

**U.S. Department of Health and Human Services** Assistant Secretary for Planning and Evaluation Office of Health Policy

# Data Sources and Data-Linking Strategies to Support Research to Address the Opioid Crisis

# FINAL REPORT

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The Office of the Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of the Department of Health and Human Services (HHS) on policy development issues, and is responsible for major activities in the areas of legislative and budget development, strategic planning, policy research and evaluation, and economic analysis.

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# Data Sources and Data-Linking Strategies to Support Research to Address the Opioid Crisis Final Report

#### Submitted to

Office of Health Policy Assistant Secretary for Planning and Evaluation U.S. Department of Health and Human Services Hubert H. Humphrey Building 200 Independence Avenue SW Washington, DC 20201

Submitted by Rosanna Smart, Courtney Ann Kase, Amanda Meyer, and Bradley D. Stein RAND Corporation 1776 Main Street P.O. Box 2138 Santa Monica, CA 90407-2138 This report presents findings from a scoping study to assess the types of data sources and data-linkage efforts that are currently being used or could potentially be leveraged to support research and evaluations relevant to the U.S. Department of Health and Human Services Strategic Priorities to combat the opioids crisis. Based on an environmental scan of the literature and interviews with opioid policy and research efforts, the purpose of the project is to provide an overview of the types of secondary data sources and data linkages commonly used in opioid-related research to highlight some of the key gaps or challenges for existing data-collection and analysis efforts and to outline potential steps that could be taken to overcome these challenges. The initial scoping study was conducted in summer 2017, with an update to the scan of the literature conducted in February 2018.

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#### About the Authors

**Bradley Stein** is a senior physician policy researcher at the RAND Corporation and an adjunct associate professor of psychiatry at the University of Pittsburgh School of Medicine. A practicing psychiatrist and health services and policy researcher, his research is focused on better understanding and improving care for individuals with mental health and substance use disorders in community settings.

**Rosanna Smart** is an associate economist at the RAND Corporation whose research centers on studying the public health and policy implications of licit and illicit substance use, drug markets and drug policy, and issues related to the criminal justice system.

**Courtney A. Kase** is a policy analyst at the RAND Corporation whose prior research includes evaluations of service integration within community-based behavioral health centers, approaches to reducing health disparities, and approaches for technology use and collaboration in rural educational settings.

**Amanda Meyer** is a research assistant at the RAND Corporation with research interests in tobacco control and regulation, mental health policy and interventions, trauma, and school health.

### Contents

About This Reporti	i
Tables	v
Abbreviations	'n
1. Introduction	1
2. Background on the U.S. Department of Health and Human Services' Strategic Priorities	3
Better Practices for Pain Management	3
Better Addiction Prevention, Treatment, and Recovery Services	4
Better Targeting of Overdose-Reversing Drugs	4
Better Data	
Better Research	
3. Current State of the Evidence: Findings from the Environmental Scan	
Better Practices for Pain Management	
Better Addiction Prevention, Treatment, and Recovery Services	
Better Targeting of Overdose-Reversing Drugs	
Better Data	
4. Sources of Secondary Data: Data Inventory Findings	
National Surveys	
Electronic Health Records and Claims Data	
Mortality Records	
Prescription Drug–Monitoring Data	
Contextual and Policy Data	
Other National, State, and Local Sources	+
5. High-Priority Research Needs and Data Efforts: Findings from the	6
Stakeholder Discussions	
Better Practices for Pain Management       20         Better Addiction Prevention, Treatment, and Recovery Services       30	
Better Targeting of Overdose-Reversing Drugs	
Better Data	
6. Challenges and Opportunities for Implementing Successful Data-Linking Strategies	
Summary	
Summary	,
References	2
Appendix—Overview of Types of Secondary Data Sources and Data Inventory Content72	

### Tables

Management Practices
Table 3.2 Contactual Data Sources and Measures Commonly Linked to Onicid Outcome Data in
Table 5.2. Contextual Data Sources and Measures Commonly Linked to Opioid Outcome Data in
Research Related to the Five-Point HHS Strategy10
Table 3.3. Commonly Used Data Sources and Measures in Research to Improve Addiction
Prevention, Treatment, and Recovery Services
Table 4.1. Data Source Categories Identified
Table 4.2. Comparison of Electronic Health Record and Administrative Claims Data
Table 5.1. Commonly Referenced Data Sources for Understanding Better Practices for Pain
Management
Table 5.2. Commonly Referenced Data Sources for Understanding Treatment Need and Access
Table 5.3. Commonly Referenced Data Sources for Understanding Naloxone Access
Table 5.4. Commonly Referenced Data Sources for Understanding the Epidemic Through Better
Public Health Surveillance
Table 6.1. Time Frame for Potential Approaches to Implementing Successful Data-Linking
Strategies
Table A.1. National Survey Data
Table A.2. Claims and Electronic Health Records Secondary Data Sources         78
Table A.3. Mortality Records    84
Table A.4. Prescription Monitoring Secondary Data Sources    86
Table A.5. Contextual and Policy Data Sources    89
Table A.6. Other National, State, and Local Secondary Data Sources

### Abbreviations

ADAM	Arrestee Drug Abuse Monitoring	
AHRQ	Agency for Healthcare Research and Quality	
ARCOS	Automation of Reports and Consolidated Orders System	
CDC	Centers for Disease Control and Prevention	
CMS	Centers for Medicare and Medicaid Services	
DAWN	Drug Abuse Warning Network	
DEA	Drug Enforcement Agency	
DEA ACSA	Drug Enforcement Agency Active Controlled Substances Act Registrants Database	
EHR	electronic health record	
EMS	Emergency medical services	
HHS	Department of Health and Human Services	
MEPS	Medical Expenditure Panel Survey	
NAMSDL	National Alliance for Model State Drug Laws	
NAVIPPRO	National Addictions Vigilance Intervention and Prevention Program	
NDI	National Death Index	
NEMSIS	National Emergency Medical Services Information System	
NESARC	National Epidemiologic Survey on Alcohol and Related Conditions	
NPDS	National Poison Data System	
NSDUH	National Survey on Drug Use and Health	
N-SSATS	National Survey of Substance Abuse Treatment Services	
NVSS MCOD	National Vital Statistics System Multiple Cause of Death	
OEND	overdose education and naloxone distribution	
PBSS	Prescription Behavior Surveillance System	
PDAPS	Prescription Drug Abuse Policy System	
PDMP	prescription drug monitoring program	
RADARS	Researched Abuse, Diversion and Addiction-Related Surveillance System	
SAMHSA	Substance Abuse and Mental Health Administration	
STRIDE	System to Retrieve Information from Drug Evidence	
TEDS	Treatment Episodes Data Set	

### 1. Introduction

The Department of Health and Human Services (HHS) has a five-point strategy for addressing the significant social and public costs associated with the opioid crisis (see Box 1) (HHS, undated). Numerous efforts are underway to implement these strategies, which are intended to address key contributors and harms related to the opioid crisis, enhance the ability of public health officials and policymakers to monitor the crisis as it evolves, and facilitate more-informed policymaking. However, progress will also be made by identifying which research questions to prioritize, data sources

#### **Box 1. HHS Strategic Priorities**

- Better practices for pain management
- Better addiction prevention, treatment, and recovery services
- Better targeting of overdosereversing drugs
- Better data
- Better research.

to support such research, and approaches that can be used to leverage or link multiple complementary data sources. Much of the research on the opioid crisis relies on information drawn from sources outside of clinical research settings. Researchers can leverage "real-world evidence" to enhance the field's ability to address the crisis and generate new evidence to inform decisions.

The ability to link data—combining data from two or more sources to study the same individual, facility, organization, event, or geographic area—often makes it possible to enhance the value of the information obtained beyond what is available from any single source. Data sets that contain unique individual identifiers make it possible to link information from different sources at the individual level. Linkages at a more-aggregate level include analyses that merge two or more data sources at the state or county level or at a finer geographic level. Finally, while they do not directly "link" data sources, many studies analyze multiple complementary data sources (e.g., geographic spatial analyses of heroin-related emergency department visits and heroin-related deaths) to provide more-robust or comprehensive evidence of policy or program impact (Hudson, Klekamp, and Matthews, 2017). Each method has strengths and limitations, but all can contribute toward informing evidence-based policymaking (Commission on Evidence-Based Policymaking, 2017).

This report provides an overview of the types of secondary data sources currently being used or that could potentially be used to evaluate interventions or conduct other analyses that address the five-part HHS strategy. The report highlights key research questions in each area and identifies opportunities to use existing data sources and implement data-linking strategies that can support assessments of the HHS strategy. Findings are based on interviews with 16 experts—academic researchers, federal researchers, and federal program officials—

complemented by an environmental scan of the literature. This report does not address all the strengths and limitations of these data sources; rather, it is intended to provide sufficient information to serve as a resource to researchers in the field of opioids and opioid use disorder.

This report is organized as follows:

- Chapter 2 provides background information on each of the HHS Strategic Priorities.
- Chapter 3 informs the Strategic Priority of better research by presenting an overview of existing research related to the first four HHS Strategic Priorities as identified through an environmental scan, including commonly used data sources and common approaches to linking or merging data sources.
- Chapter 4 broadly categorizes the types of secondary data sources used in research related to the Strategic Priorities and provides examples of specific data sources and data elements.
- Chapter 5 describes findings identified through stakeholder discussions on key research needs and the opportunities and challenges for using secondary data sources to address those needs.
- Chapter 6 summarizes key challenges facing researchers and policymakers in studying and responding to the opioid crisis and suggests potential solutions.

Addressing the opioid crisis is one of HHS's top priorities. Therefore, HHS has developed a comprehensive strategy to empower local communities on the frontlines. In 2017, HHS unveiled a five-point strategy, encompassing (1) better pain management; (2) better treatment, prevention, and recovery services; (3) better targeting of overdose-reversing drugs; (4) better data on the crisis; and (5) better research to inform strategies to combat the crisis. In this chapter, we provide an overview of information needs and research considerations underlying each component of the strategy.

#### **Better Practices for Pain Management**

An estimated 20 percent of noncancer outpatients with pain receive opioid analgesics (Daubresse et al., 2013); those who receive such medications chronically are at significant risk of developing an opioid use disorder (Boscarino et al., 2010), characterized by persistent use that is functionally impairing (American Psychiatric Association, 2013). Growth in opioid analgesic prescribing has occurred alongside increasing rates of opioid-related misuse, emergency department visits, and deaths (HHS, 2013; Rudd et al., 2016). Efforts to minimize opioid-prescribing practices that likely lead to misuse or opioid-related harms must be balanced with maintaining appropriate, high-quality pain management for patients (Interagency Pain Research Coordinating Committee, 2015).

In recent years, federal agencies such as the Centers for Disease Control and Prevention (CDC) and Centers for Medicare and Medicaid Services (CMS) have worked with private insurers, medical educators, and other stakeholders to promote safe opioid use while limiting addiction risk (Price, 2017). National medical organizations, states, and large health systems have published clinical practice guidelines for prescribing opioids for chronic pain (Nuckols et al., 2014; Haegerich et al., 2014; Mai et al., 2015). Likewise, efforts by the Interagency Pain Research Coordinating Committee (created by HHS) and CDC have worked toward providing clinicians, researchers, and the public with recommendations concerning the prescribing and use of opioids for pain management (Interagency Pain Research Coordinating Committee, 2015; Dowell, Haegerich, and Chou, 2016). Federal agencies have also called for research and science to improve the effectiveness of existing alternative pain treatments, including nonpharmacologic options (e.g., physical or behavioral therapy) and nonopioid pharmacotherapies, and to develop treatments for pain that are safer and more effective than opioid analgesics (Volkow and Collins, 2017). While research in this area continues to develop, important questions remain about how

pain can be treated more effectively while minimizing potential unintended consequences such as dependence and overdose.

#### Better Addiction Prevention, Treatment, and Recovery Services

Opioid use disorders, which, in 2016, affected over 2.1 million people in the United States (Amhsbrak et al., 2017), contribute to medical morbidity, can promote risky behaviors, and often complicate treatment for human immunodeficiency virus (HIV) and other comorbid conditions (Becker et al., 2007; Becker et al., 2008; Johnson et al., 2013; Broz and Ouellet, 2008; CDC, 2012; Hall et al., 2008; Estrada, 2005). The availability of medication-assisted therapies has been substantially improved in part because of collaborations between HHS agencies and public and private stakeholders (Volkow et al., 2014), however, substantial gaps persist between the need for treatment and the capacity to provide it (Saloner and Karthikeyan, 2015; Jones et al., 2015; Feder, Krawczyk, and Saloner, 2017; Morgan et al., 2018; Hadland, Wharam, and Schuster, 2017). Thus, there is a critical need to better understand and address existing provider, patient, and systemic barriers to treatment (Chou, Korthuis, and Weimer, 2016; Rinaldo and Rinaldo, 2013; Shen and Zuckerman, 2005; Cunningham and Nichols, 2005; Bradley, Dahman, and Given, 2009; Schuur et al., 2009; Yoo et al., 2010; Kwiatkowski et al., 2000; Maddux and Desmond, 1997; Clark et al., 2011; Burns et al., 2016) to improve access to treatment (Watkins et al., 2017) and recovery services, and to ensure high-quality care (Chou, Korthuis, and Weimer, 2016; Gordon et al., 2016). To promote evidence-based prevention and treatment activities, \$485 million in grants were distributed in 2017 to states through the 21st Century Cures Act, with additional grants forthcoming based on further assessment of effective strategies and community needs (Price, 2017).

#### Better Targeting of Overdose-Reversing Drugs

In 2016, more than 42,000 overdose deaths involved opioids; nearly 40 percent involved heroin (Rudd et al., 2016; National Institute on Drug Abuse, 2017; CDC, 2017) and almost 45 percent involved synthetic opioids (e.g., fentanyl) (CDC, 2017). Overdose deaths often involved multiple opioids or other medications such as benzodiazepines. Overdose-reversing drugs, such as naloxone, play a critical role in preventing opioid overdose death. With the emergence of new formulations of naloxone that can more easily be administered by individuals without medical training (Merlin et al., 2015; Gupta, Shah, and Ross, 2016), efforts to encourage naloxone access and use have grown rapidly, generally through three broad mechanisms: (1) community-based distribution programs to expand community access to naloxone (Wheeler et al., 2015; Fairbairn, Coffin, and Walley, 2017), (2) state laws and protocols encouraging bystanders to summon first responders in the event of an overdose (Davis and Carr, 2015) and broadening the authority of emergency services personnel and other first responders (e.g., law enforcement) to administer naloxone (Davis, Southwell et al., 2014; Davis, Ruiz et al., 2014), and (3) policies to encourage

retail pharmacy dispensing of naloxone (Davis and Carr, 2017). Given the continued growth in opioid-overdose mortality and influx of lethal synthetic opioids, promoting access to and use of overdose-reversing drugs is essential to combat this public health crisis (Price, 2017).

#### **Better Data**

To understand effective strategies to reduce opioid misuse and associated harms and monitor the evolving crisis, data are needed that can capture trends in opioid use, risk or protective factors that influence the transition to risky use or opioid use disorder, and the risk among opioid users of experiencing mortality or other harms. Given the rapidity with which opioid use and markets have evolved over the past decade, developing and using public health surveillance systems that offer near-real-time information have become essential. Historically, death certificate and hospitalization data have been used to monitor drug use trends, but these sources often suffer from data availability lags of one or two years. Variation in medical examiner and coroner procedures in determining manner of death and the specific drugs involved in overdose deaths also presents challenges for understanding the drug overdose crisis (Ruhm, 2017; Warner et al., 2013).

Some states (e.g., Rhode Island) have made strides in improving the timeliness of reporting for overdose deaths (Rhode Island Department of Health, 2015). Improved timeliness and consistency of death certificate data can enable states and local communities to more rapidly identify and respond to overdose spikes, facilitating timelier and more appropriately tailored interventions (Houry, 2017). Federal programs, such as the CDC's Data-Driven Prevention Initiative (CDC, 2017) and Enhanced State Opioid Overdose Surveillance System (CDC, 2017), are supporting the efforts of states and local authorities to track developments in the opioid crisis and implement rapid and targeted responses (Price, 2017).

Additionally, better public health surveillance tools for monitoring medical and nonmedical use of prescription opioids can promote public health and safety. Prescription drug monitoring programs (PDMPs) are increasingly used to identify opioid analgesic prescribing trends (Katz et al., 2010; HHS, 2013; O'Kane et al., 2016) and apply risk indicators for inappropriate prescriber behavior (Ringwalt et al., 2015; Kreiner et al., 2017; Porucznik et al., 2014). Other large databases, such as all-payers claims databases, are also valuable resources for understanding the crisis, particularly if they are able to accurately link individuals over time and/or link to other relevant data sources. However, the usefulness of such systems for analyses requires a data infrastructure and legal authority for creating linked health databases that are not always available.

#### **Better Research**

Data can be linked at various levels (e.g., individual, county, state, or multilevel linkages); each approach offers benefits and challenges. Individual-level linkages and analyses are most appropriate for inferring individual-level relationships (Greenland, 2002; Robinson, 1950; Finney et al., 2011) and longitudinal data can support analyses of individuallevel prescribing or treatment trajectories as well as pathways that precede opioid harms (e.g., overdose) or entry into treatment. However, very few national data sources can be linked at the person level, and efforts to develop such linked data sources and make them more accessible must address statistical issues in generating matches when unique identifiers or full personal identifiable information are not universally available across data sets

## Box 2. General Steps for Conducting Data Linkages

- Identify the necessary data sets.
- Obtain required approvals from regulatory authorities, funding sources, and institutional review boards.
- Select the data elements that will be used to link across data sources.
- Determine the most appropriate method and matching algorithms for linking.
- If a gold standard validation method is available, assess match quality through metrics such as sensitivity, specificity, positive and negative predictive value.

(Winkler, 2006; Winkler, 1999; Kum et al., 2014; Desetzina et al., 2014; Fellegi and Sunter, 1969). Potential benefits from individual-level analyses must also be balanced with potential privacy concerns (Doshi et al., 2016; Kho et al., 2015; Ross and Krumholz, 2013). The need for data owners to maintain protections for individual privacy may also limit the ability to create person-level linked data files for research. Linking or analyzing data sources at more aggregate levels is less resource-intensive, but such analyses may be more limited in their potential to identify many key factors influencing the opioid crisis.

The general steps for conducting data linkages are outlined in Box 2 (Bradley et al., 2010; Dusetzina, Tyree, and Meyer, 2014; Dusetzina et al., 2014). Each step poses potential challenges, and the most pronounced challenges generally arise in linking data at the individual level. These include several institutional challenges for obtaining required data approvals. Linking and obtaining approvals to use data sources hosted by different agencies, which may differ in their legal obligations, interests, and resource capacities, can be burdensome, time-intensive, and costly. Even when approval is obtained, there can be substantial statistical challenges in conducting the linkages, exacerbated in data sets that lack common data elements. Choices must be made regarding how to define unique person identifiers and to determine the best method(s) for linking (e.g., deterministic or probabilistic matching, Bayesian approaches, or machinelearning techniques; see Dusetzina et al. [2014] for a recent overview); and these choices will influence the quality of matches (Campbell et al., 2008; Clark, 2004; Méray et al., 2007; Sayers et al., 2016; Asnsolabehere and Hersh, 2017). Errors that may occur during this process, such as errors of incorrectly linking records that do not belong to the same person (false positive) and errors of incorrectly failing to link records that belong to the same person (false negative) influence the rigor of subsequent analyses (Méray et al., 2007; Tromp et al., 2011).

In the following sections, we document the more-common types of data and linkages that researchers are using to advance our understanding of the opioid crisis.

# 3. Current State of the Evidence: Findings from the Environmental Scan

To gather information about data sets currently used in empirical studies, we conducted an environmental scan, with special focus on research relevant to the HHS Strategic Priorities. We also sought to identify common ways in which these data sources are being linked in existing research.

We searched the peer-reviewed and grey literature for relevant articles, complemented by a snowball approach, in which we reviewed citations and references in the articles we identified to identify additional relevant materials that may not have been captured in the original search. As part of this initial stage of work, we also conducted telephone conversations with five opioid researchers currently using secondary data sources, several of whom also participated in the stakeholder discussions described in Chapter 5, to ensure that the literature review did not miss key data sources. These conversations confirmed the use of data sources identified in the literature scan but did not identify any additional data sources. In total, we identified 278 documents that we reviewed for the scan, of which 250 were peer-reviewed publications; the remainder were largely reports, working papers, and newspaper or internet articles.

Below, we summarize the environmental scan's main findings, grouping research topics, variables, and data sources by HHS Strategic Priority. The discussion focuses on highlighting more-common research questions evaluated in the existing literature, as well as the more-common specific secondary data sources and measures used to answer such questions. Chapter 4 categorizes the types of secondary data sources used in research related to HHS Strategic Priorities, with more general discussion of differences across data source types. Other important but less commonly used data sources are described in Chapter 5.

#### **Better Practices for Pain Management**

Research has improved the understanding of opioid analgesic prescribing patterns, prescription fill behavior, and prescription characteristics predictive of misuse or opioid-related harms. Research has also improved the understanding of the effectiveness of states' efforts to advance better pain management practices. PDMPs are the most commonly studied state initiatives, with more limited research examining the effects of laws-regulating "pill mills," (i.e., clinics prescribing high volumes of opioids with limited clinical oversight), abuse-deterrent opioid formulations, pain management education, and prescribing guidelines. Table 3.1 lists data sources and measures commonly used in research related to pain management practices identified through the environmental scan.

