

Health Systems Data: Opportunities for Hepatitis Programs

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Background

Health systems data sources have become increasingly important for public health programs in recent years, both because of insurance coverage expansion under the Affordable Care Act (ACA) and because of incentive programs and federal investments that help providers and programs build their data and informatics capacity.

Increasingly, there are opportunities for public health programs to leverage health systems data – including Medicaid claims, All Payer Claims Databases, and Electronic Health Records (EHRs)/Health Information Exchanges (HIEs) – to augment public health surveillance and ultimately outcomes for a number of health issues. This primer focuses on the emerging opportunities for hepatitis C programs in particular.

The National Academies of Sciences, Engineering, and Medicine's [A National Strategy for the Elimination of Hepatitis B and C: Phase Two Report](#) highlights the need to improve our understanding of public health information and data in order to move towards elimination. The report recommends increasing the capacity to use electronic data from healthcare data sources to bolster surveillance activities and to better assess prevention and care utilization. This could

include use of claims data, electronic lab reporting, EHRs, HIEs, and public and private insurance claims data. Health systems data is particularly relevant for hepatitis C programs because of how fragmented and underfunded hepatitis surveillance activities are in the United States, which makes understanding the true burden of the epidemic very challenging in most jurisdictions. Even with a recent increase in the number of funded jurisdictions, the [Centers for Disease Control and Prevention \(CDC\) only supports 14 states](#) to conduct surveillance for hepatitis C. In light of these challenges, programs are turning to other health systems data sets to help determine both prevalence of hepatitis C and prevention and care utilization.

Building off of the work that NASTAD has done to support health departments' use of health systems data within HIV programs (see [Connections: From Health Informatics to Improved HIV Outcomes](#)), this primer and forthcoming resources address how health departments are using health systems data to support their hepatitis programs.

For questions or more information about this work, please contact [Amy Killelea](#) or [Alyssa Kitlas](#).

DATA SOURCE	TYPE OF INFORMATION	WHAT CAN I DO WITH IT?
MEDICAID CLAIMS	Data attached to payment for a specific Medicaid service; includes demographic information, diagnosis or procedure codes, facility/provider codes, or national drug codes, and billing reimbursement information	Assess testing and treatment utilization; match claims data with surveillance data
ALL-PAYER CLAIMS DATABASE (APCD)	Data attached to payment for services received through a range of public and private payers (including Medicaid, Medicare, state employee benefits, and commercial plans); includes demographic information, diagnosis or procedure codes, facility/provider codes, or national drug codes, and billing reimbursement information. APCDs vary by jurisdiction	Assess testing and treatment utilization across payers; match claims data with surveillance data
ELECTRONIC HEALTH RECORDS	Electronic Health Records (EHRs) are digital copies of a patient’s medical record that provide real-time data inclusive of clinical codes and notes, demographic information, and medication	Inform case follow up and/or linkage to care services; inform provider-specific outreach and detailing
HEALTH INFORMATION EXCHANGE (HIE)	HIEs can be operated by public, private, or governmental entities regionally or statewide. HIEs contain EHRs with real-time client level information on diagnosis and procedure codes, provider notes, laboratory results, and prescription drug referrals	Inform case follow up and/or linkage to care services; inform provider-specific outreach and detailing

Health Systems Data in Action

Major Themes
<ul style="list-style-type: none"> ▪ Health systems data presents new opportunities for hepatitis programs to augment surveillance activities and to better assess prevention and treatment utilization and access ▪ Health systems data sources, particularly access to EHRs, may help jurisdictions in their efforts to build a comprehensive hepatitis C care continuum ▪ There are barriers to the ability of hepatitis programs to leverage health systems data, including lack of staff capacity, technical expertise, and necessary infrastructure to analyze complex datasets

HIV programs have been able to leverage health systems data to improve outcomes along the care continuum. This work has included using claims and EHR data to provide a better understanding of PrEP uptake in the U.S., and assessing viral suppression in Medicaid and linking individuals who have fallen out of care to providers. Similar opportunities exist for hepatitis programs to use health systems data to improve programs, such as finding demographic information that is frequently missing in case reports; assessing uptake of testing recommendations; and understanding hepatitis C treatment access in their jurisdiction. Examples of how programs are beginning to use this data are included below.

