

CONNECTIONS:

from 

HEALTH INFORMATICS

 to IMPROVED

HIV OUTCOMES

OVERVIEW

As part of NASTAD's cooperative agreement with the Centers for Disease Control and Prevention (CDC), the following issue brief provides governmental HIV/AIDS programs with salient considerations regarding leveraging health informatics – including claims data and electronic health records (EHRs) – to augment surveillance efforts, improve care coordination, enhance linkage to- and retention in care for people living with HIV, and assess the utilization of services provided outside of health departments.¹ Please contact [Amy Killelea](#) or [Kelsey Donnellan](#) if you have questions.

¹ This resource was prepared by the National Alliance of State and Territorial AIDS Directors (NASTAD) under Grant #PRV4487 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

BACKGROUND

The National HIV/AIDS Strategy (NHAS), updated to 2020, encourages all stakeholders to effectively coordinate HIV programming through the use of data systems and health information.² The actionable use of data has become a focus of effective HIV programming, as maximizing the use of individual and aggregate claims data and EHRs holds great potential to augment existing HIV surveillance care, and prevention efforts. Furthermore, as the NHAS endeavors to galvanize domestic support to end the epidemic and achieve health equity, a concurrent national movement is underway to support the meaningful use of health informatics to improve population health and care quality.³ Claims data and EHRs are two important tools for HIV programs to utilize in the national movement to eliminate new HIV infections. Governmental public health HIV programs are uniquely positioned to take a leadership role in the efforts to achieve the promise these collective visions.

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²Goal four of the *National HIV/AIDS Strategy*, specially steps 4.A.2 and 4.B.1, encourages the coordination, availability, and use of data.

³CMS operates the *Electronic Health Records (EHR) Incentive Programs* by tiered stages, outlined to 2019.

HEALTH INFORMATICS LANDSCAPE OVERVIEW

While health informatics hold promise to enhance the programmatic activities of HIV programs, there are a number of factors that impact the acquisition, use, and application of these tools. The entities that house medical data, including claims and EHRs, have implemented a myriad of policies and procedures that aim to protect the privacy of personal health information. This brief will focus on the information that is held in three types of data warehousing services:

- All-Payer Claims Databases
- Health Information Exchanges
- Medicaid Claims Databases

All-Payer Claims Databases

All-payer claims databases (APCD) are data warehousing services that collect health insurance claims from the vast majority of payers within the jurisdictions in which they operate. States began to establish APCDs in 2007 to aggregate public and private payer claims information with the hope of improving care quality while reducing per capita cost. APCDs are established by state legislation, and are generally authorized to collect information from virtually all insurers, pharmacy benefit managers (PBM), and third party administrators (TPA). Of note, some states have implemented requirements that prescribe member and/or budgetary thresholds for reporting. For example, insurance carriers in Kansas must insure a minimum of 1% of residents in the state before they are compelled to contribute to the APCD. The authorizing legislation also dictates the organization(s) that will administer and govern each jurisdiction's APCD.⁶ While governance structures vary, there are three prevailing organizational models:

1) State Agency – The authorizing legislation prescribes a state agency to administer the APCD and may grant authority to this agency to impose penalties on insurers for noncompliance.

- 2) Private – Private APCDs may be established without legislative authority. Participation in these APCDs is voluntary, and as a result the data which is available is reflective of the payers that have chosen to participate. Private APCDs do not have the authority to impose penalties for non-participation and are generally governed by a board of directors.
- 3) Shared State Agency – Some states have implemented APCDs that are administered by two or more state agencies. In this case the roles and responsibilities of each agency are outlined in the authorizing legislation.

It is important to note that APCDs were initially developed with the aim of researching and improving the population health of the jurisdictions in which they operate. This population health focus may hinder the ability of HIV programs to access personally-identifiable claims information to implement individual interventions. Also, as APCDs are a relatively new type of data warehousing service, the quality of the data that are available will vary. To address this challenge, a number of APCDs are implementing quality improvement initiatives.⁷ Additionally, some APCDs are voluntarily adhering to data structure and organizational standards prescribed by the National Association of Health Data Organizations (NAHDO), and the APCD Council. Further, as APCDs aggregate claims data, it is important to note that the information that is available is retrospective and limited to aspects of care which are potentially reimbursable. The lag time between when a service is delivered and recorded on a claim, and its availability on an APCD may be significant. The APCDs authorizing legislation, governance, and policies and procedures will outline the speed at which claims data can be accessed.

⁴On April 4, 2016 the Supreme Court of the United States issued a judgment regarding *Gobeille v. Liberty Mutual Insurance Co.*, which stated that the Employee Retirement Income Security Act (ERISA) voids state-specific APCD reporting requirements for self-funded employee health plans.

⁵The Commonwealth Fund, *All-Payer Claims Databases: State Initiatives to Improve Health Care Transparency (September 2010)*.

⁶For examples of state legislation by state, visit the [APCD Council's resource page](#). This list does not include all states with an APCD. To see if your state has an APCD, view the [APCD Council's interactive map](#).

⁷The APCD Council has developed a [fact sheet](#) about APCD standardization as well as a [proposed set of core data elements for data submission](#).

In spite of these challenges, state governments have been able to use APCD data to inform significant policy endeavors and develop valuable population information, including:

- Determining the capacity and distribution of health care resources to inform Medicaid managed care contracting.
- Comparing the cost of care and treatment by provider and setting.
- Examining the average distance that a Medicaid beneficiary must travel to access care to inform transportation resource allocations.

This brief will identify opportunities to leverage APCD data to improve HIV outcomes.

