



## **NY EMA Ryan White Part A Data Collection Workgroup Recommendations**

**Approved by the HIV Health and Human Services Planning Council, March 30, 2023**

### **Background**

The NY EMA Ryan White Part A program has had numerous Ryan White Part A program data collection challenges over the years, including but not limited to: 1) barriers to provider data access, 2) inefficient data entry including double data entry and inefficient data entry processes, 3) inability to import or export data to/from other data bases, and 4) significant data collection burden on consumers and providers. The NY HIV Health and Human Services Planning Council initiated a time-limited workgroup to develop recommendations to share with the Recipient, colleagues in NYC DOHMH, NYSDOH AIDS Institute, and HRSA to improve Ryan White Part A data collection through improved database technology that will: increase user access to data for quality improvement, reduce required data collection, and increase capacity to share information across programs so that consumer and provider data collection burden will be reduced. Recommendations in this report are for the Ryan White Part A NY EMA, for the NYC Ending the HIV Epidemic HRSA funded program, Project Prosper, these recommendations are shared in an advisory capacity.

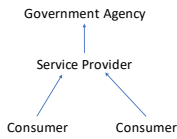
In the workgroup's initial meeting the current state of dataflow was described as inequitable with duplicative or excessive data collection, lack of recognition or accountability to consumers, and no mechanism to assess the downside of data collection (see figure A). The committee reviewed and agreed upon a schema to develop an equitable data flow which considers the ways that data can benefit all stakeholders, maintains accountability to consumers, reduces burden on consumers, and acknowledges "informal" flow of data or information between consumers (Figure B).<sup>1</sup>

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<sup>1</sup> It should be noted that the Recipient is not in complete agreement with this schema since there are multiple means (within the data system and outside the data system but pulling from it) by which reports are made available to providers who submit via eSHARE. There is certainly a 2-way flow between government agency and service provider currently, though of course there are additional reports that can and should be made. A number of them have specifications and implementation of these reports has been requested.

**Figure A**

Inequitable Data Flow (Current State)

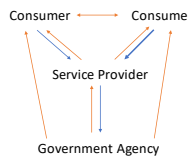


**Problems:**

- Duplicative or excessive data collection
- No formal recognition of data flow or accountability to consumer
- No mechanism to assess downside of data collection

**Figure B**

Equitable Data Flow



**Benefits:**

- Considers the ways that data can benefit all stakeholders
- Maintains accountability to consumers
- Acknowledges “informal” flow of data or information between consumers

From February to November 2022 the workgroup received a series of reports and presentations based on content pertinent to developing informed recommendations for improved, efficient, and equitable data collection. Below is a list of those presentations and a summary of their content.

**Workgroup Summary of Presentations**

**February 2022**

Presentation and Discussion on Data Equity Principles and Values - Paul Carr and Finn Schubert workgroup Co-Chairs

This presentation set the tone for the workgroup with the premise that all data collection should in some way be linked to enhancing the services provided. These links can be direct (ex: assess client needs and provide appropriate services), indirect (ex: use surveillance data to set service priorities), or by requirement only (ex: we need to provide the data to stay funded to provide services). If data cannot be justified by one of the links, there may be good reason for not collecting that data. Data collection burden influences consumer experience and the provision of services by:

- Creating a competing demand between data collection and service-related needs for people with HIV (PWH).
- Creating an erosion of trust between consumers and agency staff through required asking of repeated, stigmatizing questions, which inhibit a trusting relationship.
- Missed opportunities for higher-impact activities considering data collection burden

**March 2022**

Data Security and Privacy/ CARES Act Interoperability David Lee, MPH, MBA  
Executive Director of Information Strategy, NYC DOHMH

The Federal Government published a final rule on 5/1/2020 on the 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Ihealth IT Certification program. The rule addresses use and exchange of medical information. Physicians must respond and release patients’ medical records unless an appropriate exception can be identified and used. Exceptions include: preventing harm, privacy, security, infeasibility, and Health IT performance. Unlike HIPAA, information-blocking

regulations are directive and require actors to provide access, exchange, and use of EHI for nearly all requests. The rule does keep intact local and state rules regarding information exchange (e.g. HIV, mental health, and substance use).

