Best Practices in Data Sharing between Ryan White HIV/AIDS Program (RWHAP) Recipients and HIV Surveillance

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NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

Disclosures

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The DISQ Team is comprised of CAI, Abt Associates, and Mission Analytics and is supported by HRSA of HHS as part of a cooperative agreement totaling $4,000,000.00 over five years.

Who are we?

DISQ
Data Integration, Systems & Quality
TECHNICAL ASSISTANCE

A project of CAI in partnership with Abt Associates and Mission Analytics Group

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How can DISQ help?
1. Data Reporting

- All recipients and subrecipients of Ryan White HIV/AIDS Program (RWHAP) funds need to complete at least one annual data report
  - RWHAP Services Report **(RSR)**
  - AIDS Drug Assistance Program (ADAP) Data Report **(ADR)**
  - Ending the HIV Epidemic Initiative **(EHE)** Triannual Report
  - HIV Quality Measures **(HIVQM)** Module
  - AIDS Education & Training Centers **(AETC)** data reports
- RWHAP data are used to:
  - **Inform** Congress, the HIV community, and the public about the status of the HIV epidemic
  - **Monitor** program-related services and outcomes
  - **Analyze** disparities in viral suppression and retention in care
- DISQ offers **annual webinars**, **written resources**, and **on-demand TA** to help agencies prepare required data reports

How can DISQ help?
2. Data Integration

- Data for RWHAP reports can come from many places
- DISQ can help agencies streamline the integration process

How can DISQ help?
3. Data Systems

- Working with new or different data systems can be one of the most challenging parts of managing RWHAP data
- DISQ partners with data system vendors to facilitate communication between HRSA HAB, system vendors, and RWHAP agencies
- DISQ provides peer learning opportunities for users of the same data systems to share challenges and best practices
  - EHR User Groups (e.g., Epic, eClinicalWorks, NextGen, etc.)
  - Communities of Practice (e.g., Integrating Epic and CAREWare)
  - Office Hours (recipients presenting innovative data strategies)

How can DISQ help?
4. Data Quality

- Missing/inaccurate data can distort program outcomes
- Only high-quality data can accurately portray the work RWHAP providers do
- High-quality data can be used improve quality of care, but poor-quality data cannot
- DISQ TA providers can help you identify quality issues in your data and develop strategies to help

Why Share Data between RWHAP and HIV Surveillance?

- Supports required reporting for both programs
  - Improve data completeness
  - Improve data quality
- Supports broader activities and use of data
  - HIV Care Continuum
  - Case finding for HIV surveillance
  - Eligibility determination (confirmed HIV positive) for RWHAP
  - D2C activities for both RWHAP and HIV surveillance
  - Unmet Need estimates