The measures identified in Table 3.1 can be used to evaluate how PDMP implementation affects opioid-related consequences. The measures can also be used to evaluate the trends in opioid analgesic prescribing and associations with risky prescribing or opioid-related harms.

Data Type	Commonly Used Sources	Commonly Used Measures
Commercial insurance claims	<ul><li>IQVIA</li><li>Marketscan</li><li>Health Care Cost Institute</li></ul>	<ul> <li>Opioid analgesic prescriptions</li> <li>Prescribing patterns or prescription-fill behavior indicative of misuse</li> <li>Morphine equivalent daily dose (MEDD)</li> <li>Payment type (e.g., Medicare Part D, cash)</li> </ul>
Medicaid claims	<ul> <li>Medicaid State Drug Utilization file</li> <li>State Medicaid data sources</li> </ul>	<ul> <li>Opioid analgesic prescriptions</li> <li>Prescribing patterns or prescription-fill behavior indicative of misuse</li> <li>MEDD</li> <li>Diagnostic codes for nonfatal overdose</li> <li>Payment type</li> </ul>
Medicare claims	Medicare Prescription Drug Event data linked to Medicare Beneficiary Summary File	<ul> <li>Opioid analgesic prescriptions</li> <li>Prescribing patterns or prescription-fill behavior indicative of misuse</li> <li>MEDD</li> <li>Diagnostic codes for nonfatal overdose</li> <li>Payment type</li> </ul>
Electronic health records (EHRs) and claims data	<ul> <li>National or regional Veterans Health Administration (VHA) data warehouses</li> </ul>	<ul> <li>Opioid analgesic prescriptions</li> <li>MEDD</li> <li>Indicators of prescription opioid abuse or dependence</li> <li>Clinical diagnoses (e.g., pain conditions)</li> </ul>
PDMP data	State PDMPs	<ul> <li>Opioid analgesic prescriptions</li> <li>MEDD</li> <li>Prescribing patterns or prescription-fill behavior indicative of misuse</li> </ul>
Mortality data	<ul> <li>National Death Index (NDI)</li> <li>National Vital Statistics System Multiple Cause of Death (NVSS MCOD)</li> <li>CDC WONDER</li> <li>State death certificate data</li> </ul>	<ul> <li>Opioid overdose fatality</li> <li>Injury intent (e.g., suicide, accidental)</li> </ul>
Policy data	<ul> <li>Prescription Drug Abuse Policy System (PDAPS)</li> <li>National Alliance for Model State Drug Laws (NAMSDL)</li> </ul>	<ul><li>PDMP enactment</li><li>PDMP design features</li></ul>

Table 3.1. Commonly Used Data Sources and Measures in Research to Advance Better Pain
Management Practices

Several common research questions can be addressed using a single data source. For example, research evaluating time trends or geographic variation in opioid analgesic prescribing

among the general population has used information from state-specific PDMPs or from commercial insurance claims such as IQVIA. Other studies have assessed prescribing practices within the Medicaid, Medicare, or veteran populations using administrative claims or EHR data sets specific to those populations. Five opioid-related indicators and their respective algorithms developed by CMS for researchers to use with Medicaid and Medicare administrative claims data were recently made available for public comment (CMS, 2018); these indicators are planned for inclusion in the CMS Chronic Conditions Data Warehouse.

However, other research questions rely on linked data sets. Research evaluating the effects of PDMP implementation on opioid-related consequences commonly merges state-level policy data with state- or county-level data on opioid prescription claims or rates of fatal opioid overdose from the NVSS MCOD microdata, CDC WONDER, or state-specific death certificate data.

These analyses also generally control for state- or county-level factors linked from other data sources, such as those noted in Table 3.2. The commonly used state- or county-level measures in Table 3.2 can be linked with data on opioid-related consequences and state policy data to control for potential time-varying community-level confounders correlated with opioid outcomes of interest. These measures can also be used to estimate how community-level factors relate to opioid analgesic use and associated harms. Community-level factors of interest generally include socioeconomic factors (e.g., unemployment rate), demographics (e.g., percentage population male), or measures of health care infrastructure (e.g., physicians per capita).

Data Sources	Commonly Used Measures
Bureau of Economic Analysis	<ul> <li>Unemployment rate</li> <li>Per capita income</li> </ul>
Area Resource Files or Health Resources Files	<ul> <li>Unemployment rate, per capita income, urban-rural status</li> <li>Demographics (e.g., age, sex, race/ethnicity distribution)</li> <li>Number of hospital beds per capita, physician density</li> </ul>
American Community Survey	<ul> <li>Poverty rates, unemployment rate, education distribution</li> <li>Median home prices, median age of housing stock</li> <li>Demographics (e.g., age, sex, race/ethnicity distribution)</li> <li>Rates of public and private health insurance coverage</li> </ul>
Current Population Survey	<ul> <li>Rates of health insurance coverage</li> <li>Demographics (e.g., age, sex, race/ethnicity, marital status)</li> <li>Unemployment rate; poverty rates</li> </ul>
CMS	Rates of Medicaid and/or Medicare coverage

 Table 3.2. Contextual Data Sources and Measures Commonly Linked to Opioid Outcome Data in

 Research Related to the Five-Point HHS Strategy

Studies evaluating the association of opioid analgesic prescribing patterns or prescription-fill behavior with opioid-related harms often require data sources linked at the individual level.

Noted data-linkage strategies include linking state-specific PDMP data with other data sources, such as Medicaid administrative claims, hospital discharge data, or vital records; using multiple linked VHA databases, which have also been linked at the individual level to mortality data from the NDI; linking Medicaid claims with state vital records data; and using Medicare Prescription Drug Event data linked with the Medicare Beneficiary Summary file. While not commonly used in existing opioid-related research, information from the Medicare Current Beneficiary Survey, a survey of a nationally representative sample of Medicare beneficiaries released three times annually, has been linked at the patient-level to Medicare billing claims (Wright et al., 2014).

#### Better Addiction Prevention, Treatment, and Recovery Services

Researchers commonly evaluate how policies intended to expand the number of waivered buprenorphine prescribers (i.e., prescribers who have received a waiver from the Drug Enforcement Agency (DEA) allowing them to prescribe buprenorphine for the treatment of opioid use disorder) relate to buprenorphine prescribing, factors that predict the availability of waivered prescribers, and factors associated with the monthly patient censuses of waivered prescribers. Some studies investigate patterns of buprenorphine use among those receiving opioid use disorder treatment. Data sources and measures commonly used in research related to opioid use disorder and treatment are shown in Table 3.3.

The measures in Table 3.3 may be used to evaluate trends and geographic variation in treatment need and opioid agonist treatment capacity, as well as associations between individuallevel characteristics, opioid analgesic use, and opioid use disorder. They can also be used to evaluate trends, geographic variation, and factors associated with buprenorphine physician supply. Lastly, they can be used to evaluate national trends and patient trajectories in treatment for opioid use disorder.

### Table 3.3. Commonly Used Data Sources and Measures in Research to Improve Addiction Prevention, Treatment, and Recovery Services

Data Type	Commonly Used Sources	Commonly Used Measures
Commercial insurance claims	<ul><li>IQVIA</li><li>Symphony Health</li></ul>	<ul> <li>Buprenorphine prescriptions</li> <li>Patient censuses of buprenorphine prescribers</li> </ul>
PDMP data	State-specific PDMPs	<ul><li>Buprenorphine prescriptions</li><li>Patient censuses of buprenorphine prescribers</li></ul>
Medicaid claims	<ul> <li>National or state Medicaid data sources</li> </ul>	<ul> <li>Buprenorphine prescriptions</li> <li>Patient censuses of buprenorphine prescribers</li> <li>Opioid use disorder diagnoses</li> </ul>
EHR	<ul> <li>HealthCore Integrated Research Database</li> <li>Group Health Cooperative</li> <li>National or regional VHA data warehouses</li> </ul>	<ul> <li>Prescription opioid abuse or dependence</li> <li>Diagnostic measures of pain</li> <li>Opioid analgesic prescriptions</li> <li>Other clinical diagnoses, comorbidities, demographic characteristics</li> </ul>
Household surveys	<ul> <li>National Survey on Drug Use and Health (NSDUH)</li> <li>National Epidemiologic Survey on Alcohol and Related Conditions (NESARC)</li> </ul>	<ul> <li>Opioid use disorder treatment need</li> <li>Treatment source or source of payment</li> <li>Opioid use disorder</li> <li>Nonmedical prescription opioid misuse</li> <li>Other substance use disorders, mental health conditions, and demographic characteristics</li> </ul>
Treatment facility surveys	<ul> <li>Treatment Episodes Data Set-Admissions (TEDS-A)</li> <li>National Survey of Substance Abuse Treatment Services (N- SSATS)</li> </ul>	<ul> <li>Number of patients receiving methadone in opioid treatment programs (OTPs)</li> <li>Outpatient operating capacity of OTPs</li> <li>Number of substance abuse treatment programs providing methadone and/or buprenorphine</li> <li>Substance abuse treatment services offered</li> <li>Number of treatment admissions for opioid use disorder</li> </ul>
Provider census	<ul> <li>Substance Abuse and Mental Health Services Administration (SAMHSA) database</li> <li>DEA Active Controlled Substances Act Registrants Database (ACSA)</li> </ul>	<ul> <li>Number of buprenorphine providers</li> <li>Waiver limits</li> <li>Buprenorphine treatment capacity</li> </ul>
Policy data	RAND/National Conference of State Legislators Survey	<ul> <li>State Medicaid reimbursement policies for buprenorphine</li> </ul>

Research studying associations between individual-level characteristics, opioid analgesic use, and opioid use disorder leverages data sources that contain person-level information on these measures within the same data set. Relevant data sources include household surveys such as the NSDUH series managed by SAMHSA, NESARC sponsored by the National Institute on Alcohol

Abuse and Alcoholism, as well as EHR and claims data from various sources (Table 3.3). Research examining trends or geographic variation in demand or capacity for opioid use disorder treatment instead often uses measures from treatment facility surveys, such as the TEDS-A or N-SSATS, both of which are maintained by SAMHSA.

While studies assessing trends or geographic variation in treatment need and treatment capacity may advance research using measures from a single data source, a more comprehensive picture of the relationship between demand for and supply of treatment has been obtained by linking data sources. For example, studies estimating treatment shortage areas commonly merge information on treatment need with information on treatment capacity at the state- or county-level.

Researchers have also used data linkages to better understand factors associated with buprenorphine prescriber supply and buprenorphine utilization. Information on buprenorphine prescriber locations is available through two commonly used sources: SAMHSA's Buprenorphine Waiver Notification System or the Drug Enforcement Agency Active Controlled Substances Act Registrants database (DEA ACSA). Information on buprenorphine prescriptions often comes from insurance claims data or PDMP data. By linking information on buprenorphine prescribers or prescriptions with state-level policy and county-level contextual factors relevant for opioid use disorder treatment, research can improve the understanding of factors associated with buprenorphine treatment capacity and utilization.

#### Better Targeting of Overdose-Reversing Drugs

The most commonly studied interventions promoting use of overdose reversing drugs are community-based overdose education and naloxone distribution (OEND) programs. Emerging evidence focuses on state laws intended to increase naloxone access through retail pharmacy distribution channels (Naloxone Access Laws) or to encourage community bystanders to summon emergency aid or administer naloxone in the event of witnessing an overdose (Good Samaritan Laws). Table 3.4 lists the most commonly used variables and secondary data sources identified in research related to overdose-reversing drugs.

The measures noted in Table 3.4 can be used to evaluate trends or geographic variation in the distribution of naloxone through retail pharmacies, presence of community-based OEND programs, and naloxone administrations by emergency medical services (EMS) personnel. They can also be used to study how state naloxone policies influence opioid overdose mortality or the role of OEND programs in impacting knowledge about how to respond to a witnessed overdose, distribution of naloxone kits and naloxone administrations, and overdose reversals.

Data Type	Commonly used sources	Commonly used measures
Commercial insurance claims	• IQVIA	<ul> <li>Naloxone prescriptions through retail pharmacy channels</li> <li>Prescriber specialty</li> <li>Patient age, gender</li> </ul>
Mortality data	• CDC WONDER • NVSS MCOD	<ul> <li>Opioid analgesic overdose deaths</li> <li>Heroin overdose deaths</li> <li>Synthetic opioid overdose deaths</li> </ul>
OEND program data	<ul> <li>Massachusetts Opioid Overdose Prevention Pilot Program</li> <li>Harm Reduction Coalition</li> </ul>	<ul> <li>Reported overdose reversals</li> <li>Number of naloxone administrations</li> <li>Number persons trained and naloxone kits distributed</li> <li>Knowledge about how to respond to a witnessed overdose and administer naloxone</li> </ul>
EMS data	NEMSIS	<ul> <li>EMS naloxone administration</li> </ul>
Policy data	<ul> <li>PDAPS</li> <li>Network of Public Health Law (NPHL)</li> <li>Legal databases</li> </ul>	<ul> <li>Good Samaritan laws</li> <li>Naloxone access laws</li> </ul>

## Table 3.4. Commonly Used Data Sources and Measures in Research to Inform Better Targeting of Overdose-Reversing Drugs

Research on policies or programs to expand naloxone use often rely on data from a single source. Studies of the effects of community-based OEND programs on overdose knowledge and outcomes generally rely on case studies using surveys of OEND program participants or other data collected by the specific OEND programs. Other research has documented the evolution of state laws governing naloxone access and use, drawing on review of legal databases to obtain information about state policies related to naloxone access and use for community bystanders or first responders. Finally, some studies have described trends in naloxone distribution through different channels using retail pharmacy naloxone distribution (IQVIA) or EMS naloxone administration (National Emergency Medical Services Information System [NEMSIS]).

Data linkages are most commonly used to examine the effects of state naloxone policies or OEND programs on opioid overdose. Such research commonly merges state- or county-level mortality data from the NVSS MCOD microdata or CDC WONDER with state-level information on naloxone access policies or Good Samaritan Laws compiled by the Prescription Drug Abuse Policy System (PDAPS) or the NPHL program. Studies of state naloxone policy effects also commonly control for other state- or county-level contextual factors as described in Table 3.2. Other state-specific analyses use multiple complementary data sources to examine whether implementation of a community OEND program (Albert et al., 2011) influences trends in emergency department visits for substance abuse and accidental poisonings, opioid overdose mortality, and outpatient-dispensed controlled substances.

#### **Better Data**

Researchers concerned with surveillance often use multiple complementary data sources to better understand trends and disparities related to the opioid crisis, develop methods to improve monitoring through existing public health surveillance systems (e.g., EHR, emergency department encounter data), identify patients at high risk of prescription opioid misuse or abuse, and promote improved opioid toxicosurveillance (i.e., rapid analysis of drug exposure data). Below we briefly describe the data sources and measures most commonly used to strengthen public health surveillance research.

Much public health surveillance research uses near-real time surveillance tools to better understand product-specific abuse and emerging trends. Three databases have been designed to provide near-real-time surveillance data on opioid misuse: the Researched Abuse, Diversion and Addiction-Related Surveillance System (RADARS), the National Addictions Vigilance Intervention and Prevention Program (NAVIPPRO), and the Prescription Behavior Surveillance System (PBSS). The RADARS and NAVIPPRO compile information on opioid use, consequences, and markets from multiple sources; the PBSS compiles state-specific PDMP information from several states. In addition, opioid overdose information collected from poison control centers through the National Poison Data System (NPDS) has been used by research and surveillance efforts to capture product-specific opioid overdose events that may not result in death.

Data costs or other barriers to access may limit widespread use of these systems in existing research; however, they are increasingly used in studies related to problematic opioid use and product-specific abuse trends. Data collected through online social media has also been increasingly used to monitor illicit or problem opioid use (Parker et al., 2017; Katsuki et al., 2015; Anderson et al., 2017).

Significant progress has been made in developing metrics and leveraging existing surveillance systems to better detect opioid misuse or potentially inappropriate prescribing. As detailed in the prior sections, information on opioid prescriptions and opioid misuse indicators are available through multiple data sources, including claims and EHR data. State-specific PDMP data and all-payers claims databases (APCDs) are also emerging as useful data sources to better understand opioid prescribing and potential misuse. While we identified fewer studies examining illicit opioids, some studies have used local law enforcement data on drug seizures or arrests to better understand heroin markets, illicit opioid analgesic markets, and illicit markets for synthetic opioids. Other research using RADARS, NAVIPPRO, and the NSDUH has examined sources of prescription opioids and measures of prescription opioid diversion.

A common data-linking strategy for public health surveillance is to leverage multiple data sets and conduct complementary analyses of state- or county-level information to better understand the evolution of the opioid crisis. For example, studies have linked individual-level prescription data from PDMPs or Medicaid claims with state death certificate data to examine trends in prescribing behavior preceding overdose death.

States are also implementing strategies to better link and analyze data across state agencies. For example, with Chapter 55 of the Acts of 2015, Massachusetts' Department of Public Health has connected ten data sources managed by five state agencies to develop a data warehouse structure. These data sources include the state APCD; the Massachusetts PDMP; death certificate records and toxicology results; substance abuse treatment information; hospital, emergency department, and outpatient records; incarceration and criminal justice system treatment records; and emergency medical service incident data from licensed ambulance services. Chapter 55 is discussed further in Chapter 6 of this report. In Chapter 3, we provided an overview of the more commonly identified research questions that secondary data sources have been used to examine, organized by HHS Strategic Priorities. However, our environmental scan uncovered a broader array of existing data resources relevant to the HHS Strategic Priorities. In Table 4.1, we categorize and describe the types of additional secondary data sources and provide examples of common data sources and variables within e

Box 3. Major Sources of Secondary Data

- National surveys
- Claims and EHR data sources
- Mortality record data sources
- Prescription drug monitoring data sources
- Contextual and policy data sources
- Other national, state, or local data sources

of common data sources and variables within each type.

Box 3 highlights the six broad sources of data we identified: (1) national surveys, (2) EHR and claims data, (3) mortality records, (4) prescription drug-monitoring data, (5) contextual and policy data, and (6) other national, state, or local data sources (e.g., national poison control center data, state arrest records). The full data inventory provided in the appendix to this report contains more-detailed information on each identified data set within these broader categories. This information includes the agency hosting the data and type of data; a high-level summary of data content, including geographic coverage, timing of collection or data availability, and important measures; information on accessing the data, including a link to the website, information on access costs, and other restrictions; a link to any available analytics; and information on linking capability.

#### Table 4.1. Data Source Categories Identified

Data Description	Summary	Examples of Important Measures	Data Source Examples
National surveys	<b>Description</b> : Generally household or school-based surveys with self- reported information on drug use and health; other surveys are of hospitals, treatment facilities, or other medical service providers <b>Geographic coverage</b> : National <b>Timing</b> : Generally collected and available annually	Prescription opioid use, heroin use, opioid use disorder, medical conditions, health care utilization	National Survey on Drug Use and Health, National Ambulatory Medical Care Survey, National Survey of Substance Abuse Treatment Services Data, Medical Expenditure Panel Survey
EHR	<b>Description</b> : An EHR contains the medical and treatment histories of patients. However, it often contains more than standard clinical data, and may also include a broader view of a patient's care. EHRs may contain a patient's medical history, diagnoses, medications, treatment plans, allergies, radiology images, and laboratory and test results <b>Geographic coverage</b> : Varies by source <b>Timing</b> : Near-real time or real-time collection	Previously prescribed opioids or other medications; patient history, medications, clinical conditions, treatment plans, and lab/test results; may include clinician notes	Stanford Translational Research Integrated Database, HealthCore Integrated Research Database, Group Health Cooperative in Washington State
Claims data	<b>Description</b> : Patient-level claims data for reimbursement for services submitted by health care providers and pharmacies to insurance companies. Validated algorithms to identify opioid misuse or abuse from claims data are being developed <b>Geographic coverage</b> : Varies by source <b>Timing</b> : Varies by source	Prescription drug utilization; service utilization	IQVIA, Symphony Health, Truven Marketscan data, Medicaid claims, Medicare Part D Prescription Drug Event data
Mortality records	<b>Description</b> : Death rates and causes of death by drug compound and/or International Classification of Diseases code. Additional information can include toxicology reports <b>Geographic coverage</b> : National or single state <b>Timing</b> : Generally available annually	Rates of opioid-involved deaths; drugs involved in overdose deaths	CDC WONDER Multiple-cause-of death data; Fatal Accident Reporting System; NDI
Prescription monitoring data	<b>Description</b> : Data systems to track and monitor the distribution or prescription of controlled substances <b>Geographic coverage</b> : Varies by source <b>Timing</b> : Varies by source	Opioid prescribing rates (by type); indicators of "doctor shopping," coprescribing of opioids and other controlled drugs, geographic variation in opioid distribution	Automation of Reports and Consolidated Orders System (ARCOS); state prescription drug–monitoring programs
Contextual and policy data	<b>Description</b> : Causal analyses of the effects of policy changes on opioid-related outcomes generally use data on state laws from these sources and/or includes controls for state or county characteristics to support causal interpretation <b>Geographic coverage</b> : National <b>Timing</b> : Varies, but generally semiannually	State opioid policies, state and county demographic and socioeconomic factors, state and county health care variables	Area Health Resources Files, Policy Surveillance System, PDAPS
Other national, state, and local sources	<b>Description</b> : Includes data collected through law enforcement, national public health surveillance systems (e.g., poison control center data, emergency department visit data), OEND program data, other hospitalization and emergency department data <b>Geographic coverage</b> : Varies by source <b>Timing</b> : Varies by source	Law enforcement drug seizures, nonfatal opioid overdose, opioid- related emergency department visits and hospitalizations, naloxone distribution through community organizations	NEMSIS, NPDS, HCUP emergency department and hospitalization data

#### **National Surveys**

National survey data sources, often collected annually, include population-based surveys, such as household surveys or school-based surveys, as well as surveys of medical providers, hospitals, emergency departments, and treatment facilities. Population-based surveys often include self-reported information on lifetime or current heroin or opioid analgesic use, symptoms of opioid use disorder, and treatment or unmet treatment need for opioid use disorder; as well as a variety of measures describing respondent demographics, socioeconomics, and other mental health or substance use behaviors. Systematic data collection over time supports trend analyses at the national and sometimes state or local level; however, significant changes to survey design or implementation may limit longitudinal comparisons.