#### What is Database Architecture? Modern Database Architecture Explained:

<https://youtu.be/64TpELBlqAk>

The above video was shared with the workgroup to improve the understanding of data architecture so that it could inform the development of recommendations.

#### **May 2022**

Summary of Past eSHARE User Surveys - Robert Thomas, eSHARE Operations Manager, HIV Programs, BHHS Administration, DOHMH

Presentation included a summary of past eSHARE User surveys, including reported issues and a summary of efforts made to improve eSHARE based on this feedback followed by a list of ongoing work to improve data collection based on user survey feedback.

Documented eSHARE improvements include:

- Performance tuning (search optimization, load balancing, auto switching)
- Dedicated server (Separated eSHARE from the e-mail database)
- Session time-out adjustment
- Additional reports created
  - eSHARE Admin Report
  - HIV Clinical Reports
  - Contract Profile Report
- Architectural optimization
  - Network Identifications
  - Virtual space allocation
- Primary care Status Measures data upload
- Single sign-on via New York Client Identification (NYC.ID)
  - For information on the benefits of NYC. Navigate to this link [NYC.ID](#)
- Created an individual services form that will allow a user to select multiple services at one time for a patient/client

Planned improvements for eSHARE include:

- Duplicate client report
- Development of a more robust search engine' to prevent the creation of duplicate client profiles/records. Duplicate client prevention
- Client merge
- Raw data extracts
- Client Demographics Report implementation
- Forms engine change
- Enhanced upload capabilities
- Multi-service individual services form expansion to additional programs
- Hire a User Experience designer and User Interface developer to update eSHARE. The User Experience designer examines the user friendliness of an application to make it more intuitive

and improve the ability to flow from one module to another. The user interface developer codes the changes that bring the findings of the User Experience Designer to life.

## **July 2022**

Ryan White Part A Intake Assessment and Reassessment Data Collection in the NY EMA - Mary Irvine, DrPH, MPH, Director and Jacinthe Thomas, Manager of Informatics both of the Research and Evaluation Unit of the HIV Care and Treatment Program, NYC DOHMH

Presentation of all data elements required for at least one Ryan White Part A service category on the intake and/or reassessment and the rationale for collection of that data (consumer, QM, evaluation, federal data collection requirement, or other requirement rationale). Through this analysis the following fields were identified as not having a current rationale for ongoing data collection:

- Date of client's first known visit to this agency, for any service (previously required for RSR)
- If AIDS, AIDS diagnosis date (previously required for RSR)
- Hospitalizations for year prior to program enrollment: counts and start date (previously included as a Comprehensive Strategic Plan indicator)
- ED visits for year prior to program enrollment: counts and start date (previously included as a Comprehensive Strategic Plan indicator)
- In the past 6 months, have you had sex with anyone? (anal or vaginal sex)
- In the past 6 months, have you had any HIV-negative partners or partners whose HIV status you did not know?
- In the past 6 months, have you had sex in exchange for drugs, money, food, or shelter?
- Other assessment used?
- Type of other assessment used

## **September 2022**

God's Love We Deliver Comments on eSHARE Reconsideration for HIV Planning Council Data Workgroup

Dorella Walters, Sr. Director of Business Development & Community Partnerships

Julie Van Dore, Senior Director of Technology and Information Systems

Alexandra Roem, Program Operations Coordinator

The Presentation highlighted the following issues for data collection:

- Double Data Entry – consumes valuable staff time and increases the chances of data entry error. There is no crosswalk or interoperable solution.
- The forms could be customized for FNS: There are several sections on the eSHARE assessment form that we do not ask our clients. Maybe those sections can be removed. Ex: Page 5 of 9 (General Health and wellbeing questions).<sup>2</sup>
- The system is slow: Uploading any information to eSHARE at the end of every month can take up to 2 days to complete. Reopening clients in eSHARE requires 2 working days because one must wait 24 hours after reopening a client to add the services.
- Inability to Run Reports - Running and receiving accurate reports from eSHARE continues to be a problem due to the volume of data.