Data Sharing for Data Quality

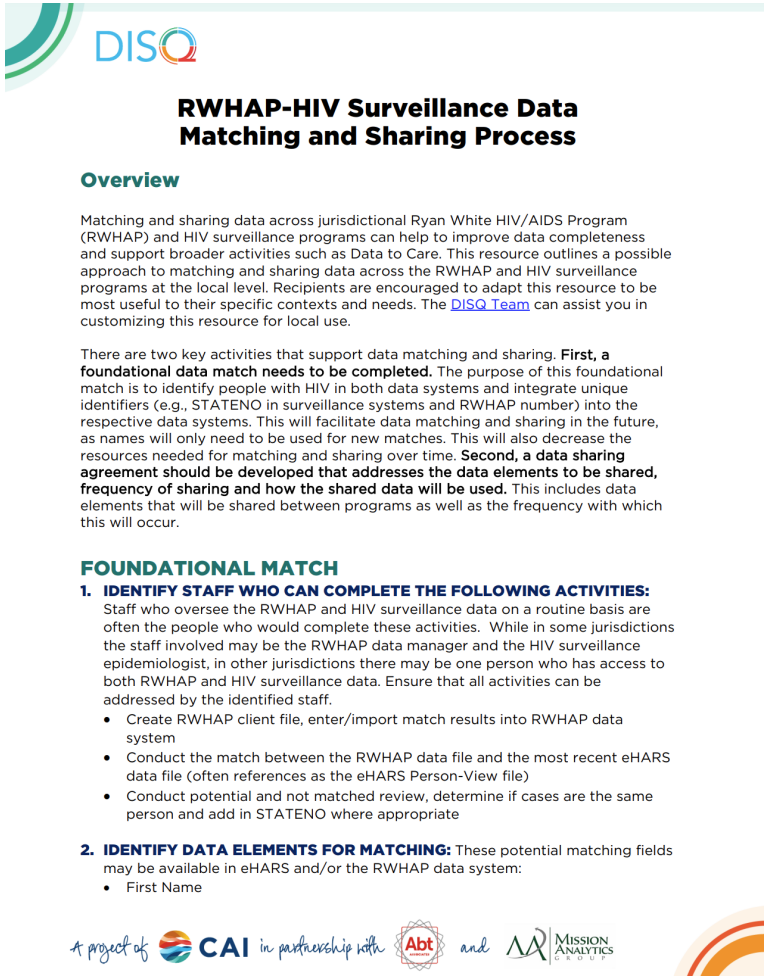
Data that HIV surveillance can share with RWHAP	Data that RWHAP can share with HIV surveillance
• Labs (CD4 and VL)	• Demographics (Race/ethnicity, sex at birth, current gender identity)
• Demographics (Race/ethnicity, sex at birth, current gender identity)	• Intake information (HIV risk factor(s))
• HIV case information (diagnosis date, risk factor(s), HIV/AIDS status)	• Contact information (current address)
• Contact information (most recent known address)	• Current ARV use

Data Sharing for Data To Care

Data that HIV surveillance can share with RWHAP	Data that RWHAP can share with HIV surveillance
• Labs (CD4 and VL)	• Labs (CD4 and VL)
• Current medical provider/facility	• RWHAP provider/services

Data Sharing Considerations

- There is no one-size-fits-all approach to sharing data
- The DISQ Team has outlined a possible process to use



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RWHAP-HIV Surveillance Data Matching and Sharing Process

Overview

Matching and sharing data across jurisdictional Ryan White HIV/AIDS Program (RWHAP) and HIV surveillance programs can help to improve data completeness and support broader activities such as Data to Care. This resource outlines a possible approach to matching and sharing data across the RWHAP and HIV surveillance programs at the local level. Recipients are encouraged to adapt this resource to be most useful to their specific contexts and needs. The DISQ Team can assist you in customizing this resource for local use.

There are two key activities that support data matching and sharing. **First, a foundational data match needs to be completed.** The purpose of this foundational match is to identify people with HIV in both data systems and integrate unique identifiers (e.g., STATENO in surveillance systems and RWHAP number) into the respective data systems. This will facilitate data matching and sharing in the future, as names will only need to be used for new matches. This will also decrease the resources needed for matching and sharing over time. **Second, a data sharing agreement should be developed that addresses the data elements to be shared, frequency of sharing and how the shared data will be used.** This includes data elements that will be shared between programs as well as the frequency with which this will occur.

FOUNDATIONAL MATCH

1. **IDENTIFY STAFF WHO CAN COMPLETE THE FOLLOWING ACTIVITIES:** Staff who oversee the RWHAP and HIV surveillance data on a routine basis are often the people who would complete these activities. While in some jurisdictions the staff involved may be the RWHAP data manager and the HIV surveillance epidemiologist, in other jurisdictions there may be one person who has access to both RWHAP and HIV surveillance data. Ensure that all activities can be addressed by the identified staff.
   - Create RWHAP client file, enter/import match results into RWHAP data system
   - Conduct the match between the RWHAP data file and the most recent eHARS data file (often references as the eHARS Person-View file)
   - Conduct potential and not matched review, determine if cases are the same person and add in STATENO where appropriate

