

# dataCHATT 101:

What do you want and need to collect?

**Mira Levinson**, JSI Research & Training Institute, Inc.

**Kim Lawton**, Quality and Information Management

**Lisa Hirschhorn**, JSI Research & Training Institute, Inc.

# Presentation Overview

1. Collecting data accurately, completely, and efficiently
2. Conducting your Data Inventory
3. Implementing your Data Collection Plan
4. Getting Technical Assistance (TA)
5. Participant Feedback

# But First, Why Collect Data?

# Required Reporting

- Reporting to HAB:
  - Ryan White HIV/AIDS Program Data Report (RDR)
  - AIDS Drug Assistance Program (ADAP) Quarterly Report (AQR)
  - Part A Minority AIDS Initiative (MAI) Report
- Reporting to other funders and entities

# Additional Reasons for Collecting Data

- Individual client management/service coordination
- Program monitoring and improvement
  - Understand and improve daily operations of HIV programs
  - Measure and improve quality of care
- Inform HIV program planning and service system coordination activities
- Identify and demonstrate need for additional funds from HAB and other funders

# How to Collect Data Accurately, Completely, and Efficiently

# Important Things to Know

- The basic steps of data flow from what you need to collect to reporting
- Organizing your information
- What data do you need to collect?
- How should the data be collected?

# The Data Life Cycle

- What do you want/need to collect? (Identifying and Defining Data Elements)
- Where can you find what you need to collect? (Data Sources)
- How can you get the data you need to collect? (Data Collection)
- How does data collection fit into the Data Life Cycle (the bigger picture of how you work with data)?



# The Data Life Cycle

1. Identifying and Defining Data Elements:  
*What do you want/need to collect?*
2. Data Sources:  
*Where can you find what you need to collect?*
3. Data Collection:  
*How can you get the data you need to collect?*
4. Data Validation and Data Quality Procedures:  
*How do you know the data you get is good and accurately reflects what you are trying to measure or report?*

## 5.Data Reporting:

*How do you submit the data you have?*

## 6.Communicating about Data:

*How do you use the data you have to inform our program about how you are doing?*

## 7.Using the Data:

*How do you use the data you have to inform our program decisions?*

## Assessing the Effectiveness of the Current System:

*How can you improve our data system in order to effectively accomplish steps 1 – 7?*

# Step 1: Identifying & Defining Data Elements

- Identify what needs to be collected or what the program wants to collect, and why:
  - identify data elements necessary for program reporting
  - improve quality of care
  - improve overall capacity to meet the needs of target populations
- Once identified, data elements must be defined so that everyone understands what they need to collect

# Step 2: Data Sources

- What needs to be collected from original sources versus what is available from existing databases or other sources of collected data
- Steps needed to access the data including: requesting, capturing, recording and storing data from these identified sources
- May also include development of inter-organizational agreements to ensure secure and appropriate access to data

# Step 3: Data Collection

Implement the process of capturing data from identified data sources by following the steps defined above in Data Sources:

- sharing/requesting data
- entering data
- storing data

# Step 4: Data Validation & Quality Procedures

How do we know the data we get is good and accurately reflects what we are trying to measure or report?

- Design and implement procedures to make sure data are complete, accurate, timely, and valid.

# Step 5: Data Reporting

Follow procedures to correctly and efficiently prepare and submit data to meet the data reporting requirements of the Ryan White HIV/AIDS Program (or other funding sources).

# Step 6: Communicating About Data

How do we use the data we have to inform our program about how we are doing and where we need to go?

- Interpret and present data to inform an audience
- Use the data to inform planning, evaluation, allocations, or quality improvement.

# Step 7: Using the Data

How do we use the data we have to inform our program decisions?

- Evaluate and improve program activities
- Identify gaps
- Strengthen planning or expansion.



# Assess the Effectiveness of your Current System

How can we improve our data system in order to effectively accomplish steps 1 – 7?

