Review article

Strengths and weaknesses of existing data sources to support research to address the opioids crisis

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ARTICLE INFO

Keywords:
Opioids
Data sources
Data linkage
Opioid research
Scoping study

ABSTRACT

Better opioid prescribing practices, promoting effective opioid use disorder treatment, improving naloxone access, and enhancing public health surveillance are strategies central to reducing opioid-related morbidity and mortality. Successfully advancing and evaluating these strategies requires leveraging and linking existing secondary data sources.

We conducted a scoping study in Fall 2017 at RAND, including a literature search (updated in December 2018) complemented by semi-structured interviews with policymakers and researchers, to identify data sources and linking strategies commonly used in opioid studies, describe data source strengths and limitations, and highlight opportunities to use data to address high-priority public health research questions.

We identified 306 articles, published between 2005 and 2018, that conducted secondary analyses of existing data to examine one or more public health strategies. Multiple secondary data sources, available at national, state, and local levels, support such research, with substantial breadth in data availability, data contents, and the data’s ability to support multi-level analyses over time. Interviewees identified opportunities to expand existing capabilities through systematic enhancements, including greater support to states for creating and facilitating data use, as well as key data challenges, such as data availability lags and difficulties matching individual-level data over time or across datasets.

Multiple secondary data sources exist that can be used to examine the impact of public health approaches to addressing the opioid crisis. Greater data access, improved usability for research purposes, and data element standardization can enhance their value, as can improved data availability timeliness and better data comparability across jurisdictions.

1. Introduction

The United States is suffering its most serious drug-related public health crisis in a generation (Kolodny et al., 2015). Prescription opioid-related mortality rates increased by nearly 400% between 2000 and 2014; this period has also seen substantial increases in prevalence of opioid use disorder and rates of opioid-related hospitalizations (Dart et al., 2015; Han et al., 2015; Jones et al., 2015; Rudd et al., 2016; Tedesco et al., 2017). Heroin overdose deaths have more than quadrupled since 2010, and of the more than 47,000 opioid overdose deaths in 2017, nearly one-third involved heroin and over half involved synthetic opioids (e.g., fentanyl) (Scholl et al., 2018). Multiple factors have contributed to the rise in opioid-related morbidity and mortality, and reducing the social and public health costs of opioid harms requires a multi-pronged approach (Cicero et al., 2015; Cicero et al., 2014; Kolodny et al., 2015; Lasser, 2017; Webster et al., 2011). To this end, the Department of Health and Human Services (HHS)¹ has identified five key strategies to combat the opioid crisis: 1) advancing better pain management practices; 2) improving addiction prevention, treatment, and recovery services; 3) promoting use of overdose reversing drugs; 4) strengthening data for better public health surveillance; and 5) supporting better research across the first four strategies (Price, 2017; U.S.

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¹ Selected abbreviations, see Appendix 2 for full abbreviations list. EHR = Electronic health record; EMS = Emergency medical services; HHS = Department of Health and Human Services; OEND = Overdose education and naloxone distribution; PDMP = Prescription drug monitoring program.

https://doi.org/10.1016/j.pmedr.2019.101015
Received 11 May 2019; Received in revised form 22 October 2019; Accepted 2 November 2019
Available online 06 November 2019
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Health and Human Services, xxxx).

Advancing these strategies often relies on analyses of non-clinical secondary data, yet researchers may be unaware of many available existing data sources (Sherman et al., 2016). Organized by the first four HHS strategies (Commission on Evidence-Based Policymaking, 2017), this review seeks to address this issue through identifying commonly used secondary data sources, the types of outcomes they are used to examine, their strengths and limitations, and promising data-linkage opportunities to support better research. Using a mixed-methods approach combining qualitative interviews with a scoping study to identify commonly used secondary data sources and data linkage strategies that could support better research, this article complements existing reviews of available data sources and metrics for studying prescription opioid use (Cochran et al., 2015; Schmidt et al., 2014; Secora et al., 2014).

2. Methods

We employed a multi-phase approach to synthesize information from the literature, opioid research experts, and policymakers as part this HHS-funded study. We first conducted a scoping study, consistent with established methods (Arksey and O’Malley, 2005; Levac et al., 2010), to identify commonly used data sources and data linking strategies in existing opioid research, focused on the United States context. The scoping study was complemented by semi-structured interviews with policymakers and opioid services and policy researchers to identify existing data source strengths and limitations, innovative uses of data and data linkages, and opportunities to use such data to address high-priority research questions. The RAND Institutional Review Board determined the project exempt.