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<sup>2</sup> These questions are confirmed as optional by the Care and Treatment Research and Evaluation Program

- Due to the volume of meal data, once the meals have been uploaded into eSHARE, organizations are no longer able to run eSHARE Individual Service Reports for that time period (monthly or weekly, both fail). Individual service reports must be run just prior to the meal upload and are not available afterwards.
- Monthly Master Itemization Report (MIR): The monthly MIR is consistently missing tab 6, which contains the full complement of services and highlights problem services. Without this tab, it is impossible to check our work in eSHARE (unless received individually by contract managers). Burden on Clients and Staff – If PLWH are receiving multiple services from the EMA, they are answering similar, often stigmatizing questions, and submitting similar documentation to all Ryan White providers. To reduce the burden, eSHARE should provide back-end access to documentation and intake interview questions – with client permission – to reduce the burden on staff, but more specifically, to eliminate barriers to service for clients.
- Shared Documentation of Eligibility - A tremendous amount of effort goes into collecting proof from clients. It would be ideal if there was a way to share information and proof(s) among care providers.
- Barriers: During the pandemic, we continue to experience issues on a day-to-day basis:
  - Labs: Clients report less frequent HIV RNA and CD4 testing and are unable to submit new lab results every six months. This situation is consistent with updates to HIV clinical guidelines for virologic and immunologic monitoring, especially for patients who are consistently virally suppressed.

Provider Experience with eSHARE Gregg Bruckno, Research Foundation, SUNY Downstate

Presentation included numerous challenges with collecting data including inconsistent data collection, downtime in updates and wait times to access data, requests for incorrect or outdated data, duplicate data entry, excessive data collection, multiple opportunities for inaccurate data entry, lack of access to data at the provider level.

**October 2022**

Data collection importance from a Federal Perspective - Tracy Matthews, CAPT, Acting Director, Division of Policy and Data, HIV/AIDS Bureau, Shelita Merchant, Branch Chief, Data Management and Analysis Branch, and Kwasi Apraku-Gyau (JK), Management Analyst Division of Policy and Data

Presentation included a rationale for Ryan White Services Report (RSR) data collection, including:

1. Necessity for identifying new clients
2. 2009 Ryan White HIV/AIDS Program Legislation requirement
3. Necessity to assess RWHAP performance as required for HRSA HAB’s programmatic measures
4. Necessity to track enrollment or vital status over the course of the reporting period
5. Informs the denominator of other items
6. Used to identify important population subgroups

Data required for the RSR include:

| Services | Demographics Reported |
|----------|-----------------------|
|----------|-----------------------|

|   |  |
|---|--|
| All Services  | <ul style="list-style-type: none"> <li>• Year of Birth</li> <li>• Ethnicity</li> <li>• Race</li> <li>• Hispanic Subgroup</li> <li>• Asian Subgroup</li> <li>• NHPI Subgroup</li> <li>• Gender</li> <li>• Sex at Birth</li> <li>• New Client</li> </ul>   |
| All core medical, non-medical case management (NMCM), Ending the HIV Epidemic (EHE)             | <ul style="list-style-type: none"> <li>• Health Care Coverage</li> <li>• Received Service in previous year (if not new)</li> </ul>   |
| Outpatient ambulatory health services (OAHS), medical case management (MCM), NMCM, Housing, EHE | <ul style="list-style-type: none"> <li>• Housing Status</li> <li>• Housing status collection date</li> </ul>   |
| OAHS, MCM, NMCM, EHE  | <ul style="list-style-type: none"> <li>• Federal Poverty Level</li> <li>• HIV/AIDS Status</li> <li>• Vital Status</li> <li>• HIV Diagnosis Year</li> <li>• Client HIV Risk Factor</li> </ul>   |
| Outpatient Ambulatory Health Services (OAHS)  | <ul style="list-style-type: none"> <li>• First Outpatient/Ambulatory Care Visit Date</li> <li>• Outpatient Ambulatory Care Visits</li> <li>• CD4 Counts and Dates</li> <li>• Viral Load Counts and Dates</li> <li>• Prescribed ART</li> <li>• Syphilis screening</li> <li>• Pregnant</li> <li>• Dates of First Positive HIV Test*</li> <li>• Date of OAHS visit after first positive test</li> </ul> |