2. **IDENTIFY DATA ELEMENTS FOR MATCHING:** These potential matching fields may be available in eHARS and/or the RWHAP data system:
   - First Name

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Data Sharing Process

- Foundational Match to identify people in both data systems and integrate unique IDs to facilitate future sharing
  - Identify staff who can complete activities
  - Identify data elements for matching
  - Create RWHAP client file for initial match
  - Determine matching algorithm and match data
  - Process matched results and return to RWHAP
  - Integrate STATENO and RWHAP IDs into respective data systems
    - Any IDs can be used as long as they exist in the source data

Data Sharing Process (contd.)

- Data Sharing-uses IDs from foundational match for existing clients
  - Identify data elements to be shared by both programs
    - There are lots of data elements beyond just labs
  - Determine frequency of data sharing; consider:
    - Reporting deadlines
    - Data completeness
    - Amount of time it takes to complete activities
    - Use of data
  - Review/establish rules for shared data

Challenges & Potential Solutions Part 1

Challenges	Solutions
• Confidentiality/privacy concerns	• Engage privacy/legal staff • Align with local public health statute/agency policy • Establish DSA/MOU • Crosstrain staff • Include data sharing in client consents/acknowledgements
• Competing priorities	• Identify a data champion

Challenges & Potential Solutions Part 2

Challenges

- Lack of HIV surveillance resources
- Programmatic hesitancy to share data
- Lack of understanding in how to do the matching

Solutions

- RWHAP can provide funding for staffing
- Crosstrain staff
- Engage leadership/leadership support
- Request DISQ TA

Recipient Panelist #1: Colorado Department of Public Health and Environment

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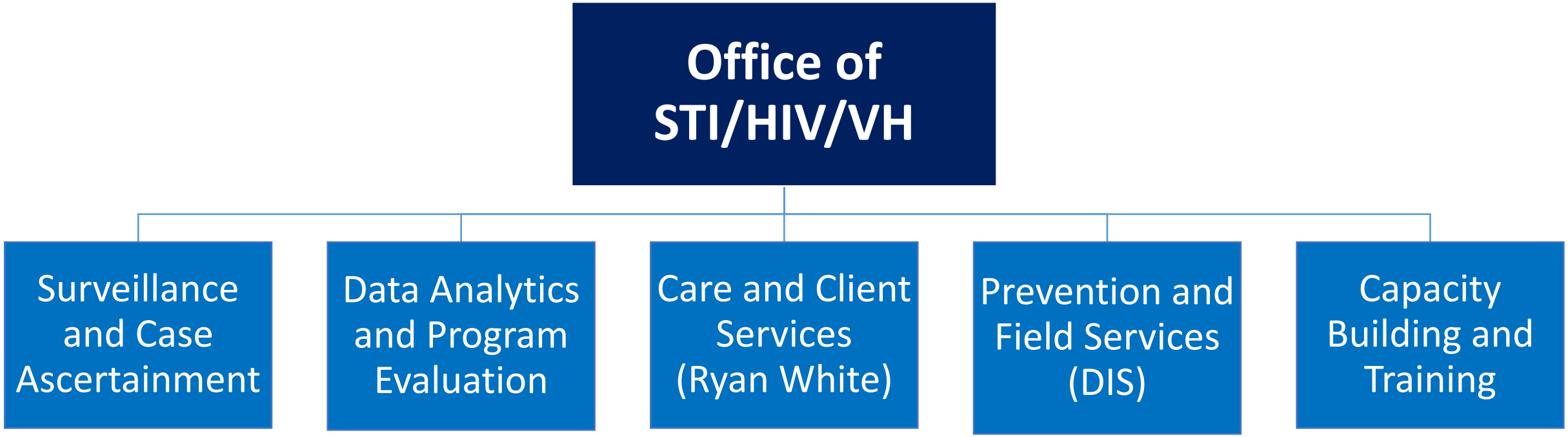
Outline