To identify data sources, we searched for literature published between 2005 and 2017 through databases including PubMed, OVID, CINAHL, and PsycINFO using terms such as “opioid,” “buprenorphine,” “methadone,” “naxalone,” as well as terms specific to opioid policy interventions such as “prescription monitoring program,” “pill mill,” and “Good Samaritan.” We used similar terms to conduct an internet search for relevant non-peer reviewed reports or presentations, and we reviewed additional articles and reports cited in key documents. We extracted information related to each document’s content, including research objective, outcome measures, and key variables and identified specific data sources, geographic coverage, time period, and data linkages in documents using empirical data. Data linkages were defined as any analysis combining data from multiple sources to study the same individual, policy, or geographic area.

The scoping study was complemented by 30-minute semi-structured interviews with sixteen opioid policy researchers and federal program officials conducted in August and September of 2017 (see Appendix for interview guide). Interviewees were selected by HHS officials to obtain a diverse set of perspectives. Discussions were tailored to the interviewees’ expertise and designed to gather insights on existing dataset strengths, limitations, and promising opportunities for dataset linkage. Research team members used detailed interview notes to identify common themes related to current dataset uses as well as potential opportunities to address key policymaker questions. In the twelve months subsequent to the interviews, the scoping study was updated to capture more recent literature published through December 2018, with particular attention to research questions, datasets, or data linkages previously identified as gaps by interviewees.

3. Review

The scoping study identified 446 articles and reports; 306 (68.6%) involved discussion or analyses of existing datasets; the remainder involved primary data collection or did not use empirical data (e.g., editorials, reviews). Existing datasets were wide-ranging but categorized generally as national surveys, electronic health records (EHR) and claims, mortality records, prescription drug monitoring program (PDMP) data, contextual or policy data, and other national, state, or local data sources (e.g., national poison control center data, state arrest records). Interviewees discussed barriers or challenges in accessing datasets, their experiences linking datasets, and how datasets could be used to answer key research questions.

In Sections 3.1 through 3.4, we provide further detail on commonly used data sources, organized by HHS strategy. In the tables, we provide information on commonly used data sources and specific data elements, strengths and limitations for the different types of data, as well as data linking strategies for each HHS area. We subsequently highlight common topics arising during semi-structured interviews.

3.1. Advancing better pain management practices

An estimated 20% of non-cancer outpatients with pain receive opioid analgesics (Daubresse et al., 2013), chronic use of which increases risk of opioid use disorder (Boscarino et al., 2010; Chou et al., 2014) and opioid-related harms (Chou et al., 2015; Substance Abuse and Mental Health Services Administration, 2013). Researchers have commonly sought to identify the relationship between prescribing policy interventions, opioid analgesic prescribing and distribution, opioid-related overdose, and state- or community-level contextual factors (Table 1). In this section, we review measures, data sources, and linkages commonly used in this research, and we summarize common themes in this area from the interviews.

The most common studies of opioid prescribing interventions examine the impact of PDMPs on opioid analgesic prescribing and opioid-related overdose. Data regarding PDMP policies (Dave et al., 2017; Rutkow et al., 2015) commonly comes from the National Alliance for Model State Drug Laws (NASMDL) or Prescription Drug Abuse Policy System (PDAPS) (Baehren et al., 2010; Bao et al., 2016; Buchmueller and Carey, 2018; Chang et al., 2016; Delcher et al., 2015; Gilson et al., 2012; Green et al., 2013; Li et al., 2014; Lin et al., 2017; Mayo et al., 2017; Pardo, 2017; Patrick et al., 2016; Paulozzi and Stier, 2010; Rasubala et al., 2015; Ringwalt et al., 2015a; Rutkow et al., 2015; Wen et al., 2017; Yarbrough, 2017), with additional information about PDMP components obtained from Temple University’s Policy Surveillance Program or Brandeis’ PDMP Training Technical Assistance Center (Buchmueller and Carey, 2018; Dave et al., 2017; Pardo, 2017; Patrick et al., 2016; Rasubala et al., 2015; Weiner et al., 2017a; Wen et al., 2017). Case studies of opioid prescribing guidelines or directives generally rely on data from site-specific implementation (Bujold et al., 2012; Chen et al., 2016; del Portal et al., 2016; Hansen et al., 2017; Johnson et al., 2011; Von Korff et al., 2016; Westman et al., 2015). Studies of other state prescribing regulations such as ID laws, continuing education requirements, doctor shopping laws, and physician exam requirements use CDC Public Health Law Program or original review of legal documents (Barber et al., 2017; Dave et al., 2017; Davis and Carr, 2016; Kuo et al., 2016; Popovici et al., 2017). Finally, studies evaluating the effects of Florida’s pill mill laws use information on the policy’s implementation (Chang et al., 2016; Kennedy-Hendricks et al., 2016; Rutkow et al., 2015).