Health Information Exchanges

Health Information Exchanges (HIE) are data warehousing services that facilitate the use of electronic health records (EHR) by authorized users. The goal of HIEs is to provide safer, cost-effective, high-quality, equitable and patient-centered care and treatment to patients across providers and facilities. EHRs are the basic building block of HIEs; therefore, the data that are available differs from those offered by APCDs.⁸ A medical claim is fundamentally a financial instrument used to secure reimbursement for services and products that have been delivered to a patient. Conversely, EHRs are intended to record a more robust set of patient medical data and make that information dynamically available. This means that the speed at which EHR data can be accessed through an HIE after a service or product is delivered is much faster than an APCD, and is often instantaneous. The extent to which HIV programs can participate in an HIE is based on the policies of each individual exchange.

HIEs can be administered by public, private or hybrid organizations. Additionally, the governance, structure and geographic scope of HIEs vary across the country. Some HIEs serve a small geographic region, while others serve an entire state or multi-state region. HIEs also differ in technical models, with some acting as conduits of health information and others serving as repositories of health data. There is also

wide variance in the types of clinical data exchanged and services offered by HIEs. Health Level Seven International (HL7) is a standards organization that works with many HIEs and other health information technology stakeholders to provide a comprehensive framework and related to the exchange, integration, sharing, and retrieval of electronic health information that supports clinical practice and the management, delivery and evaluation of health services. Most HIEs adhere to HL7 standards to ensure that their data is uniformly structured to facilitate the exchange of health information consistently.

The Affordable Care Act invested heavily in the development of HIEs and incentivized clinical providers to adopt the meaningful use of EHRs. The Medicare and Medicaid EHR Incentive Program provide incentive payments to eligible professionals, eligible hospitals and critical access hospitals (CAHs) as they adopt, implement, upgrade or demonstrate meaningful use of certified EHR technology. Eligible professionals can receive up to \$44,000 through the Medicare EHR Incentive Program and up to \$63,750 through the Medicaid EHR Incentive Program.

Additionally, the Centers for Medicare and Medicaid Services (CMS) has published guidance on how Medicaid programs can take steps to participate in HIEs.⁹

Medicaid Claims Data

The extent to which Medicaid claims data is housed in APCDs and/or HIEs varies throughout the nation. As more than 30% of people who are living with HIV nationally are Medicaid beneficiaries,¹⁰ the data that are housed in state Medicaid programs can be invaluable to HIV programs. HIV programs that are interested in accessing Medicaid claims data should consider the following:

1) What organization(s) house Medicaid claims data in your jurisdiction?

- a As Medicaid is a partnership between the federal government and a state, state Medicaid programs are given latitude with regard to the organization or agencies

⁸More information about the governance structure for Health Information Exchanges is provided by the *Office of the National Coordinator for Health Information Technology*.

⁹The *CMS Medicare and Medicaid EHR Incentive Program* resource page includes basic information about the program as well as financial payment amounts.

¹⁰Information on health care coverage was obtained from the *HRSA Annual Client-Level Data Report Ryan White HIV/AIDS Program Services Report (RSR) for 2014*.

that must compile Medicaid claims data in accordance with CMS data collection standards. Some states choose to collect and house claims data within their Medicaid office, whereas others may choose to contract with a third party. Medicaid managed care organizations (MCO) are a prominent type of third party which stores Medicaid claims data. Medicaid MCOs are organizations that contract with jurisdictional Medicaid programs to administer benefits to beneficiaries. By contracting with various types of MCOs to deliver Medicaid program health care services to their beneficiaries, states aim to control Medicaid program costs and better manage utilization of health services. Many state Medicaid programs are implementing a range of initiatives to coordinate and integrate care beyond traditional managed care. These initiatives are focused on improving care for populations with chronic and complex conditions, including HIV.¹¹

- b Accessing MCO claims data is unique to each jurisdiction's Medicaid program and/or each MCO. Managed care data access is often facilitated with a written agreement between the Medicaid office and an HIV program, and/or a multi-lateral agreement which also includes the desired MCO.

2) Is your program interested in aggregate or personally-identifiable information?

- a HIV programs may have the opportunity to access aggregate or personally-identifiable Medicaid claims data, albeit with a lag time of up to six months. Requesting personally-identifiable information is best achieved through a written agreement with Medicaid and/or an applicable third party administrator. Depending on the level of detail desired, aggregate information can be accessed through two sources:
 - i. CMS Chronic Conditions Warehouse (CCW): Access to Medicaid and Medicare claims data via the CMS CCW is limited to state Medicaid programs and health researchers. Medicaid programs can request an addendum for governmental public health HIV programs to use their data. The addendum agreement

that specifically authorizes health departments as downstream users to access the warehouse. Importantly the warehouse contains information related to Medicaid beneficiaries and those dually-eligible for Medicaid and Medicare.¹²

- ii. Medicaid Analytic eXtract (MAX) program: The MAX program is designed to provide aggregate jurisdiction-wide Medicaid data regarding beneficiary eligibility and services utilization. Participation in the program is voluntary, however most jurisdictions elect to participate.¹³

Health department use of Medicaid claims is addressed further in this brief.

Data Interoperability

The vast and evolving landscape of health technology presents a myriad of data integration challenges for those seeking to make actionable use of the information that is available in data warehousing services. Public health use of claims and other health data is complicated given the diversity of technology systems, data structures, and organizational policies that govern the use and acquisition of claims data and EHRs. Data interoperability is a concept that aims to address these challenges. According to the Health Information and Management Systems Society (HIMSS), data interoperability is defined as “the extent to which systems and devices can exchange data, and interpret that shared data. For two systems to be interoperable, they must be able to exchange data and subsequently present that data such that it can be understood by a user.”¹⁴ In practice data interoperability is a concept that transcends specific data warehousing services as it aims to combine individual sources of data to create a collective stream of useful information.

For key terms and definitions, please see the appendix.

