

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

- Last Name
- Date of Birth (mm/dd/yyyy)
- Sex at Birth (Male, Female)
- Current Gender (Male, Female, Transgender MTF, Transgender FTM, Transgender Other)
- Social Security Number (SSN)
- UCI (Ryan White Identifier) - first and third character of the first and last name, full date of birth and gender code (1=Male, 2=Female, 3=Transgender, 9=Unknown)
- eUCI (encrypted UCI)

3. CREATE RWHAP CLIENT FILE FOR INITIAL MATCH: Create a file from the RWHAP data system. Be sure to include RWHAP clients who are currently active (eligible for RWHAP services) and those who have been recently active (a two-year period is common, but this can be determined at the local level). Be sure that the file includes all data elements that you are using from Step 2.

4. DETERMINE MATCHING ALGORITHM AND MATCH RWHAP CLIENT FILE TO eHARS: Complete a match between the RWHAP data file and the most recent eHARS Person-View file. Please note that what is listed below is an example; the approach will need to be finalized before matching can occur and should be based on available staff resources and analytic skills as well as the data fields available. A record of matches/non-matches for each match review conducted should be kept. This will support an evaluation of the matching approach and assist with refinement of the algorithm for the future.

- Exact Matches
 - Example data elements to match on:
 - First Name, Last Name, DOB, Sex at Birth, and full SSN
 - First Name, Last Name, DOB, Sex at Birth, partial SSN
 - First Name, Last Name, DOB, full SSN
 - First Name, Last Name, DOB, partial SSN
 - First Name, Last Name, DOB, Sex at Birth
- Potential Matches: These cases will require manual review to confirm a match and should be the priority cases to validate.
 - Example data elements to match on:
 - UCI (create UCI in eHARS)
 - Last Name, DOB, Sex at Birth
- Not Matched: These cases will also require manual review to resolve.
 - Cases that do not match in either Exact or Potential

5. PROCESS MATCHED RESULTS AND RETURN TO RWHAP: The results of matching from Step 4 have additional steps based on the type of match. In some cases, the file is ready to go back to the RWHAP. In others, HIV surveillance staff

may need to conduct additional reviews to determine if the person is indeed a match.

- Exact Matches
 - Provide an Exact Match file for the RWHAP with the matched clients. The file should include STATENO (a unique identifier in eHARS) to facilitate future matching activities. This can be done manually or through an import process.
- Potential Matches
 - Provide a Potential Match file that includes the clients and all data elements listed in Step 2 for review to determine if the cases are the same person. This may include reviewing the Alias table in eHARS and other documentation available in both eHARS and the RWHAP data system. Enter STATENO in the file where appropriate.
 - Provide a file to the RWHAP with the list of successful Potential Matches that contains the same information provided for the Exact Match file.
- Not Matched
 - The Not Matched cases should be reviewed manually in a similar way to the Potential Matches as time permits. Updates should be provided to the RWHAP and HIV surveillance programs in a similar way to the Exact Match file. Essentially, every RWHAP client should have a result from the match.
 - The Not Matched cases may result in case finding activities for the HIV surveillance program. It may be useful to develop a process for this if one does not already exist.

6. INTEGRATE STATENO AND RWHAP IDENTIFIER(S) INTO RESPECTIVE DATA SYSTEMS:

The final step in the foundational match is to integrate the results of the foundational match into the respective data systems. This means that for the RWHAP data system, any STATENOs for matches will be added to the data system. For eHARS, the RWHAP identifier should also be added.

- By adding a unique identifier into both the RWHAP and HIV surveillance data systems, future data sharing and matching can be simplified. Specifically, programs could use a client's unique code for matching rather than their name and the manual review process outlined above would not be necessary. Please note that individuals who are new to the RWHAP data system would still need to be matched by name.

DATA SHARING

7. IDENTIFY DATA ELEMENTS TO BE SHARED: In determining which data elements will be shared, consider uses for data not only for data completeness but to inform other activities, such as Data to Care. These data elements will also need to be integrated into any written agreements (data use agreement, memorandum of understanding) between programs. Possible data elements that would be helpful to share are outlined in the table below.

Data that HIV surveillance can provide RWHAP	Data that RWHAP can provide HIV surveillance
<ul style="list-style-type: none"> • Data quality <ul style="list-style-type: none"> ○ HIV/AIDS Status ○ CD4 counts/dates ○ Viral loads/dates ○ Race/Ethnicity (but not subgroups) ○ Sex at birth ○ Current gender identity ○ HIV Diagnosis date ○ HIV Risk Factor ○ Possibly more current address ○ SSN ○ Date of death 	<ul style="list-style-type: none"> • Data quality <ul style="list-style-type: none"> ○ Most recent known address ○ Race/Ethnicity (but not subgroups) ○ Sex at birth ○ Current gender identity ○ SSN ○ HIV Risk Factor ○ Current ARV medication(s) <ul style="list-style-type: none"> ▪ ARV use (Yes/No) ▪ ARV name (exportable list?) ▪ Current use date (MM/DD/YYYY) ▪ First use date (MM/DD/YYYY)
<ul style="list-style-type: none"> • Data to Care activities <ul style="list-style-type: none"> ○ Recent labs or current medical provider can assist RWHAP in determining if clients are truly lost to care 	<ul style="list-style-type: none"> • Data to Care activities <ul style="list-style-type: none"> ○ Service dates or recent labs can help address missing lab data in HIV surveillance to more accurately determine if a client is out of care.
	<ul style="list-style-type: none"> • Case finding <ul style="list-style-type: none"> ○ Given that surveillance data includes all people living with diagnosed HIV infection in the state/territory, RWHAP can assist in identify new diagnosis or people who have moved into the state. This will help ensure the most accurate surveillance data.

8. DETERMINE FREQUENCY OF DATA SHARING: There are some important considerations in determining the frequency of data sharing. These include:

- Reporting deadlines - Consider when reports are due to funders
- Data completeness -For both RWHAP and HIV surveillance, there are guidelines for when and how data are entered or imported into data systems. For example, HIV surveillance may have specific timeframes for when they

process lab data. RWHAP may have a specific timeframe or approach for importing a file from a provider/vendor. Aligning data sharing with existing guidelines helps ensure that each respective data system is as complete as possible prior to sharing and that the sharing of data has the optimal benefit.

- Amount of time it takes to complete activities - Each time data are shared, each program will need to set aside time to process the data. In addition, any new clients will require the initial matching process to occur. It is important to determine available resources when considering frequency. While monthly may seem ideal, quarterly or even semiannual may be adequate.
- Use of data - How you are using the data should help inform sharing. For example, if you are using the data sharing to help prepare a not in care (NIC list), you want to align the sharing with the frequency of the NIC list being generated.

9. RULES FOR USING SHARED DATA: Shared data may be integrated into the respective data systems or may be used for informational purposes only. If data will be integrated, it is important to determine if data will only be used to improve data completeness or if data will be used regardless in cases where the accuracy of data from one program is believed to be better than another. It is also important to discuss if there are any legal or privacy concerns in sharing any data, particularly for the RWHAP where data elements integrated into the data system are usually viewable by RWHAP providers.

Need help in developing your own data matching and sharing process?
Contact the DISQ Team at data.ta@caiglobal.org