The Workgroup had the following questions for HRSA staff. Responses are pending:

1. The RSR will only allow one service per service category to be reported in a day. Is there any possibility to change this limitation?
2. The HRSA HAB policy which lifted the 6-month recertification requirement to reduce barriers to care is applauded however are there any unforeseen effects on data collection as a result of the lifting of this requirement? Are there any data collection requirements that can or should be changed?
3. Are there any jurisdictions that have successfully reduced provider and consumer data collection burden through their data collection system? If yes, which jurisdictions and what data collection system did they use?
4. HRSA requires collection of AIDS diagnosis (and date of diagnosis), would it be possible to better align with CDC’s definitions of HIV disease to update our data collection?

5. In regard to the collection of Race/Ethnicity Data, what changes can be made to better collect this data given multiple identities and understandings in regard to race and ethnicity? (see OMB listening session link below).

## **November 2022**

Social Determinants of Health Networks and Health Equity Regional Organizations in the NYS 1115 Medicaid Waiver - Amy Shah Director, Health Systems Planning, Equitable Health Systems, and Samantha DeLeon, Executive Director, Prog Eval & Planning, Equitable Health Systems, NYCDOHMH

An 1115 Medicaid waiver amendment has been submitted by the NYS Department of Health which would utilize an array of multi-faceted and interconnected initiatives in order to fundamentally change the way the Medicaid program integrates and pays for social, physical health, and behavioral health care in New York State.

The Medicaid waiver, if approved would also lay the groundwork for reducing long standing racial, disability-related, and socioeconomic health disparities, increase health equity through measurable improvement of clinical quality and outcomes. The waiver also includes plans for an interoperable services-based database.

NYS and Federal Laws and Policies that Govern Data Sharing Across Provider Networks - Nicholas Elcock, Executive Agency Counsel/Chief Privacy Officer, Legal Affairs, NYC DOHMH

Presentation summarized City, State, and Federal policies and rules governing Ryan White Part A data collection. Specific permissions are required for sharing HIV-related information.

- Consent must be in writing.
- Consent must not be a general release of medical information.
- Consent must specifically state that confidential HIV information will be disclosed.
- Consent must be signed by the protected individual or a person who is authorized to act on behalf of the protected individual.
- All written disclosures of confidential HIV information must be accompanied by a statement prohibiting redisclosure except for disclosures to the protected individual, for treatment, or insurance purposes.
- The statement must include the following language or substantially similar language:
- “This information has been disclosed to you from confidential records which are protected by State law. State law prohibits you from making any further disclosure of this information without the specific written consent of the person to whom it pertains, or as otherwise permitted by law. Any unauthorized further disclosure in violation of State law may result in a fine or jail sentence or both. A general authorization for the release of medical or other information is not, except in limited circumstances, sufficient authorization for further disclosure. Disclosure of confidential HIV information that occurs as the result of a general authorization for the release of medical or other information will be in violation of the State law and may result in a fine or a jail sentence or both.” (10 NYCRR 63.5)

HIV related disclosures allowed without consent (NY Pub Health Law 2782), include:

- A provider of health or social services may possess HIV information relating to individuals who are recipients of the service, and a federal, state or local government agency supervises or monitors the provider or administers the program under which the service is provided.
- HIV information relating to a recipient of such service may be disclosed to an authorized employee or agent of such provider or government agency, when reasonably necessary for such supervision, monitoring, administration, or provision of such service.
- To a health care provider for the purpose of treatment of the individual.
- To a Federal, State, or local health officer when such disclosure is mandated by Federal or State law, including reporting and contact notification.
- To Insurers for the purposes of health care reimbursement.
- To qualified researchers for medical research purposes upon approval by a human research review committee or an institutional review board.
- To any person to whom disclosure is ordered by a court of competent jurisdiction.

Mental Health Information is confidential and may not be disclosed without patient consent, unless an exception is met under MHL 33.13 (such as to prevent imminent serious harm to a person, and to locate missing persons).