¹¹For more information regarding the Medicaid MCO landscape in your jurisdiction, see the [CMS Managed Care State Profiles](#) or the [Kaiser Family Foundation Medicaid Managed Care Market Tracker](#).

¹²See the following CCW resources: [CCW's data dictionaries](#); [CCW condition categories](#); and [HIV-related “flags.”](#)

¹³See the [Medicaid Analytic eXtract \(MAX\) General Information](#) resource page.

¹⁴See [HIMSS Resource Library, Interoperability and Standards](#).

LEVERAGING CLAIMS DATA AND ELECTRONIC HEALTH RECORDS TO IMPROVE OUTCOMES AND INFORM CORE HEALTH DEPARTMENT ACTIVITIES

As the administration of HIV programming continues to grow in complexity, it is imperative that health departments maximize opportunities to use data in new ways and from new sources to improve outcomes among people at risk for and living with HIV. To this end, the meaningful use of tools within the dynamic field of health informatics, including claims and EHRs, represent an opportunity to strengthen core health department activities related to HIV in the following ways:

- Augment HIV surveillance efforts
- Support services coordination and outcomes-based interventions across the HIV Care Continuum
- Implement targeted interventions based on community risk and geography
- Monitor pre-exposure services utilization, including pre-exposure prophylaxis (PrEP) uptake

Augmenting HIV surveillance efforts

The response to the HIV epidemic has included a national surveillance system since 1981.¹⁵ In the more than three decades since all 50 states and the District of Columbia implemented AIDS case reporting, iterative revisions of this surveillance system have yielded numerous improvements to the accuracy and the availability of information. These advancements have been integrally important in shaping health department interventions, yet there is still a depth and breadth of personally-identifiable and aggregate data about clients who access services not funded by the health department which cannot be easily captured through traditional surveillance activities. Claims data and EHRs can modernize

HIV surveillance activities by providing information on the utilization of services reimbursable by public and private insurance.

Supporting services coordination and outcomes-based interventions across the HIV Care Continuum

Services coordination (including HIV linkage services) and case management are important factors that contribute to viral suppression among people living with HIV, and successful HIV prevention for those at-risk for seroconverting. Information from EHRs allow HIV programs to efficiently acquire timely data about people living with and those at great risk for acquiring HIV to design care coordination models and interventions that are informed by the holistic health status of specified individuals and communities. Conversely, claims data provide a retrospective view of all reimbursable services delivered to individuals or communities. Collectively, these two sources of information can contribute to a more comprehensive understanding of the factors impacting HIV service utilization and outcomes so that more informed interventions can be implemented.

Implementing targeted health equity interventions based on community vulnerability and demography

An abundance of evidence indicates that specific communities are disproportionately impacted by the HIV epidemic.¹⁶ Chiefly, Black gay men, other men who have sex with men (MSM),¹⁷ and Black transgender individuals¹⁸ are affected most by HIV. While insurance claims do not collect sexual orientation and gender identity data, a growing number of EHRs are beginning to recognize the value of the information. In concert, claims data and EHRs allow HIV programs to assess opportunities to implement interventions based on a variety on demographic and geographic considerations.

Monitoring PrEP uptake and assessing services utilization among people at risk for HIV

Claims data and EHRs can be leveraged to offer unprecedented insight into the health status of those who are not living with HIV. While the extent to which governmental HIV programs have the authority to collect personally-identifiable information on people without an HIV diagnosis is variable, claims data and EHRs can be used to assess aggregate medical services utilization, including PrEP uptake and adherence.

¹⁵Information about the National HIV Surveillance System (NHSS) is available through the [Health Indicators page](#).

¹⁶According to the 2014 HRSA Ryan White RSR, Black and African American MSM have the lowest percentage of viral suppression (75.3%) compared to the national average (81.4%). Further, viral suppression rates among young Black MSM was considerably lower (62.1%) compared to both adult Black MSM (75.3%) and the national average (81.4%). Black transgender youth had the lowest rates of viral suppression (49.7%), next to unstably housed Black and African American adolescents (50.7%).

ACCESSING INFORMATION

Eligibility Considerations

Data warehouses with claims data and EHRs often restrict access to the information housed based on a number of factors. These restrictions are intended to protect sensitive health information and the patient's identity. While eligibility to access data varies by source and purpose of use, there are several notable considerations:

- **APCD** – Eligibility to access APCD data is generally determined by state law. Most APCDs allow access to users interested in research, advancing the goals of the triple aim (improving patient care, improving population health, and reducing cost of care), rate setting by insurance companies, and/or improving health outcomes for the population on which they are collecting claims. Generally, APCDs do not allow users to access personally-identifiable claims. Accessing information based on specific attributes (age, geography, gender, etc.) is permitted provided that the information sought is in alignment with a data strategy approved by the APCD. Notably, accessing data from HIEs and APCDs may require that a potential user undergo an extensive application review process, known as a case use analysis. This process is intended to confirm the proposed dataset is consistent with the mission of the APCD or HIE, and the potential user's data strategy.¹⁹
- **HIEs and RHIOs** – generally restrict access to clinical providers and support staff. Accessing HIEs and RHIOs can be dependent upon acquiring membership and/or paying dues. Cost considerations are detailed below. A case use analysis may also be required to access HIE informatics.
- **Medicaid Claims Databases** – The extent to which Medicaid programs will allow health departments to access to their claims data is variable. The claims will be coded for services, diagnosis, and prescriptions whether the beneficiary is under traditional Medicaid or a Medicaid Managed Care Organization (MCO). Claims information may be restricted to aggregate (vs. personally-identifiable) information. A data sharing agreement or data use agreement will be required to access Medicaid claims data. To streamline analysis and reduce state Medicaid burden, some programs contract with their state university system to conduct analysis of Medicaid data.
- **CMS CCW** – Access to Medicaid and Medicare claims data via the CMS CCW is limited to state Medicaid programs and health researchers. Governmental HIV programs must work with state Medicaid programs to receive an addendum to their data use agreement that specifically authorizes health departments as downstream users to access the warehouse. Importantly the warehouse contains information related to Medicaid beneficiaries and those dually-eligible for Medicaid and Medicare.