- Review and understand the features and relationships within a data management system (e.g. current databases and their interfaces, users, hardware, software, and security) with the goal of improving the overall effectiveness of that system.

# What should you do first?

# Form a Data Oversight Team

Include people involved in producing, collecting, managing, and using the data:

- Data managers
- Administrators
- Clinicians
- IT staff
- Others

# What will the team do?

- Define what data to collect, and how to collect it
- Catalogue your data needs and sources through a Data Inventory
- Review the data elements in the inventory
  - Where are areas where data collection can be combined?
  - Are there options for your database to link with existing data sources to access needed data?

# What else will the team do?

Ensure that data will be collected efficiently, appropriately and accurately

- Address identified overlaps to improve efficiency
- Identify what resources are needed
- Identify data collection approaches and activities which need change and propose solutions (e.g. changes to database, forms, data collection methodology)

# What questions will they answer?

- Are all required data being collected correctly and consistently?
- Who is collecting the data?
  - What training have they had? What guidance is provided on data reporting?
  - Is the most appropriate person (clinician, administrator, data manager) collecting the data?
  - How are data being submitted by contracted service providers? Is the data submission system working?

# Next, what data do you need to collect?

What determines the data you need to collect?

- Data Reporting:
  - HRSA/HAB (mandated collection of RDR and other data elements)
  - Other funding agencies
  - Other mandated data requirements
- Program needs:
  - Planning, internal evaluation and monitoring, QI, grant writing, reporting to stake holders

# What data to collect

- Required data must be reported using the guidance and definitions which are provided
- Plans for what other data to collect for program activities can be more flexible and should reflect why and how you want to use the data



# The data you need for reporting

Always start with a clear understanding of all data reporting requirements:

- What you need to collect for reporting is strictly defined through guidances
- Resources are available to support your understanding of these requirements
  - Example: training and telephone-based TA are available to supplement the RDR guidance

# Additional data needed for your program

Additional data collection is in response to needs identified by your program

The data collected and should be based on why and how you want to use the data

# Program-Initiated Data: Why?

- Internal data reporting needs (monitoring and evaluation)
- Planning
- Quality improvement
- Grant writing
- Reporting to community members and other entities

# Program-Initiated Data: What?

- What do you need to know?
- What reports will be needed?
- Who needs the data and why?

# Minimize how much additional data you will collect

Narrow, as much as possible, what data you need to collect to answer your program's questions:

- Be prepared to limit new data collection and pare down existing data collection efforts.
- Carefully consider the necessity of adding other new data elements
  - How will it help you answer your questions?
  - Determine the “cost” of collecting the new data
  - Can you get the data you want?
  - Can you use data you are already required to report?

# Next, review the characteristics of each data element you plan to collect

- Is it mandatory or program-defined?
- How should the data be identified?
  - will you need to link with other data at a client level?
- From where will you get the data (data source)
  - Existing or new
- How can you make collection easier?
  - Look for areas of overlap between data elements
  - Can you combine with other data collection?

# More characteristics

- What are you capturing?
  - Pelvic AND Pap, or just Pap smear?
  - age group vs. DOB
  - CD4<200 vs. actual result
  - aggregate vs. client level
- Should it be qualitative or quantitative?
  - qualitative (self-reported reasons for missed visits) or quantitative (percent of visits missed)?
- Which clients do you need the data from?
  - all clients, all of a subpopulation of clients, or just a sample of the target population?

# Example: Required Data

## Cervical cancer screening and the RDR:

- Required? Yes
- What: Pap and Pelvic
- Who: All women receiving medical care
- How often: Annually
- Data type: Received/not received
- Source: Will differ between programs



# How should the data be collected?

While the required data elements that need to be collected are detailed in the guidance...

how you collect these data is more specific to your program and the data flow.

# More questions to ask before data is collected

- From what sources?
  - Clients
  - existing data sources (medical records, EMR, databases, other)
- By whom?
  - Administrative staff, clinical staff, data manager?
- Using what tools?
  - Forms? Databases? Software patches?