Research examining opioid analgesic prescribing characteristics, prescribing behavior, and dispensing patterns (Table 1) commonly uses prescription information from commercial (Cepeda et al., 2012, 2013a; Cepeda et al., 2013b; Chang et al., 2016; Dowell et al., 2016; Guy et al., 2017; Larochelle et al., 2016; Liu et al., 2013; Qureshi et al., 2015; Rutkow et al., 2015; Schnell and Currie, 2018) and Medicaid pharmacy claims (Braden et al., 2016; Cochran et al., 2017; Garg et al., 2017; Hartung et al., 2017; Kim et al., 2016; Liu et al., 2013; Mack et al., 2015; Ray et al., 2016; Roberts et al., 2016; Turner and Liang, 2015; Wen et al., 2017; Yang et al., 2015), Medicare Part D Prescription Drug Event data (Buchmueller and Carey, 2018; Gellad et al., 2017; Hernandez et al., 2018; Kuo et al., 2015; Mayo et al., 2017; Willy et al., 2014; Yarbrough, 2017), Veterans Health Administration (VHA) data
overdose, studies use person-level mortality records from the National System (ARCOS) (Alpert et al., 2016; Brady et al., 2014; Paulozzi and distribution using the Automation of Reports and Consolidated Orders indicators. Several studies have examined state-level opioid analgesic 2015), has allowed for multi-state comparisons of opioid misuse in-

PDMP studies usually entail single-state analyses, although the Prescription Behavior Surveillance System (PBSS), which compiles PDMP data from multiple states (Paulozzi et al., 2015), has allowed for multi-state comparisons of opioid misuse indicators. Several studies have examined state-level opioid analgesic distribution using the Automation of Reports and Consolidated Orders System (ARCOS) (Alpert et al., 2016; Brady et al., 2014; Paulozzi and Stier, 2010; Reisman et al., 2009).

To examine the relationship between opioid analgesic use and overdose, studies use person-level mortality records from the National Death Index (NDI) (Bohnert et al., 2016; Bohnert et al., 2011; Park et al., 2015) or state death certificate data (Dasgupta et al., 2016; Dunn et al., 2010; Garg et al., 2017; Gwira Baumblatt et al., 2014; Hall et al., 2008; Hirsch et al., 2014; Mercado et al., 2018; Ray et al., 2016) and opioid-related toxicity or overdose event measures from Medicare (Buchmueller and Carey, 2018; Kuo et al., 2016), commercial claims (Bradon et al., 2010; LaRochelle et al., 2016; Turner and Liang, 2015), Medicaid (Cochrane et al., 2017; Yang et al., 2015), and VHA databases (Miller et al., 2015; Zedler et al., 2014). Other research examines aggregate state- or county-level rates of fatal opioid overdose using state death certificate data (Kennedy-Hendricks et al., 2016), the National Vital Statistics System Multiple Cause of Death (NVSS MCOD) micro-data (Alpert et al., 2016; Dowell et al., 2016; Li et al., 2014), and CDC WONDER (Compton et al., 2016; Gomes et al., 2018; Pardo, 2017; Patrick et al., 2016; Rigg et al., 2018).