¹⁷Based on data available from the CDC, Black men were burdened by 42% of new HIV cases in 2011, 72% of those cases are contracted through male to male sexual contact. To see more information about health disparities affecting Black communities, click [here](#).

¹⁸Testing data from the CDC in 2013 show the highest rate of newly identified HIV-positive persons were transgender people. Although information about transgender people is limited, in HRSA's 2014 RSR, Black transgender people have lower percentages of retention in care compared to transgender people of other races and ethnicities.

¹⁹Information regarding enrollment and data sharing agreements were obtained during interviews with state health department staff, APCD representatives, and HIE representatives. Please see the resources section of this paper or NASTAD OnTAP Community of Practice for examples of data sharing agreements.

ACCESSING INFORMATION

Develop a Data Strategy

Based on current surveillance methods and future goals, HIV programs must develop a data strategy to serve as the overarching pathway for reaching program objectives. Data strategies are inclusive of how to store, share, analyze, and secure data. Detailed information on what data will be used, how data will be stored, shared, analyzed, and secured, who has access to the data, and why the data outlined are necessary for achieving the program objectives. The data strategy is typically reviewed by an advisory committee to ensure program objectives and security considerations can be met, which is known as a case use analysis.

KEY DATA STRATEGY ELEMENTS²⁰

Term	Meaning
Objectives	The aims of data use, i.e. the state health department will assess testing across the state using Current Procedural Terminology (CPT) codes, or for Medicare beneficiaries Healthcare Common Procedure Coding System (HCPCS) codes.
Timelines	First, to lay out the time frames for accessing and analyzing data from the APCD, HIE, and/or Medicaid data. Data from an APCD is typically available four to five months from time of service, while HIE data is available within days of service. Medicaid data is available based on the state Medicaid office. Second, to determine relative dates of service to pull data. For longitudinal trend analysis use an APCD and for more immediate and frequent analysis use of an HIE provides.
Level of data	Determine whether the data needed to meet the data strategy objectives is personally-identifiable or aggregate, or for defined individuals or populations with attributes.
Technical infrastructure requirements	Internal or contracted software and server needs for staff to access, securely store, and analyze data based on objectives and levels of data.
Compliance with confidentiality considerations	State health department must determine who can access data, how the data must be stored, and what staff can view personally-identifiable data. Review HIPAA, state laws, and data use agreement for specific considerations.
Staff protocols	Determine training for staff accessing and utilizing APCD and HIE data.

²⁰This table was created by NASTAD staff from information obtained during interviews with stakeholders outlined in the acknowledgements section.

Staff and Infrastructure Considerations

Prior to attempting to access claims data and EHRs through an APCD, HIE, State Medicaid, or CMS CCW, health departments should assess their ability to house and analyze large datasets based on their data strategy. APCDs, HIEs, State Medicaid, and CMS CCW list systems hardware and software requirements for prospective users. Additionally, it is important to consider health department staff and capacity to utilize the data to improve outcomes. The aforementioned data warehousing services often provide prospective users with insight in to the structure and format of the data that they are housing.

Cost Considerations

While the ACA provided funding for the establishment of APCD and HIEs, revenue for ongoing operations are based on a variety of models. For example, the cost of accessing APCD and HIE information may be subsidized in part or full by tax revenue. Other forms of financing include:

- **User licensing** – Charging a specified amount based on the number of users for which an organization is interested in acquiring access
- **Organizational membership** – A fee that covers all eligible users from a specific organization
- **Bifurcated** – A financial structure that charges different fees dependent on the type of user or organization. An example of a bifurcated structure is an APCD or HIE that charges hospitals a set organizational rate, while allowing access to community-based providers free of charge.
- **Volume-based** – A financing structure based on the volume of data or patient records accessed.

Establish Data Use Agreement

Utilizing claims, EHR, and Medicaid data is complex. To make sense of this information, it is imperative to establish a data use agreement. A data use agreement is a contract or agreement with a data warehouse to access the data stored in the warehouse, i.e. APCD, HIE, RHIO, etc. The data use agreement will outline how data can be accessed, who can access the data, what data is available to the user, and timeline for both use and destruction of data. The data strategy will serve as a blueprint of the scope of use and purpose for gathering data.

²¹Some states, such as Louisiana, opt to contract with their state university system to run analysis from their APCD, HIE, and/or Medicaid office.

²²For example, Utah has executed a *comprehensive APCD data use agreement*.

Pinpointing People —

FROM ACCESS TO INFORMATION

A prominent consideration regarding accessing claims data and EHRs is determining whether the desired information is personally-identifiable or aggregate in nature. Aggregate data can be honed to define individuals or populations that exhibit specific attributes.

