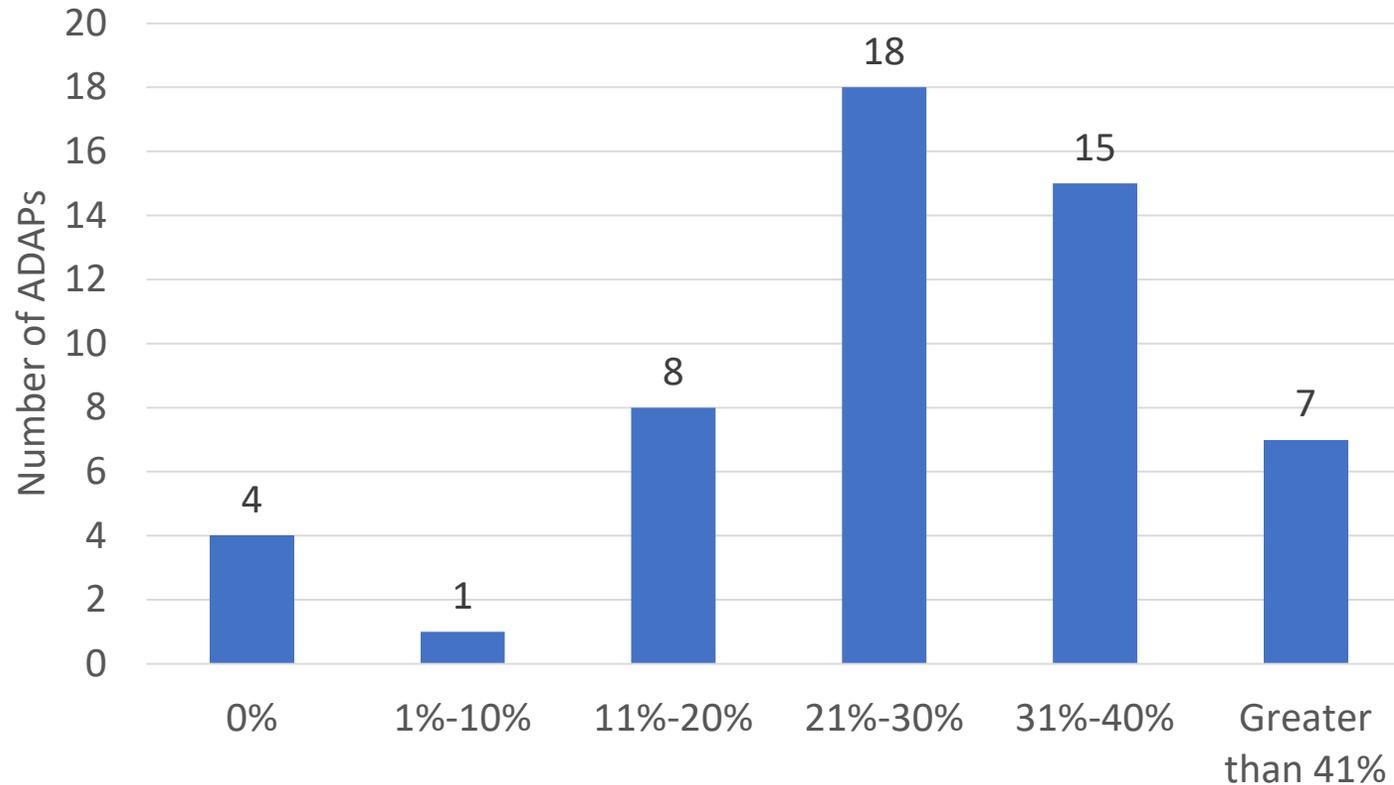
- 90th percentile of drug cost divided by the 10th percentile of drug code
- Example: 5 = the daily cost of some fills are five times higher than the daily cost of others

Stribild, Genvoya

- Less than 2: 37 ADAPs (*consistent daily cost*)
- Between 2-4: 5 ADAPs (*some fills are 2-4 times more expensive*)
- Greater than 20: 8 ADAPs (*some fills are 20 times more expensive*)