To evaluate contextual factors related to opioid prescribing or

| Table 1 | Secondary Data Sources to Support Research toward Advancing Better Pain Management Practices. |
|---|---|
| **Data Elements (by Topic)** | **Sources** | **Strengths and Limitations** |
| **Policy data** | • PDAPS | Strengths: + Can be linked with outcome data to examine state policy impact |
| • Pain clinic laws | Limitations: - Some data not provided in analyzable format |
| • Education requirements | - May not fully capture heterogeneity in state laws |
| • Prescribing limits | - Some policy information not available historically for longitudinal analysis |
| **EHR and claims data** | • Commercial claims | Strengths: + Multi-payer and may include cash payments |
| **Opioid prescribing and distribution** | • Healthcare | Limitations: - Not set up to track people long-term given insurance coverage transitions |
| • Prescription characteristics (opioid type, dose, days' supply, MED) | - Limited information on patient diagnoses or healthcare utilization |
| • Other prescriptions | - Difficult to link to outcomes (e.g., mortality) |
| • Payment | **Opioid-related overdose** | + Can link hospital and pharmacy claims |
| • Diagnostic codes for nonfatal overdose | + Can look at Rx histories of patients who go to a hospital/ED for overdose |
| • Inpatient stays and ED visits | **Detection of opioid misuse & morbidity** | + Provides information on one population (Medicare or Medicaid enrollees) |
| • Diagnoses and procedures | - Not set up to track people long-term given insurance coverage transitions |
| • Costs | - Cannot measure opioid mortality as provides date but not cause of death |
| **VHA data warehouse** | **Prescription drug monitoring data** | + VHA data warehouse enables linkages across datasets |
| **Opioid prescribing and distribution** | • State PDMPs | Limitations: + Has been linked to NDI |
| • Prescription name/type | + Comprehensive data on distribution (ARCOS) or prescribing (PDMP) |
| • Prescription dose, days' supply, MED | + PDMPs used to develop measures for patient/prescriber risk behaviors |
| • Prescriber | Limitations: - Access barriers |
| • Payment | - ARCOS not available in computable formats (i.e., in PDF form) |
| **Mortality data** | **Contextual data** | - State capacity issues may limit ability to link PDMP data with other datasets |
| **Opioid-related overdose** | • BEA<sup>a</sup>; CPS<sup>a</sup>; BLS<sup>a</sup>; ACS<sup>a</sup> | - PDMP systems may lack unique IDs or have ID entry errors, creating issues in identifying individual-level matches |
| • Cause of death | • AHRF<sup>a</sup>; CMS<sup>a</sup> | - Limited information on patient diagnoses or healthcare utilization |
| • Drugs involved in death | **Contextual factors** | - Variation in quality of reporting detail on drug involvement |
| • Demographics | • Unemployment rate; Demographics | Strengths: + Allows analyses to control for state or county factors related to opioid analgesic use or opioid analgesic prescribing |
| **PDMPs** | Limitations: + Lags in data availability |
| **PDAPS** | - National data with information on opioid overdose mortality |
| **NAMSDL<sup>a</sup>** | + CDC WONDER is readily downloadable and publicly available |
| **ARCOS** | Limitations: - Lags in data availability |
| **PDAP** | - Variation in quality of reporting detail on drug involvement |
| **PDAPS** | + Allows analyses to control for state or county factors related to opioid analgesic use or opioid analgesic prescribing |
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<sup>a</sup> Publicly available at no cost.
Table 2
Secondary Data Sources to Support Research on Improving Prevention, Treatment, and Recovery Services.

| Data elements (by Topic) | Sources | Strengths and limitations |
|-------------------------|---------|---------------------------|
| **EIH and claims data** | Commercial claims | Strengths: + Prescription data can capture the population treated with buprenorphine |
| Opioid misuse or use disorders | Commercial claims | Limitations: - Limited information on patient diagnoses or other healthcare utilization |
| Opioid use disorder diagnosis | IQVIA | - Requires triangulating with other sources to fully assess treatment need |
| Opioid-related inpatient stays and ED visits | Marketscan | - Issues in tracking individuals over time |
| Treatment demand & utilization | Symmetry Health | - Single-state analyses have linked to death data |
| Buprenorphine prescriptions | National or state Medicaid datasets | - Only provides information on Medicaid enrollees |
| Payment | National or state Medicaid datasets | - Misses those receiving other publicly funded substance abuse treatment |
| Monthly prescriber patient census | VHA data warehouse | - Has been linked to NDI |
| **Individual-level risk factors** | National or state Medicaid datasets | Limitations: - Limited accessibility and specific population |
| Other Rx use or healthcare utilization |HCUP (national and state inpatient and emergency department databases) | Strengths: + Large collection of longitudinal data, nation-wide and state-level; free portal access to opioid-related data |
| Socio-demographics | + State data is mapped to a standardized format |
| | + Not all states participate in the databases |
| | - Costs to obtain full datasets |
| **National surveys** | + Costs to obtain DEA ACSA |
| Opioid misuse or use disorders | Household surveys | Strengths: + National data with rich information on substance use & mental health |
| Nonmedical use of opioids | NSDUH* | + NSDUH 2015 redesign asks about any pain reliever use (not only misuse) |
| Opioid use disorder symptoms | NESARC | Limitations: - Does not ask about medications used for treatment or treatment retention |
| Treatment demand & utilization | TEDS* | - Screens for use disorder symptoms, but does not ask about formal diagnosis |
| Opioid use disorder treatment | N-SATS* | - Sample may miss high-risk populations (e.g., homeless, arrestees) |
| Source of payment | VHA data warehouse | - State identifiers restricted |
| **Individual-level risk factors** | Treatment facility surveys | Strengths: + National data on admissions to treatment & public-sector specialty care |
| Mental health, substance use | NDI | + TEDS has patient demographic data |
| Socio-demographics | NVSS MCOD | + Up to 3 drugs of abuse listed (differentiate heroin & opioid analgesics) |
| Treatment demand & utilization | CDC WONDER* | - N-SATS includes both public and private facilities |
| # treatment admissions | State vital records | Limitations: - TEDS only includes agonist treatments; cannot differentiate MAT types |
| # patients receiving methadone in OTPs (N-SSATS) | + Limited information on payment |
| Reference source | - Quality control issues with TEDS, as states may not consistently report on similar patients or have consistent procedures to assess data quality |
| Treatment supply & capacity (N-SSATS only) | - Limited accessibility and specific population |
| + Treatment facility characteristics | | - Requires triangulating with other sources to fully assess treatment need |
| Estimated operating capacity | | - Limited accessibility and specific population |
| **Mortality data** | | |
| Opioid-related overdose | | |
| Cause of death | | |
| Drugs involved in death | | |
| Demographics | CDC WONDER* | Strengths: + National data with information on opioid overdose mortality |
| Other national data sources | N-SATS* | + CDC WONDER is readily downloadable and publicly available |
| Treatment supply & capacity | + Lags in data availability |
| Waivered physicians | State vital records | - Variation in quality of reporting detail on drug involvement |
| Patient caps | + Measures supply/capacity of waivered physicians at geographic detail |
| Physician address, ZIP | + Can link to AMA Physician Masterfile |
| **Policy data** | DEA AGSA | - Costs to obtain DEA AGSA |
| Treatment policies | SAMHSA publicly available data captures around 55% of physicians |
| Medicaid coverage information | + SAMHSA publicly available data captures around 55% of physicians |
| Formulary placement | RAND/NCSL | - Issues in tracking individuals over time |
| Copays, prior authorization, etc. | ASAM | - Requires triangulating with other sources to fully assess treatment need |
| **Contextual data** | BEA* | + Can control for state or county factors related to healthcare access or treatment need |
| Physician density | AHRF* | Limitations: - Lags in data availability |
| Hospital beds per capita | | |
| State or county economic factors | | |