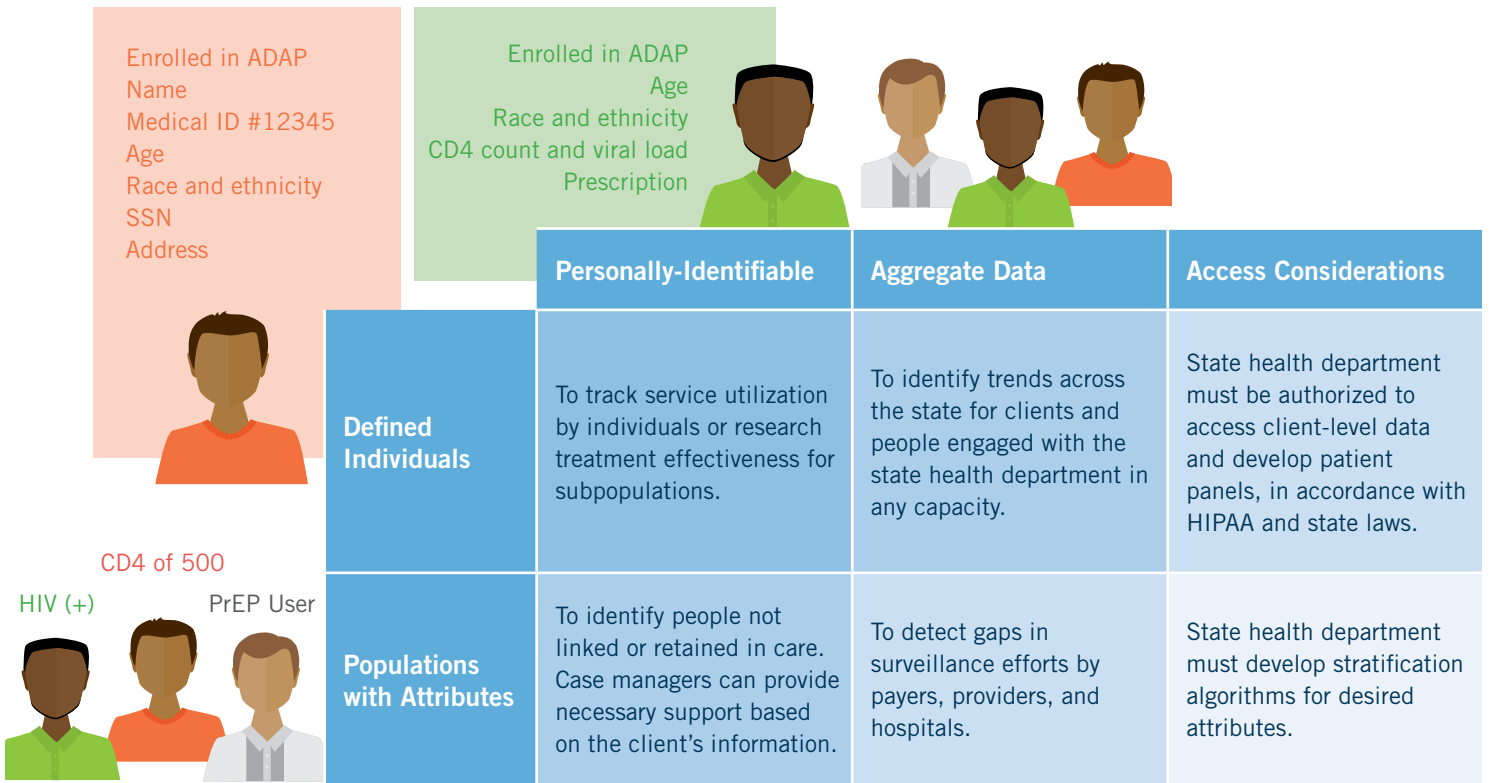
Personally-identifiable data

Personally identifiable data could be used to potentially identify a specific individual (for instance to link that individual to care). Any data that can be used to distinguish one person from another and can be used to distinguish one person among aggregate data can be considered personally-identifiable. Examples include name, address, social security number, birth date, and insurance policy number. For governmental HIV programs, personally-identifiable information is best used to monitor care and treatment adherence, and to inform interventions conducted on specific individuals. There may be state legal considerations in use of personally identifiable data relating to someone's HIV diagnosis. The Public Health Law Research Institute's brief on utilizing personally-identifiable information can be found [here](#).

PINPOINTING PEOPLE – FROM ACCESS TO INFORMATION

Aggregate data

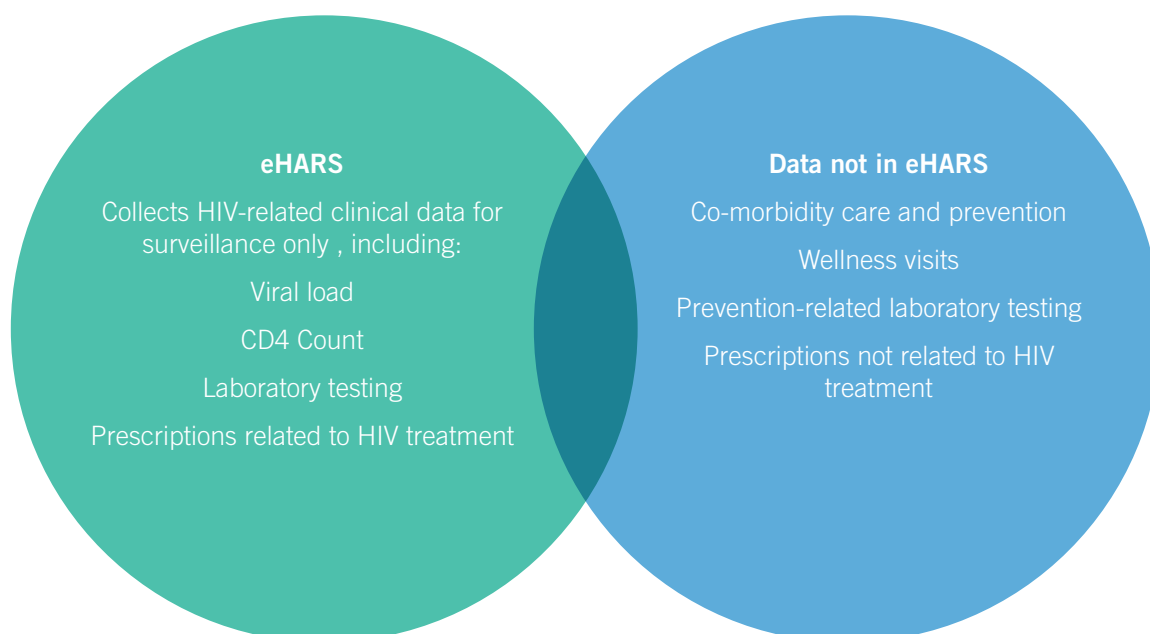
Aggregate data are de-identified pieces of information for a specific population or group of people with specific attributes. Examples include birth year, race/ethnicity, zip code, diagnoses, or gender. Importantly, health data warehousing organizations that allow users to access aggregate information may restrict the amount of queries to the aggregate data. This protection is based on a fear that an end user could potentially identify individuals within aggregate data if the queries are excessively detailed. Many organizations impose a maximum number of query results to avoid this risk. The maximum number is known as a query threshold. For governmental HIV programs, aggregate data are best used to assess the risk of specific populations, monitor services utilization, and identify diagnoses trends. The mechanism used to limit aggregate data to population or individuals with specific attributes is known as a query template or a stratification algorithm.