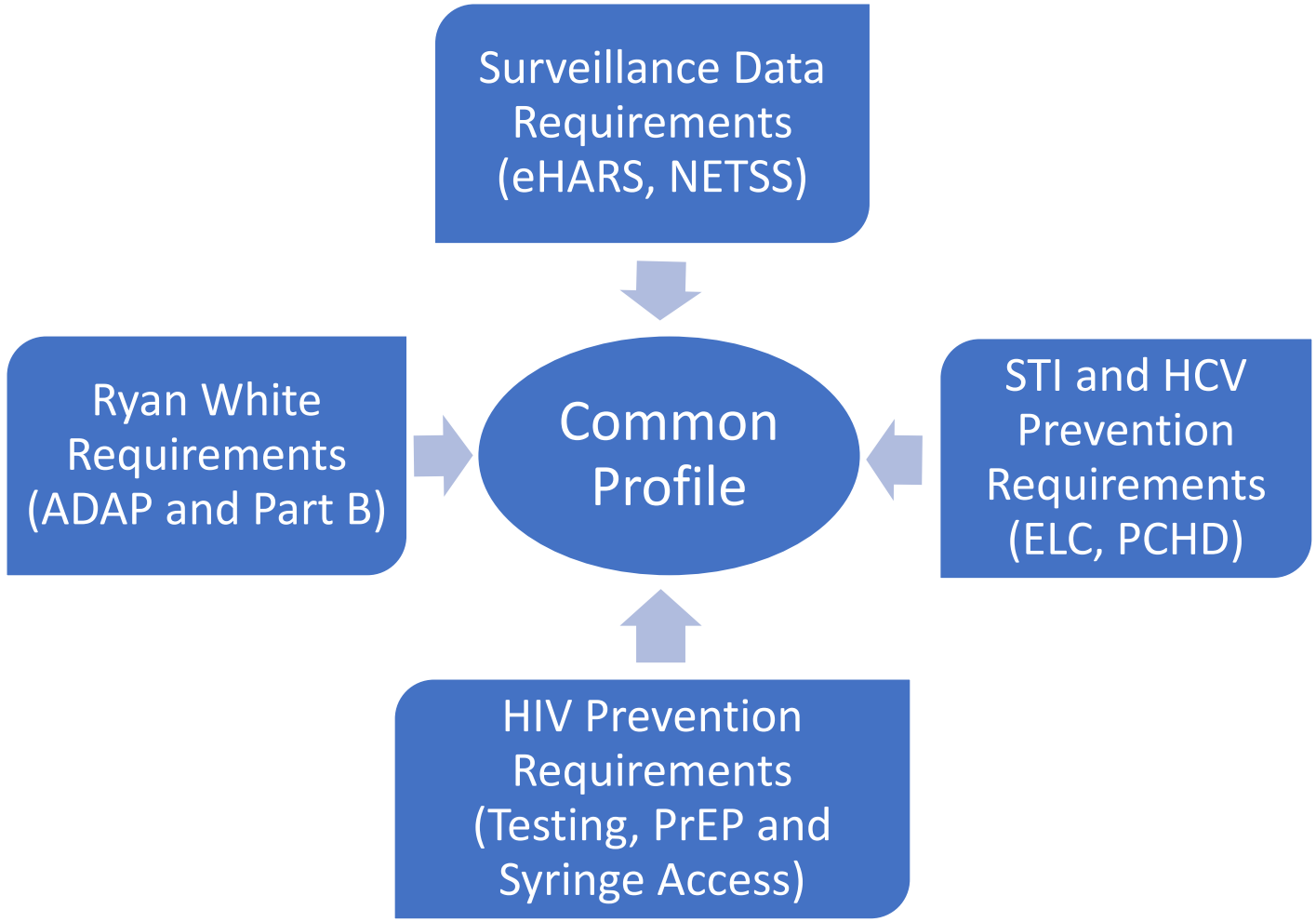
- Background
- Systems Integration
- Lessons Learned