# How should the data be collected?

- How often?
  - One time per client? Annually? Time-limited?
- Is it being done correctly?
  - Do all involved understand the guidance and what is expected for collection
  - Do you have a plan in place that everyone understands?
- Are you already collecting the data?
  - Check your Data Inventory

So what is a “Data Inventory” and how do you develop one?

# What is a Data Inventory?

- A tool that can be employed to allow you to catalogue your available and needed data based on:
  1. required data reporting
  2. other data collection needs of your program
  3. Available data sources
- Allows you to catalog what data you currently collect and identify what data you need to collect and identify the gaps:
  - Current data sources
  - Data Requirements
  - Other data you need to collect

# A Sample Data Inventory

Variable	How it is captured?	Why Collect?	Currently Collecting	Population	Source/ Potential Source	How Often?
Variable name, code and definition	Response options and codes; type of field number, date, open response)	Is this required data? For whom? If not, what is the reason for collecting this variable?	Are you currently collecting this variable in exactly this format? (Y/N)	From which clients (or from which service providers) do you need this information?	Where do you get the data (e.g. EMR, Access database, paper)?	How often do the data need to be collected (Annual? Quarterly? Time-limited?)

# What else can you capture in a Data Inventory?

- Sampling information
  - are some data collected only on a sample of clients?
- How are data received?
  - aggregate vs. client level?
  - degree of detail (e.g. age group vs. DOB, CD4<200 vs. actual result)
- Desired Modifications
  - Should anything change about this data element?
  - What needs to happen in order to make this change?
- Notes
  - Overlap between two data collection activities
  - Challenges/solutions
  - Next steps

# How to conduct a data inventory

- What data are you currently collecting?
  - Input the details of all data you currently collect for reporting or program management
- What data elements are not currently being collected, but are needed for reporting or program management
  - Input the details for these data elements
  - Be sure that all required data can be reported exactly as defined in the guidance



# Review the details of each data element

## 1. Variable

- Is your variable clearly defined?

## 2. How is it captured

- Are data as detailed as they need to be?
- Age groups versus actual age
- CD4 < 200 or actual CD4 count

## 3. Why Collect

- If it isn't required for reporting, do you really need to collect it?
- Does the data element contribute to reporting, analysis and/or provide a link between datasets?
- Do you want to be collecting it in this way?

## 4. Currently Collecting

- Are there required elements you are not currently collecting
  - Prioritize for expansion of current efforts

# Review the details of each data element

## 5. Population

- For which clients do you need this information?

## 6. Source (or Potential Source)

- Are data being collected more than once and should that be changed?
- Are data being collected from the best source?

## 7. How Often?

- Are you collecting the data from each client as often as you need it?  
More often than you need it?

# Conduct your data inventory

Variable	How captured?	Why Collect?	Currently Collecting	Population	Source or potential source	How Often?
Pap	Normal, abnormal, not done	RDR	Yes	- All women in medical care - Client level	EMR	Annual
Pregnant HIV (+) women on ART	Yes/no	Funder	No	All women in medical care  aggregate	EMR	Quarterly
Outreach for missed visit	Done/not done	QI	Yes	- Patients in medical care who missed visits - Client level, sample	Chart Review	Limited for QI project (through 11/15/08)

# Review your Data Inventory

- Compare variables across reporting requirements and program-specific data collection:
  - Identify where there is overlap between data sources
  - Identify potential areas for simplification
  - Are you capturing all the data you need?
- Does the data capture what you need to know?
- Can any data elements be eliminated or simplified?

# Getting it done: Implementing your Data Collection Plan

# Planning for Data Collection

- What is the goal of a data collection plan?
- Meet with your team to ask the big-picture questions and iron out the little stuff
- Operationalize your plan

# What is a data collection plan?

A data collection plan details how your data will be collected so you can:

- Ensure that right data are being collected as planned
  - See dataCHATT 201 (Wednesday at 10:00 am in Washington 4)
- Ensure efficient data collection
  - avoid duplication of efforts
- Ensure program reporting and other data collection needs are met.