One caveat with regard to many national population-based surveys is that they restrict their sample to the civilian, noninstitutionalized population, thus excluding some high-risk groups, such as homeless individuals not residing in shelters and incarcerated individuals. However, a few national surveys, such as the Arrestee Drug Abuse Monitoring System (ADAM) and the National HIV Behavioral Surveillance System, have focused specifically on high-risk populations, arrestees, and persons at risk for HIV infection.

Other national survey data-collection efforts gather information from hospitals, emergency departments, and outpatient departments. These data sources offer information on prescriptions received through various health care settings as well as acute health care visits attributable to opioid use or misuse; data from three of these surveys have been integrated into the National Hospital Care Survey (CDC, 2015). Finally, national surveys of mental health or substance abuse treatment facilities collect information relevant to treatment utilization and treatment capacity for opioid use disorder.

While most national survey data sources (with some exceptions, see Table A.1 in the appendix) allow public access at no cost, access to certain data elements may be restricted. Restricted data elements often include geocoded variables that would allow analyses or linkages at the state or substate level. Obtaining access to these geocoded variables typically involves an application process; use of such information is often only allowed through a Research Data Center (U.S. Census Bureau, 2015) or other secure access data portal and, in some cases, is restricted to use by federal employees. Similarly, while several national surveys permit person-level linkages with other national data sources (e.g., the National Health Interview Survey [CDC, 2017] supports person-level linkages with the NDI, Medicare data sources, and AHRQ's Medical Expenditure Panel Survey) upon approval of the research project, access to the linked files is typically only permitted through secure Research Data Centers. Currently, national survey data from substance use treatment facilities may not be linked to units below the county level.

#### Electronic Health Records and Claims Data

An EHR is an electronic version of a patient's medical history. It may include a variety of key clinical data, including demographics, medical history, medications, progress notes, problems, and other physician or nurse documentation. Efforts to expand the adoption and use of EHRs have been focused primarily on improving the quality of health care (Appari et al., 2013; Blumenthal and Tavenner, 2010; Campanella et al., 2016). However, there has been growing interest in using EHR data for public health surveillance and response efforts (Friedman, Parrish, and Ross, 2013; Coorevits et al., 2013). EHRs have been proposed as a tool to help practitioners implement better pain assessment and management practices (Anderson et al., 2016; Harle et al., 2014), as well as a potential data resource to better identify factors associated with opioid misuse, adverse events, or development of opioid use disorder (Lingren et al, 2018; Hser et al., 2017; Green et al., 2017; Carrell et al., 2017). Typically available in real time, EHR systems may contain a variety of measures, such as health behaviors indicative of opioid misuse, that may not be needed for billing purposes and thus would not be captured in claims data. For example, EHRs may contain relevant laboratory values, such as urine drug screens, as well as allowing a calculation of abandoned opioid analgesic prescriptions (prescriptions that are written but never filled by patients).

However, there are several challenges to using EHR data, including issues with fragmented or incomplete data, the need for text note processing and validation, and a lack of consistency in methods to assess EHR data quality (Madden et al., 2016; Weiskopf and Weng, 2013; Häyrinen, Saranto, and Nykänen, 2008; Raghupathi and Raghupathi, 2014). Data-quality concerns can generate serious issues in determining unique patient identifiers, which in turn creates errors in person-level record linkage with other data sources (McCoy et al., 2013; Murray, 2014). Challenges with gaining approvals and access to EHR data may also restrict the use of EHR data in secondary research (Russo et al., 2016).

Table 4.2 compares EHR and administrative claims data sources. Because claims data are intended to support reimbursement for services submitted by health care providers and pharmacies to insurance companies, they tend to have fewer data-quality issues, have a more-standardized structure and method for entering data, and assign standardized definitions for data-point entry. Claims records can come from data sources hosted by a single federal insurer, single state insurer, integrated database of a privately insured population, multipayer claims database owned by a private agency, or state all-payer claims database. While access restrictions are often not as burdensome as those for EHR data, the required approval process and costs of obtaining person-level claims data may be a barrier to use for research purposes.

#### Table 4.2. Comparison of Electronic Health Record and Administrative Claims Data

	EHR Data	Insurance Claims Data
Coverage or source of data set (examples)	<ul> <li>Single institution (private)</li> <li>Health information exchanges or group health network</li> <li>National or regional VHA systems</li> </ul>	<ul> <li>Commercial claims from private payers</li> <li>Federal and state claims (Medicaid, Medicare)</li> <li>Integrated databases with medical and pharmacy claims</li> </ul>
Potential scope of patients	All patients, including those with no insurance coverage (in systems that have adopted an EHR)	Insured patients, may be restricted to single payer population
Breadth of data	Richer data but greater variability in data element availability	More limited set of data elements but more standardized collection
Prescription data	Information on whether medication was prescribed, not whether it was filled or refilled	Detailed information on filled prescriptions and refilled prescriptions (assuming there was a claim)
Data structure and quality	Data format, completeness, and overall quality can vary greatly. Researcher may need to operationalize how variables of interest are defined, and this may look different with different EHRs	Fairly standardized claim data formats, although data warehouse structures can vary by payer. Variables (e.g., diagnostic codes, drug dispensing) typically well-defined and complete when required for payment
Data access	May require on-site access, remote access may be restricted to limited data set, security protocols, costs unclear	Costs vary depending on request. Some data must be requested and approved. Varying privacy levels for some CMS Medicaid and Medicare files

#### Mortality Records

Information on opioid overdose mortality from death records and postmortem toxicology data can be obtained from state-specific death certificate or from national data sets that compile death certificate data submitted by states into a single source. There are three primary sources for national data on mortality, one of which (CDC WONDER [CDC, 2018]) is publicly available, does not carry fees, and supports readily downloadable data files through an easy-to-use online system. However, the public version of the multiple-cause-of-death files provided through CDC WONDER masks subnational estimates in which fewer than ten deaths occurred. Thus, for county- or state-level analyses stratified by demographic variables—where cell sizes may become quite small—obtaining access to the underlying NVSS MCOD microdata may be necessary (national opioid mortality data analytics are available online [CDC, 2017]). While one limitation of mortality data is the long lag time for data to become available, the Vital Statistics Rapid Release Provision Drug Overdose Death Counts (CDC, 2018) is an effort by the National Center for Health Statistics to provide timelier information on drug overdose mortality based on provisional fatality counts from the NVSS MCOD.

While both CDC WONDER and NVSS MCOD support linkages and county-level analyses, person-level linkages with national geographic coverage are only supported through the NDI, a centralized national database of death records that is not available to the general public, has a fee schedule with charges per record requested, and entails costs to obtain cause-of-death information. The NDI can be linked at the individual level to multiple other data sources, including national surveys, VHA health care data, and other national or state sources. State death records, while not publicly available, can also be linked at the person level to other state-specific databases, including PDMP data.

#### Prescription Drug–Monitoring Data

Prescription drug–monitoring data sources are those designed to monitor controlled substance prescribing, distribution, or dispensation. These include a federal database monitoring national distribution of controlled substances from manufacture to sale (i.e., ARCOS) as well as state PDMP systems, electronic databases generally hosted by a state licensing, health, or criminal justice agency and intended to track controlled prescription drugs dispensed to patients within the state (Pardo, 2017). The lag time for data reporting, degree of coverage, ability to identify providers, and specific measures captured within a given PDMP system vary across states depending on the state law regulating the PDMP (Greenwood-Ericksen et al., 2016; Manasco et al., 2016).

States also vary in the degree to which their state PDMP system allows interstate information sharing, authorizes access for research and public health purposes, and/or permits person-level linkage to other state-owned data sources. As of December 5, 2017, 48 states and U.S. territories

are authorized to provide de-identified PDMP data to researchers, and 25 of these states have released PDMP data for research, epidemiological, or educational purposes (PDMP, 2017).

#### Contextual and Policy Data

Contextual data sources are generally used in opioid research to assess state- or county-level factors associated with opioid-related outcomes or to account for time-varying state- or county-level demographic, health care, or socioeconomic factors that may confound estimation in analyses of policies targeting opioid use, treatment, or opioid-related harms. When used in research related to the HHS strategic areas, measures derived from contextual data sources are generally obtained at more aggregate levels (e.g., state, county) or are aggregated up from person-level data sources to the state or county level.

Most contextual data sources are hosted by federal agencies, although some private organizations (e.g., Kaiser Family Foundation) and some federal entities (e.g., the Health Resources and Services Administration) compile information from several federally hosted contextual data sources into a single location and also maintain their own data sources. Depending on the source, data may be representative at the state or substate level, with supported linkage or unit of analysis as finely geographically detailed as the ZIP level (e.g., the U.S. Census Bureau Zip Code Business Patterns data) (Cerdá et al., 2017), although this level of detail is generally not available in public data sets. Additionally, contextual information compiled from national person-level survey data sources (e.g., the Current Population Survey) is less likely to be representative at the substate level (Blewett and Davern, 2006) or to provide microdata for all counties. Reviewing all contextual data sources identified through the environmental scan was outside the scope of this project. However, we highlight a few of the most commonly used data sources in Table A.5 in the appendix.

Policy data sources capture information on state opioid policies and thus are generally analyzed and linked using state as the unit of analysis. A variety of agencies, including federal, federally funded, and private organizations, collect information on state opioid policies. Information on state PDMP policies, naloxone access laws, and Good Samaritan laws have been compiled by several sources, including PDAPS and NAMSDL, although these sources often vary in the exact classification they use to define the components and timing of such laws. In many cases, policy data are publicly available at no cost. However, free and publicly available policy data are often not provided in analytic formats or as a historical data set; instead, they often represent a "snapshot" of current policies. Additionally, few data sources are available that systematically track and provide information on how state opioid policies are being implemented, note changes in local efforts related to the opioid crisis (e.g., law enforcement carrying naloxone), or describe large-scale opioid policies or guidelines implemented by payers or health care systems to address opioid prescribing.

#### Other National, State, and Local Sources

Several data sources relevant to the HHS opioid strategies do not directly fit within any of the aforementioned categories. These include national censuses of waivered buprenorphine providers; national proprietary data systems, such as RADARS, that combine information from various sources to describe and surveil misuse, abuse, and diversion of prescription drugs; and national data on emergency medical services utilization such as NEMSIS, drugs seized by law enforcement, and calls to poison control centers.

This data source category also includes a suite of national- and state-level data products capturing hospital inpatient stays and hospital-based emergency department visits available through the Healthcare Cost and Utilization Project (HCUP), managed by the Agency for Healthcare Research and Quality (AHRQ). Access to the state or national HCUP data files must be applied for and purchased; however, the HCUP website offers a publicly available online query system (Agency for Healthcare Research and Quality, 2018) and a limited set of user-friendly graphics and tables showing state and national trends in opioid-related inpatient stays and emergency department visits (Healthcare Cost and Utilization Project, 2018). Finally, increased public attention to the opioid crisis has led to the emergence of online state opioid data-compilation efforts; as well as increased attention to data sources that may capture the complex role of clinical conditions, health care delivery and access, prescribing, and opioid misuse or development of opioid use disorder (see Box 4 for examples).

#### Box 4. Other Data Sources Relevant to the HHS Strategic Priorities

The data inventory was intended to provide an overview of commonly used secondary data sources in research related to the HHS strategic areas. It is not an exhaustive list of secondary data currently or potentially available to further our understanding of the opioid crisis. We here note several data sources that are not commonly used in existing research, but may be of interest.

- State opioid dashboards provide state statistics related to the opioid crisis. Examples include
  - Arizona Department of Health Service's Arizona's Real-Time Opioid Data (2017–2018)
  - Minnesorta Department of Public Health's Opioid Dashboard (undated)
  - Tennessee Department of Health's Drug Overdose Dashboard (undated)
- National opioid data collections compile or support the compilation of relevant data from a variety of sources into a single location. Examples include
  - Opioid and Health Indicators Database by amfAR (undated), the Foundation for AIDS Research
  - Opioid Mapping Initiative (undated), an open-data project with several participating local governments and local agencies
- PCORNet Clinical Data Research Networks include a range of participating health care-based networks (pcornet, undated) engaged in partnering to link claims and EHR data. These include resources such as the Chicago Area Patient Centered Outcomes Research Network (Capricorn, undated) and OCHIN's Data Warehouse (OCHIN, 2014–2018)
- The Health Resources and Services Administration (HRSA)'s Health Center Program offers several resources, including
  - HRSA's Uniform Data System (HRSA, 2018) provides publicly available aggregate data on patients who have opioid use disorder diagnoses or who are receiving medication-assisted treatment through HRSA-funded health center grantees and lookalikes.
  - The Health Center Patient Survey (HCPS) data, made available with support from Assistant Secretary for Planning and Evaluation, provides information on health center patients' conditions and demographics, health behaviors, service use, and satisfaction (HRSA, undated).

To assess high-priority research areas and data efforts relevant to the HHS strategy, we conducted a set of stakeholder discussions to gather insights into opportunities to enhance data collection and data linkages. In consultation with staff within the Office of the Assistant Secretary for Planning and Evaluation, we identified 25 key stakeholders with particular expertise or research experience related to the HHS strategy, 16 of whom participated in phone discussions. Each discussion was tailored and focused on the HHS strategy about which the stakeholder was most knowledgeable.

In this section, we highlight themes that emerged from stakeholder discussions of research opportunities using secondary data sources to support the HHS strategy. We also provide a table summarizing strengths and limitations of data sources that stakeholders referenced with respect to each Strategic Priority. The appendix to this report provides additional data source details.

#### **Better Practices for Pain Management**

Common themes emerging from discussions related to key research aims for advancing better practices for pain management include:

- **Opioid prescribing guidelines and clinician education**: Better documentation of opioid-prescribing guidelines and clinician education requirements, linked with outcome data at the prescriber or patient level, would shed light on how variation in these protocols relates to variation in treatment for pain, and how this in turn impacts patient outcomes.
- Nonopioid treatments for pain: Opioid analgesics may not be more effective than other treatments in the management of many tyes of long-term pain (Krebs et al., 2010; Krebs et al., 2018). More evidence is needed regarding the full range of long-term effective treatments for chronic pain, including combinations that might be more effective than opioid analgesics.
- Patient trajectories: Longitudinal patient-level data linking prescriptions with outcomes can enhance better understanding of the pathways and sequences of events leading to adverse outcomes such as hospitalization and overdose death. Medicaid and commercial claims data can be useful, but each provide information on only one population and often cannot track individuals when they transition across different types of insurance (Table 5.1). APCDs (in states that have them) provide a comprehensive picture of health care claims across a state's insured population to track utilization and compare rates across different populations with different types of insurance, although the ability to track patients across changes in insurance varies by state (The Commonwealth of Massachusetts, Executive Office of Human Services, Department of Public Health, 2017).

Table 5.1 highlights common data source strengths and limitations noted during stakeholder discussions regarding better practices for pain management. Key takeaways regarding the advantages and limitations of various data source types include the following:

- Overall, EHR, PDMP, and claims data can provide detailed information on prescription characteristics and payment, but the systems may not allow longitudinal follow-up of a given individual across longer periods of time or across insurance coverage transitions.
- While commercial claims and PDMP data may have strengths in capturing information from multiple payers, Medicaid claims and VHA data warehouses appear to better support individual-level linkages with other national-level data sources, such as national mortality records.
- The ability to conduct cross-state analyses may bolster research examining the effects of interventions on prescribing outcomes, and the compilation of historical information on PDMP enactment in several data sources has supported such research.
- Other efforts to target opioid prescribing (e.g., guidelines, prescribing limits) have not yet been systematically collected in a way that facilitates research on their effects.

Data Type and Example Sources	Strengths	Limitations
Commercial claims • IQVIA • Truven	<ul> <li>Multipayer; may include cash payments (e.g., IQVIA)</li> <li>Captures detail on opioid analgesic prescription characteristics and other prescriptions filled</li> </ul>	<ul> <li>Data systems are not set up to track people long-term given insurance coverage transitions</li> <li>Limited information on diagnoses or other health care utilization</li> <li>Difficult to link to outcomes (e.g., mortality)</li> </ul>
<ul><li>Medicaid claims</li><li>National or state Medicaid data sources</li></ul>	<ul> <li>Can link hospital and pharmacy claims</li> <li>Can look at prescription histories of patients who make it to the hospital or emergency department for fatal or nonfatal overdose</li> <li>Captures detail on opioid analgesic prescription characteristics and other prescriptions filled</li> </ul>	<ul> <li>Only provides information on one population (Medicaid enrollees)</li> <li>Data systems are not set up to track people long- term given insurance coverage transitions</li> <li>Cannot measure opioid mortality: dates of death commonly not available and cause of death not included</li> </ul>
<ul><li>EHR and claims data</li><li>National or regional VHA data warehouses</li></ul>	<ul> <li>VHA data warehouse enables linkages across multiple VHA data sources</li> <li>VHA data have been linked with NDI to connect prescribing to mortality</li> <li>Captures detail on opioid analgesic prescription characteristics and other prescriptions filled</li> </ul>	<ul> <li>Access is highly limited</li> <li>Findings from veteran population may not be directly generalizable to other populations</li> </ul>
PDMP data • State PDMPs • PBSS	<ul> <li>Not restricted to one payer</li> <li>Can be used to develop measures around patient, prescriber, and pharmacist risky behaviors</li> <li>Detail on scheduled substance prescriptions (coverage varies across states)</li> </ul>	<ul> <li>Access barriers</li> <li>Many states have capacity issues that limit ability to link PDMP data with other data sources</li> <li>Many PDMPs do not collect unique identiers or have errors in entry, creating technical issues in matching at the individual level</li> </ul>

#### Table 5.1. Commonly Referenced Data Sources for Understanding Better Practices for Pain Management

Data Type and Example Sources	Strengths	Limitations		
Mortality data <ul> <li>NDI</li> <li>NVSS MCOD</li> <li>CDC WONDER</li> <li>State death certificate data</li> </ul>	<ul> <li>Information on cause of death and drugs involved</li> <li>NDI has been linked at person-level to other data sources</li> <li>State vital records can offer detail on cause of death</li> <li>CDC WONDER publicly available</li> </ul>	<ul> <li>Generally updated annually; up to 11-month delay</li> <li>Data request and approval can take up to three months</li> <li>For NDI, cause of death codes are an additional cost</li> </ul>		
Policy data <ul> <li>PDAPS</li> <li>NAMSDL</li> </ul>	<ul> <li>Information on PDMPs, pain clinic laws, education requirements, prescribing limits</li> <li>Can be linked with outcome data to examine impact of state policies</li> </ul>	<ul> <li>Some data not provided in analyzable format</li> <li>Some policy information not provided available historically (e.g., only provides a snapshot)</li> </ul>		

# Better Addiction Prevention, Treatment, and Recovery Services

Common themes emerging from discussions related to improving access to treatment and recovery services include the following:

- **Supply of treatment:** Understanding how policies and initiatives are influencing access to treatment and recovery services requires access to treatment supply and capacity data. Claims data and data on Drug Addiction Treatment Act–waivered physicians have been used to examine buprenorphine treatment capacity (Table 5.2) (Rosenblatt et al., 2015; Knudsen et al., 2015; Stein et al., 2015; Stein et al., 2015; Dick et al., 2015). However, developing a fully comprehensive picture of the treatment landscape is challenging: We lack data on individuals receiving methadone from opioid treatment programs or receiving treatment provided under state block grants, federal grants provided to support substance abuse treatment services that are not tied to public or private insurance.
- **Treatment demand and utilization:** Better understanding the size and characteristics of the population with opioid use disorder, and who gets treatment, could inform efforts to close the treatment gap. Analyses of national cross-sectional surveys and claims data have been useful, but longitudinal data with unique patient identifiers would allow longer-term analyses of treatment patterns, identifying gaps or limited access points, events leading to induction or dropout, and processes to improve continued abstinence.
- **Treatment processes and quality:** Understanding the quality of opioid use disorder care could benefit from the development of a set of standard performance measures with respect to quality of opioid use disorder treatment and specifically for medication-assisted treatment, potentially by leveraging information from EHRs, as well as the more commonly used services and pharmacy claims. Standardized or systematic reporting of treatment process measures (e.g., frequency of urinalysis, drug screens, dosing) or patient-reported outcomes (e.g., abstinence, craving, illicit drug use) would be valuable.
- **Treatment and outcomes for criminal justice populations:** Linking criminal justice and treatment services data sources can clarify the treatments being used in the criminal justice system and continuity of care for individuals who leave the criminal justice system. For instance, under Chapter 55, Massachusetts has aimed to link person-level data on substance abuse treatment received by prisoners with mortality data to understand whether treatment during incarceration reduces likelihood of experience a fatal opioid-related overdose (The Commonwealth of Massachusetts, Executive Office of Health and Human Services, Department of Public Health, 2017).