Unusual Prescription Rates of ARVs

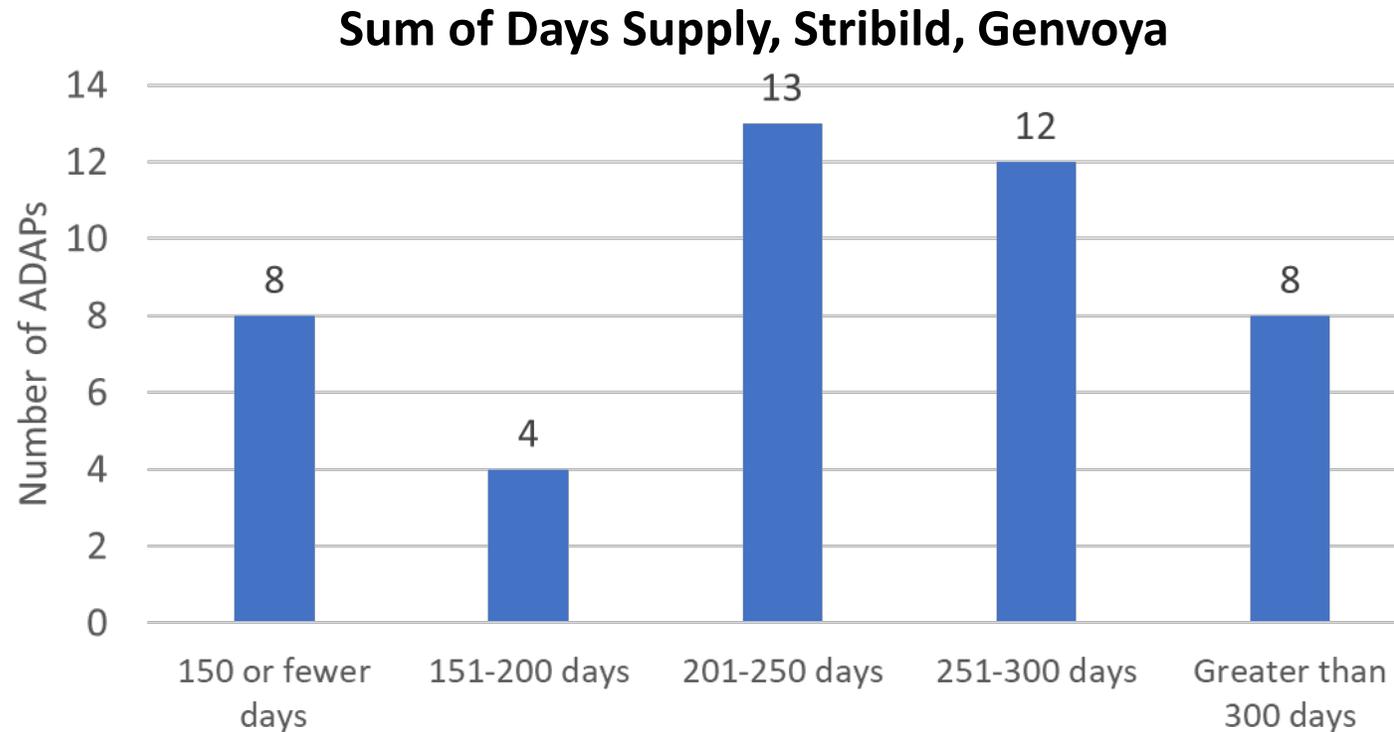
Percent of Clients on Stribild, Genvoya: National Average = 30%



Unusually High or Low Drug Spells

Measure:

- Sum of days supply for a client/d-code combination
- Only includes uninsured clients, enrolled throughout the year



Insurance Services

Partial premium not being reported accurately. Examples of partial premium assistance:

- Client enrolled in the Health Insurance Exchange and receives a subsidy
- Client enrolled in employer-sponsored insurance, but the ADAP pays for the client cost share

\$0 reported from some amounts

Clients get multiple types of premium assistance, but only one is reported

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Tips and Solutions: Voices from the Field

- Samantha Penn and M. Thomas Blissett, Nevada Department of Health and Human Services
- Ann Nakamura and Luna Woo, California Department of Public Health

Data Quality Exercise on Using the Upload Completeness Report (UCR)

Nevada ADAP

Samantha Penn & M. Thomas Blissett

Samantha Penn, MBA
Management Analyst I
Nevada Department of Health and Human Services

M. Thomas Blissett
Health Program Specialist I
Nevada Department of Health and Human Services

Overview of the Nevada ADAP

- Universal Eligibility
- One Statewide Provider (Access to Healthcare Network, AHN)
- Medication Assistance Program
- Premium Assistance
- Copay Assistance
- Access and Adherence Navigation (*coming in 2019*)

Data Quality and Program Challenges

- 2016 ADR
- Major challenge - labs
- Data uploads from Pharmacy Benefit Manager to CAREWare every 15 days
- Mid-year switch from Optum Rx to Ramsell