Pinpointing in Practice

FROM DATA to INFORMATION

Once a data strategy is developed and access to a data source is acquired, programs can begin to acquire data for analysis. The graphic below identifies the unique data elements that can be queried in APCDs, HIEs, RHIOs, or Medicaid datasets. eHARS, an electronic system developed by the CDC, is used for HIV surveillance efforts.



	Personally-Identifiable Data	Aggregate Data Attributes
Claims data (Medicaid, Medicaid MCO, APCD)	<ul style="list-style-type: none"> • Employer Name • Patient Marital Status • Patient or Insured Address • Patient or Insured Date of Birth • Patient or Insured Name • Phone Number • Social Security Number 	<ul style="list-style-type: none"> • Amount Reimbursed • Diagnoses • Insurance Company • Lab orders • Place of Service • Procedures • Rendering Provider • Rendering Provider Code • Total Charges
HIE and RHIO	<ul style="list-style-type: none"> • Address • Date of Birth • Emergency Contact Information • Insurance Status and Information • Name • Phone Number • Social Security Number 	<ul style="list-style-type: none"> • Biological Information (height, weight, blood pressure, etc.) • Diagnoses • Lab Results • Place of Service • Procedures • Provider Notes • Prescriptions

Foundational Querying Aggregate Data and Developing a Stratification Algorithm for Aggregate Data

Health informatics databases can offer users a great deal of information based on query specifications. These specifications are known as a query template or stratification algorithm. Acquiring the most actionable data requires an effective querying strategy that prioritizes the most useful data while rejecting data which are least pertinent. The following are categories on which a foundational query template or stratification algorithm could be based:

- **Temporal** – Data elements related to time.
 - Time (or time range)
 - Date (or date range)
- **Biographic** – Data elements related to individual identity.
 - Race/Ethnicity
 - Gender and/or sex
 - Age or Date of Birth
- **Geographic** – Data elements related to the address of individuals or points of service
 - Zip Code
 - Area Code
 - City
 - State
 - Address

Coding and Querying

Procedure and diagnosis codes provide a uniform method of documenting diagnoses, treatments, laboratory orders, procedures, and prescriptions. To see a sample claim, click [here](#). The following are the most prominent coding structures pertinent to leveraging claims and health informatics to improve HIV outcomes.

- **International Classification of Diseases (ICD)** - The ICD is the global health information standard for mortality and morbidity statistics. ICD is increasingly used in clinical care and research to define diseases and study disease patterns, as well as manage health care, monitor outcomes and allocate resources. Recent changes to the codes has resulted in two common iterations of ICD coding versions nine (9) and 10 being used, known as ICD-9 and ICD-10 respectively. Health informatics specialists are in the process of moving EHRs, claims, and other electronic tools to ICD-10, which could take years.
- **Current Procedural Terminology** - CPT is a medical code set that is used to report medical, surgical, and diagnostic procedures and services to entities such as physicians, health insurance companies and accreditation organizations.
- **Healthcare Common Procedure Coding System** - HCPCS, often pronounced acronym “hick picks” is a set of health care procedure codes based on the American Medical Association’s Current Procedural Terminology (CPT).
- **Code Modifier** - Code modifiers help further describe a procedure code without changing the definition of the code. Modifiers can be applied to CPT and HCPCS.

DATA IN ACTION

Assess Testing Gaps

The most recent NHAS aims to ensure that 90% of people living with HIV know their status. To achieve this goal, statewide assessments of testing efforts must be conducted. While current surveillance efforts use positive laboratory results and pharmacy data to monitor testing and linkage-to-care, negative laboratory results are typically not required to be reported to the health department. Additionally, public health authority does not typically include the ability to compel data on people who have tested negative HIV. To remedy this gap in information, health departments may access aggregate data from APCDs and Medicaid claims databases and personally-identifiable information from HIEs. Health departments can use a query or stratification algorithm to explore testing utilization in their state.

Identify Populations and Individuals at the Greatest Risk for Seroconversion

Trends in sexually-transmitted infection (STI) can be monitored using aggregate claims data and personally-identifiable health informatics. Individuals with a history of rectal chlamydia, rectal gonorrhea, or syphilis are at greater risk for seroconversion, claims data and health informatics can be used to target interventions for individuals and populations exhibiting the corresponding CPT and diagnosis codes.

Monitor Pre-exposure Prophylaxis (PrEP) Uptake

Medicaid claims, APCD, and HIEs can be used to monitor PrEP uptake in jurisdictions. This can be accomplished by querying for individuals or groups of people that have been prescribed Truvada yet have a preceding negative HIV test, or are taking a monotherapy of Truvada.