Table 5.2 highlights common data source strengths and limitations noted during stakeholder discussions regarding opioid use disorder treatment. Key takeaways regarding the advantages and limitations of various data source types include:

- Many national data sources, including claims data, EHR data, and national surveys, offer insights into treatment need, treatment utilization, and treatment supply. Each source uses different measures to assess these outcomes.
- Information on buprenorphine prescriptions and buprenorphine-waivered prescribers is available through several data sources, but using these data may entail costs.

Furthermore, these data provide information on only one type of treatment for opioid use disorder.

- State-level information on treatment admissions for opioid use disorder and facilities providing treatment for opioid use disorder are publicly available through national treatment facility surveys. The quality of admissions data varies across states and over time.
- Many of these data sets can be triangulated at the county- or state-level to better assess the overall picture of how treatment need aligns with treatment capacity. However, none supports person-level linkages across different potential sources of treatment for the general population.

Data Type and Example Sources	Strengths	Limitations
Commercial claims <ul> <li>IQVIA</li> <li>Truven Marketscan</li> <li>Symphony Health</li> </ul>	<ul> <li>Multipayer and includes cash payment</li> <li>Prescription data can capture the population treated with buprenorphine</li> <li>Can examine provider-patient censuses</li> <li>Information on comorbidities and other prescriptions (e.g., opioids)</li> </ul>	<ul> <li>Limited information on diagnoses, other healthcare utilization</li> <li>Requires triangulating other data sources to assess opioid use disorder and treatment access</li> <li>Issues tracking individuals over time</li> <li>Opioid use disorder treatment is often private cash pay and thus not appropriately captured in claims and is not captured at all in pharmacy claims</li> <li>Costs to obtain</li> </ul>
<ul> <li>Medicaid claims</li> <li>National or state Medicaid data sources</li> </ul>	<ul> <li>Can link hospital and pharmacy claims</li> <li>Some single-state analyses have linked to death certificate data</li> <li>Can examine opioid use disorder diagnosis</li> <li>Information on comorbidities and other prescriptions (e.g., opioids)</li> </ul>	<ul> <li>Only provides information on one population (Medicaid)</li> <li>Data systems not set up to track people long-term given insurance coverage transitions</li> <li>Cannot see if receiving other publicly funded substance abuse treatment</li> <li>Diagnosis codes billed for do not necessarily reflect actual diagnosis</li> </ul>
EHR • HealthCore Integrated Research Database • Group Health Cooperative	<ul> <li>Can capture nonmedication treatment (e.g., psychosocial therapy)</li> <li>Able to review patient test results, history, diagnoses, and plans for treatment</li> <li>Clinical text has rich data on progress and problems that often lack International Classification of Diseases codes</li> <li>Detailed information on pain, comorbidities, symptoms</li> </ul>	<ul> <li>Multiple laws regarding confidentiality/privacy preclude access to clinician notes</li> <li>Data quality is tied to data entry, and there are various data-entry issues</li> <li>In many treatment systems, only half of all providers have adopted EHRs</li> </ul>

#### Table 5.2. Commonly Referenced Data Sources for Understanding Treatment Need and Access

Data Type and Example Sources	Strengths	Limitations
Household surveys <ul> <li>NSDUH</li> <li>NESARC</li> </ul>	<ul> <li>National data</li> <li>Rich information on mental health and substance use, including opioid misuse and use disorder</li> <li>NSDUH collected annually</li> <li>NSDUH offers some insights on diversion</li> <li>NSDUH 2015 redesign has information on any prescription pain reliever use (not only misuse)</li> </ul>	<ul> <li>Historically have not included medications used for treatment</li> <li>Screen for use disorder symptoms, but do not ask about formal diagnosis</li> <li>No measure of care quality, treatment retention</li> <li>Sample may miss high-risk groups (e.g., homeless, arrestees)</li> <li>NESARC not collected annually or made readily available to researchers</li> <li>State identifiers restricted</li> </ul>
Treatment facility surveys • TEDS-A • N-SSATS	<ul> <li>National data on admits to treatment and public sector specialty care</li> <li>Up to three drugs of abuse listed</li> <li>Information on referral source (e.g., criminal justice system)</li> <li>N-SSATS includes public and private facilities and measures of capacity</li> </ul>	<ul> <li>Medication-assisted treatment is reported as a single variable in TEDS so cannot differentiate between buprenorphine and methadone; TEDS only includes agonist treatments</li> <li>Limited information on payment</li> <li>Quality control issues with TEDS, as states may not consistently assess data quality or report on similar patients</li> <li>TEDS do not include private for-profit facilities</li> </ul>
Provider census <ul> <li>SAMHSA</li> <li>database</li> <li>DEA ACSA</li> </ul>	<ul> <li>Measures supply/capacity of waivered physicians</li> <li>Can link to the American Medical Association Physician Masterfile</li> <li>Geographic detail</li> </ul>	<ul> <li>Costs to obtain DEA ACSA</li> <li>SAMHSA's publicly available data set captures around 55 percent of physicians</li> </ul>

# Better Targeting of Overdose-Reversing Drugs

Common themes emerging from discussions related to promoting use of overdose-reversing drugs include the following:

- Naloxone distribution: Data about naloxone distributed outside of standard outpatient pharmacy channels would help to identify capacity problems and ways to get naloxone to the right individuals. There have been several case studies of OEND programs (Doyon et al., 2016), but data on naloxone distribution through such programs are not systematically collected or made publicly available.
- Naloxone effectiveness: Better data on the circumstances surrounding overdoses and naloxone reversals would improve our understanding of under what circumstances and how frequently naloxone fails to reverse an overdose. These data could also inform efforts to modify naloxone use in communities facing increased fentanyl or carfentanil overdoses. EMS data may be of particular value in this area.
- **Treatment for individuals receiving naloxone**: Linking individual-level naloxone administration data with health care utilization data would improve our understanding of the emergency department services and subsequent opioid use disorder treatment provided to individuals receiving naloxone.

Table 5.3 highlights common data source strengths and limitations of data sources noted during stakeholder discussions regarding naloxone access and use. Key takeaways regarding the advantages and limitations of various data source types include the following:

- Commercial claims data may help in understanding trends and geographic variation in naloxone distribution through retail pharmacy channels; however, pharmacies are just one of the sources through which naloxone is distributed.
- A national data source containing information on community-based OEND programs is managed by the Harm Reduction Council, but these data are not publicly available.
- While EMS data through NEMSIS can offer valuable insights regarding EMS administration of naloxone, these data cannot include state identifiers, serving as a barrier to analyses of the effects of state policy on EMS use of naloxone.
- There are some sources of systematically collected data on state naloxone policies, which enhances assessment of how such policies affect outcomes such as mortality; however, few data sources capture policy implementation or variation in local regulations or protocols.
- Opioid-related mortality is an important outcome to evaluate in this area but greater use of EMS or hospitalization data—particularly if the sources could be linked—would offer value in understanding the trajectories of individuals treated with naloxone.

Data Type and Example Sources	Strengths	Limitations
Commercial claims <ul> <li>IQVIA</li> </ul>	<ul> <li>Measures pharmacy distribution of naloxone</li> <li>Information on prescriber specialty</li> <li>Data on formulation</li> </ul>	<ul> <li>Only captures the distribution of naloxone via pharmacy channel</li> <li>Does not capture purchase and distribution via state or community programs</li> <li>Costs to obtain</li> </ul>
Mortality data • CDC WONDER • NVSS MCOD	<ul> <li>National data on opioid overdose mortality</li> <li>Information on opioid type</li> <li>CDC WONDER is readily downloadable</li> </ul>	<ul> <li>Lags in data availability</li> <li>Variation in quality of reporting detail on drug involvement</li> </ul>
<ul> <li>OEND program data</li> <li>MA Opioid Overdose Prevention Pilot Program</li> <li>Harm Reduction Coalition</li> </ul>	<ul> <li>Fills in some data gaps regarding naloxone distributed via state or community programs</li> <li>Information on where sites located, number of kits distributed, etc.</li> </ul>	<ul> <li>Not standardized</li> <li>National data not systematically collected or updated</li> <li>Not publicly available</li> </ul>
EMS data • NEMSIS	<ul> <li>Naloxone administration is reportedly a fairly high- quality variable, and NEMSIS offers a Public Naloxone Administration Dashboard (NEMSIS, undated)</li> <li>Standardized collection of 911 call, incident, and transport information across multiple EMS agencies</li> <li>Can do small-area analysis</li> </ul>	<ul> <li>Not a registry of patients receiving care</li> <li>Data quality differs across agencies/states</li> <li>Some measures restricted</li> <li>No diagnosis information</li> <li>Barriers to linking or accessing geographic identifiers</li> </ul>
Policy data • PDAPS • NPHL • Legal databases	<ul> <li>Information on state policies to increase naloxone access or use</li> <li>Can be merged at the state level with other data on opioid-related outcomes</li> </ul>	<ul> <li>Variation in naloxone-related regulations between states may not be fully captured</li> <li>Data on EMS protocols not readily available</li> <li>Some historical data may not be provided in readily analyzable formats</li> </ul>

#### Table 5.3. Commonly Referenced Data Sources for Understanding Naloxone Access

# **Better Data**

Common themes emerging from discussions related to strengthening data to improve public health surveillance include the following:

- Understanding the dynamic opioid ecosystem: The opioid crisis is a dynamic system with multiple agents and networks of interacting individuals and agencies (Wakeland et al., 2015; Burke, 2016). Greater efforts are needed to model and understand the dynamics of the crisis, network patterns (e.g., prescriber, patient) at play, as well as macro-level factors (e.g., sociological, economic, technological) involved. Such analyses would require leveraging multiple data sources, including data about users of illicit opioids and the illicit drug market. For instance, drug-seizure and drug-testing data from the National Forensic Laboratory Information System (NFLIS) or System to Retrieve Information from Drug Evidence (STRIDE), both managed by the DEA, contain product-specific data on substances secured in law enforcement operations (see Table 5.4).
- Early warning signs of problematic use or problematic prescribing: Linking PDMP data with outcomes data (e.g., hospital discharge, emergency department visit, treatment, death, or criminal justice data) can facilitate development and validation of risk indicators for opioid analgesic misuse, diversion, and/or potential overdose. For instance, one study validated prescriber risk indicators derived using PDMP data by linking prescriber-level data from Maine's PDMP with data on medical board actions to assess how well their prescriber risk indicators predicted likelihood of receiving a disciplinary action (Kreiner et al., 2017).
- **Detail on drugs involved in overdoses:** Improved standardization across local jurisdictions regarding testing for and recording specific drugs and drug types during autopsies would enhance the consistency, validity, and reliability of information about drug-related overdose deaths (Ruhm, 2017). Data about nonfatal overdose may also help fill gaps in knowledge, although data costs are a potential barrier.
- Near-real-time data collection and access: Timely collection and access to data are necessary to keep pace with the rapid evolution of the crisis, would facilitate understanding emerging developments and local variation in the illicit supply of opioids, and may facilitate timely responses. Other opportunities for surveillance could include ways to leverage novel data sources (e.g., analysis of social media, the Dark Web, wastewater analysis) to produce near-real-time insights (Kalyanam and Mackey, 2017; Kalyanam et al., 2017).

Table 5.4 highlights common data source strengths and limitations noted during stakeholder discussions regarding public health surveillance. Key takeaways regarding the advantages and limitations of various data source types include the following:

- Each data source has notable strengths in identifying product-specific abuse or risk, understanding interactions between licit and illicit markets for opioids and providing timely information for surveillance and monitoring.
- Stakeholders noted common challenges that may limit the use of such data sources by researchers. These include barriers to access (e.g., high costs, no explicit documentation

on how to access) and barriers to analyses (e.g., data files not provided in computable formats, absence of unique identifiers).

• Some data sources, such as ADAM, that could offer insights on drug use and treatment among high-risk populations are no longer fully operational.

Data Type and Example Sources	Strengths	Limitations
Mortality data <ul> <li>NVSS MCOD</li> </ul>	<ul> <li>Detail on drugs involved in overdose death</li> <li>Information on cause of death</li> <li>Complete census of deaths over time</li> </ul>	<ul> <li>Access to microdata is limited</li> <li>Can be difficult and cumbersome to download</li> <li>Variation in quality of reporting detail on drug involvement</li> <li>Reporting delays</li> </ul>
Prescription drug monitoring data • PDMP • PBSS • ARCOS	<ul> <li>Comprehensive data on distribution (ARCOS) and prescribing (PDMP)</li> <li>Not restricted to one payer</li> <li>PDMPs can be used to develop measures around patient, prescriber, and pharmacist risky behaviors</li> </ul>	<ul> <li>Access barriers</li> <li>ARCOS not available in computable formats (i.e., only in PDF form)</li> <li>Many states have capacity issues that limit ability to link PDMP data with other data sources</li> <li>Many PDMPs do not collect unique IDs or have errors in ID entry, creating technical issues in matching at the individual level</li> </ul>
National surveys <ul> <li>ADAM</li> </ul>	<ul> <li>Captures a high-risk population (arrestees)</li> <li>Has urinalysis results in addition to self-reported drug use</li> <li>Collects drug market information (e.g., drug acquisition and payment)</li> <li>Collects information on substance abuse treatment history</li> </ul>	<ul> <li>No longer fully operational</li> <li>Limited to few sites collecting data</li> <li>Recent data limited to adult male arrestees</li> </ul>
<ul><li>Drug arrest data</li><li>Criminal justice agencies</li></ul>	<ul> <li>Could be used to examine network patterns of co-arrests</li> <li>If linked with other data, could be used to examine systematic histories leading to arrest or indications of diversion-related behaviors</li> </ul>	<ul> <li>Often not available in electronic form that is usable</li> <li>Often difficulties in obtaining permissions to use data</li> </ul>
Nonfatal overdose data • NPDS • RADARS	<ul> <li>Captures broader set of overdose incidents than fatalities</li> <li>Detailed product- and drug-specific information</li> <li>Near-real time data</li> <li>Can analyze at local level</li> <li>RADARS has additional programs capturing measures of diversion, use, street price</li> </ul>	<ul> <li>Must be requested and purchased</li> <li>Data availability lags may vary by poison center</li> <li>High costs to obtain</li> </ul>

#### Table 5.4. Commonly Referenced Data Sources for Understanding the Epidemic Through Better Public Health Surveillance

Data Type and Example Sources	Strengths	Limitations
Drug seizure and drug testing data • National Forensic Laboratory Information System (NFLIS) • STRIDE	<ul> <li>Data on illicit drug supply, prices (STRIDE), and purity</li> <li>Product-specific information</li> <li>Seizure data generally available with less lag time</li> <li>Useful for assessing prevalence and location of emerging drugs</li> </ul>	<ul> <li>Access barriers</li> <li>Summary data may be available but are not generally provided at the substate level</li> <li>Some drugs seized by law enforcement are not analyzed by participating laboratories</li> </ul>

Most of our findings from the environmental scan, data inventory, and stakeholder discussions were applicable across the five-part HHS strategy. Thus, we do not structure our discussion in this section around Strategic Priorities; rather, we identify general opportunities to improve data quality and data linkages to enhance the ability of researchers to answer questions related to the opioid crisis.

In the next section, we present nine key observations about challenges to data linkage or analyses that emerged from our study. After each, we describe approaches that could potentially help to reduce the challenge(s).

#### Key Observation 1

To advance research studying the effects of changes in state policies related to opioids, the absence of national data collected in a standardized manner across states can limit the rigor and robustness of potential analyses. While there are various state-based data initiatives aimed at synthesizing data from different agencies into one data warehouse, national standards that align states' reporting in existing data systems would allow for nationally representative policy studies. Barriers to research could also be lowered by ensuring that collected data are recorded and made available in usable formats that support empirical analyses. There is thus a benefit to be gained from standardizing how data currently being collected are recorded, reported, and made available.

Approach 1.1: Establish national standards on data collection and reporting for currently available data sources. Challenges identified by stakeholders included limited information on individuals who overdose and are attended to by EMS personnel but decline transport to the hospital so are generally not captured in administrative claims data. Thus, one approach may be to further encourage high-quality reporting by EMS providers of a standardized set of information (Becknell and Simon, 2016) that would ultimately flow up to state health systems and systems such as NEMSIS. Another challenge identified was variation in reporting quality to TEDS across states and, over time, such as variation in what states determine are eligible reporting facilities, what counts as a treatment episode, and what data elements are required for reporting. This variation may indicate a need to promote standardized high-quality reporting by states and to establish improved documentation of potential differences across states and over time in reporting to TEDS. Data transparency can be further enhanced by supporting the development and dissemination of a data inventory for opioid research, accompanied by appropriate technical documentation outlining the contents, characteristics, quality, and potential limitations of individual data sets. This could be modeled similarly to the new U.S. Census Bureau Data Repository (U.S. Census Bureau, 2017).

- Approach 1.2: Enhance data usability by ensuring that available data are provided in readily analyzable formats. A substantial barrier noted by stakeholders was that useful data sources are sometimes provided in formats (e.g., PDF formats) that do not readily support empirical analyses. Examples include the ARCOS data, as well as state data made available in a PDF table even though it had originally been created in Excel. Having to work with such formats creates a cost for researchers, who must translate data into a format that can be analyzed with statistical programs. The translation creates unneeded risk of further data-entry errors. For data that are already being made available, and particularly for data that may already exist in formats that facilitate incorporation into analytic software, costs to researchers can be reduced by ensuring that data are provided in files that support analysis is a straightforward way.
- Approach 1.3: Establish standardized performance measures for quality of treatment processes and outcomes and encourage state treatment programs to report on these measures. There are several challenges in developing performance measures, including the need for rigorous assessment of their importance, feasibility, and validity. One potential opportunity comes from EHRs which, depending on the quality of the information contained within, may provide an opportunity to collect more in-depth information, facilitate text mining of clinicians' notes (e.g., through natural language programming), and provide ongoing data collection during the course of treatment (Garnick et al., 2012). Developing such standardized measures or guidelines for quality of opioid use disorder treatment would facilitate assessment of which efforts effectively improve access to treatment and recovery services while maintaining high-quality care. Systematically reporting on the measures would enhance provider accountability and provide evidence on treatment quality. Some states have already taken steps in this area. For instance, Vermont has created a public dashboard that includes comparative reporting on each of its treatment service "spokes," and Rhode Island requires that medical homes within opioid treatment programs track performance data (Boss, 2017) and report data to the state to receive an enhanced payment rate (Chalk and Mark, 2017). Process-related measures of care and patient-centered outcomes data would be valuable for understanding not just treatment utilization but quality of care.

## Key Observation 2

Stakeholders consistently noted the particular value of state all-payer claims databases and criminal justice data.

• Approach 2.1: Enhance researcher use of all-payer claims databases. While all-payer claims data are not available for all states, stakeholders highlighted their benefits in potentially capturing health care claims across an entire state's population, allowing studies to track utilization and compare rates across different populations with different types of insurance. By making these data accessible and comparable in a single source, all-payers claims data may be less costly to obtain or burdensome to analyze, compared with obtaining and analyzing data from many different claims data sources. Furthermore, some states (e.g., Massachusetts) have expended significant resources to enable record linkages across payers (The Commonwealth of Massachusetts, Executive Office of Health and Human Services, Department of Public Health, 2017), which potentially offers a key advantage over other claims data sources (Dworsky, 2017). It is also worth

noting that Massachusetts' all-payer claims database forms the spine of their Chapter 55 data system (discussed further in Approach 9.1) to enable linkages across multiple interagency data sources (The Commonwealth of Massachusetts, Executive Office of Health and Human Services, Department of Public Health, 2017).

Research could potentially be enhanced by promoting awareness of the benefits of such data sources, socializing best practices for their creation and use in research, and making resources available to increase awareness and prompt greater use by the research community. Many discussants believed that significant benefits could be gained by encouraging more states to create such databases and to make them more available to researchers while maintaining fidelity to confidentiality and privacy requirements. However, self-insured plans can opt out of APCDs, a significant limitation in examining the employer insured market (U.S. Supreme Court, 2016).

• Approach 2.2: Encourage incorporation of criminal justice data into public health research. Person-level linkages of public health data sources (e.g., death records, PDMPs, treatment facility data) with criminal justice data on arrests, incarcerations, or treatment within the criminal justice system could be of value. Prior research has obtained de-identified data that link state administrative data on clients receiving publicly funded substance abuse treatment in specialty settings to arrest and incarceration data from state criminal justice agencies (Acevedo et al., 2015; Garnick et al., 2014). Smallarea analyses of drug-seizure data complemented by analyses of detailed drug-overdose data could also inform our understanding of illicit drug markets and supply-side dynamics and may be less challenging to implement than person-level linkages.

One way to implement this approach would be a research partnership to develop data systems focused on the criminal justice system and the opioid crisis and to potentially provide researchers with de-identified files that would support analyses at the level of fine geographic detail. At the state level, a recently published study (DeHart and Shapiro, 2016) offers insights into the implementation and use of integrated criminal justice and public health data in South Carolina (DeHart, 2015). Further efforts in this area could advance our understanding of treatments being used in the criminal justice system and continuity of care for individuals who leave the criminal justice system; factors that precede or follow criminal justice involvement related to opioids; and the evolution or dynamics of illicit opioid markets and illicit opioid use.