2016 ADR

Total clients: 1921

- Received Insurance Assistance: 997 (52%)
- ADAP- Funded Medication Dispersed: 738 (38%)

| Client Most Recent Viral Load Date Reported (Item #34) | | |
|---|------------|------------|
| Most Recent Viral Load Date Reported | Count | Percentage |
| Yes | 549 | 74 |
| No | 189 | 26 |
| Total | 738 | 100 |

| Client Most Recent CD4 Date Reported (Item #32) | | |
|--|------------|------------|
| Most Recent CD4 Date Reported | Count | Percentage |
| Yes | 539 | 73 |
| No | 199 | 27 |
| Total | 738 | 100 |

Data Management/System Changes

- In 2017, began to manually match clients every quarter between the HIV Surveillance system, eHARS, to CAREWare
- Began working with providers who have large data entry to use the PDI feature of CAREWare
- Began contracting with AJBoggs for more than CAREWare hosting, we are working on four data interfaces:
 - Ramsell PBM
 - Medicaid
 - HIV Surveillance eHARS
 - Part A

2017 ADR

Total clients: 3170

- Received Insurance Assistance: 1223 (56%)
- ADAP- Funded Medication Dispersed: 762 (35%)

Viral Load Values Reported (Item #35)

Denominator: Number of unique clients reported who received ADAP-Funded medications (N = 762)

| Description | N | Percentage |
|--|-----|------------|
| Clients with viral load less than 200 | 612 | 80.3% |
| Clients with viral load 200 or greater | 110 | 14.4% |
| <i>Missing/Out of range</i> | 40 | 5.2% |

CD4 Count Values Reported (Item #33)

Denominator: Number of unique clients reported who received ADAP-Funded medications (N = 762)

| Description | N | Percentage |
|--|-----|------------|
| Clients with CD4 count less than 200 | 66 | 8.7% |
| Clients with CD4 count between 200 and 349 | 105 | 13.8% |
| Clients with CD4 count 350 or greater | 553 | 72.6% |
| <i>Missing/Out of range</i> | 38 | 5.0% |

Improvements to Client Experience and Data Quality

- Data integration = holistic client and programmatic view
- Client-driven process aimed to reducing client burden
 - Removed barriers from the eligibility process
- Data driven activities
 - The data is used on the provider level to direct efforts, example used on the quarterly reports
 - The data is used for Retention-In-Care and Case Management activities
 - Clients who have lapsed or will lapse in eligibility
 - Clients who did not pick-up medications in 45 days
 - Clients without labs in CAREWare for the past 12 months
 - Clients who are not-virally suppressed, virally suppressed, undetectable

Improving AIDS Drug Assistance Program (ADAP) Data Quality: California's ADAP Enrollment and Reporting System

Ann Nakamura and Luna Woo

Ann Nakamura, MPH Interim Chief, ADAP and Care Evaluation and Informatics Branch, Office of AIDS, California Department of Public Health

Luna Woo, MA Research Scientist III, ADAP Fiscal Forecasting, Evaluation, and Monitoring Section, Office of AIDS, California Department of Public Health