Background

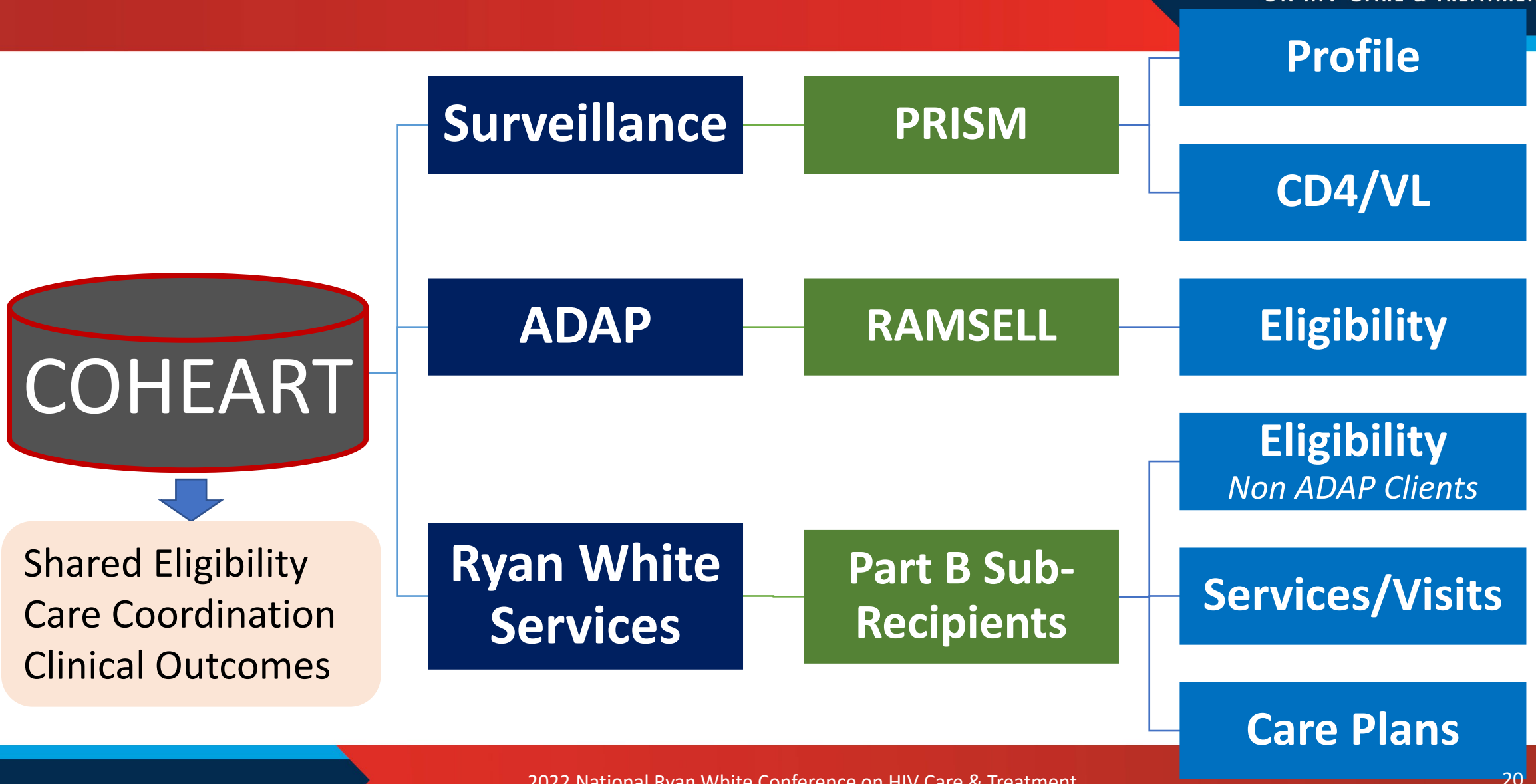

Office of STI/HIV/VH
Surveillance and Case Ascertainment
Data Analytics and Program Evaluation
Care and Client Services (Ryan White)
Prevention and Field Services (DIS)
Capacity Building and Training

Colorado Integration

- **Goal: Create a Common Client Profile**
  - **Track outcomes across the Prevention and Care Continuum**
  - **Improve data-to-action for Case Managers**
  - **Improve data quality and completeness**
  - **Reduce data entry burden**



Colorado Integration (contd.)