#### Key Observation 3

Stakeholders noted that some data that were useful in strengthening public health surveillance or capturing high-risk populations are no longer being collected (e.g., Drug Abuse Warning Network [DAWN], ADAM). In addition, there are current data-collection efforts that are well-positioned to collect measures relevant to the opioid crisis but historically have not captured that information or are currently not making the information readily available to researchers.

• Approach 3.1: Support reinstitution of useful data sets no longer being collected. Stakeholders noted that the arrestee interview and drug-testing data collected through ADAM provided insights not offered through other household surveys. Furthermore, ADAM provided a national data source on individual users' consumption and expenditures, which offered valuable information on illicit drug markets. DAWN provided a vital source of information on emergency room visits at the local level. Bringing back and improving these data sets could help fill gaps in our understanding of the opioid crisis. SAMHSA is planning to release an improved replacement of DAWN (i.e., SAMHSA's Emergency Department Surveillance System) (SAMHSA, 2016), and research could be enhanced by promoting awareness of its value and supporting its analysis.

• Approach 3.2: Augment existing federal data collections to capture information relevant to the opioid crisis and facilitate researcher access to such data. Federally funded surveys that are collected annually could incorporate new data elements or new modules relevant to the opioid crisis. For instance, the NSDUH could begin collecting information on pain, pain treatment, or diagnosis of opioid use disorder. TEDS could be modified to include whether pharmacotherapy (and what types) is planned or offered at discharge (Thomas et al., 2011). Interested researchers or other individuals could be invited to propose new elements or modules to be incorporated into existing systems. To maximize the benefits of these secondary data sources, there is a concurrent need to facilitate researcher access to important but sensitive data elements (e.g., state identifiers in the NSDUH are collected but are not widely available to researchers, and even researchers with permission to use restricted NSDUH state identifiers have experienced lengthy disruptions in access over the last several years).

#### Key Observation 4

An accessible source of consistent national data on opioid policies and strategies being implemented is essential for evaluating the impacts of policies and initiatives. The Alcohol Policy Information System (undated) is an exemplar of a rich source of policy data, providing detailed state-by-state information for a variety of alcohol policies (and more recently for cannabis policies). PDAPS (undated) offers an excellent source of policy data for state laws related to PDMPs, naloxone access laws, Good Samaritan laws, and pain management clinic laws. Continuing to expand and support such efforts in light of the rapidly evolving policy environment offers a vital benefit to researchers evaluating the impact of state opioid policies and initiatives.

• Approach 4.1: Support the construction and dissemination of a national database of state policy and initiatives. Efforts in this area could include expanding the scope of policies currently collected by systems such as PDAPS or developing new systems that provide consistent information on state policies or efforts that have received less evaluation (e.g., opioid prescribing policies, clinician education efforts, insurance policies regarding reimbursement for pain treatment). Making data available on the timing of policy enactment or implementation would also help support evaluations of the impact of these interventions.

## Key Observation 5

In the areas of treatment for opioid use disorder and use of naloxone, data currently being used to understand and address these issues offer an incomplete picture. With respect to treatment, there is not a strong set of measures that captures the extent to which treatment for opioid use disorder is occurring through state block grants. With respect to naloxone, there is not a strong set of measures available to track the distribution of naloxone through nonretail pharmacies. This limits evaluation of the impact of naloxone programs and policies.

- Approaches 5.1: Support the systematic collection and availability of data on individuals being treated through state block grants. Several data sources capture information on prescriptions for buprenorphine and availability of treatment with buprenorphine. However, stakeholders noted that administrative claims data fail to capture individuals receiving treatment outside of the payment system (e.g., through state block grants and community treatment programs). Additionally, better information is needed about the population receiving treatment outside of the public sector (e.g., full private facilities, which may still be subject to public credentialing). One approach to begin filling this gap could be exploring ways to incentivize substance abuse treatment programs to report to Medicaid using information about services provided for individuals receiving capitated services (e.g., shadow claims) as occurs currently in some jurisdictions. Careful consideration of patient privacy and confidentiality would be critical in these efforts.
- Approach 5.2: Support reporting of and access to data on naloxone distribution through nonpharmacy channels. While commercial claims data (e.g., IQVIA) can offer insights on access to naloxone through outpatient retail channels, other important distribution channels for naloxone are not captured in these data. These include naloxone being provided to first responders directly through hospitals, grants, or other sources, as well as naloxone being provided directly to the public through OEND programs and other entities. Identifying methods to track naloxone being distributed through such channels, such as working with manufacturers, is critical to developing a more comprehensive understanding of the effectiveness of policies and initiatives seeking to enhance naloxone distribution.

## Key Observation 6

A fundamental need for linking data at the individual level is collection of individual identifiers. Unique identifiers (e.g., social security numbers) have traditionally not been collected or made available because of a number of regulatory and privacy concerns (Dokholyan et al., 2009). Instead, linkages often rely on indirect identifiers (e.g., some combination of age, sex, date of birth, geography). To accurately link data based on indirect identifiers, it is critical to have matching algorithms that allow for the accurate extraction and utilization of meaningful information, given the quantity and quality of the data elements available to link (Dusetzina, Tyree, and Meyer, 2014).

• Approach 6.1: Support methodological research to develop improved algorithms for matching individuals across and within data sources. Stakeholders noted a key barrier for data linkages is that we cannot match as well as we need to across databases (or in some cases, within databases). Identifying reasons for insufficient matching and developing and validating improved matching algorithms is key to supporting data linkages.

## Key Observation 7

Mortality data are a key resource for both researchers and policymakers, but existing collection and reporting efforts need to be improved. Up to 25 percent of all death certificates fail to note the specific drug responsible for fatal overdose, and there are substantial geographic disparities in rates of missingness (Ruhm, 2017). This reporting variation complicates both research efforts and targeted enforcement or treatment efforts. Furthermore, stakeholders noted that there are particular opportunities for linking mortality data with other sources, given the more-limited confidentiality violations and hence lower privacy barriers in linking data once someone is deceased (Code of Federal Regulations, 2009). The National Center for Health Statistics has linked several surveys (e.g., the National Health Interview Survey) with death certificate data from the NDI (CDC, 2018), although stakeholders noted that these data are underused. Improving mortality data, leveraging these linking opportunities, and making linked data more readily available could offer substantial progress toward better understanding opioid-related harms.

- Approach 7.1: Support improved toxicology studies and reporting. The CDC has expanded funding to help states and medical examiners improve data collection and reporting for nonfatal surveillance and fatal overdose data and has funded states to increase comprehensive toxicology testing (with 60 percent of this funding going toward medical examiners and coroners). Facilitating access to these data will enhance the ability of researchers and policymakers to better understand and respond to the rapidly evolving opioid crisis by understanding trends such as the use of adulterants in illicit opioids.
- Approach 7.2: Support universal and timely reporting of overdose deaths by states and encourage states to leverage interagency partnerships. Partnerships between departments of public health, local police departments, emergency medical services, hospitals, and other agencies could enhance the ability of states to obtain complete and timely information on overdose deaths in the community. Combined with improved toxicology studies and reporting, these efforts could support targeted interventions to aid community organizations, law enforcement, public health agencies, and the broader general public.
- Approach 7.3: Enhance linkage mortality data to other data sources and promote their use by researchers. Stakeholders noted that a key opportunity for advancing our understanding of the opioid crisis is linking Medicaid claims with mortality data. One approach could be to develop standards and requirements for data sharing by state agencies overseeing Medicaid data and mortality data. Stakeholders mentioned prior efforts to link CMS claims data with mortality data that were supported by the American Recovery and Reinvestment Act of 2009, but it is unclear to what extent such initiatives have been undertaken in more recent years. Given the scope of the opioid crisis, there

may be greater value in supporting such linkages than there has been historically. Such linkages can enhance policy and program evaluations; for instance, the U.S. Census Bureau Center for Administrative Records Research and Application, in partnership with Chapin Hall at the University of Chicago and supported by the Laura and John Arnold Foundation, are promoting research studies and methods for combining data across agencies and levels of government to advance evidence-based policymaking (Goerge, Gjertson, and De La Cruz, 2017).

#### Key Observation 8

Effective responses to the rapidly evolving opioid crisis rely on the timely collection, reporting, and analyses of crucial health information. Near-real time data collection at fine geographic detail can support identification of high-risk locations and help inform timely and effective community interventions. Several states have made great strides toward improving the speed at which data on nonfatal overdose are collected and analyzed.

However, there are several challenges with near-real time surveillance systems. Substantial costs and resources are required to implement and manage such systems, and the costs of data management and analysis increase as systems receive increasing amounts of data with increasing speed and diversity. Stakeholders also mentioned that laws governing the process by which data collection occurs, such as the Paperwork Reduction Act, may also create substantial lags in starting up new data collection efforts for surveillance, as the time to obtain the requisite permissions often exceeds six months. Near-real time data collection also suffers from greater data-quality challenges compared with data collection that occurs over a longer time frame, and potential issues with record completeness and accurate processing and transmission necessitate ongoing monitoring and communication (Ising et al., 2016). Despite these challenges, there is significant public health value to be gained by supporting the collection and analysis of such systems.

- Approach 8.1: Use evidence on innovative state or local approaches to develop and utilize near-real time surveillance systems to advance the use and operations of such systems more broadly. Many existing state approaches to near-real-time surveillance systems leverage data on nonfatal overdoses (Box 5). Evidence on how states have used these systems, challenges faced in their implementation and use, and insights about how challenges have been overcome can be used to support the development of near-real-time surveillance tools in other jurisdictions.
- Approach 8.2: Support innovative research on the use of nontraditional data sources (e.g., social media, the Dark Web) to inform public health action. There has been increasing research interest in methods to mine and analyze nontraditional data resources to bolster public health surveillance. Studies have analyzed Twitter messages and web forum postings to understand various forms of opioid misuse and prescription drug diversion (Katsuki, Mackey, and Cuomo, 2015; Anderson et al., 2017; Chan, Lopez, and Sakar, 2015), used Google trends data to forecast state-level mortality (Parker et al., 2017), and used information from cryptomarket forums on the Dark Web to assess emerging trends in new psychoactive substances (Van Hout, Claire, and Hearne, 2017).

While cryptomarkets represent only a slice of the total illicit drug trade, studies have used web crawlers to scrape cryptomarket listings, vendor profiles, and forum discussions to map online illicit drug distribution networks, assess prevalence and trends in the illicit online sales and prices of different drug types, and identify emerging drug trends (see Barratt and Aldridge, 2016, for an overview of challenges and opportunities in cryptomarket research) (Van Hout, Claire, and Hearne, 2017; Bhaskar, Linacre, and Machin, forthcoming, Ladegaard, 2017; Broséus et al., 2016). Advancing methods to harness these data sources as a public health surveillance tool can offer a key resource for identifying risks and emerging trends (Brownstein et al., 2009).

**Box 5. Examples of State Efforts to Develop and Use Near-Real Time Surveillance systems** 

**Rhode Island**'s Opioid Overdose Reporting System is a flexible near-real time surveillance system that compiles information on cases of opioid overdose from the state's hospitals and emergency departments, although noted challenges have included incomplete compliance with reporting requirements (McCormick, Koziol, and Sanchez, 2017).

**North Carolina**'s statewide syndromic surveillance system (the North Carolina Disease Event Tracking and Epidemiologic Collection Tool) provides near-real time collection and analysis of statewide emergency department data, poison center call data, and emergency medical services data (Ising et al., 2016).

## Key Observation 9

PDMPs are a valuable resource for understanding the opioid crisis, and there is significant value to be gained by linking PDMPs with a variety of other data sources. All states now operate a PDMP system (PDMP, Training and Technical Assistance Center, 2017), but they vary substantially in data collection, reporting, and interoperability (Pardo, 2017; Manasco et al., 2016). Developing a complete and consistent PDMP data set for analysis is essential for studying prescription drug abuse. Linking these data with public health and criminal justice data sources would support public health surveillance of opioid-related problems. Several state-level efforts, often organized around PDMPs, are underway toward developing individual-level data linkages across multiple data sources, and there is an opportunity for further partnerships between federal and state agencies to support such efforts and invest in making these state linkages more useful to research and practice. An exemplar of such an approach is the Bureau of Justice Assistance's Harold Rogers PDMP, which supports local, state, or regional collaborative efforts to collect and analyze multiple sources of data. The program's goal is to enhance understanding of the opioid crisis and develop data-driven strategies to support surveillance, treatment, and prevention efforts for at-risk individuals (Paulozzi, Kilbourne, and Desai, 2011).

• Approach 9.1: Use evidence on innovative state approaches to leveraging and linking PDMP systems to publish guidance and recommendations on how states can support linking PDMP data with other data sources. Given regulatory and confidentiality concerns, it may be helpful to explore if a directive could be issued indicating that there should be no attempts to subpoena PDMP data (or associated data linked to PDMPs) for federal investigations. Establishing guidance for allowing researchers controlled access to de-identified linked data could further promote the value of linking PDMP with other sources, particularly if de-identified statistical data from multiple states could be made available through a single federal or federally supported source, such as the Brandeis PBSS. Some examples of state PDMP data-linkage efforts are highlighted in Box 6.

There is also substantial interest in linking PDMP data with social services data (e.g., child welfare data) to better understand how opioid misuse affect child welfare outcomes. While our stakeholder discussion did not identify states that are currently making these linkages, a recent study linked county-level data on controlled substance prescriptions rates from Florida's Drug-Related Outcomes Surveillance and Tracking System with county-level data on child removal rates (Quast, Storch and Yampolskaya, 2018), and developing broader data linkages to support analyses of the effects of the opioid crisis on children and families is an area to consider supporting.

#### Box 6. Examples of Approaches to Linking PDMP Data with Other State Sources

**Washington state** links PDMP data to the state's Medicaid and Worker's Compensation claims data through Washington State's Data Sharing Initiative with Medicaid and Workers' Compensation (PMDP, 2013).

**Massachusetts** is a noted example of state success in linking PDMP data to a broad range of other public health and criminal justice data sources. Chapter 55 of the Acts of 2015 permitted the linkage and analysis of several government data sources to inform programmatic decisions, guide the development of policies, and advance understanding of the opioid crisis. Under Chapter 55, Massachusetts' Department of Public Health has connected (in most cases, at the individual level) ten data sources managed by five state agencies to develop a data warehouse structure. The system also collects community-level data on naloxone (e.g., enrollments, refills, and rescues through the Massachusetts Department of Public Health Naloxone program), drug seizures, and socioeconomic and demographic characteristics (The Commonwealth of Massachusetts, Executive Office of Health and Human Services, Department of Public Health, 2017).

**Maryland** is another example of a state that has overcome interpretational challenges of 42 CFR Part II (establishing special privacy protections for health care records related to the treatment of substance use disorders) and is currently advancing efforts to link person-level data from the PDMP, drug use and alcohol treatment admissions, hospital admissions, fatalities investigated by the medical examiner, and criminal justice data (Saloner, 2016; Lyons, 2017).

• Approach 9.2: Encourage states to improve PDMP systems to ensure data compatibility with other states. Standardization of electronic data collection for key elements for all state PDMPs would facilitate cross-state sharing and collaboration with other agencies (e.g., Medicaid, Department of Veterans Affairs). The American Society for Automation in Pharmacy guidelines created a PDMP standard for reporting, most recently updated in 2016 (American Society for Automation in Pharmacy, 2016). Encouraging states to use the most recent version of the guidelines could support interoperability and comprehensive data analysis (Greenwood-Ericksen et al., 2016). To enhance interstate accessibility of PDMPs, one approach could include legislation enabling sharing between PDMPs in all states.

#### Summary

Significant work is being done at the federal, state, and local level to combat the opioid crisis. There has also been a substantial increase in research that has improved our understanding of the complex and multidimensional nature of the opioid crisis, and that has advanced the evidence base regarding the effectiveness of opioid policies and initiatives to reduce opioid-related harms. There are significant resources within reach for the use and analysis of secondary data, but not all are being taken advantage of. This report outlines a range of strategies that can improve and promote available data to better understand the crisis.

Meaningful progress can be made on many of our potential approaches; doing so would likely provide significant value to opioid policy researchers and inform policy developments. Potential approaches that can be taken in the short-term include the following:

- Enhance data usability by ensuring available data are provided in readily analyzable formats (Approach 1.2, Section 6): Progress over the short term can be made by ensuring that publicly available data that are already electronically compiled in analyzable formats are made readily accessible in machine-readable formats (e.g., CSV, XML, ASCII) and by providing adequate technical documentation about important aspects of the data. Entities publishing data in graphical format could enhance data transparency by including links to analyzable formats of the data underlying the graphs.
- Support universal and timely reporting of overdose deaths by states and improve toxicology reporting (Approach 7.2, Section 6): Progress over the short term can be made in this area by updating best practices for coroners and medical examiners to report overdose fatalities by disseminating such best practices and by continuing to support improved toxicology reporting. Studies have supported that centralized medical examiner systems have more-complete recording of specific drugs involved in drug intoxication deaths compared with states with a decentralized county coroner system (Warner et al., 2013).
- Use evidence on innovative state approaches to leverage and link PDMP systems to publish guidelines and recommendations for states to support linking PDMP data with other data sources (Approach 9.1, Section 6): There are several innovative state approaches currently underway to link PDMP systems with other data sources—in some cases, at the individual level. Short-term progress can be made in this area by developing

guidelines based on the challenges states have faced and how they have been overcome and investing in making these linkages more useful to research and practice.

In Table 6.1, we provide an overview of timelines, based on conversations with stakeholders, in which it may be possible to achieve meaningful progress toward the approaches discussed above. We recognize, however, that there may be a range of complexities that stakeholders are unaware of that may challenge meeting such aggressive timelines. Nevertheless, given the human and societal toll of the opioid crisis and the potential benefits from additional high-quality research that these approaches could support, we believe it is a public health imperative to create and make available improved data assets that will support more informed efforts to address the opioid crisis.

Approach	Approach Description	Short Term*	Intermediate Term*	Long Term*
1.1	Establish national standards on data collection and reporting for currently available data sources.	х	Х	
1.2	Enhance data usability by ensuring available data are provided in readily analyzable formats.	Х		
1.3	Establish standardized performance measures for quality of treatment.		Х	Х
1.4	Encourage state treatment programs to report on treatment processes and outcomes.	Х	Х	
2.1	Enhance researcher use of all-payer claims databases.		Х	
2.2	Encourage incorporation of criminal justice data into public health research.		Х	Х
3.1	Support reinstitution of useful data sources no longer being collected.	Х	Х	
3.2	Augment existing federal data collections to capture information relevant to the opioid crisis and facilitate researcher access to such data.		х	Х
4.1	Support the construction and dissemination of a national database of state policy and initiatives.		Х	Х
5.1	Support the systematic collection and availability of data on individuals being treated through state block grants.	Х	х	
5.2	Support reporting of and access to data on naloxone distribution through nonpharmacy channels.	х	х	
6.1	Support methodological research to develop improved algorithms for matching individuals across and within data sources.		Х	х
7.1	Support improved toxicology studies and reporting.		Х	Х
7.2	Support universal and timely reporting of overdose deaths by states and encourage states to leverage interagency partnerships.	х	Х	
7.3	Enhance linking mortality data to other data sources and promote their use by researchers.	Х	Х	

# Table 6.1. Time Frame for Potential Approaches to Implementing Successful Data-Linking Strategies

Approach	Approach Description	Short Term*	Intermediate Term*	Long Term*
8.1	Use evidence on innovative state or local approaches to develop and utilize near-real time surveillance systems to advance the use and operations of such systems more broadly.	Х	х	
8.2	Support innovative research on the use of nontraditional data sources (e.g., social media, the Dark Web) to inform public health action.	х		
9.1	Use evidence on innovative state approaches to leverage and link PDMP systems to publish guidelines and recommendations on how states can support linking PDMP data with other data sources.	х		
9.2	Encourage states to improve PDMP systems to ensure data compatibility with other states.	х	x	

\* Short term = meaningful progress within six months; intermediate term = meaningful progress within 12 months; long term = meaningful progress may take more than 12 months

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Appendix—Overview of Types of Secondary Data Sources and Data Inventory Content

# Appendix Table of Contents

Overview of Types of Secondary Data Sources and Data Inventory Content	74
Table A.1. National Survey Data	75
Table A.2. Claims and Electronic Health Records Secondary Data Sources	
Table A.3. Mortality Records	84
Table A.4. Prescription Monitoring Secondary Data Sources	
Table A.5. Contextual and Policy Data Sources	89
Table A.6. Other National, State, and Local Secondary Data Sources	91

## Overview of Types of Secondary Data Sources and Data Inventory Content

Data Description	Summary	Examples of Important Measures	Data Source Examples	Information on Linking Capability
( <u>Table A.1</u> )	<b>Description</b> : Generally household or school-based surveys with self- reported information on drug use and health; other surveys are of hospitals, treatment facilities, or of other medical service providers <b>Geographic coverage</b> : National <b>Timing</b> : Generally collected and available annually	Prescription opioid use, heroin use, opioid use disorders, medical conditions, health care utilization	Use and Health, National	State, substate, and person-level linkages possible. See <u>Table A.1</u> for details.
records (EHRs) ( <u>Table A.2</u> )	While an EHR contains the medical and treatment histories of patients, an EHR system is built to go beyond standard clinical data	medications, clinical conditions, treatment plans, and lab/test	Stanford Translational Research Integrated	State, substate, and person-level linkages possible. See <u>Table A.2</u> for details.
( <u>Table A.2</u> )	<b>Description</b> : Patient-level claims data for reimbursement for services submitted by health care providers and pharmacies to insurance companies. Validated algorithms to identify opioid misuse or abuse from claims data are being developed. <b>Geographic coverage</b> : Varies by source <b>Timing</b> : Varies by source	utilization		for details.
records ( <u>Table A.3</u> )	<b>Description</b> : Death rates and causes of death by drug compound and/or International Classification of Diseases (ICD) code. Additional information can include toxicology reports. <b>Geographic coverage</b> : National or single state <b>Timing</b> : Generally available annually	Rates of opioid-involved deaths, drugs involved in overdose deaths	Centers for Disease Control and Prevention (CDC) WONDER Multiple Cause of Death data, Fatal Accident Reporting System, National Death Index (NDI)	State, substate, and person-level linkages possible. See <u>Table A.3</u> for details.
monitoring data ( <u>Table A.4</u> )				State, substate, and person-level linkages possible. See <u>Table A.4</u> for details.
policy data ( <u>Table A.5</u> )	opioid-related outcomes generally use data on state laws from these sources and/or includes controls for state or county characteristics to support causal interpretation. <b>Geographic coverage</b> : National <b>Timing</b> : Varies, but generally semiannually	county demographic and socioeconomic factors, state and county health care variables	System, Prescription Drug Abuse Policy System	Typically merged at the state or county level with other data on opioid-related outcomes
Other national, state, and local sources ( <u>Table A.6</u> )	<b>Description</b> : Includes data collected through law enforcement, national public health surveillance systems (e.g., poison control centers, emergency department visits), overdose education and naloxone distribution programs, and hospitalization and emergency departments <b>Geographic coverage</b> : Varies by source <b>Timing</b> : Varies by source	nonfatal opioid overdose, opioid- related emergency department visits and hospitalizations, naloxone distribution through community	Data System, Healthcare Cost and Utilization	State, substate, and person-level linkages possible. See <u>Table A.6</u> for details.