Obtaining Additional Demographic Information and Details for Case Follow-Up

Because EHRs and HIEs may provide additional information about positive cases, such as race and ethnicity and risk history, that is frequently not included in electronic lab reports, health departments may be able to use these datasets to support case finding efforts and move from passive to more active surveillance. The New York City Department of Health and Mental Hygiene, for instance, uses the Bronx Regional Health Information Organization (RHIO) to access more information about people living with hepatitis C, such as their fibrosis score, to prioritize who must be linked to care most immediately. They match the RHIO with their surveillance data to fill in gaps that exist. Other jurisdictions also use Medicaid claims or

pharmacy data to match and examine the completeness of surveillance data.

Expanding and Evaluating Public Health Programs

Health departments are increasingly working with healthcare providers to improve the capacity of primary care providers to diagnose and cure hepatitis C infection. Programs such as [CDC's Test and Cure Grant](#) focus on increasing the availability of population-level data to assess the impact within the community. Public Health-Seattle King County worked with their grantees, which included hospital systems and Federally Qualified Health Centers (FQHCs) both to use these systems in their interventions (including EHR prompts) and to use these data to evaluate programs. Grantees sent the health department monthly EHR reports to track the impact of these interventions within Seattle and King County.

Assessing Testing Uptake and Gaps

Since 2012, the CDC recommends that all people born between 1945 and 1965, also known as baby boomers, be screened at least once since they are five times more likely to have hepatitis C than other adults. In 2014, New York State [passed a law](#) requiring that a hepatitis C screening test be offered to all individuals in this birth cohort that are receiving inpatient hospital care or primary care. By developing queries based on testing Current Procedural Technology (CPT) codes, many health department programs have used claims data, predominately Medicaid claims, to assess and evaluate uptake of these testing

recommendations and/or state testing mandates and identify gaps that exist where they can target additional efforts.

Monitoring Treatment Access

The FDA approved the first direct acting antiviral (DAA) treatment for hepatitis C in 2013. Since then, a number of other medications have come to market and all have been proven highly effective and capable of curing hepatitis C with minimal side effects. Despite the incredible promise these treatments offer, a number of restrictions have been put in place by payers to limit access including: 1. fibrosis criteria; 2. Sobriety; requirements; and 3. prescriber limitations. Through querying pharmacy and medical claims, public and private insurance claims data has been used to assess uptake of and access to hepatitis C treatment.

Key Recommendations and Next Steps

While there are a number of emerging opportunities for hepatitis C programs to access and use health systems data, these complex data sets also present challenges:

- It can be difficult to identify the appropriate contact or “gatekeeper” for health systems datasets and to navigate the privacy and confidentiality requirements attached to these types of data queries
- Health systems datasets may have different purposes than traditional public health datasets. For example, Medicaid often limits data sharing to activities that will explicitly improve care quality of Medicaid beneficiaries.

Similarly, EHRs are designed and collected specifically to improve clinical care and coordination. Public health programs must navigate these considerations in framing their data use requests

- Many hepatitis C programs are understaffed and may not have the bandwidth to delve into new health systems datasets beyond the day-to-day responsibilities
- Health department public health programs may not have the infrastructure (technology, staff, resources, etc.) to store or analyze the data

The following are initial steps for expanding access to and increased use of health systems data to respond to the hepatitis C epidemic:

1. Build Health Department Capacity to Use Health Systems Data

Increasing the number of staff and the resources within epidemiology programs can make a big impact on capacity. Increased funding for state and local health departments is needed to improve their ability to leverage these data for public health interventions. Many states have benefited from small investments, such as a grant program from the Association of State and Territorial Health Officials (ASTHO) to create epidemiological profiles. Over the past three years, ASTHO funded 20 states and provided technical assistance over a six-month period to support the development of state hepatitis epidemiologic profiles. These efforts provided an opportunity for jurisdictions such as Rhode Island to raise hepatitis C awareness within the state, which had

not received much attention previously, and build relationships to expand the state's expertise and capacity.