* Publicly available at no cost.

To examine how policies or community factors influence pain management practices, studies link state policy data and state- or county-level contextual factors to data on opioid prescribing (Brady et al., 2014; Buchmueller and Carey, 2018; Halfajee et al., 2018; Kuo et al., 2016; Moyo et al., 2017; Wen et al., 2017; Yarbrough, 2017) or overdose mortality records (Dowell et al., 2016; Li et al., 2014; Pardo, 2017; Patrick et al., 2016). Research examining potentially inappropriate prescribing generally links opioid prescription data with opioid overdose data at the person level. These include studies linking PDMP data with Medicaid claims (Hartung et al., 2017; Kim et al., 2017).
Veterans Health Administration data (Bohnert et al., 2011; Edlund et al., 2014; Liu et al., 2013; Ray et al., 2016; Turner and Liang, 2015), Commercial and Medicaid claims data (Braden et al., 2010; Edlund et al., 2015; Saloner and Karthikeyan, 2015; Wu et al., 2016). (Becker et al., 2008; Feder et al., 2017a; Han et al., 2015; Jones, 2017; Massachusetts Department of Public Health, 2016; Olfson et al., 2018; Ray et al., 2016).

3.1. Common interview themes

The insufficient understanding of factors influencing opioid analgesic use and subsequent outcomes was a common theme, with interviewees noting a paucity of empirical research examining how changes in opioid prescribing guidelines, pain reimbursement policies, or clinician education protocols influence treatment of pain and subsequent risk for opioid misuse, addiction, and overdose. While recent studies have examined the impact of opioid prescribing guidelines within a single state (Gillette et al., 2018; Tenney et al., 2019; Weiner et al., 2017b), the absence of systematically collected information on how guidelines are being implemented across states and over time complicates identification of the policy features that are effective. Interviewees also stressed the need for additional research examining longer-term effectiveness of opioid and non-opioid analgesic interventions for chronic pain given questions about the comparative effectiveness of opioid analgesics in managing some types of chronic pain (Krebs et al., 2018; Krebs et al., 2010).

Additional common themes were the need for analyses of provider- or hospital-level opioid prescribing patterns to identify factors underlying provider- or practice-level variation in risky or inappropriate prescribing, and the need for longitudinal patient-level analyses with sufficient temporal coverage to examine the pathways and sequences of events associated with adverse outcomes following opioid analgesic prescribing. Interviewees also frequently observed that all-payer claims databases, such as that developed by Massachusetts (Massachusetts Department of Public Health, 2017), may facilitate important longitudinal analyses that unlike Medicaid and commercial claims can track individuals as they transition across different types of insurance or across plans within a given insurance type.

3.2. Improving addiction prevention, treatment, and recovery services

Despite considerable improvement in the availability of medication-assisted treatment (Volkow et al., 2014) substantial gaps between opioid use disorder treatment need and capacity persist (Feder et al., 2017b; Dick et al., 2015; Hadland et al., 2017; Jones et al., 2015; Morgan et al., 2018; Saloner and Kharthikeyan, 2015). In this section, we provide information about measures, data sources, and data linkages commonly used to study prevalence of opioid misuse or use disorders, treatment demand and utilization, supply and capacity of treatment, treatment policies, and contextual factors associated with treatment need and access (Table 2), and we summarize common themes in this area from the interviews.