# Table A.1. National Survey Data

Agency	Coverage	Timing	Measures	Costs and Restrictions	Available Analytics	Linking Capability
			tem (ADAM): Urinalysis results and self-repo			
after their a	arrests; prevale	ence estima	tes are annualized to analyze trends. https://	www.nij.gov/topics/drugs/markets/adar	n/pages/welcome.aspx	
National	National	Annual,	Urine screen results, self-reported drug use,	No costs stated, some data available only	None identified. See	No individual-level
Institute of	(subset of	1998–	self-reported lifetime treatment history,	to users at Inter-university Consortium	recent report <u>here</u> .	linkages identified
	-	2003 and	some information on illicit drug markets	for Political and Social Research (ICPSR)		
(federal)	varies by	2007–		member institutions or upon signing a		
	year)	2013		Restricted Data Use Agreement		
-			MEPS): A set of large-scale surveys of families	· · · · · ·		
	•		the cost and use of health care (including pre-	• •	•	PS participants from
nealth care	providers and	facilities ar	e cross-referenced with survey responses fro	m the participants. <u>https://meps.ahrq.gov</u>		-
Agency for	National	Annual	Health care visits, use, events, and	No costs stated. Researchers and users	See online query system	MEPS link files to
Healthcare			expenditures, names of any prescription	with approved projects can access	<u>here.</u>	National Health
Research			medications, and the name and location of	restricted data or state/county		Interview Survey
and			the pharmacy where they obtained the	identifiers that have not been publicly		person-level public use
Quality			prescription. Data on pharmacy-filled	released for reasons of confidentiality at		data files
(AHRQ)			prescription include type, dosage, and	the AHRQ Data Center in Rockville,		
(federal)			payment	Maryland, or through the U.S. Census		
				Research Data Center (RDC) network.		
-			Nationally representative survey of self-repo	orted drug use by 8th, 10th, and 12th grade	ers. Longitudinal data coll	ection (designed to be
		1	ve). http://www.monitoringthefuture.org/			
University	National	Annual	Opioid misuse rates. Contains specific	5 1	None identified. See	No individual-level
of			questions for OxyContin and Vicodin	are not public access	recent figures provided	linkages identified. Has
Michigan					<u>here.</u>	been linked with other
(private)						state-level information
			urvey (NAMCS): Information about the provi	-	-	
• •		•	marily engaged in direct patient care and, sta		o community health cente	ers. Estimates generally
		1	nsus region levels (depends on year). <u>https://</u>		l.a. ii	
CDC	National	Annual	Utilization of physician, hospital outpatient,		Online query system	No individual-level
(federal)			and emergency department services; the	can only be accessed through National	available <u>here</u> ; other	linkages identified
			conditions most often treated; and the	Center for Health Statistics (NCHS) RDC	research tools <u>here</u>	
			diagnostic and therapeutic services			
			rendered, including medications prescribed			

Agency	Coverage	Timing	Measures	Costs and Restrictions	Available Analytics	Linking Capability
		-	cohol and Related Conditions (NESARC): This		-	
• •	iatric disorders. ww.niaaa.nih.g		Wave II were a longitudinal panel. Wave III is	s a new sample. Sampling is designed to be	e nationally representative	2.
	National	2001–	Nonmedical prescription opioid use and	No costs stated. Only provided to	None identified	Access to geocode
National	National		opioid disorder; mood and anxiety	investigators who agree in advance to	None Identified	identifiers may permit
Institute on Alcoho		2002, 2004–	disorders; other substance use, alcohol	adhere to established policies for		linkage at state level
Abuse and		2004– 2005,	disorder, and other drug use disorder	distribution		lillkage at state level
Alcoholis	1	2005, 2012–	disorder, and other drug use disorder			
(NIAAA)		2012-				
(federal)		2015				
· /	Jospital Ambul:	atory Medi	L cal Care Survey (NHAMCS): Information on th	Le utilization and provision of ambulatory of	l are services in hosnital er	l nergency and outpatient
	•	-	locations based on a national sample of visit	• • •	•	• · ·
-			-stay hospitals. Estimates only representative		-	
			Receipt of opioid prescription; visits	No costs stated. Some restricted items	Online query system	No individual-level
(federal)		lindan	specifically for chronic pain condition;	can only be accessed through NCHS RDC	available <u>here</u> ; other	linkages identified
(			utilization and provision of ambulatory care		research tools here	
			services in hospital emergency department,			
			outpatient departments, and ambulatory			
			surgery locations			
National I	lospital Care Su	arvey (NHCS	6): NHCS integrates inpatient data formerly co	llected by the National Hospital Discharge	Survey, emergency depar	rtment and outpatient
	•		CS, and substance-involved visit data previous	, , , ,		•
-		-	rovided across treatment settings. https://ww		, , ,	•
CDC	National,	Annual	Emergency department	No costs stated, but fees may apply for	Analytics for some	Can link with the NDI,
(federal)	participating		visits for substance abuse and/or resulting	use of the RDC. Access to the data is	components of the	MedPAR, and Medicaid
. ,	hospitals		from substance misuse or abuse, adverse	allowed through a proposal submission	NHCS available through	Statistical Information
			reactions to medications taken as prescribed		ICPSR	System data sets
			or directed, accidental ingestion of drugs,	NCHS RDCs.		
			and drug-related suicide attempts			
National I	lealth Interviev	v Survey (N	HIS): Data on a broad range of health topics (	medical conditions, health insurance, doct	or's office visits, physical	activity, and other health
behaviors	) are collected t	hrough pers	sonal household interviews. <u>https://www.cdo</u>	c.gov/nchs/nhis/about_nhis.htm		
CDC	National	Annual	Medical conditions, health insurance,	No costs stated. Some variables are	Online analysis provided	Can be linked to MEPS,
(federal)			doctor's office visits, physical activity, and	considered restricted data (including	through ICPSR with	NDI, Medi-care
			other health behaviors	some linkages and geocoded variables)	account	enrollment and claims
						data, and Social Securit
						benefit history data

	Coverage	Timing	Measures	<b>Costs and Restrictions</b>	Available Analytics	Linking Capability
			e System (NHBSS): NHBSS collects data relatir	-	· · · ·	
• •	-		receipt of prevention services, and use of pre		addition to these intervie	w data, all NHBSS
			indings from NHBSS are published in annual	reports and other scientific publications.		
	1		/systems/nhbs/index.html	1	T	Γ
CDC	National (22		HIV behavioral risk factors (e.g., sexual	No costs stated. Not publicly available;	None identified	None identified
(federal)	city "subject		behaviors, drug use), HIV testing behaviors,	as a component of HIV/acquired		
	areas")	n cycle	injection drug use, receipt of prevention	immunodeficiency syndrome (AIDS)		
		rotation	services, use of prevention strategies (e.g.	surveillance, NHBSS data are protected		
			condoms, PrEP)	by the Assurance of Confidentiality		
				(Section 308[d] of the Public Health		
				Service Act, 42 U.S.C. 242 m[d]), which		
				prohibits the disclosure of any		
				information that could be used to		
L				directly or indirectly identify individuals.		
National Su	urvey on Drug	Use and He	alth (NSDUH): Self-reported information on c	Irug use and abuse or dependence, menta	I health, and substance us	e disorder treatment
among resp	ondents ages	12 and olde	er. Results available at the national level and f	or some metropolitan statistical areas and	l sub-state areas. Designed	to be representative at
the nationa	l and state lev	els. <u>https://</u>	/nsduhweb.rti.org/respweb/homepage.cfm			
Substance	National	Annual	Lifetime nonmedical opioid, heroin use;	No costs stated. Geographic identifiers	Online analysis provided	Merged at the state
Abuse and			first-time nonmedical opioid use, heroin	are restricted access. Restricted access	through ICPSR with	level with other data
Mental			initiates; past-year, past-month heroin,	data elements must be applied for and	account	sets
Health			nonmedical opioid, and opioid use by	approved, with access to data provided		
			therapeutic drug class; treatment for opioid			
Administra				0		
Administra tion			use disorder: self-reported unmet treatment	Mental Health Data Archive (SAMHDA)		
tion			use disorder; self-reported unmet treatment	. ,		
tion (SAMHSA)			use disorder; self-reported unmet treatment need	Mental Health Data Archive (SAMHDA) <u>data portal</u> .		
tion (SAMHSA) (federal)	rvey of Substa	ance Abuse	need	<u>data portal</u> .	ance use treatment faciliti	es to collect information
tion (SAMHSA) (federal) <b>National Su</b>			need Treatment Services Data (N-SSATS): N-SSATS	data portal. 5 is an annual survey of participating subst		
tion (SAMHSA) (federal) <b>National Su</b> on location,	, characteristic	s, services o	need Treatment Services Data (N-SSATS): N-SSATS offered, and utilization. Information from N-S	data portal. S is an annual survey of participating subst SATS is used to compile and update the Na	ational Directory of Drug a	
tion (SAMHSA) (federal) <b>National Su</b> on location, Treatment	, characteristic	s, services o	need <b>Treatment Services Data (N-SSATS):</b> N-SSATS offered, and utilization. Information from N-S Substance Abuse Treatment Facility Locator.	data portal. S is an annual survey of participating subst SATS is used to compile and update the Na https://www.dasis.samhsa.gov/dasis2/ns	ational Directory of Drug a sats.htm	nd Alcohol Abuse
tion (SAMHSA) (federal) <b>National Su</b> on location, Treatment I SAMHSA	, characteristic Programs and	s, services of the online S	need <b>Treatment Services Data (N-SSATS):</b> N-SSATS offered, and utilization. Information from N-S Substance Abuse Treatment Facility Locator. Type of care provided, including detox and	data portal. S is an annual survey of participating subst SATS is used to compile and update the Na	ational Directory of Drug a sats.htm State profiles accessible	nd Alcohol Abuse
tion (SAMHSA) (federal) <b>National Su</b> on location, Treatment	, characteristic Programs and	s, services of the online S	need <b>Treatment Services Data (N-SSATS):</b> N-SSATS offered, and utilization. Information from N-S Substance Abuse Treatment Facility Locator. <u>I</u> Type of care provided, including detox and opioid treatment programs, substance	data portal. S is an annual survey of participating subst SATS is used to compile and update the Na https://www.dasis.samhsa.gov/dasis2/ns	ational Directory of Drug a sats.htm	nd Alcohol Abuse Merged at the county or
tion (SAMHSA) (federal) National Su on location, Treatment I SAMHSA	, characteristic Programs and	s, services of the online S	need <b>Treatment Services Data (N-SSATS):</b> N-SSATS offered, and utilization. Information from N-S Substance Abuse Treatment Facility Locator. <u>I</u> Type of care provided, including detox and opioid treatment programs, substance abuse problem treated, types of services	data portal. S is an annual survey of participating subst SATS is used to compile and update the Na https://www.dasis.samhsa.gov/dasis2/ns	ational Directory of Drug a sats.htm State profiles accessible	nd Alcohol Abuse Merged at the county or state level with other
tion (SAMHSA) (federal) <b>National Su</b> on location, <u>Treatment I</u> SAMHSA (federal)	, characteristic Programs and National	s, services of the online S Annual	need <b>Treatment Services Data (N-SSATS):</b> N-SSATS offered, and utilization. Information from N-S Substance Abuse Treatment Facility Locator. <u>I</u> Type of care provided, including detox and opioid treatment programs, substance abuse problem treated, types of services offered, facility funding and capacity	data portal. S is an annual survey of participating subst SATS is used to compile and update the Na https://www.dasis.samhsa.gov/dasis2/ns No costs stated. Publicly available	ational Directory of Drug a sats.htm State profiles accessible here.	nd Alcohol Abuse Merged at the county or state level with other data sets
tion (SAMHSA) (federal) National Su on location, Treatment I SAMHSA (federal) Treatment	, characteristic Programs and National <b>Episodes Data</b>	s, services of the online S Annual set (TEDS):	need <b>Treatment Services Data (N-SSATS):</b> N-SSATS offered, and utilization. Information from N-S Substance Abuse Treatment Facility Locator. <u>I</u> Type of care provided, including detox and opioid treatment programs, substance abuse problem treated, types of services offered, facility funding and capacity Admissions to publicly funded treatment pro	data portal. 5 is an annual survey of participating subst SATS is used to compile and update the Na https://www.dasis.samhsa.gov/dasis2/ns No costs stated. Publicly available grams and opioid substitution programs b	ational Directory of Drug a sats.htm State profiles accessible here. y primary, secondary, and	nd Alcohol Abuse Merged at the county or state level with other data sets
tion (SAMHSA) (federal) National Su on location, Treatment I SAMHSA (federal) Treatment administrat	, characteristic Programs and National Episodes Data	s, services of the online S Annual set (TEDS): graphics. D	need <b>Treatment Services Data (N-SSATS):</b> N-SSATS offered, and utilization. Information from N-S Substance Abuse Treatment Facility Locator. <u>I</u> Type of care provided, including detox and opioid treatment programs, substance abuse problem treated, types of services offered, facility funding and capacity	data portal. 5 is an annual survey of participating subst SATS is used to compile and update the Na https://www.dasis.samhsa.gov/dasis2/ns No costs stated. Publicly available grams and opioid substitution programs b	ational Directory of Drug a sats.htm State profiles accessible here. y primary, secondary, and	nd Alcohol Abuse Merged at the county or state level with other data sets
tion (SAMHSA) (federal) National Su on location, Treatment SAMHSA (federal) Treatment administrat https://ww	, characteristic Programs and National Episodes Data	s, services of the online S Annual set (TEDS): graphics. D	need <b>Treatment Services Data (N-SSATS):</b> N-SSATS offered, and utilization. Information from N-S Substance Abuse Treatment Facility Locator. <u>I</u> Type of care provided, including detox and opioid treatment programs, substance abuse problem treated, types of services offered, facility funding and capacity Admissions to publicly funded treatment pro rata are available at the national and state lev	data portal. 5 is an annual survey of participating subst SATS is used to compile and update the Na https://www.dasis.samhsa.gov/dasis2/ns No costs stated. Publicly available grams and opioid substitution programs b	ational Directory of Drug a sats.htm State profiles accessible here. y primary, secondary, and cal treatment agencies.	nd Alcohol Abuse Merged at the county or state level with other data sets tertiary drug, route of
tion (SAMHSA) (federal) National Su on location, Treatment I SAMHSA (federal) Treatment administrat	, characteristic Programs and National Episodes Data tion, and demo wdasis.samhs	s, services of the online S Annual set (TEDS): graphics. D a.gov/webt	need <b>Treatment Services Data (N-SSATS):</b> N-SSATS offered, and utilization. Information from N-S Substance Abuse Treatment Facility Locator. <u>I</u> Type of care provided, including detox and opioid treatment programs, substance abuse problem treated, types of services offered, facility funding and capacity Admissions to publicly funded treatment pro- rata are available at the national and state leve <u>c/information.htm</u>	data portal. S is an annual survey of participating subst SATS is used to compile and update the Na attps://www.dasis.samhsa.gov/dasis2/ns No costs stated. Publicly available grams and opioid substitution programs b els. Data are submitted from state and loc	ational Directory of Drug a sats.htm State profiles accessible here. y primary, secondary, and cal treatment agencies.	nd Alcohol Abuse Merged at the county or state level with other data sets

Agency	Cove	rage Tim	nσM	leasures	Costs and Restrictions	Available Analytics	Linking Capability
<u> </u>					covered outpatient drugs paid for by sStat	-	• · ·
	-		-		tions for Medicaid-covered outpatient dru	-	
					ov/medicaid/prescription-drugs/state-dru		
Centers for	Nation				Medicaid open data publicly available	View data by state	Linked at the state leve
Medicare a			identify specific o	•	here. Because of privacy restrictions, all	online or access CMS	with other data sets
Vedicaid					direct identifiers are removed in the	drug spending	
Services (CN	/IS)		reimbursed	•	public data and aggregate data fewer	dashboard here.	
federal)					than 11 counts are suppressed.		
<b>Medicare</b> D	ata Files: T	ne Master Be	neficiary Summary File	ncludes several segme	nts including enrollment information, chro	nic conditions data (e.g.,	mental health, substanc
ise conditio	ons), service	utilization, N	ledicare payment amou	unts, and place of reside	ence at the zip-code level. Other notable o	latabases include the Med	dicare Carrier File (final
ction fee-f	or-service c	laims submitt	ed on a CMS-1500 clair	n form); Medicare Outp	patient Standard Analytic File (claims and t	reatment codes); Medica	re Provider Analysis and
Review files	(hospital in	ipatient servi	ces), and Part D Prescri	otion Drug Event data (	contains prescription drug cost and payme	ent data). <u>https://www.re</u>	esdac.org/cms-
lata/search	n?f%5B0%5	D=im_field_c	ata_file_category%3A	<u>16</u>			
Research	National	Annual or	Notably, Medicare en	rollment, mental	May include costs. Varying privacy levels	See statistics, trends,	Linked at the state,
Data		semiannual	health and substance	use conditions, service	for CMS files; requires data use	and reports here.	county, or zip-code lev
Assistance				re payment amounts,	agreements		to various data sets.
Center			death information (on				Linked at the person
ResDAC),			prescription drug info	rmation			level with other
CMS							Medicare files; Veterar
federal)							Health Administration
							(VHA) data; or Medicai
							claims for Medicare-
							Medicaid enrollees
			-		cription under Medicare Part D, a prescrip		-
	-	• –			ins prescription drug cost and payment da		
					escription-Drug-Coverage/PrescriptionDru		
CMS (federa	al) Nation	al Annua		costs, payment data,	Includes request fee; must be	Medicare Part D Opioid	Linked at the state,
				age information, and	requested; certain data elements may	Mapping Tool	county, or zip-code lev
			prescription infor	mation	be encrypted and/or unavailable		to various data sets.
					depending on the particular requestor		Linked at the person-
					entity and the demonstrated need for		level with other
					an element		Medicare files; VHA
							data; or Medicaid clair
							for Medicare-Medicaid
							enrollees