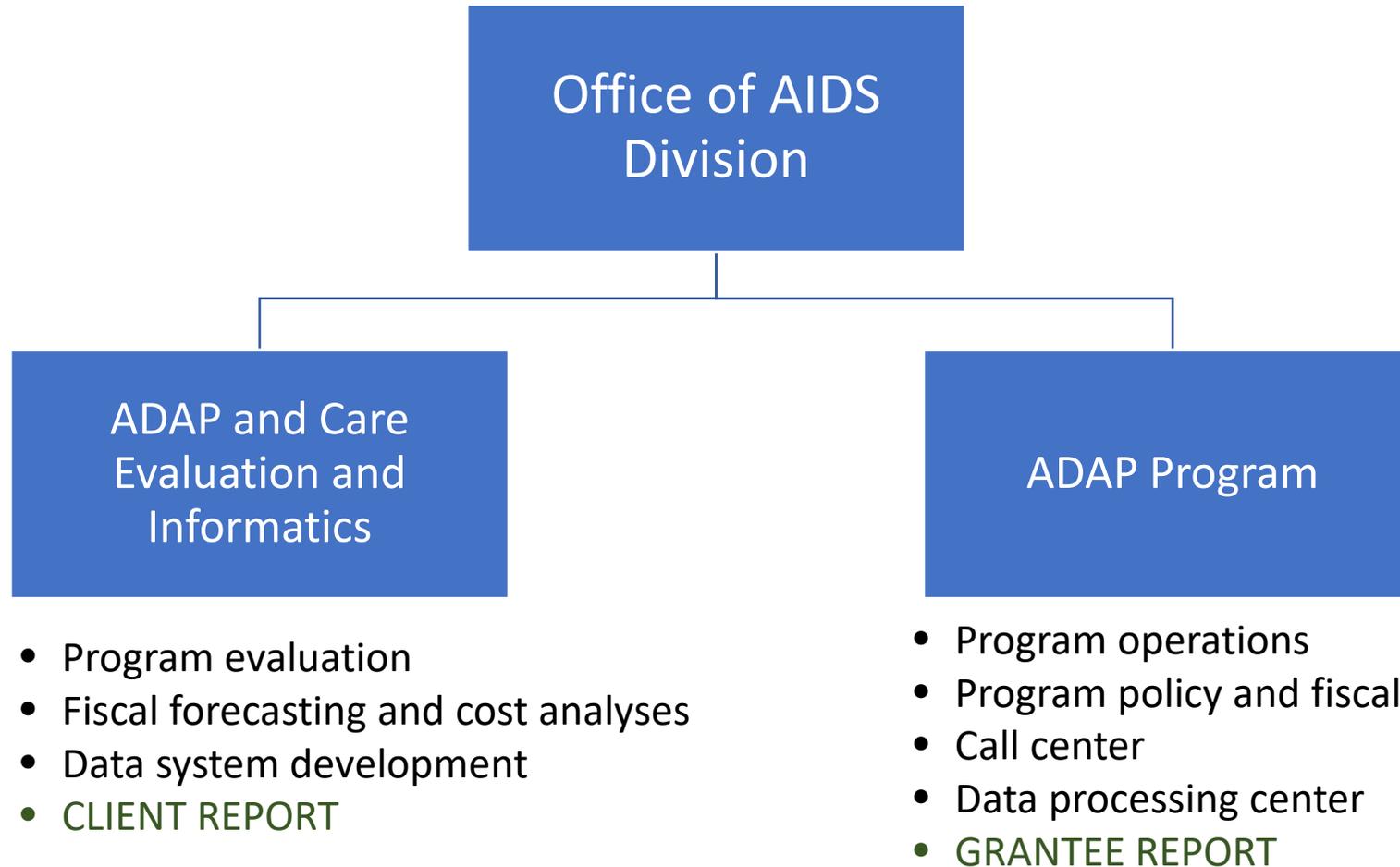
Part 1

System overview and strategies to ensure data quality and inform program activities

Ann Nakamura, MPH

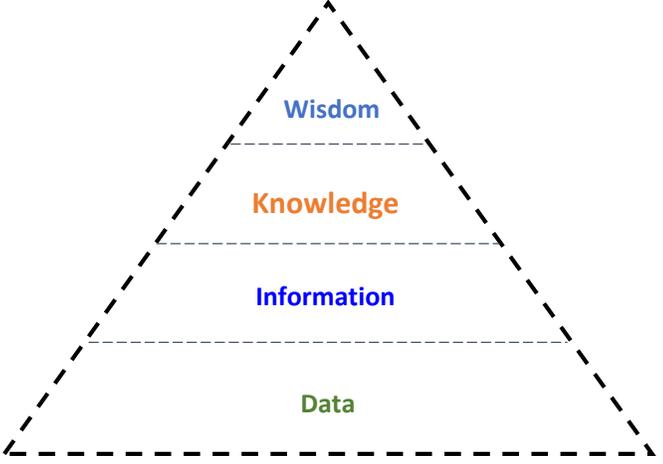
Interim Chief, ADAP and Care Evaluation and Informatics Branch