Self-reported measures of opioid misuse or opioid use disorder symptoms come from national household surveys such as the National Survey on Drug Use and Health (NSDUH) and National Epidemiologic Survey on Alcohol and Related Conditions (NESARC) (Becker et al., 2008; Compton et al., 2016; Martins et al., 2012; McCabe et al., 2008; Rigg and Monnat, 2015; Secora et al., 2014). The NSDUH’s information on self-reported receipt of and need for opioid use disorder treatment has also informed research on treatment need and utilization trends (Becker et al., 2008; Feder et al., 2017a; Han et al., 2015; Jones, 2017; Jones et al., 2015; Saloner and Kharthikeyan, 2015; Wu et al., 2016). Commercial and Medicaid claims data (Braden et al., 2010; Edlund et al., 2014; Liu et al., 2013; Ray et al., 2016; Turner and Liang, 2015), Veterans Health Administration data (Bohnert et al., 2011; Edlund et al., 2007), inpatient and emergency department databases (Guy et al., 2018; Tedesco et al., 2017), and electronic health records (Boscarino et al., 2010; Carrell et al., 2015; PCOR, 2018) are also used to estimate rates of potential opioid misuse or opioid use disorders. These data sources are also commonly used to examine person-level sociodemographic and clinical risk factors associated with development of opioid use disorder (Becker et al., 2008; Bohnert et al., 2011; Braden et al., 2016; Compton et al., 2016; Edlund et al., 2014; Edlund et al., 2007; Martins et al., 2012; McCabe et al., 2008; Ray et al., 2016; Rigg and Monnat, 2015; Secora et al., 2014; Turner and Liang, 2015).

Opioid use disorder treatment rates have often been studied using the National Survey of Substance Abuse Treatment Services Data (NSATTS) and the Treatment Episodes Data Set (TEDS) (Ducharme and Abraham, 2008; Feder et al., 2017b; Jones et al., 2015; Martin et al., 2015; Saloner et al., 2016). Analyses of treatment trajectories, variation in buprenorphine utilization, quality of care and patient adherence to buprenorphine, as well as buprenorphine providers’ patient censuses (Stein et al., 2016), instead generally use commercial or Medicaid claims (Baxter et al., 2015; Gordon et al., 2015; Lo-Ciganic et al., 2016; Morgan et al., 2018; Saloner et al., 2017; Stein et al., 2012; Stein et al., 2016; Turner et al., 2013; Turner et al., 2015).

Research describing national trends and geographic variation in treatment supply and capacity often uses SAMHSA’s Buprenorphine Waiver Notification System (Dick et al., 2015; Stein et al., 2015a; Stein et al., 2015b) or the DEA’s Active Controlled Substances Act Registrants Database (ACSA) (Andrilla et al., 2019; Knudsen, 2015; Rosenblatt et al., 2015) to examine the supply of buprenorphine waivered physicians, while studies assessing the capacity of opioid treatment programs or availability of various types of medication-assisted treatment use N-SSATS state- or county-level data (Dick et al., 2015; Ducharme and Abraham, 2008; Jones et al., 2018; Jones et al., 2015; Stein et al., 2015b).

Studies of state Medicaid policies’ effects on treatment access and utilization of methadone and buprenorphine commonly use policy information from the RAND/National Conference of State Legislatures (RAND/NCSL) Survey (Burns et al., 2016; Stein et al., 2015a) or the American Society of Addiction Medicine (ASAM) survey of Medicaid programs (Rinaldo and Rinaldo, 2013; Saloner et al., 2016), while research examining state- or county-level factors related to treatment supply or demand often use BEA or AHRF measures of the unemployment rate and income per capita (Dick et al., 2015; Knudsen, 2015; Stein et al., 2015a); and AHRF information on physician density, percent of adults uninsured, hospital beds per capita, and urbanicity (Dick et al., 2015; Stein et al., 2015a; Stein et al., 2015b).

To examine state and community-level factors associated with treatment utilization or supply, studies often link policy and contextual data sources at the state or county level to outcome data on the location of buprenorphine waivered physicians or buprenorphine use (IMS Institute for Healthcare Informatics, 2016; Knudsen, 2015; Saloner et al., 2016; Stein et al., 2015a; Stein et al., 2012). Others link aggregate measures of treatment need with measures of treatment capacity to identify areas with treatment shortages (Dick et al., 2015; Jones et al., 2015).