Agency	Coverage	Timing	Measures	Costs and Restrictions	Available Analytics	Linking Capability
			Corporate Data Warehouse (CDW): The CI			-
	• •		n and Technology to provide a high-perfo		e through standardizatio	n, consolidation, and
		1	os://www.hsrd.research.va.gov/for_resea			
VA (federal)		Near real-	Patient-level data on prescriptions and		Maps of VA opioid	Links data across
		time	health care utilization	use. Research requests must go through	prescribing data here.	multiple VHA data
				the Data Access Request Tracker		source system
				application. With approval, data access		
				to CDW can be obtained from CDW		
				through approved SQL tables delivered		
				to a research project or accessed		
	<u> </u>	<u> </u>		through SAS Proc SQL.		
			e National Patient Care Database (NPCD),		•••••••••••••••••••••••••••••••••••••••	
	-		NPCD collects integrated patient care date		stems and Technology A	rchitecture (VistA)
			www.data.va.gov/dataset/national-pati			I
VA (federal)			Clinical data resulting from ambulatory	•	Maps of VA opioid-	Can be linked with othe
		daily	care patient encounters; primary care	use. Research requests must go through	prescribing data here.	VHA patient-level data
			patient to provider assignments and	the Data Access Request Tracker		systems and across
			provider utilization data	application. With approval, data access		years to generate
				to CDW can be obtained from CDW		episodes of care for
				through approved SQL tables delivered		individuals; can be
				to research project or accessed through		linked with mortality
				SAS Proc SQL.		data by Social Security
						Number
		1				
Clinical Data Ba	se/Resource	Manager of	Vizient Inc.: The Vizient Clinical Data Base	and Resource Manager™ (formerly Unive	rsity Helathsystem Conso	Drtium) is an
		-	Vizient Inc.: The Vizient Clinical Data Base base providing clinical, discharge, procedu			
administrative,	clinical, and fi	inancial data		ure, and outcome data for hospital encour ical-Data Base	iters from a consortium o	
administrative, health centers.	clinical, and finhttps://www.	nancial data .vizientinc.co	base providing clinical, discharge, procedu	ure, and outcome data for hospital encour ical-Data Base		of hospitals and academi
administrative, health centers. <mark> </mark> Vizient Inc.	clinical, and finhttps://www.	nancial data .vizientinc.co	base providing clinical, discharge, procedu om/Our-solutions/Clinical Solutions/Clini	ure, and outcome data for hospital encour ical-Data Base	iters from a consortium o	of hospitals and academi May be linked at the zig
administrative, health centers. <mark> </mark> Vizient Inc.	clinical, and finter the second secon	nancial data .vizientinc.co	base providing clinical, discharge, procedu m/Our-solutions/Clinical Solutions/Clinical Solutions/Clinical Patient outcome data including	ure, and outcome data for hospital encour ical-Data Base Costs not stated; may need to be a	iters from a consortium o	of hospitals and academi May be linked at the zig
administrative, health centers. <mark> </mark> Vizient Inc.	clinical, and finter the second secon	nancial data .vizientinc.co	base providing clinical, discharge, procedu m/Our-solutions/Clinical Solutions/Clinical Solutions/Clinical Solutions/Clinical Solutions/Clinical Solutions Patient outcome data including mortality, length of stay, complication	ure, and outcome data for hospital encour ical-Data Base Costs not stated; may need to be a	iters from a consortium o	of hospitals and academic May be linked at the zip code tabulation area or
administrative, health centers. <mark> </mark> Vizient Inc.	clinical, and finter the second secon	nancial data .vizientinc.co	base providing clinical, discharge, procedu om/Our-solutions/Clinical Solutions/Clini Patient outcome data including mortality, length of stay, complication rates, and readmission rates—can	ure, and outcome data for hospital encour ical-Data Base Costs not stated; may need to be a	iters from a consortium o	of hospitals and academi May be linked at the zig code tabulation area or more-aggregate level;
administrative, nealth centers. Vizient Inc.	clinical, and finter the second secon	nancial data .vizientinc.co	base providing clinical, discharge, procedu om/Our-solutions/Clinical Solutions/Clinical Patient outcome data including mortality, length of stay, complication rates, and readmission rates—can categorize by opioid use (does not	ure, and outcome data for hospital encour ical-Data Base Costs not stated; may need to be a	iters from a consortium o	of hospitals and academi May be linked at the zig code tabulation area or more-aggregate level; supports linkage with American Hospital
administrative, health centers. Vizient Inc. (private)	clinical, and finttps://www. National (across network)	nancial data vizientinc.co	base providing clinical, discharge, procedu om/Our-solutions/Clinical Solutions/Clinical Patient outcome data including mortality, length of stay, complication rates, and readmission rates—can categorize by opioid use (does not	ure, and outcome data for hospital encour ical-Data Base Costs not stated; may need to be a Vizient member to access data	nters from a consortium o	of hospitals and academi May be linked at the zig code tabulation area or more-aggregate level; supports linkage with American Hospital Association survey data
administrative, health centers. Vizient Inc. (private) EHRs from Grou	clinical, and finttps://www. National (across network) up Health Coo	nancial data vizientinc.co Not stated	base providing clinical, discharge, procedu m/Our-solutions/Clinical Solutions/Clinical Patient outcome data including mortality, length of stay, complication rates, and readmission rates—can categorize by opioid use (does not appear to collect dose information)	ure, and outcome data for hospital encour ical-Data Base Costs not stated; may need to be a Vizient member to access data	nters from a consortium o	of hospitals and academi May be linked at the zip code tabulation area or more-aggregate level; supports linkage with American Hospital Association survey data
administrative, health centers. Vizient Inc. (private) EHRs from Grou	clinical, and finttps://www. National (across network) JP Health Coo Washington	nancial data vizientinc.co Not stated	base providing clinical, discharge, procedu m/Our-solutions/Clinical Solutions/Clinical Patient outcome data including mortality, length of stay, complication rates, and readmission rates—can categorize by opioid use (does not appear to collect dose information) HC, now Kaiser Permanente): Information	ure, and outcome data for hospital encour ical-Data Base Costs not stated; may need to be a Vizient member to access data	nters from a consortium of None identified	of hospitals and academi May be linked at the zip code tabulation area or more-aggregate level; supports linkage with American Hospital Association survey data
administrative, health centers. Vizient Inc. (private)	clinical, and finttps://www. National (across network) JP Health Coo Washington	nancial data vizientinc.co Not stated perative (GI Near-real	base providing clinical, discharge, procedu m/Our-solutions/Clinical Solutions/Clinical Patient outcome data including mortality, length of stay, complication rates, and readmission rates—can categorize by opioid use (does not appear to collect dose information) HC, now Kaiser Permanente): Information Prescribing of opioids, past prescribing, and reason for admission (opioids	Costs not stated; may need to be a Vizient member to access data	nters from a consortium of None identified	of hospitals and academic May be linked at the zip code tabulation area or more-aggregate level; supports linkage with American Hospital Association survey data Has been linked at the individual level to
administrative, health centers. Vizient Inc. (private) EHRs from Grou	clinical, and finttps://www. National (across network) JP Health Coo Washington	nancial data vizientinc.co Not stated perative (GI Near-real	base providing clinical, discharge, procedu m/Our-solutions/Clinical Solutions/Clinical Patient outcome data including mortality, length of stay, complication rates, and readmission rates—can categorize by opioid use (does not appear to collect dose information) HC, now Kaiser Permanente): Information Prescribing of opioids, past prescribing,	Costs not stated; may need to be a Vizient member to access data	nters from a consortium of None identified	of hospitals and academic May be linked at the zip code tabulation area or more-aggregate level; supports linkage with American Hospital Association survey data / Has been linked at the

Agency	Coverage	Timing	Measures	Costs and Restrictions	Available Analytics	Linking Capability
		_		Research Integrated Database has three ir over 1.3 million pediatric and adult patier		
			-	rm; and a biospecimen data management		-
	-			d.stanford.edu/researchit/infrastructure		
Stanford University (private)	Stanford University Medical Center	Real time	Prescribing information; has been used to identify patient research cohorts by condition	Costs not stated. Identified clinical data in the CDW is only released to Institutional Review Board (IRB)– approved research studies that have received the appropriate IRB approval. De-identified data are made available for Stanford research projects that qualify as a nonhuman subject research study. Answers to data-access questions are available <u>here</u> .	<u>cohort tool</u> only through connection to Stanford network or virtual private network	The Stanford Translational Research Integrated Database exists in part as a tool for data linkages, although no linkages specific to opioids identified.
				nsured population. Contains medical and p		
				Cross/Blue Shield) across 14 states. https:/		
HealthCore (private)	National (subset of states)	NOT STATED	Insurance holder demographics, claims data relevant for opioid use, including emergency department visits and adverse drug events; prescription information	Costs not stated. Data primarily available only through consultants. HealthCore does not sell data to third parties for their independent use or otherwise.	None identified	Linked with hospital, local, and federal data
medical and c capitated hea (HMOs), and c	lrug data for se Ith plans, incluc consumer-direc	veral million ling preferre ted health p	individuals annually. Health care for these d and exclusive provider organizations (PF	encounters database consists of employe e individuals is provided under a variety of POs and EPOs), point-of-service plans, inde ent prescription drug claims and person-le research-databases	fee-for-service, fully capi emnity plans, health main	tated, and partially tenance organizations
Fruven Health		Quarterly	Prescribing trends, rates of opioid	Costs vary. Customized data sets and	Online access available,	Can be linked with oth
Analytics private)			prescribing	licensing agreements available. Accessing the data requires data management software. DataProbe <sup>®</sup> and MarketScan Online Tools (e.g., Sample Select, Sample Select Prevalence, Inpatient View, Outpatient View,	but must be purchased	MarketScan databases
				Disease Profiler, Treatment Pathways) can facilitate access.		

Agency	Coverage	Timing	Measures	<b>Costs and Restrictions</b>	Available Analytics	Linking Capability
			ase: The MarketScan Medicaid database o		rollee-level de-identified	
			s for both fee-for-services and capitation p			-
addition to stan	dard demogra	aphic variabl	es such as age and gender, the database i	ncludes variables of particular importance	e for investigating Medica	id populations, such as
aid category (bli	nd/disabled,	Medicare eli	gible) and race. Data are collected from e	mployers, health plans, or state Medicaid	agencies. https://truven	health.com/your-
healthcare-focu	s/analytic-re	search/marl	ketscan-research-databases			
Truven Health	Multistate	Semiannua	Pharmaceutical claims for filled	Costs vary. Customized data sets and	Online access available,	Can be linked with other
Analytics	(12 states in	lly	prescriptions, outpatient service claims	licensing agreements available.	but must be purchased	MarketScan databases
(private)	2010)		records, inpatient admissions records	Accessing the data requires data		
				management software. DataProbe® and		
				MarketScan Online Tools (e.g., Sample		
				Select, Sample Select Prevalence,		
				Inpatient View, Outpatient View,		
				Disease Profiler, Treatment Pathways)		
				can facilitate access.		
Optum databas	<b>e:</b> Large datal	base of eligit	pility-controlled claims information (comm	nercial and Medicare members of affiliate	d plans, and commercial r	members of Optum
Employer custor	mers' and Op	tum Payer cu	ustomers' health plans). Comprises comple	ete inpatient, outpatient, and pharmacy c	laims.https://www.optu	m.com/solutions/data-
analytics/data/r			-a-cpl/claims-data.html			
Optum	National	Not stated	Opioid episode duration and dosage;	Costs and access restrictions not stated.	None identified	State (and possibly
(private)			opioid overdose; enrollment, utilization,			county) identifiers
			all available clinical data in EMR/EHR			support linkage at
						aggregate level
		-	Dataverse: Comprehensive source providi			-
	-	-	scription data, nonretail invoice data, and			
			han 80 percent of pharmacies nationwide		-	
			s filled at retail pharmacies in the United S			
			cription drug claim processors and payers	, using the same data that get verified aga	ainst standard reporting in	iformation to the U.S.
	1		pm/product/idv/	Casta usara hu na muant	Non a talantifical	Com has many dissible
	National	Not stated	Medical, hospital and prescription claims	Costs vary by request	None identified	Can be merged with
Health (private)			related to opioid prescribing and/or			other state- or county-
			overdose, point-of-sale prescription data, nonretail invoice data, and			level information
			demographic data			
IOVIA (formarly	IMS) Nation		nd Therapeutic Index (NDTI): The NDTI is .	n monthly audit of office based physician	that provides informatic	n about pattorns and
			nited States. For each patient seen during			
			about diagnoses and drug therapies. Eac			
			o the ICD-9. http://www.imshealth.com/		T is lifted to a specific six	
IQVIA (private)			Diagnosis codes; underlying and	Costs vary depending on request	Available (with	Can be merged with
		• ·	concomitant conditions; prescription	costs vary depending on request	payment) via the	other state- or county-
			information; drug appearance or drug		customer portal	level information
			use; patient and physician characteristics			

Agency	Coverage	Timing	Measures	Costs and Restrictions	Available Analytics	Linking Capability
		al Prescripti	on Audit: Measures retail dispensing of pr	escriptions to consumers via formal prese	criptions. http://www.im	shealth.com/en and
https://www.ic		I				
QVIA (private)	National	Monthly	Prescriptions (by National Drug Code),	Costs vary depending on request.	Available (with	Can be merged with
			channel (i.e., where prescription filled),	Geographic identifiers not available	payment) via the	other state- or county-
			prescriber specialty	below three zip-code levels	customer portal. The	level information
					CDC has online graphs	
					of aggregate data by	
					state and county here	
QVIA (formerly	/ IMS) Nation	al Sales Pers	spectives: Measures sales volume of dolla	rs and units of pharmaceutical products p	urchased by retail and no	nretail providers. Data
ollected from a	a large sample	e of manufac	cturers, wholesalers, outlets, and projecte	d to national estimates. <u>http://www.imsh</u>	nealth.com/en/ and https	://www.iqvia.com/
QVIA (private)	National	Monthly	Prescription sales volume (by product	Costs vary depending on request. Flat	Available (with	Projected data intende
	(projected)		type), number of units sold	files can be delivered through secure	payment) via the	for national analyses;
				File Transfer Protocol platform	customer portal	however, state or
						county linkages may b
						possible
QVIA (formerly	/ IMS) PaverT	rak: PaverTr	ak is a web-based approach to trends in p	rescription drug utilization by payer. Paye	rTrak provides access to p	
	· · ·	-	tail channel. With the PayerTrak tool, sub			
			ol. Data are projected to national estimate			onp non producto or
QVIA (private)	1	Monthly	Total prescriptions (by product), pay	Costs vary depending on request	Available (with	Projected data intend
Quint (private)	(projected)	wienny	type, state, copay	costs vary depending on request	payment) via the	for national analyses;
	(projected)		type, state, copay		customer portal	however, state or
						county linkages may b
		in a sur d Farm			althe alations and an assume	possible
			ollment Data (MassHealth): Massachuset			· · · · · · · · · · · · · · · · · · ·
-	-		ization and expenditures, as well as assoc		ind behavioral health serv	lices sector across a
		1	//www.mass.gov/eohhs/provider/insura			
Massachusetts	Single state		Treatment for addictions, diagnosis of	Not stated	None identified	Has been merged with
lealth and		(may be	opioid dependence, expenditures on			other state data sets a
luman		-	treatment, mortality (in the eligibility			the individual level
ervices (state)		other	file)			
		levels)				
Massachusetts	All-Payer Clai	ims Databas	e (MA APCD): The MA APCD is the most c	omprehensive source of health claims dat	a from public and private	payers in Massachuset
Vith informatic	on on the vast	majority of	Massachusetts residents, the MA APCD pr	omotes transparency and affords a deep	understanding of the Mas	sachusetts health care
ystem. <u>http://</u>	www.chiama	ss.gov/ma-a	ipcd/			
/lassachusetts	Single state	Annual	Health and pharmacy insurance claims	Fees may apply. Data must be	None identified	Forms the spine of the
Center for		(may be	related to opioids or other prescription	requested and approved. See links to		Chapter 55 data set,
lealth		possible at	medication, infant diagnosis codes for	"Steps to Request the Data" for		linked to mortality,
nformation		other	neonatal abstinence syndrome,	government and non-government		prescription drug
nd Analysis		levels)	demographics	entities: http://www.chiamass.gov/ma-		monitoring program
state)				apcd/		(PDMP), criminal justi
						treatment, and other
						data sets
						uald sels

Agency	Coverage	Timing	Measures	Costs and Restrictions	Available Analytics	Linking Capability				
/ermont Health Care Uniform Reporting and Evaluation System (VHCURES): Vermont's APCD, a comprehensive, longitudinal, multipayer data set that regularly collects										
medical and pha	nedical and pharmacy claims data and eligibility data from both private and public payers. <u>http://gmcboard.vermont.gov/hit/vhcures</u>									
Vermont Green	Single state	Annual	Medical expenditures, costs of treatment	Costs apply. Through data use	None identified	None identified				
Mountain Care		(may be	for opioid use disorders	agreements, de-identified VHCURES						
Board (state)		possible at		data is being utilized by state agencies,						
		other		state contractors, and academic						
		levels)		researchers to support analysis of						
				health care access, spending, utilization,						
				and quality.						

# Table A.3. Mortality Records

Agency	Coverage	Timing	Measures	Costs and restrictions	Available analytics	Linking capability
	-		ath Data: The Multiple Cause of Death data ava			
-			leath certificates for U.S. residents. Each death	certificate contains a single underlying ca	ause of death, up to 20 ac	Iditional multiple
.auses, a CDC	National	Released	://wonder.cdc.gov/mcd.html Number of deaths, crude death rates, age-	No costs and publicly available.	Online data portal here	Merged with other
federal)	National	annually	adjusted death rates (can be analyzed by	Subnational data representing zero to		state- or county-level
(leueral)		(but can	drug and alcohol related causes of death,	nine deaths are suppressed		information
		obtain	injury intent and injury mechanism	inne deaths are suppressed		Information
		monthly	categories)			
		aggregate)				
National	Death Index (		I HS established the NDI as a resource to aid epic	l demiologists and other health and medica	l investigators with their	l mortality-ascertainme
		-	s/ndi/index.htm			montanty-ascentamine
CDC	National	Annual		Fee per study subject with fee schedule	None identified	Can be linked at the
(federal)			the corresponding death certificate numbers.			individual level to the
			NDI Plus provides cause of death	investigators solely for statistical		NHIS; National Health
				purposes in medical and health		and Nutrition
				research. The service is not accessible		Examination Survey;
				to organizations or the general public		longitudinal study of
				for legal, administrative, or genealogy		aging; and VA health
				purposes.		care data; has been
						linked with a variety
						state-specific health
						data sets
National	Vital Statistics	s System (NVS	SS) Multiple-Cause-of-Death files: Mortality da	ta from NVSS are a fundamental source o	of demographic, geograph	ic, and cause-of-death
	-	-	eographic areas and available for a long time p		-	teristics of those dying
			e expectancy and to compare mortality trends.		lity_methods.htm and	
	1		tistics-mortality-data-multiple-cause-of-death			
CDC	National	Annual	Mortality with information on drugs involved		NVSS is the underlying	Merged at the county
(federal)			in death	requested and approved before being	data for <u>CDC WONDER</u>	level with other data
				provided on CD or DVD.		sets
	-		<b>RS):</b> Data derived from a census of fatal traffic			
			s, but also from death certificates, state corone		id vehicle registration reco	ords, and emergency
	1		vw.nhtsa.gov/research-data/fatality-analysis-			
	National	Annual	143 different coded data elements (as of	No costs and publicly available	See online query system	
Highway			2013) that characterize the fatal crash,		<u>here.</u>	support linkage at the
Traffic			including toxicology reports			city, county, and stat
Safety						levels.
Administ						
ration						
(federal)						

Agency Coverage Timing	Measures	Costs and restrictions	Available analytics	Linking capability
Examples of State Death Certificate Data		costs and restrictions	Available analytics	Linking capability
Florida Department of Health mortality		/statistics-and-data/		
Death certificate data for the state of Flo				
Data access: application form and inform				
Prior studies using this data: Kennedy-He				
Past linkages: Merged at the state level v	vith Florida PDMP information			
North Carolina State Center for Health S	tatistics: <u>http://www.schs.state.nc.u</u>	is/aboutus.htm		
Death certificate data for the state of No	0			
	, , , , , ,	may be subject to a charge and completed a	•	S.
-		ota et al. ( <u>2016</u> ); Kennedy-Hendricks et al. ( <u>2</u>		
Past linkages: Linked at the individual lev	el, matching decedent names to cont	rolled substance-prescription histories thro	ugh PDMP data	
North Carolina Office of the Chief Medic				
		vell as natural deaths that are suspicious, un	usual, or unattended by a m	edical professional;
contains postmortem serum toxicologica	•			
		ords and once finalized, may be obtained fro	om the Office of the Chief Me	edical Examiner. To
request any of these documents, use the				
Prior studies using these data: Albert et	· · · · · · · · · · · · · · · · · · ·			
Past linkages: Linked at the individual lev	el to state death certificate data and	state PDMP data		
Massachusetts Registry of Vital Records	and Statistics: http://www.mass.gov	v/eohhs/gov/departments/dph/programs/	admin/dmoa/vitals/	
Vital records and deaths for Massachuse	tts			
Data access: Information provided here				
	al. ( <u>2013</u> ); The Commonwealth of Ma	assachusetts, Executive Office of Health and	Human Services, Departmer	it of Public Health
2016, 2017) <b>Past linkages</b> : Linked at the individual lev	el to multiple other state databases u	under Chapter 55 (see The Commonwealth c	of Massachusetts, Evecutive	Office of Health and
Human Services, Department of Public H	•		n wassachusetts, Executive	
	ion of Health Statistics, Death Statist	tical System: https://www.tn.gov/health/	health-program-areas/stat	istics/health-data/
death-statistics.html				
	-	has many public health statistics publicly av	ailable)	
Data access: Individual-level data not pub		or further information.		
Prior studies using this data: Baumblatt				
Past linkages: Linked at the individual lev	el to state PDMP data			

## Table A.4. Prescription Monitoring Secondary Data Sources

Agency	Coverage	Timing	Measures	Costs and Restrictions	Available Analytics	
	-		ated Orders System (ARCOS): Measure of pre			
			and IV substances from manufacture to sale. I	Data for each substance reported by quant	tity (e.g., mg, dosage	unit) and three-digit zip
code. <u>http</u>			oj.gov/arcos/		•	
Drug	National	Annual	Amount of manufactured controlled	Costs not stated. Available to all DEA	Summary reports	Merged with other data
Enforcem			substance circulating through legal means,	manufacturers and distributers; must	publicly available	sources at the county or
ent			by compound	procure data through Freedom of		state level
Administr				Information Act (FOIA) request; public		
ation				data are usually released only at the		
(DEA)				state level, but three-digit zip-level data		
(federal)				have been used under special agreement		
-		-	<b>stem:</b> Epidemiological surveillance and evalu	•		DMPs to measure trends i
	-	-	dispensing and indicators of medical use and	possible nonmedical prescription drug ab	use and diversion.	
			/prescription-behavior-surveillance-system		•	
-	12 states	Quarterly	Forty-three prescription behavior	Costs not stated. Data-sharing	Online access for	Compiles PDMP
Brandeis	submitting;		measures: overall usage within drug classes	agreement specifies how Brandeis will	authorized federal	information across state
• •	more being		and for selected individual drugs; daily	manage, secure, and protect the PDMP	researchers	
funded)	reviewed to		dosage; overlapping prescriptions within	data; data are maintained securely at		
	join		each drug class or across classes;	Brandeis, and access by Brandeis		
			questionable activity; payment source;	research staff is limited in accordance		
			indicators of possible pill mills;	with the IRB-approved protocol.		
				Procedures are in process to provide		
			pharmacy-based measures of possible	access by authorized federal researchers.		
			inappropriate dispensing			
Examples	of State Pres	ription Drug-	Monitoring Program (PDMP) Data			
Maine Pre	scription Mo	nitoring Progr	am: http://www.maine.gov/dhhs/samhs/os	sa/data/pmp/index.htm		
Maine's PI	OMP data, ho	sted by the M	aine Substance Abuse and Mental Health Ser	vices		
Data acces	s: Agency ha	s demonstrate	d willingness to provide data sets needed for	research to address the problem of opioid	d misuse and abuse. D	e-identified data have be
made avai	lable to resea	rchers.				
Prior studi	es using this	<b>data</b> : Piper et	al. ( <u>2016</u> ), Kreiner et al. ( <u>2017</u> )			
Past linkag	<b>ges</b> : Linked at	the individual	level to other prescriber information; merge	d at the county level with Maine Diversion	Alert Program data	
Maryland	Prescription	Drug Monitor	ing Program: <u>https://bha.health.maryland.g</u>	ov/pdmp/Pages/Home.aspx		
	•					
Maryland	s PDMP data,	hosted by the	Maryland Department of Health and Mental	Hygiene, Behavioral Health Administratio	n	
•			ata must complete training prior to submittin			
		data: Lin et al		, - <u>1</u>		
Prior studi						
	-		r level to a different survey on physician attit	udes and use of PDMP		

#### Massachusetts Prescription Drug Monitoring Program: http://www.mass.gov/eohhs/gov/departments/dph/programs/hcq/drug-control/pmp/reports-and-data.html

Massachusetts's PDMP data, hosted by the Massachusetts Department of Public Health

Data access: Data request form available here

Prior studies using this data: Katz et al. (2010), The Commonwealth of Massachusetts, Executive Office of Health and Human Services, Department of Public Health (2016, 2017)

Past linkages: Linked at the individual level to multiple other state databases under Chapter 55 (see The Commonwealth of Massachusetts, Executive Office of Health and Human Services, Department of Public Health [2016, 2017]); also allows interstate data sharing

Tennessee Controlled Substances Monitoring Program/Database: https://www.tn.gov/health/health-program-areas/health-professional-boards/csmd-board.html

Tennessee's PDMP data, hosted by the Tennessee Department of Health

Data access: The law allows a number of other state and federal officials to register with the database, including certain law enforcement officers, medical examiners, drug court judges, and others.