Lessons Learned #1

Lesson Learned #1: Have a Process for Record Matching

Reduce duplicate records

- Complex for many reasons
- Names and DOBs can vary over time and from different sources
- Spelling, typos and special characters/spaces
- Various algorithms can be used

Modified URN

- Relatively Unique
- Over 14,000 PLHIV in Colorado
- ~20 have the same URN

Lessons Learned #2

Lesson #2: Have a process to add clients who are enrolled in Ryan White but do not have a surveillance record

Data quality and completeness

- Surveillance and Ryan White

Involve your Case Ascertainment Team / DIS

- Develop a process for older records
- New to state and not yet reported to surveillance
- Mismatch
- Confirm HIV status

Lessons Learned #3

Lesson #3: Determine how you will handle updates/changes to data in the common profile

Involve all staff and stakeholders

- Surveillance
- DIS
- Ryan White Program Staff

Process to update inaccurate or missing data

- Rank your data sources
- Accurate and complete
- Most Recent
- Use audit tables

Thank You and Acknowledgements

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Michigan Public Health Code

- Michigan has a broadly written public health code
- The public health code states surveillance information can be used for two purposes:
  - To care for an individual **OR**
  - To prevent transmission to others
- CAREWare is how we take care of individuals living with HIV
  - Able to share laboratory data in this system

Background of MI Data Sharing

- History of Partnership
  - Longstanding Partnership strengthened by collaboration around projects

Driver of Data Sharing and Collaboration

- Shared sense of responsibility to use public health information and data to improve health outcomes for people living with HIV in Michigan
- Shared appreciation for transparency
- Desire to reduce redundancy at the State, provider, and consumer level
- Bi-weekly CAREWare calls between MDHHS and DHD

Shared Data and Products *(What we do)*

Surveillance program imports labs (CD4 count and viral load) on individuals with a RWHAP service into CAREWare every two weeks

MDHHS Surveillance creates jurisdiction-wide care cascades by subpopulation and Ryan White Parts

MDHHS performs annual match to RWHAP clients and multiple other data systems so programs can get additional coinfection data

MDHHS Surveillance shares an “out of care list” for all individuals with HIV for follow up by Detroit

MDHHS assists DHD in annual analysis of Linkage and Unmet Need

Surveillance partners with DHD to develop new measures, for example Maintenance of Viral Suppression

Detroit shares detailed client demographics and risk factors with the surveillance program