# Creating a data collection plan

- Initial information comes from your Data Inventory:
  - What to collect?
  - Where you will collect it from? (data source)
  - How often and when?
- Then answer...
  - Who will collect it?
  - How will it be collected?
  - How will you know it is being done?
  - How will you know the quality of the data is good? (dataCHATT 201)



# Example: A plan for collecting Pap smear data for reporting

Women seen at a clinic may get their Pap smears done by providers working at the clinic (internal providers), or from providers who work outside the clinic (external providers)

- **What:** both pelvic and Pap on all women in care
- **From where:** it depends!
- **By whom:** nurse for both internal and external providers
- **How:** Manually extract from EMR and lab results into HIV database
- **How often:** monthly at the end of each month

# To implement your plan...

- Circulate your data collection plan and provide training
- Make sure your staff are engaged in the plan, and value the data collection
  - Explain how data will be used
  - Share the data with your staff
  - Get their input on the data

# Pay ongoing attention to your plan

- Provide the support and resources detailed in the plan
- Review your plan once it is in action
- Revise your plan as indicated
  - based on experience
  - Based on new data needs and requirements

# What if it's not working well?

- Changes may need to be made to improve data collection
- Implementation of a data collection plan can involve changes to:
  - Database structure
  - Data output
  - Data management
  - Data flow
  - Data storage

# Changes to improve data collection

- Making changes often requires negotiation with multiple decision makers
  - Multiple priorities for using data
  - Difficulties modifying a database
  - Limited IT resources
- Making changes can be difficult...
  - Don't go it alone
  - Stay focused on reducing data collection burden
  - Remember: an efficient data collection plan will really pay off!

# Examples from the real world

# What if you need help?

# Getting Technical Assistance

- You may need TA at any point in the steps for defining what data you need to collect and how you're going to collect it. Multiple sources exist (HAB, peers, fellow programs...)
- TA from HAB
- TA from other programs
- Data Academy



# Technical Assistance from HAB

- Project officer
- TARGET Center
  - <http://www.careacttarget.org>
- dataCHATT
  - <http://www.datachatt.jsi.com/>
- Ryan White HIV/AIDS Program Data Report TA
  - <http://datasupport.hab.hrsa.gov/>
- CAREWare TA
  - <http://hab.hrsa.gov/careware/>
- National Alliance of State and Territorial AIDS Directors Cooperative Agreement (NASTAD)
  - <http://www.nastad.org/Programs/hivcareandtreatment>
- National Quality Center (NQC)
  - <http://www.nationalqualitycenter.org/>
- HRSA Information Center
  - <http://ask.hrsa.gov/>

# Additional Resources

Talk with other Ryan White grantees and providers:

- When considering a new data collection strategy, or collecting a new type of data, be willing to ask:
  - Have other programs asked about this before?
  - What works?

# Data Academy

- dataCHATT is developing a series of web-based training modules.
- The **Data Academy** will include training modules on data collection, data quality, data reporting and using data.
- We need your feedback to make sure the information is presented effectively.

# Feedback

- Was this content useful?
- Appropriate?
- Did it meet your needs?
- Any suggestions?
- Can we contact you to review future training modules?

# Acknowledgements

- The HIV/AIDS Bureau for support of this Cooperative Agreement
- The 101 Grantees who participated in the Request for Information
- JSI contributing staff (Julie Hook, Kim Watson and the dataCHATT team)
- Positive Outcomes, Inc.

# For more information...

Visit the dataCHATT website:

[www.datachatt.jsi.com](http://www.datachatt.jsi.com)

For copies of today's presentation, contact

us at: [datachatt@jsi.com](mailto:datachatt@jsi.com)