California ADAP Functional Organization



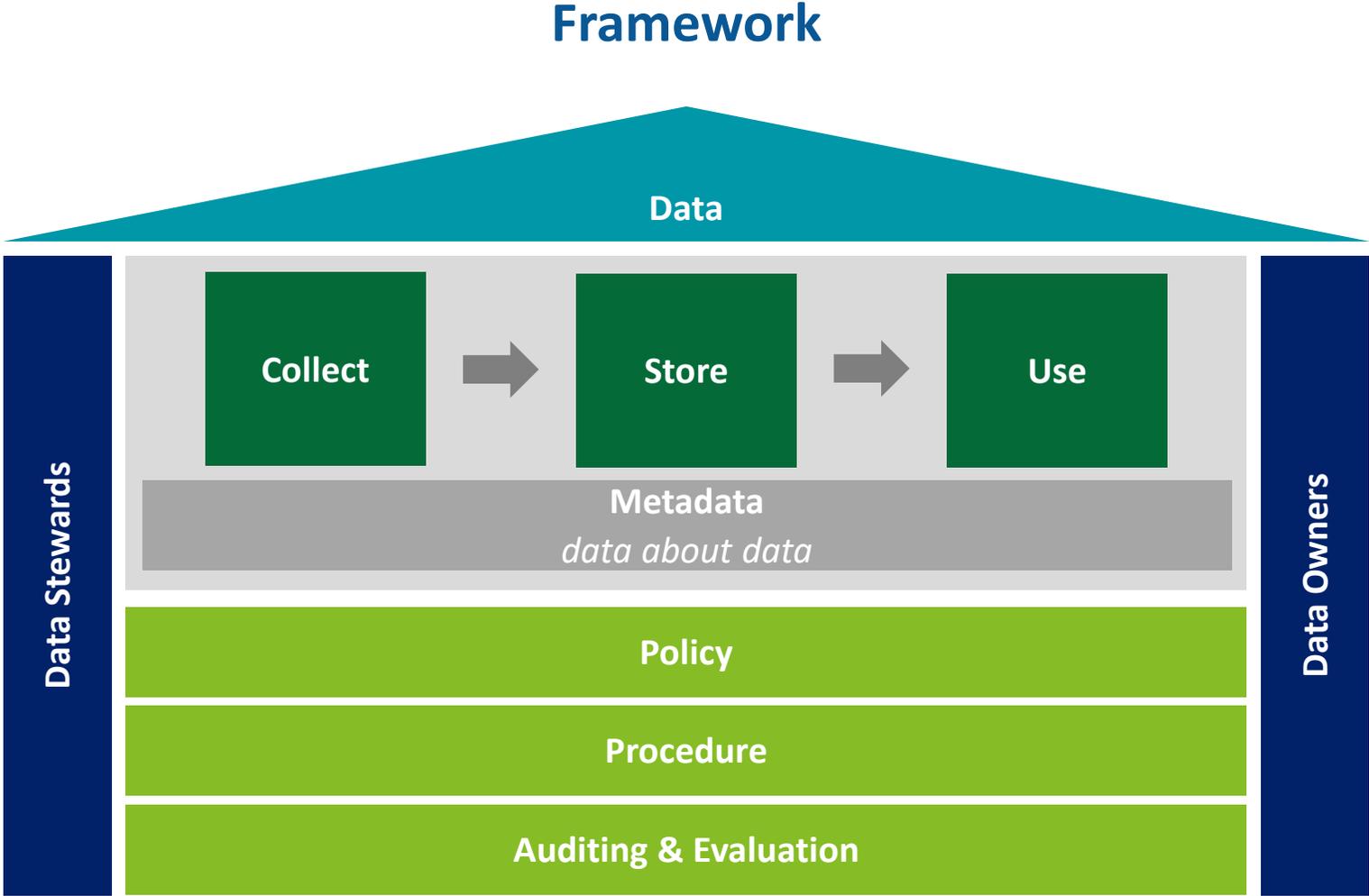
Federal Reporting responsibilities for each branch appear in green font.

ADAP Enrollment System Development and Governance Approaches

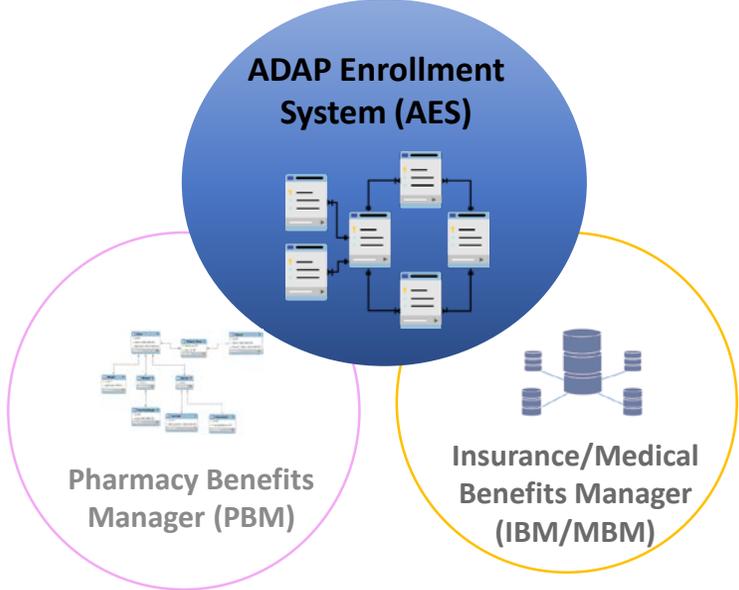
| Development | Governance |
|---|--|
| <p>Planning</p> <ul style="list-style-type: none"> • Agile • Focus on stakeholder business and data needs • Early evaluation and Quality Improvement (QI) planning • Collaborative priority setting <p>Development</p> <ul style="list-style-type: none"> • Focus on data governance and fluency • Flexibility for routine monitoring and ad hoc analyses <p>Evaluation and QI</p> <ul style="list-style-type: none"> • Adaptive/Developmental approaches • High concordance with business needs • Ongoing assessment of user experience | <p>Focus on Data Fluency</p> <p>“Making data useful is a problem that ultimately must be solved by people, people who understand the specific context of the data, people on the frontlines of decisions, and people who deeply understand the problems that data can illuminate.” *</p>  |