HEALTH INFORMATICS IN PRACTICE

Spotlight on

Utah



The Utah Department of Health recently partnered with the Utah APCD to receive HIV-specific aggregate data. The health department aims to utilize the data to inform their statewide HIV care continuum, verify the same number of data entries are received from laboratory and physician reporting, assess treatment adherence by searching for national drug codes during a specific date range, and contribute to prevention programming.

Spotlight on

Colorado



The Colorado Department of Public Health and Environment recently partnered with the Center for Improving Value in Health Care (CIVHC), an APCD in their jurisdiction to gather aggregate data on PrEP utilization, hepatitis C (HCV) diagnosis and treatment, and HIV testing practices. Colorado aims to use this information to inform its PrEP outreach strategy, inform HCV surveillance efforts, and assess HIV testing effectiveness by provider and treatment setting. Colorado's look up table can be found [here](#).

Spotlight on

Louisiana



The Louisiana Department of Health and Hospitals established a public health information exchange known as the Louisiana Public Health Information Exchange (LaPHIE). LaPHIE allows the health department to receive daily personally-identifiable information on patients that test positive for HIV or syphilis, significantly reducing the lag time associated with receiving the same information through traditional HIV and STD surveillance activities. Louisiana also receives aggregate Medicaid data to monitor the overall health expenditures of beneficiaries living with HIV, even care and treatment that is not related to an HIV diagnosis. This information is used in a variety of financial and budgeting activities undertaken by the health department.

PROS+

- 1) APCDs, HIEs, and RHIOs have comprehensive data on services received, coded with ICD-9/ICD-10, CPT, HCPCS, and/or NDC.
- 2) HIEs and RHIOs have clinical records of participating clients.
- 3) APCDs, HIEs, and RHIOs collect and store data for years, which can be used to track trends longitudinally.
- 4) HIEs and RHIOs typically used HL7 standards to aid in interoperability and streamline data sharing between users.

CONS-

- 1) Accessing data from an APCD can take more than five months after date of service.
- 2) Claims data does not have a coding standard, like HL7.
- 3) Self-insured plans are not required to submit claims to APCDs, unless stipulated



ACTION ITEMS & CONCLUSIONS

Medical claims databases, APCDs, and HIEs hold great promise to augment the existing surveillance activities of HIV programs. The following considerations should be implemented to maximize opportunities to leverage claims data and health informatics.

- 1) **Develop a data strategy.** Data strategies serve to establish a conceptual and operational endgame for HIV programs. This framework is amendable and will outline the policies and procedures by which programs will store, share, analyze, and secure data. The strategy also identifies the broad objectives and impetus for acquiring information from data warehousing services.
- 2) **Create and evaluate existing data sharing agreements and relationships.** According to recent NASTAD survey, more than half (54%) of state and territorial HIV program have existing data sharing relationships Medicaid and other data warehousing services. Some health departments are also able to access information without a formal written agreement. Assessing existing data sharing agreements and relationships will help to avoid duplicative data sharing efforts where applicable.
- 3) **Gain access to the desired data.** Gaining access to the desired data will be unique to the policies, procedures, and participant eligibility considerations of each data warehousing services. Personally-identifiable Medicaid claims data may be accessed through implementing data sharing agreement with jurisdictional Medicaid programs, and MCOs where applicable. Aggregate Medicaid claims data is available via CMS' Chronic Conditions Warehouse, or the MAX program. HIEs possess personally identifiable information, but each exchange has its own unique participant eligibility requirements. APCDs will typically allow access to aggregate data and also have unique participant eligibility requirements.
- 4) **Assess staff and system capability and capacity.** Accessing Medicaid claims databases, HIE, and APCDs is complicated. It is important that HIV programs assess the extent to which they have staff and technology capacity and capability to make actionable use of the information that is available. Most APCD, HIEs and Medicaid databases disclose the technology requirements and structure of the data that they house. Finally, consider the interoperability of the information that HIV programs are seeking.



RESOURCES

HIE

- CMS guidance on how Medicaid programs can take steps to participate in HIEs, available [here](#).
- CORHIO Opt-out Request Form, available [here](#).
- CORHIO Pricing Sheet, available [here](#).
- CORHIO Sample Patient Notification, see [here](#).

APCD

- APCD Council interactive state map, click [here](#).
- APCD Council Core Data Elements, see [here](#).
- National Association of Health Data Organizations, click [here](#).
- Standard Report, available [here](#).
- Data Submission Guide from CIVHC, see [here](#).

Medicaid Claims

- CMS Data Collection Standards, available [here](#).
- CMS Managed Care State Profiles, available [here](#).
- Kaiser Family Foundation's Medicaid Managed Care Market Tracker, available [here](#).
- CMS Chronic Conditions Warehouse (CCW), view [here](#).
- CCW Look-up Table, available [here](#).

State Examples

- Colorado Look-up Table, available [here](#).
- Colorado and CIVHC data sharing agreement, view [here](#).
- Colorado and Medicaid data sharing agreement, view [here](#).
- Utah and APCD data sharing agreement, view [here](#).
- Utah Application including patient notification, click [here](#).
- Utah Recertification Form including patient notification, click [here](#).

Appendix

KEY TERMS & DEFINITIONS

The world of health informatics, specifically the use of claims, EHRs, and Medicaid datasets, is complicated in its breadth and depth. Leveraging these unique types of data to improve HIV outcomes compels a basic understanding of key terms, including:

ALL-PAYERS CLAIMS DATABASE (APCD)

All-Payers Claims Database (APCD) - Provides users with a comprehensive survey of medical claims from public and private payers. The aim of the APCD is to provide a single database for access to technical information about utilization and cost of both services and treatments. The payers contributing to APCDs include Medicaid, Medicare (all parts), employer-sponsored coverage (participation is optional for the self-insured), and Qualified Health Plan issuers (both on- and off-Marketplace). Reports from APCDs are comprised of aggregate claims data, which includes clients' demographic information, diagnosis and procedure codes, national drug codes, private insurance plan type (HMO, PPO, POS), provider information, facility type (hospital, office, clinic), and billing and reimbursement information. You confirm that your jurisdiction has an APCD, by checking out the APCD Council's directory, linked [here](#).