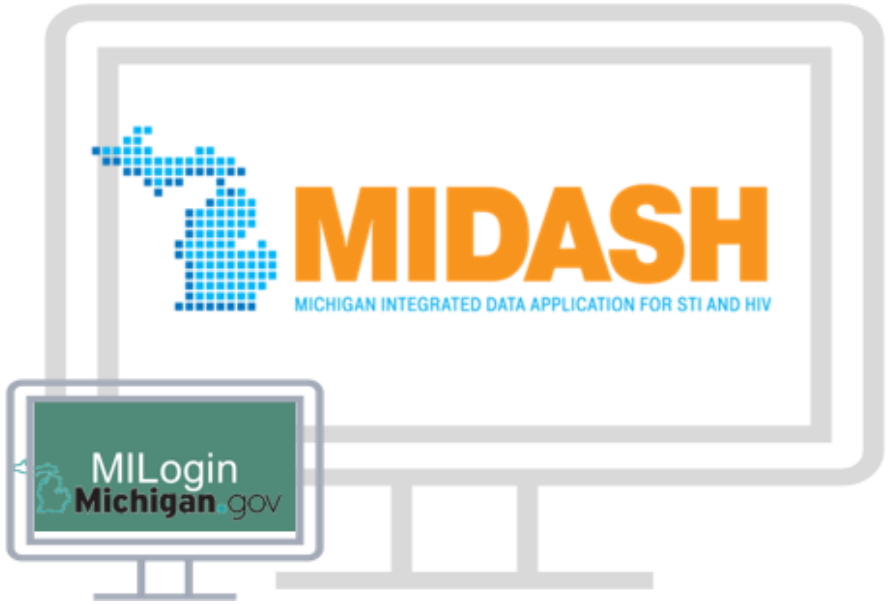
Facilitators *(How we do it)*

- Statewide CAREWare system behind MDHHS firewall; Detroit staff have administrative access, will be moving to MIDASH
- Michigan public health code allows Detroit access to surveillance data for “public good”
- Extensive meetings with stakeholders to discuss role of surveillance data and data sharing across agencies
- Epidemiologist within surveillance program are highly capable and willing to conduct analyses for Detroit

MIDASH

A NEW, INTEGRATED & COMPREHENSIVE DATA SYSTEM

Combines the functionality of 6 systems into 1 that everyone can access securely



- STI SURVEILLANCE DATA (MDSS)
- PATIENT RECORDS (CareWare)
- LAB RESULTS (LMS)
- HIV SURVEILLANCE DATA (eHARS)
- TESTING AND PARTNER SERVICES (Aphirm)
- DRUG ASSISTANCE PROGRAM INFORMATION (MIDAP)

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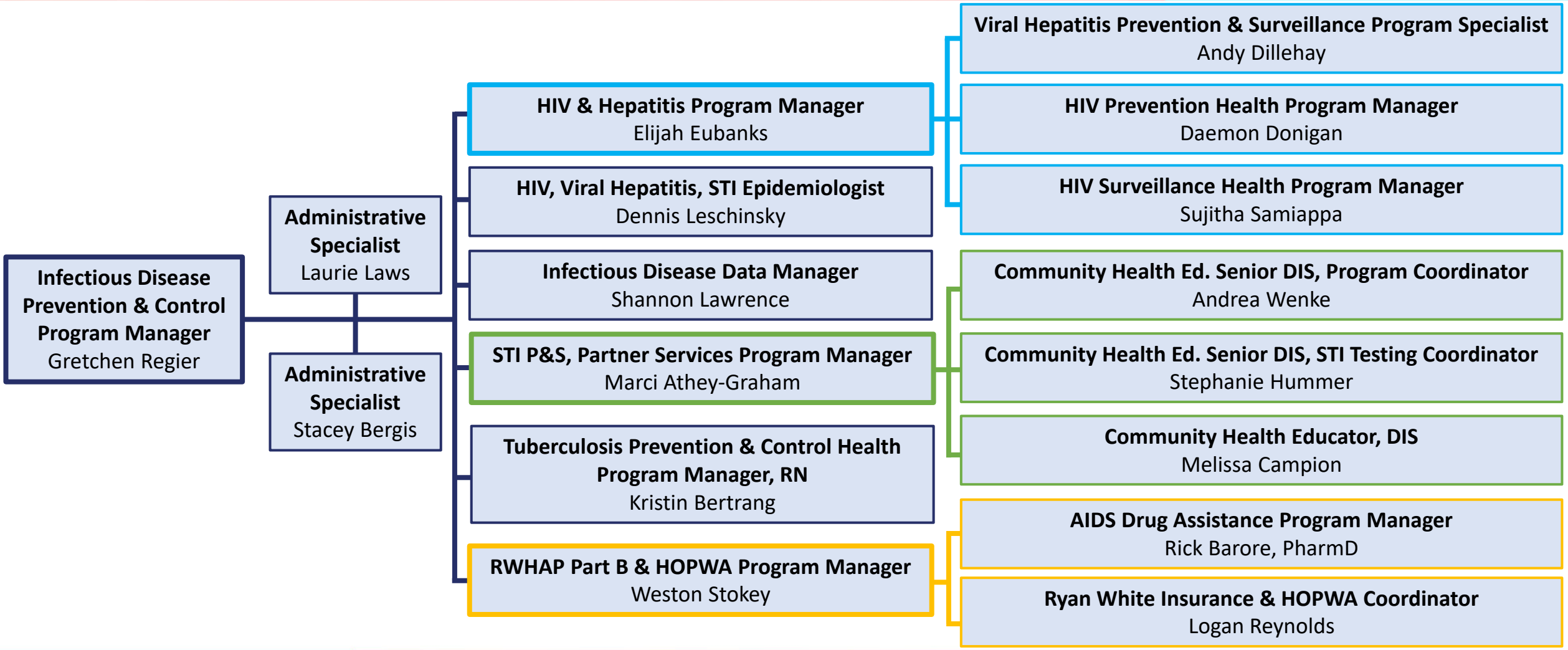
Overview of NE Ryan White Part B