*Source: Zach Gemignani, Chris Gemignani, Dr. Richard Galentino, Dr. Patrick Schuermann. Data Fluency: Empowering Your Organization with Effective Data Communication. (2014) John Wiley & Sons, Inc., Indianapolis, Indiana.

CA ADAP Data Governance Framework

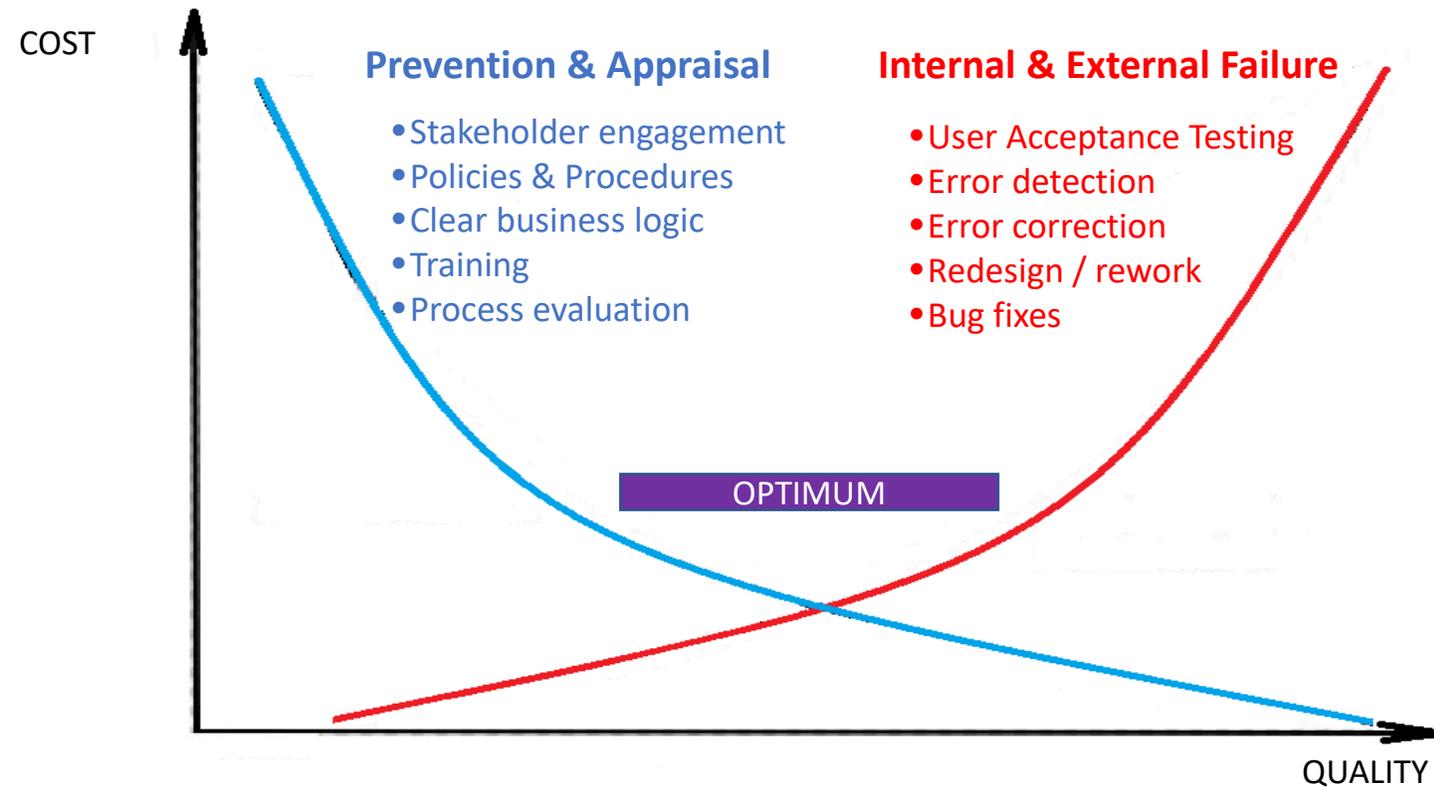


ADAP Enrollment System Business Uses and Structure

| Business Uses | Structure |
|---|--|
| <p>ADAP Enrollment</p> <ul style="list-style-type: none">• AIDS Drug Assistance Program (ADAP)• Pre-Exposure Prophylaxis Assistance Program• Health insurance premium and medical out-of-pocket assistance• Access Adherence and Navigation• Reporting <p>Pharmacy and Insurance Benefits Management</p> <ul style="list-style-type: none">• Bi-directional data interfaces<ul style="list-style-type: none">• Eligibility transfers• Claim payment information <p>Evaluation and QI</p> <ul style="list-style-type: none">• Adaptive/Developmental approaches• High concordance with business needs• Ongoing assessment of user experience |  <p>The diagram illustrates the structure of the ADAP Enrollment System (AES). At the top center is a blue circle labeled "ADAP Enrollment System (AES)" containing several server icons connected by lines. Below this are two overlapping circles: a pink one on the left labeled "Pharmacy Benefits Manager (PBM)" containing a network diagram, and a yellow one on the right labeled "Insurance/Medical Benefits Manager (IBM/MBM)" containing a database icon.</p> |

CA ADAP Data Quality Approach

Cost of Quality



This chart illustrates the prevention-appraisal-failure (PAF) model. In the PAF model, investing in prevention & appraisal and in failure costs involve trade-offs that can be balanced to maximize quality and limit costs.

Part 2

Ensuring data quality to support federal monitoring activities

Luna Woo, MA

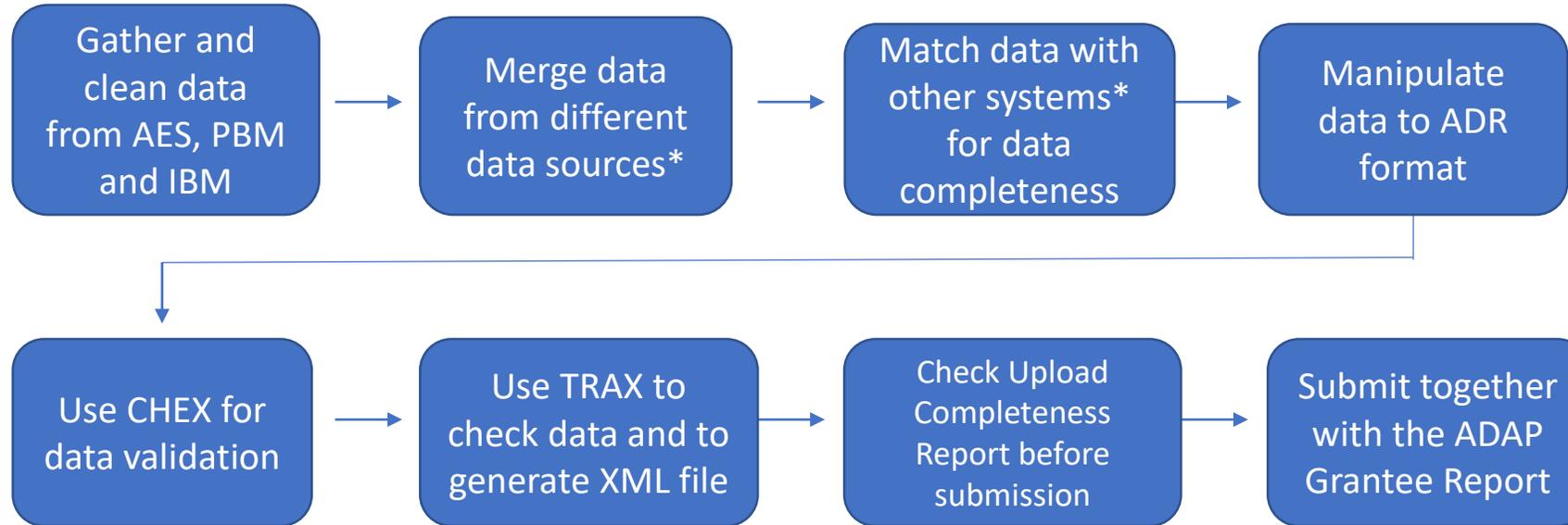
Research Scientist III, ADAP Fiscal Forecasting, Evaluation and Monitoring Section

Quick CA ADAP System Statistics

- Roughly 200 Enrollment Sites and 650 enrollment workers
- Roughly 30,000 medication and 6,500 insurance assistance clients served annually
- Roughly 6,000 participating pharmacies
- 208 medications on formulary, including 43 antiretroviral medications*
- 750-1,025 pharmacy claims processed per day
- 75 – 100 applications processed per day (includes initial, re-enrollment, re-certification, updates, and dis-enrollments)

* As of September 2018

CA ADAP Data Report (ADR) Data Flow



* Described in the next slides.