The information protected from disclosures under MHL 33.13 includes information that identifies patients or clients of mental health service providers, clinical records or clinical information tending to identify patients or clients, and records and other mental health information.

- Consent can be oral or written.
- Patient or client may consent.
- Someone authorized to act on patient or client's behalf may consent.
- Disclosure must be to persons or entities that have a demonstrable need for the information.
- Disclosure must not be detrimental to the patient or client or another person.

Substance abuse information is confidential and may not be disclosed except where the patient has given written consent, or the patient has a medical emergency, or other limited purposes (audit and evaluation). The limitations on disclosure of substance abuse information applies to organizations (such as DOHMH) that receives the information from a substance abuse program and the program notifies the organization that the information is protected by federal law.

A written consent may be paper or electronic and must include:

- (1) The name of the patient.
- (2) The specific name of general designation of the substance abuse program or entity that will make disclosure.
- (3) An explicit description of the substance abuse information that will be disclosed.
- (4) The name of the entity that will receive the information.
- (5) The purpose of the disclosure. The disclosure must be limited to that information which is necessary to carry out the stated purpose.



- (6) A statement that the consent is subject to revocation at any time except to the extent that the substance abuse program or recipient of the information has already acted in reliance on it.
- (7) The date, event, or condition upon which the consent will expire if not revoked before.
- (8) The signature of the patient or of an individual authorized to give consent.
- (9) The date on which the consent is signed.

## Workgroup Recommendations:

### **Recommendations for Short-term Implementation**

1. As suggested by the Care and Treatment Program Research and Evaluation Unit staff, implement the following changes to eSHARE intake data collection by removing:
  - a) *If AIDS, AIDS diagnosis date*
  - b) *Hospitalizations for year prior to program enrollment: counts and start date*
  - c) *ED visits for year prior to program enrollment: counts and start date*
  - d) *In the past 6 months, have you had sex with anyone? (anal or vaginal sex)*
  - e) *In the past 6 months, have you had any HIV-negative partners or partners whose HIV status you did not know?*
  - f) *In the past 6 months, have you had sex in exchange for drugs, money, food, or shelter?*
  - g) *Other assessment used?*
  - h) *Type of other assessment used*
2. With the exception of Outpatient Ambulatory Care, eliminate requirement for collection of laboratory test data as part of the Primary Care Status Measures (PCSMs);
  - a) In lieu of laboratory test data collection, use surveillance data to report back to programs for quality improvement needs and line level reports for those out of care or with unsuppressed viral load.
  - b) Maintain data collection for adherence and ART regimen type (accounting for long-acting ART options as well as conventional ART regimens).
3. Increased coordination between Recipient and Planning Council to ensure agreement on data collection needs and data reporting for the Planning Council.
4. Request that the Recipient work with eSHARE administration or a future information system to develop routine service category data reports to inform the community planning process.
5. Request that the Recipient inform Council of any additional data collection requirements communicated to Ryan White Part A funded programs

### **Recommendations for Longer Term, Implementation to Begin Immediately**

6. Ryan White Part A Program consumers shall have access to any of their data entered into eSHARE in a reasonable timeframe. Such information shall include a list of staff who have access to their data.
7. Develop a database that is interoperable for data collection needs at the agency level which accommodates multiple funders, provision of services, billing, quality management, and quality assurance.
8. Database should be shared or interoperable between NYS AI and the NYC DOHMH to reduce data entry and data management burden for agencies with multiple contracts from various funders.
9. Strongly encourage the Recipient to implement the sharing of intake, eligibility, and demographic data between providers to reduce barriers to services for consumers and reduction of data collection burden for providers and consumers. Include in this effort checks and balances to ensure data is accurately shared with legal permission.
10. Ensure organizations have access to their own data for performance measuring, quality assurance, and quality management.
11. Given the NYS DOH 1115 Medicaid waiver amendment's inclusion of an interoperable services-based database, the Council and Ryan White Part A data collection efforts should be aligned with Medicaid data collection to increase interoperability, reduce redundancy, and burden. This alignment should not impede progress in implementing the other recommendations in this report.

### **Acknowledgements**

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