- 2,287 people diagnosed and living with Nebraska as of 12/31/2021; 1,198 received RWHAP-funded services in calendar year 2020
- NDHHS receives Part B funding
  - Receive Formula and ADAP funding
- No Part A in the state
- Part B Program is located in the same unit as other Infection Disease programs
  - Historically was in a separate unit

Organization of NDHHS



Data Investment As Organizational Priority

- Increased investment in data
- Buy-in support from DHHS leadership
  - Held meetings regarding data sharing and how all programs would benefit from data collaboration
- Buy-in support from across multiple programs

Why Implement Data Sharing?

- HRSA reporting
- CDC reporting
- Data to Care
- Linkage to Care
- Eligibility Determination

Historical Challenges in Data Sharing

- Part B was operating as a siloed program in DHHS
  - Limited relationships/collaborations
- Past efforts to share data had been unsuccessful
- Awareness of the need to improve data quality
  - Part B was receiving self-reported data from the consumers and subrecipients on a variable basis
- Not sure where to start
  - Part B staff reached out to the DISQ team for TA

How We Got Started

- DISQ Team provided TA to support the development of a data sharing process between RWHAP and HIV surveillance
- Part B and HIV Surveillance staff had joint meetings with DISQ team regarding data quality improvement
- Utilized DISQ materials to start process

The TA was helpful, but there was a lot that we had to do to make this a reality!

Process to Share Data

- Additional activities –
  - Upper administration prioritized process
  - Part B Manager took the lead (data champion)
  - Scheduled internal meetings to discuss barriers
  - Met with privacy person
  - Implemented a new data management system

Process to Share Data (contd.)

- Ongoing activities – (to ensure data sharing)
  - Work with HIV Surveillance to pull quarterly reports
  - Weekly meetings with program managers
  - Data manager that is unit specific (i.e., Infectious Disease Unit Data Manager)
  - Leveraging all available resources
  - Crosschecking SAS code – validating SAS code to catch errors

Recommendations

- Get everyone on same page internally (upper administration and other programs)
  - Necessary step to detail the need prior to presenting to Legal Department, so can show why it is a need (how each program can benefit)
  - Highly recommend TA because it helped figure this out and steps to take/process of implementation
- RWHAP and HIV Surveillance meet together with TA provider (if used)
  - Collaboration gets lost if not doing together
  - Helped build relationships and close gaps internally
  - Met biweekly internally for post-TA debriefing
- Document everything
  - Together, drafted a detailed policy and procedure for approval
  - On-going process to show the benefits of data collaboration

Contact DISQ

- DISQ can help you think through your **goals**, **data needed**, and **processes**
- Contact us at data.ta@caiglobal.org and/or chat in your contact info

Questions?

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Thank you!

You can contact the DISQ Team at **data.ta@caiglobal.org**.

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