CA ADAP ADR Data Sources

AES Data

- Client Demographics (Race, Ethnicity, Gender, Poverty level, HIV/AIDS Status, Poverty Level, High Risk Insurance, Health Insurance, etc.)
- Enrollment and Certification (New or Existing Client, Date Completed Application Received, Date of Recertification, Reason for Disenrollment, etc.)
- Clinical Information (CD4 Count Date, CD4 Count Value, Viral Load Date, and Viral Load Value)

CA ADAP ADR Data Sources (cont.)

PBM

- Drugs and Drug Expenditures (Medication Dispensed, Amount Paid for Medications, etc.)
- ADAP Health Insurance Services (Amount Paid for Co-pays and Deductibles)

IBM

- ADAP Health Insurance Services (Amount Paid for Premiums, Months Coverage of Premiums Paid, etc.)

CA ADAP Data Quality Measures

| Measure(s) | Key Question(s) |
|---|--|
| Reliability and Validity: Data are stored in an acceptable format with valid values from a verifiable source. | Are the data providing stable information when expected? |
| Accuracy: Data represent reality and matching values are the same across files. | Have data fields passed edit checks and other controls |
| Timeliness: Data are available in a timely manner, as required | How current is the information? |
| Completeness: (1) All records have been entered for the population and (2) data fields have no missing or unknown values | Is there enough information available to answer the questions being asked? |
| Uniqueness: No unintended duplicate records exist. | Do records have one primary key? |

Strategies to Improve Data Completeness & Accuracy

Data matches with other systems

- Surveillance data for clients with missing or out of date clinical information
- California Franchise Tax Board for clients with missing income
- Medi-Cal (California Medicaid) Eligibility Data System to verify Medi-Cal status
- Centers for Medicare & Medicaid Services to verify Medicare Part D status
- Future match with a healthcare data management system to verify commercial insurance status

Routine data quality reporting: eligibility, client demographics, etc.

ADR Tools to Check Data Quality

- Convert data to ADR required format
- CHEX: Validate data
- TRAX
 - No need for UCI or URN. TRAX uses FirstName, LastName, DOB and GenderID to generate eUci.
 - Error messages
- Upload Completeness Report
 - Values within reasonable range
 - Significant change from previous submission

Using Data to Inform State and Federal Program Activities

- Federal ADR requirements informed system design
 - More complete reporting of racial and ethnic subgroups
 - Capture of detailed insurance plan information and insurance source (individual vs. group coverage) for all clients
 - Timely identification of clients who have one or more break in service
 - Timely collection of disenrollment information

Using Data to Inform State and Federal Program Activities (Cont.)

- Real-time reporting for State ADAP to use
 - Monitoring enrollment site activities
 - Prioritizing site visits
 - Providing technical assistance

Using Data to Inform State and Federal Program Activities (Cont.)

- Client interactions and enrollment worker activities stored centrally
 - More timely identification of issues with eligibility and claim adjudication
 - Task assignment features support program workload management
 - Automatic notifications to alert ADAP Advisors and Enrollment Workers when clients may lapse in care
 - Support communication with clients for eligibility and program updates

Thank You

For questions about the AES System Development, contact Ann Nakamura at Ann.Nakamura@cdph.ca.gov

For questions about data quality planning, implementation, and reporting, contact Luna Woo at Luna.Woo@cdph.ca.gov

Presentation Outline

Overview and Progression of the ADR

Remaining Challenges

Tips and Solutions: Voices from the Field

Data Quality Exercise on Using the Upload Completeness Report (UCR)

Answer the Following UCR Questions

Do you notice anything strange about the data?

What data-related issues could be behind this trend?

How could you spot this issue prior to ADR submission?

What can be done to improve the quality of the data?

Resources

Access Check Your XML: https://careacttarget.org/sites/default/files/file-upload/resources/Using_Check_Your_XML_ADR_16MAR2016.pdf

The DART Team: Data.TA@caiglobal.org

TARGET Center website: <https://careacttarget.org/category/topics/adap-data-report-adr>

Ryan White HIV/AIDS Program Data Support

- 888.640.9356; RyanWhiteDataSupport@wrma.com

HRSA Contact Center

- 877.Go4.HRSA (877.464.4772); <http://www.hrsa.gov/about/contact/ehbhelp.aspx>

CAREWare helpdesk

- 877-294-3571; cwhelp@jprog.com
- Sign up for the listserv!