Scope of Use	Sources of Data	Types of Data
Provides users with a comprehensive survey of medical, laboratory, and pharmacy claims from public and private payers. The aim of the APCD is to provide a single database for access to technical information about utilization and cost of both services and treatments.	The payers contributing to APCDs include Medicaid, Medicare (all parts), employer-sponsored coverage (participation is optional for the self-insured), and Qualified Health Plan issuers (both on- and off-Marketplace).	Reports from APCDs are comprised of aggregate claims data, which includes: <ul style="list-style-type: none"> • clients' demographic information • diagnosis and procedure codes • national drug codes • private insurance plan type (HMO, PPO, POS) • provider information • facility type (hospital, office, clinic) • billing and reimbursement information

CLAIM

A medical and financial tool traditionally processed between the healthcare provider or hospital and the insurance provider, and includes patient's demographic information, provider and hospital details, all billable service codes, and billed amount (not the amount paid).

KEY TERMS & DEFINITIONS

HEALTH INFORMATION EXCHANGE (HIE)

Scope of Use	Sources of Data	Types of Data
Allows authorized users to appropriately access and securely share a patient's vital medical information electronically. The aim of exchanges is to improve the speed, quality, safety and cost of patient care. To see the name of federally-funded HIEs in your state, click here .	Exchanges can be operated by public, private, or governmental entities regionally or statewide.	Electronic health records (EHRs) with client-level information on: <ul style="list-style-type: none">• diagnosis and procedure codes• provider notes• laboratory results• prescription drug referrals

TYPES OF HIEs

HEALTH INFORMATION EXCHANGE

Exchanges can be operated by public, private, or governmental entities regionally or statewide. HIEs contain electronic health records (EHRs) with client-level information on diagnosis and procedure codes, provider notes, laboratory results, and prescription drug referrals. There are three types of HIEs:

Directed Exchanges	Query-based Exchanges	Consumer Mediated Exchanges
Allow users to send and receive secure information electronically between care providers to support coordinated care. The information is comprehensive (includes information from all other providers participating in the exchange) and available in real-time	Allows users to find and request a specified information for a specific client from another provider, laboratory, and/or pharmacy	Allows clients explicit control over the information which is allowed to be accessed by authorized users, commonly associate with behavioral health

ELECTRONIC HEALTH RECORD

Electronic Health Records (EHRs) are digital copies of a patient's medical record inclusive of clinical codes and notes, demographic information, and medications.

REGIONAL HEALTH INFORMATION ORGANIZATION (RHIO)

small health information exchanges within a specified geographic region that bridge the gap between providers, hospitals, pharmacies, and laboratories. Some RHIOs also provide services to move their members from paper-based systems to IT-based systems.

STATE MEDICAID DATA WAREHOUSE

each Medicaid office houses a data warehouse for claims and EHR data linked to its beneficiaries. The aim of the state Medicaid data warehouse is to streamline data collection of all services received under traditional Medicaid or a managed care organization (MCO).

CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS) CHRONIC CONDITIONS WAREHOUSE (CCW)

The CCW is a data warehouse operated by CMS and only provides clinical information for beneficiaries dually-eligible for Medicaid and Medicare. Claims data in the CCW are available months after the date of service.

²³See [HealthIT.gov Health Information Exchange resource page](#) for basic definitions and overview of different HIE types.



ACKNOWLEDGEMENTS

Brandon Neiswender, Vice President of Operations; CRISP Health Maryland

Colin Flynn, Chief, Center for HIV Surveillance, Epidemiology and Evaluation; Maryland Department of Health and Mental Hygiene

Elizabeth Cole, MPH, Research Associate; AcademyHealth

Erin Holve, Ph.D., MPH, MPP, Senior Director, Research and Education in HSR; AcademyHealth

Eva Thomas, Branch Director, AIDS Drug Assistance Program (ADAP); Mississippi State Department of Health

Jennifer Donnelly, Statistical Analyst, STI/HIV Surveillance; Colorado Department of Public Health and Environment

Jonathan D. Mathiue, Ph.D., Vice President of Research & Compliance and Chief Economist; Center for Improving Value in Health Care (CIVHC)

Karyn Kai Anderson, Ph.D., MPH, Technical Director; Medicare-Medicaid Coordination Office, Centers for Medicare & Medicaid Services

Kelly Joines, Chief Information Officer; CORHIO

Kira Radtke Friedrich, Services Manager, STD/HIV Program; Louisiana Office of Public Health

Marcee Mortensen, AIDS Drug Assistance Program (ADAP) Coordinator; Utah Department of Health

Kristina Larson, HIV Epidemiologist; Utah Department of Health

Mary Bahr, Center Chief (MADAP); Maryland Department of Health and Mental Hygiene

Matthew Mietchen, HIV/STD Epidemiologist; Utah Department of Health

Patricia Van Dyke, Board Chair; Health Level 7 International (HL7)

Peter DeVault, Vice President; Epic Systems

Samuel Burgess, MA, MSHCM, Prevention Manager; Louisiana Department of Health and Hospitals

Todd Grove, Health Care Access Unit, AIDS Drug Assistance Program (ADAP), Colorado Department of Public Health and Environment

Wendy Alexander, Ph.D., Technical Director; Medicare-Medicaid Coordination Office, Centers for Medicare & Medicaid Services

William L. Jeffries IV, Associate Chief for Science, Capacity Building Branch, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention

Xavior Robinson, Director, Practice Improvement; National Council for Behavioral Health