Providing professional development for epidemiology staff such as fellowship opportunities and training programs will also be critical since advanced understanding and ability to use statistical software to analyze large data sets are needed to use health systems data.

2. Make the Case for Public Health

Access to Health Systems Data Health departments bring value to health systems, and some states have been able to make this case with public payers such as Medicaid. The advent of curative hepatitis C treatment and the price associated with those medications has opened up new opportunities for dialogue between hepatitis programs and their Medicaid counterparts about how to best serve this population. As providing comprehensive, cost-effective care and treatment to this population becomes a growing Medicaid priority, there may be emerging opportunities for collaboration with Medicaid programs to query claims data to better understand the population living with and at risk for hepatitis C.

3. Leverage the HIV Program's Infrastructure and Experience

Health department hepatitis programs may be able to build off of the work that HIV programs are doing with regard to health systems data, particularly around access to and use of Medicaid claims data. Nineteen jurisdictions participate in an [HIV Health Improvement Affinity Group](#) convened by the Health Resources

and Services Administration (HRSA), CDC, and the Centers for Medicare and Medicaid Services (CMS) and focused on supporting partnerships between the state HIV program and state Medicaid program. There may be opportunities to build off of the HIV data sharing activities that jurisdictions are pursuing as part of the Affinity Group. For instance, Wisconsin's hepatitis program is discussing modifying the HIV-specific data use agreement the health department has with Medicaid to include hepatitis. This is one of many examples of working with the HIV program to open doors for the hepatitis program. This will allow them to both match Medicaid data with their surveillance registry and have a clearer idea of the percentage of people within Medicaid who are living with hepatitis C.

4. Develop or Strengthen Partnerships with Academic Institutions

Partnerships with academic institutions could provide additional support and expertise to hepatitis programs looking to build their public health informatics capacity. These partnerships take many forms, including:

- Student support to clean data, conduct data matches, and analyze data (e.g., interns or students fulfilling their practicum requirements at the health department)
 - Most health departments rely on interns or fellows through the Council for State and Territorial Epidemiologists (CSTE) to conduct data matches and answer larger research questions that fall

outside of the purview of surveillance staff

- Formal partnership with an academic institution, allowing the health department to use the technology and infrastructure that the health department is missing

5. Share Strategies and Lessons Learned

It is challenging to develop data queries to identify hepatitis C since a second confirmatory test is required. A good and consistent list of procedure and diagnosis codes around tests and treatment that can be shared among health departments is an important resource. Also, strategies for negotiating bi-directional data sharing agreements, including examples of data-sharing agreements that have been developed by different states, is another way to support health departments and prevent jurisdictions from having to duplicate efforts underway elsewhere. NASTAD has a clearinghouse of data sharing agreements and is working to disseminate templates and best practices. NASTAD along with other partners such as CSTE convene regular workgroup calls, such as [CSTE's HCV subcommittee](#), and annual meetings, such as NASTAD's Hepatitis Technical Assistance meeting, allowing health departments to share these strategies and learn from each other.

Broader networking opportunities around Informatics such as the [Public Health Informatics Conference](#) that National Association of County and City Health Officials (NACCHO) and CDC host every other year, are also important to developing the workforce.

Support from NASTAD

NASTAD has a number of resources to support health departments as they begin to access or expand their utilization of health systems data. Below is a list of the most relevant resources:

- [Connections: From Health Informatics to Improved HIV Outcomes](#)
- [NASTAD's Informatics Page](#)

Additional Resources

- [HIV Health Improvement Affinity Group; HRSA, CDC, and CMS](#)
- [Health Information Technology and Informatics, NACCHO](#)
- [Public Health Informatics, ASTHO](#)
- [Joint Public Health Informatics Taskforce \(JPHIT\)](#)
- [Digital Bridge](#)

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