3.2.1. Common interview themes

Interviewees frequently noted that most existing data sources do not contain information on block grant funded treatment, thereby providing only a partial picture of treatment utilization, and limiting accurate identification of treatment shortage areas. Interviewees also observed that current analyses of treatment patterns (i.e., patient or provider trajectories) are commonly unable to track individuals across insurance coverage transitions. Interviewees stressed the need to better understand the effects of opioid use disorder treatment quality on outcomes, studies for which EHRs can complement claims data (Campbell et al., 2019; Garnick et al., 2012; Haddad et al., 2015). Finally, interviewees highlighted the need for further study of opioid use.
disorder treatment among justice-involved individuals (Acevedo et al., 2015; Garnick et al., 2014; Krawczyk et al., 2017), likely requiring linked substance abuse treatment and arrest or incarceration databases.

3.3. Promoting use of overdose-reversing drugs

Overdose-reversing drugs, such as naloxone, play a critical role in opioid overdose prevention (Boyer, 2012; Davis and Carr, 2015; van Dorp et al., 2007). In this section, we describe measures, data sources, and data linkages used to describe policies to promote naloxone distribution and use, and to evaluate how naloxone policies or programs relate to naloxone distribution, opioid overdose mortality, and contextual factors.

Information on state naloxone policies regarding use by community bystanders, emergency medical services (EMS) personnel, and other first responders is generally drawn from original reviews of legal databases (Brodrick et al., 2016; Burris et al., 2017; Davis and Carr, 2015; Davis et al., 2014a), with some groups, such as PDAPS, compiling data on the timing and provisions of certain laws into a single source (Table 3).

Studies of community-based overdose education and naloxone distribution (OEND) programs (Clark et al., 2014; Giglio et al., 2015; Haegerrick et al., 2014; Kerensky and Walley, 2017; Mueller et al., 2015) commonly rely on surveys of OEND program participants, including reported overdose reversals, number of naloxone administrations, number of naloxone kits distributed, and overdose response, collected by OEND programs (Bennett et al., 2011; Doe-Simkins et al., 2014; Enteen et al., 2016; Jones et al., 2014b; Oliva et al., 2016; Walley et al., 2013a; Walley et al., 2013b; Wheeler et al., 2012; Wheeler et al., 2015). National data on the locations of OEND programs has been compiled by the Harm Reduction Council, but the data are not publicly available (Lambdin et al., 2018a; Lambdin et al., 2018b). Fewer studies have examined retail pharmacy naloxone dispensing using pharmacy claims (e.g., Symphony Health, IQVIA) (Freeman et al., 2018; Jones et al., 2016; Xu et al., 2015) or EMS naloxone administration using National EMS Information System (NEMSIS) data to examine trends and geographic variation in naloxone distribution (Cash et al., 2018; Faul et al., 2015; Faul et al., 2017). Another set of studies evaluated naloxone prescribing through the VHA OEND program (Bountavong et al., 2017; Oliva et al., 2017).

To examine how state naloxone policies or local OEND programs influence mortality, multi-state analyses generally use state-level data on opioid overdose mortality from the NVSS MCOD microdata or CDC WONDER (Frank and Pollack, 2017; Pardo, 2017; Rees et al., 2017; Wheeler et al., 2015), while single-state analyses more commonly use state-or county-level measures collected from state death certificates (Albert et al., 2011; Burrell et al., 2017; Maxwell et al., 2006; Walley et al., 2013b). Studies of state naloxone policies’ effects on opioid overdose generally merge state-level opioid overdose mortality data with information on state naloxone policies (Pardo, 2017; Rees et al., 2017); other community-level contextual factors, such as unemployment rates or per capita income from the CPS or US Census (Pardo, 2017; Rees et al., 2017; Walley et al., 2013b); and information about other state opioid policies (e.g., pain clinic laws) from PDAPS, the Policy Surveillance Program, or NAMSDL (Pardo, 2017; Rees et al., 2017). Studies of the impact of OEND programs instead often use multiple complementary datasets, including parallel analyses of trends in emergency department

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Table 3
Secondary Data Sources to Support Research Promoting Use of Overdose-Reversing Drugs.

