



Data Sharing Agreement Template

User Guide

August 2017

Overview

Clients participating in the Ryan White HIV/AIDS Program (RWHAP) benefit from coordination of HIV care, including data sharing across providers. Data sharing is the practice of making data collected by one provider/entity available to others within a specific set of parameters. With an intricate network of services offered through the RWHAP, clients accessing services across multiple payors (e.g., RWHAP, Medicaid, private insurance), and the increased availability of healthcare data through disease surveillance, insurance claims, and service monitoring, there exists a growing need for data sharing agreements (DSAs) between agencies and across programs to ease client burden, create greater system efficiencies, and support overall linkage to and retention in HIV care and treatment. RWHAP Part B and AIDS Drug Assistance Programs (ADAPs) can particularly benefit from access to various data sources and the development of DSAs with entities such as state HIV surveillance programs, state Medicaid programs, and RWHAP Part A funded Eligible Metropolitan Areas and Transitional Grant Areas.

In 2016, NASTAD conducted a 'request for resource' from RWHAP Part B and ADAPs to capture existing DSAs. NASTAD maintains a health department DSA resource bank of the resources that were collected through the [Online Technical Assistance Platform \(OnTAP\)](#).¹ NASTAD understands that these resources have been useful for RWHAP Part B and ADAPs, and also recognizes that having a framework within which to develop a new DSA assists in moving the implementation of a DSA forward. Thus, NASTAD has developed three DSA templates: [Part B/ADAP and Part A EMA/TGA](#); [Part B/ADAP and Medicaid](#); and [Part B/ADAP and Surveillance/Epidemiology](#).

This User Guide provides an overview of the DSA templates that were created. These templates can be used to develop new DSAs in your jurisdiction or to enhance an existing DSA. NASTAD has provided general guidance that is relevant in most cases, however, **each jurisdiction should work with their health department's legal counsel to ensure that the DSA is compliant with all regulations.**

¹ To access the OnTAP platform, please send an email to OnTAP@NASTAD.org with the subject heading "Register," including your first name, last name, and health department in the body of the email.

Elements of a DSA

The following sections provide a step-by-step overview of each component of the DSA templates. While this overview may not be all-encompassing, it should be helpful guidance for your DSA development process.

Project Description

Outline the projects covered within the agreement in this section, including the data to be shared, names of variables, and one or two sentences that outline the project. The project description should also include the following: 1) type of data; 2) where the data is stored/shared; 3) why the data is being used; and 4) whether the requesting party intends to disclose the data to a contractor or other data agent over the course of the project. For example, one state Department of Health's project description reads:

“HIV Laboratory Results for RWHAP clients. Provide CD4 and quantitative viral load laboratory test results collected in the enhanced HIV/AIDS Reporting System (eHARS) among persons enrolled in RWHAP services to upload to the Securing Client Outcomes Using Technology (SCOUT) database used to monitor RWHAP programs.”

Specifics of the project should be explained in the data strategy section.

Specific Data Requested

The data elements requested should aim to achieve specific goals, such as determining eligibility, helping to coordinate services, or analyzing gaps in services.

The DSA templates include a sample list of data elements, based on data projects/query requests encountered on a regular basis.

NOTE: Algorithms are used to query or limit data to a code or series of codes used by medical providers (e.g., CPT, HCPCS, and ICD-9/ICD-10). Some agreements require a list of codes to define a population, such as searching Medicaid claims for all people with an HIV diagnosis. Complete algorithms may be added as an appendix or in the agreement itself.

Data Characteristics

The characteristics of the data should include the following:

- Data level, which can be as defined first by aggregate or record-level. If record level, by de-identified or identifiable. Examples of how different levels of data can be utilized include:
 - Aggregate data can be used to evaluate pre-exposure prophylaxis (PrEP) uptake by searching for Truvada mono-therapy across the jurisdiction

- Record-level data that is client-level can be used to coordinate HIV and/or hepatitis C services and identify people out of care
 - Record-level data that is deidentified can be used to define risk factors for hepatitis C or gaps in services for HIV and/or hepatitis C care and prevention.
- Frequency of sharing, which represents how often the party requesting the data wishes to receive the data.
 - Geographic region, which can be defined by the entire state or jurisdiction, EMA/TGA, county(ies), or other specified perimeters, depending on need.

Duration of Agreement

The duration of the agreement outlines the dates the agreement is in effect between each program and/or agency. Projects within the agreement may have different effective dates, which should be specified in the data strategy and data analysis sections. DSAs generally last three to five years. Agreements can be cancelled by either party upon written notice, which ranges on average from 30 to 90 days prior to termination.

Technical Exchange

The technical exchange section provides the acceptable formats for shared data ((i.e., the type of program that will be used to analyze data (e.g., Excel, SAS, SPSS, etc.)), as well as the acceptable modes of transferring the data (e.g., secure download from one program system to another, or secure USB).

Justification for Access

Protocols and procedure developed under the agreement should be consistent with both federal regulations and state statutes and these should be cited in the agreement.

Federal Requirements

For data sharing agreements between ADAP/Part B and Medicaid and Medicaid Managed Care Organizations (MCOs), refer to Section 1902 (a) (7) of the Social Security Act (as amended) for safeguards which restrict the use or disclosure of information concerning Medicaid applicants and recipients. Also, refer to 42 CFR 431.302 and 45 CFR 164.506. Medicaid MCOs are covered entities by the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

State Requirements

All agreements should be consistent with state statutes. Please work with health department legal counsel to identify relevant statutes regarding protection of client information.

Project Personnel

This section lists individuals who will have permission to transfer, analyze, and/or use data. The project role should be defined for each person with access to the data. Jurisdictions should adhere to internal requirements for maintaining HIPPA compliance.

Disposal of Data

Disposal of data details the protocols and procedures for the proper disposal of the data.

Signatures

The DSA should be executed by individuals with authority to ensure the data protections described above. In addition, individuals signing off on the agreement should be willing and able to serve as primary contacts for the agreement.

Conclusion

In the past, DSAs have allowed ADAPs to ensure payer of last resort requirements, locate out-of-care individuals, and generally improve the quality of services offered. Well designed and executed DSAs can allow for the development and/or enhancement of collaborative relationships between ADAPs and other state or local entities. This often leads to better communication and the identification of specific individuals who can be of assistance in other contexts, such as formulary advisory bodies and inter-departmental working groups. In general, DSAs improve ADAPs' ability to provide well-informed and comprehensive services to individuals living with HIV in their community.

Related Resources:

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- [HRSA Performance Measure Portfolio](#)
 - [AIDS Education and Training Centers Resources for HRSA HAB Performance Measures](#)
 - [HRSA HAB HIV Performance Measures](#)
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