Prior studies using this data: Baumblatt et al. (2014)

Past linkages: Linked at the individual level to state death certificate data

Ohio Automated Rx Reporting System: https://www.ohiopmp.gov/

Ohio's PDMP data, hosted by the State of Ohio Board of Pharmacy

Data access: Not stated

Prior studies using this data: Baehren et al. (2010), Weiner et al. (2017)

Past linkages: Linked at the individual level with patient emergency department data

Kentucky All Schedule Prescription Electronic Reporting System: https://chfs.ky.gov/agencies/os/oig/dai/deppb/Pages/kasper.aspx

Kentucky's PDMP data, hosted by the Kentucky Cabinet for Health and Family Services

Data access: Not stated

Prior studies using this data: Blondell et al. (2004), Brady et al. (2014), Becker et al. (2017), Slavova et al. (2017)

**Past linkages**: Merged with zip-, county-, or state-level social and economic variables. The Kentucky Department of Public Health, Cabinet for Health and Family Services, has established a multisource drug-overdose surveillance system, including the PDMP and various other state data sources (e.g., emergency department discharges, overdose death and postmortem toxicology, and heroin/fentanyl submissions to Kentucky State Police crime labs).

Florida's Prescription Drug Monitoring Program: http://www.floridahealth.gov/statistics-and-data/e-forcse/

Florida's PDMP data, hosted by the Florida Department of Health **Data access**: Not stated **Prior studies using this data**: Delcher et al. (<u>2015</u>)

Past linkages: Merged with other state-level data sources (e.g., mortality)

North Carolina Controlled Substances Reporting System: <u>https://nccsrsph.hidinc.com/nclogappl/bdncpdmqlog/pmqhome</u> https://www.ncdhhs.gov/divisions/mhddsas/ncdcu/csrs

North Carolina's PDMP data, hosted by the North Carolina Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services

**Data access**: Permission to query the system must be obtained from system administrators.

Prior studies using this data: Albert et al. (2011), Hirsch et al. (2014), Ringwalt et al. (2015), Dasgupta et al. (2016), Roberts et al. (2016)

Past linkages: Linked at the individual level with Medicaid claims data and mortality data

California's Controlled Substance Utilization Review and Evaluation System: https://oag.ca.gov/cures

California's PDMP data, hosted by the California Department of Justice

**Data access**: For access, researchers must obtain a background check from the California Department of Justice. An SQL server is used within the Department of Justice to deidentify the database using a record-linkage methodology to permit identification of sequential prescriptions for each patient. Unique computer-generated identifiers are devised for each provider and pharmacy to remove identifying information at the patient, provider, or pharmacy level.

Prior studies using this data: Wilsey et al. (2011), Gilson et al. (2012), Han et al. (2014)

Past linkages: No individual-level linkages identified.

Oregon's Prescription Drug Monitoring Program: <u>http://www.orpdmp.com/researchers.html</u>

Oregon's PDMP data, hosted by the Oregon Health Authority

**Data access**: The Oregon Health Authority may provide de-identified PDMP data for research purposes. The Oregon Health Authority is accepting research requests. **Prior studies using this data**: Hartung et al. (2012); O'Kane et al. (2016); Deyo et al. (2017)

Past linkages: Linked at the patient level to state vital records, hospital discharge registry, and Medicaid administrative pharmacy claims

#### Table A.5. Contextual and Policy Data Sources

•	2	<u>-</u> · ·			Available	
Agency	Coverage	Timing	Measures	Costs and Restrictions	Analytics	Linking Capability
	•	•	F data include county, state, and national-level files	•		· • •
		-	is training, hospital utilization, hospital expenditures	, and environment. The AHRF d	ata are obtained fr	om more than 50 sources.
https://www.hrsa	1					
Health Resources	National	Annual	Information on health care cost and utilization,	No costs and publicly	See tools and	Merged county-level
and Services		(some	demographics, health care facilities and services,	available	data portal here.	contextual factors with
Administration		measures are	vital events, and other health information based			other data on opioid
Data Warehouse			on geographic region			outcomes
(federal)		monthly, and				
Coment Develotie		quarterly)				
-			urce of labor force statistics for the U.S. population.			-
			and cover a wide variety of topics such as child sup		ance coverage, and	d school enrollment.
	-		or biannually. https://www.census.gov/programs-			<b>.</b>
U.S. Census	National	Monthly	Information on educational status, health	No costs and publicly		Merged state- or county-
Bureau and the			insurance, work and labor market outcomes,	available. Not all counties are		level contextual factors
U.S. Bureau of			income, disability, household characteristics (e.g.,	included, and data are not		with other data on opioid
Labor Statistics			household size), demographics (e.g., age, race,	available for most sampled		outcomes
(federal)			gender), labor force participation, and poverty	counties due to		
		-	rates	confidentiality laws.		
		-	s (NAMSDL) policy data: Provides information on cu	rrent state statutes and policies	related to controll	ed substances and
prescription drugs				1	I	T
	National	Updated	Statutes related to naloxone access; pain	No costs and publicly		Merged with state-level
(federally funded)		semiannually	management, pain clinics, and prescribing	available. Historical data are	policies here.	data on opioid-related
			practices; Good Samaritan Laws; PDMPs; doctor	not available or readily		outcomes
			shopping laws; prescription trafficking statutes;	downloadable for all policies.		
			regulation of internet pharmacies			
			ICSL) policy data: NCSL maintains legislative tracking			
• • •			ortation, health care access, and public health. User	<b>-</b>	-	
keyword. Users ca	n download	d state legislatio	on as a PDF file. http://www.ncsl.org/research/heal	th/ncsl-prescription-drug-polic	y-resources-center	r.aspx
NCSL	National	Annual		No costs and publicly	Online database	Merged with state-level
(nongovernment			drug policies; PDMPs; prescribing guidelines;	available. Historical data are	search here.	data on opioid-related
al organization)			naloxone; pain clinics	not available or readily		outcomes
				downloadable for all policies.		

Agency	Coverage	Timing	Measures	Costs and Restrictions	Available Analytics	Linking Capability
	Abuse Poli		PS): Tracks key state laws related to prescription dr	ug abuse. PDAPS provides accu	rate, detailed inform	
. –	-		controlled medicines and reduce overdoses. PDAPS	users interact with and downlo	ad legal data throu	gh the MonQcle software
platform. http://w		.org/	1	1	1	Γ
Legal Science, LLC		Updated	Notably, state laws regarding: access to naloxone,	Data download is a paid		Merged at the state-leve
(federally funded)			Good Samaritan 911 immunity, PDMPs	feature.		with opioid-related
			administration, and regulation and reporting		·	outcomes
	•	• •	data on a variety of public health issues and opinior	ns. Also compiles information fr	om other secondar	y sources (e.g., CPS) to
provide state-level	data on he	ealth indicators.	http://www.kff.org/			
KFF (private)	National	Varies	Public opinion on opioid use; polling data from	No costs stated. Publicly	Access state	Merged with state-level
			public and medical officials; health insurance	available	profiles here.	data on opioid-related
			coverage			outcomes
<b>Policy Surveillance</b>	e Program (	PSP): Program	aiming to increase the use of policy surveillance and	legal mapping as tools for imp	roving the nation's	health. Data from legal
mapping to unders	stand the la	aws on a given t	opic and how those laws differ over time and across	jurisdictions. http://lawatlas.c	org/	
Temple	National	Updated	Opioid policies and regulations across states	No costs stated. Publicly	Maps are	Merged at the state leve
University		semiannually		available. Historical data are	available online	with information on
LawAtlas Project				not available or readily	here.	opioid-related outcomes
(private)				downloadable for all policies		
PDMP Training an	d Technica	l Assistance Cer	nter (TTAC) at Brandeis: The PDMP Training and Tec	hnical Assistance Center (PDM	PTTAC) at Brandeis	University provides a
wide range of serv	ices and re	sources to PDM	P agencies, researchers, and other stakeholders in a	in effort to advance the effectiv	eness of PDMPs to	combat misuse and abus
of prescription dru	ıgs. <u>http://</u>	www.pdmpassi	ist.org/			
TTAC @ Brandeis	National	Updated fairly	Information on timing of state PDMP laws and	No costs stated. Publicly	See maps and	Merged at the state leve
(federally funded)		regularly	PDMP law components	available. Historical data are	tables of PDMPs	with information on
				not available or readily	available here.	opioid-related outcomes
				downloadable for all policies		
<b>CDC Public Health</b>	Law Progra	am (PHLP): Law	s summarizing legal strategies used by states to add	ress the misuse, abuse, and hea	alth impacts of pres	cription drugs.
https://www.cdc.	gov/phlp/i	ndex.html				
CDC (federal)	National	Not stated	Time and dosage limit laws; physical exam	No costs stated. Publicly	See state laws on	Merged at the state leve
			requirements; doctor shopping laws; patient	available. Historical data are	prescription drug	with information on
			identification laws; pain management clinic	not available or readily	misuse and abuse	opioid-related outcome
			regulations; Good Samaritan laws	downloadable for all policies	here.	
		1	1		1	1

					Available	
Agency	Coverage	Timing	Measures	<b>Costs and Restrictions</b>	Analytics	Linking Capability
	-	• •	treatment locator: SAMHSA tracks the number of DATA-Cert	• •	scribe buprenorph	ine in each state and
			/medication-assisted-treatment/physician-program-data/tr		•	
SAMHSA	National	Daily	Number and location of DATA-Certified physicians; waiver	No costs. Public use files are	See counts by	Merged with other zip
(federal)			limits	not a complete census of	<u>state here.</u>	code–, county- or state-
				providers, but a complete		level information
				census is available as		
				restricted-use files		
			Act Registrants Database (ACSA): Contains a full list of addres	sses for physicians with DATA w	aivers, as well as a	full list of practitioners
registered to	handle cont		tances. https://classic.ntis.gov/products/dea-csa/	1	1	
,	National	Daily	Number and location of DATA-Certified physicians		Online access	Merged with other
distributed					available with fee	county- or state-level
by the						information
National						
Technical						
Information						
Services of						
the U.S.						
Department						
of						
Commerce						
(federal)						
-	-	•	VN): DAWN is a public health surveillance system that monito	• • • •		
	•		lies on a nationally representative sample of general, non-fee		• • •	-
			d metropolitan areas. In each participating hospital, emergen			ospectively to find the
	epartment v	r	volved recent drug use. https://www.samhsa.gov/data/data	a-we-collect/dawn-drug-abuse	-warning-network	
	National		Opioid misuse and abuse-related emergency department	No stated costs. DAWN was	Online analysis	Compared with other
(federal)				discontinued in 2011, but	· · · · · · · · · · · · · · · · · · ·	surveillance data sources
			drugs are included. Alcohol is considered an illicit drug		ICPSR with	
			when consumed by patients aged 20 or younger. For	sources of data on drug-	<u>account</u>	
				related emergency visits		
			is used in conjunction with other drugs.			
	-		(FDA) Adverse Event Reporting System: The FDA Adverse Ev			
			reports submitted to FDA. The database is designed to support			
therapeutic b	piologic proc		://www.fda.gov/Drugs/GuidanceComplianceRegulatoryInfo			70093.htm
	National		Reports of abuse-related adverse events. Contains detail on		See FAERS public	None identified
(federal)			product and substance with formulation- and composition-		dashboard here.	
			specific differentiation	case safety reports can be		
				obtained by sending a FOIA		
				request to the FDA		

Agonov	Coverage	Timing	Measures	Costs and Restrictions	Available Analytics	Linking Capability
Agency National Em			es Information System (NEMSIS): Provides data on EMS ever			
			ive of national EMS activity. <u>https://nemsis.org/</u>			
NHTSA (Federal)	National (49 states as of 2016)		illness, medications administered (including naloxone), and Emergency Medical Service (EMS) provider level, dispatch call indicated overdose event, recorded overdose as injury	No stated costs. Public-use files must be requested; certain variables are restricted use and must go through separate approval	See data explorer available here.	Has been merged with mortality data based on urbanicity
enforcemen	it and analyze	ed by state,	nation System (NFLIS): Drug cases investigated by the DEA. T county, and volunteer forensic labs. Available for states, part	process. he data set provides informatio	•	of drugs seized by law
DEA (federal) System to R		Monthly mation from	Drug identification results from drug cases submitted to forensic laboratories		<u>System here.</u>	
-	-	s://www.do Annual	ea.gov/resource-center/stride-data.shtml Street drug price by geographic area; street drug purity by geographic area; volume of drug acquisitions (through seizures, stings, purchases by undercover agents); product- specific information	Some state-level annual statistics available for download online. More detailed data can typically only be obtained through a FOIA request.	See state-level annual statistics here for heroin, cocaine, and	Linkages at the state, city, and metropolitan statistical area level possible with access to geocode identifiers

Agency	Coverage	Timing	Measures	Costs and Restrictions	Available Analytics	Linking Capability
			): Data reported by the American Association of Poison Cont			
	-	•	of exposure calls by drug/substance at state and national lev		•	
American Association of Poison Control Centers (federal)	National		Poison control calls related to opioids or other drugs by "intentional exposures" (includes abuse, misuse, and suspected suicidal) or "intentional abuse exposures." Contains detail on product type/composition	Fees vary depending on request and requesting organization. AAPCC NPDS Data Request Policy requires certain levels of internal approval prior to agreement execution	NPDS offers a	Can be merged with other state or county level information
			and State Inpatient Databases (SID) from HCUP: The NIS is t			
	inpatient da	atabases tha	nospital inpatient stays. Weighted, it estimates more than 35 at contribute to HCUP (currently 48 states participate in the S overview.jsp	•		-
HCUP, AHRQ (federal)	National or state- specific		Opioid-related inpatient stays for specific diagnosis; patient demographic characteristics; expected payment source; total charges	See database catalog for costs. All users, including purchasers and collaborators, must complete the online training and must read/sign the DUA for state databases	system through <u>HCUPnet</u> <u>Opioid-specific</u>	Previously linked at the metropolitan statistical level to other data sets. Hospital identifier unavailable for all states beginning with 2012 NIS
emergency d hospitalizatio	lepartment v on (currently	visits. NEDS 936 states p	States, providing national estimates of hospital-based emergents is sampled from the SID and SEDD—the SEDD capture emergenticipate in the SEDD). <a (asi-mv="" (fda-aers,="" aapcc="" and="" are="" asi-mv<="" available="" connect="" core="" data="" database).="" dawn="" detection="" followed="" href="https://www.hcup-us.ahrq.gov/necond-s&lt;/td&gt;&lt;td&gt;gency visits at hospital-affiliated&lt;/td&gt;&lt;td&gt;emergency depart&lt;/td&gt;&lt;td&gt;•&lt;/td&gt;&lt;/tr&gt;&lt;tr&gt;&lt;td&gt;HCUP,&lt;br&gt;AHRQ&lt;br&gt;(federal)&lt;/td&gt;&lt;td&gt;National or&lt;br&gt;state-&lt;br&gt;specific&lt;/td&gt;&lt;td&gt;1&lt;/td&gt;&lt;td&gt;Opioid-related emergency department stays for specific&lt;br&gt;diagnosis; patient demographic characteristics; expected&lt;br&gt;payment source; total charges&lt;/td&gt;&lt;td&gt;See database catalog for&lt;br&gt;costs. All users, including&lt;br&gt;purchasers and collaborators,&lt;br&gt;must complete the online&lt;br&gt;training and must read/sign&lt;br&gt;the DUA for state databases&lt;/td&gt;&lt;td&gt;Online query&lt;br&gt;system through&lt;br&gt;&lt;u&gt;HCUPnet&lt;/u&gt;&lt;br&gt;&lt;u&gt;Opioid-specific&lt;/u&gt;&lt;br&gt;&lt;u&gt;analytics&lt;/u&gt;&lt;/td&gt;&lt;td&gt;Linked at the state-level&lt;br&gt;with other data. Hospital&lt;br&gt;identifiers permit linkage&lt;br&gt;to hospital inpatient&lt;br&gt;databases&lt;/td&gt;&lt;/tr&gt;&lt;tr&gt;&lt;td&gt;other Schedu&lt;br&gt;with signal ve&lt;/td&gt;&lt;td colspan=8&gt;National Addictions Vigilance Intervention and Prevention Program (NAVIPPRO): NAVIPPRO is a comprehensive risk-management system for prescription opioids and other Schedule II or III therapeutic agents. Continuous and " http:="" live!,="" misuse)="" monitors="" navippro="" new="" on="" prescription="" proprietary="" publicly="" real-time"="" services="" several="" signal="" sources="" spatiotemporal="" strategies,="" streams="" subjected="" survey="" system="" td="" temporal="" to="" two="" up="" verification.="" web-onformed="" with="" www.inflexxion.com=""></a>			
Inflexxion (private)	Most of the United States	Near-real	Lifetime nonmedical opioid, heroin use; first-time nonmedical opioid use, heroin initiates; past-year and - month heroin use; nonmedical opioid use by product; route of administration; lifetime and past-year nonfatal opioid overdose; source of opioids	Costs and access restrictions apply. Costs vary by request.		Geographically detailed information may support linkages at aggregate level

Agency	Coverage	Timing	Measures	Costs and Restrictions	Available Analytics	Linking Capability
Researched	Abuse, Dive	rsion and A	ddiction-Related Surveillance System (RADARS): RADARS co of Key Informants, college survey, StreetRx (streetrx.com for	nsists of several programs: dru	g diversion, poison	center, opioid treatment,
Rocky Mountain Poison and Drug Center, Denver Health and Hospital Authority (private)	Most of	Near-real time	opioid use, heroin initiates; past-year and -month heroin use, nonmedical opioid use by product; measures of diversion; street price of opioid products	Costs vary by request. Each program in RADARS is approved by the institutional review board of the principal investigator's institution	will provide	Can be linked at the zip code level to other information
staff in a sar distribution	nple of U.S. o and number	organization of individua	ta on organizations providing naloxone to laypersons: In Oct as known to distribute naloxone to laypersons. Surveys asked als receiving training, as well as reported number of overdose k to recent report using data	about year of program implem	nentation and total	amount of naloxone kits
Harm Reduction Coalition (private)	National	annually (2010 and	5 6 T 5,	Costs not stated. Data not available publicly		Merged with state-level rates of overdose mortality
overdose re		nmunities t	distribution (OEND) program data: OEND programs serve as hroughout the United States. Several studies have used data ugs.			•
Varies, but generally state agency	State or site- specific	Varies	Number of trainings, overdose rescue behaviors, naloxone administrations, naloxone kits distributed	Data generally not available publicly, although some state agencies provide aggregate statistics.	information for Rhode Island available here	Linked with state- or community-level information on overdoses and/or hospital utilization rates