| Data Elements (by Topic) | Sources | Strengths and Limitations |
|--------------------------|---------|---------------------------|
| **Policy data** | | |
| Naloxone policies | PDAPS, NAMSDL* | Strengths: + Can be linked with data on opioid outcomes to examine state policy impact  
Limitations: - May not capture state variation in nominally identical naloxone policies  
- Data on EMS protocols not readily available  
- Some data not provided in readily analyzable format |
| Mortality data | | |
| Opioid overdose mortality | CDC WONDER*, NVSS MCOD | Strengths: + National data with information on opioid overdose mortality  
- CDC WONDER is readily downloadable and publicly available  
Limitations: - Lags in data availability  
- Variation in quality of reporting detail on drug involvement due to differences across states in rigor of medical examiner/coroner procedures |
| **EHR and claims data** | | |
| Naloxone distribution | Pharmacy claims, IQVIA, Symphony Health | Strengths: + Measures pharmacy distribution of naloxone  
Limitations: - Only captures the distribution of naloxone via pharmacy channel; does not capture purchase and distribution via state or community programs  
- Limited ability to examine naloxone refills and renewals |
| **Other national and local sources** | | |
| Naloxone distribution | OEND Program Data, MA OOP Pilot Program, Harm Reduction Coalition | Strengths: + Fills in some gaps regarding naloxone distributed via state or local programs  
Limitations: - Data collection on OEND programs not standardized  
- National data not systematically collected, updated, or made publicly available |
| Naloxone formulation | VHA data warehouse | Strengths: + Rich information on patient characteristics  
Limitations: - Limited accessibility |
| **Other national sources** | | |
| EMS naloxone administration | EMS data, NEMSIS* | Strengths: + Naloxone administration is a fairly high-quality variable  
+ Can do small area analysis |
| EMS provider level | | |
| 911 call info | | |
| Information on incident and transport | | |
| **Contextual data** | | |
| Contextual factors | CPS*, BLS*, US Census*, PDAPS, NAMSDL* | Strengths: + Can control for state or county factors associated with opioid mortality  
Limitations: - Lags in data availability  
- Policy data often not available in readily analyzable format |

* Publicly available at no cost.
visits, fatal accident poisonings, and outpatient-dispensed controlled substances (Albert et al., 2011; Walley et al., 2013b). Sub-county level studies using linked data are rare. One study linked police naloxone use to EMS data to assess the proportion of cases in which EMS administered additional naloxone doses (Fisher et al., 2016), while another single-county study mapped naloxone-carrying pharmacies with overdose death data at the ZIP Code level (Burrell et al., 2017).

3.3.1. Common interview themes

Interviewees frequently noted that more systematic collection of data on naloxone distribution outside of outpatient pharmacy channels would further understanding of naloxone access barriers and inform effective approaches for distribution and use. Interviewees also discussed how determining optimal naloxone dosing, particularly in the context of more widespread use of synthetic opioids (Frank and Pollack, 2017), would benefit from better data about naloxone reversals and the surrounding circumstances. Several interviewees noted the potential value of EMS data (Table 3), but observed that variation in EMS data quality and completeness across agencies and regulatory barriers precluding individual level linkages currently limit its value, as analyses of EMS naloxone administration and subsequent patient outcomes are often confined to a single jurisdiction (Belz et al., 2006; Knowlton et al., 2013; Levine et al., 2016; Ray et al., 2018). Many interviewees also noted the potential value of longitudinal studies linking data on persons receiving naloxone with claims data, which would enable researchers to follow individuals through the health care system.

3.4. Strengthening data for better public health surveillance

The rapid evolution of opioid use and markets has generated efforts to improve data collection and surveillance tools to monitor medical and non-medical opioid use. In this section, we describe measures, data sources, and linkages used to study opioid surveillance topics not discussed extensively in the sections above, including detection of misuse, product-specific use and emerging trends, toxico-surveillance, and illicit markets (Table 4), and we summarize common themes in this area from the interviews.

State PDMP data systems, now present to some degree in all 50 states, are increasingly being used to develop risk indicators for inappropriate prescriber behavior (Kreiner et al., 2017; Porucznik et al., 2014; Ringwalt et al., 2015b) and to detect inappropriate or problematic patterns in opioid analgesic prescribing, dispensing, and use (Katz et al., 2010; O’Kane et al., 2016; U.S. Department of Health and Human Services and Behavioral Health Coordinating Committee, 2013). EHR data is also used to improve surveillance of problematic opioid use and opioid-related harms (Olivia et al., 2017), occasionally using natural language processing to text mine clinicians’ notes (Canan et al., 2017; Carrell et al., 2015).

Proprietary databases, such as RADARS and NAVIPPRO, are also being used for near real-time surveillance of opioid use. RADARS consists of several programs that collect and compile data on product-specific drug diversion and nonfatal overdose, opioid use and treatment, and street drug prices (Bau et al., 2016; Butler et al., 2013; Cassidy et al., 2014; Cepeda et al., 2017; Cicero et al., 2007; Coplan et al., 2016; Dart et al., 2015; Davis et al., 2014b; Inciardi et al., 2009; Secora et al., 2014). NAVIPPRO collects and compiles information on product-specific opioid use, initiation, route of administration, and source of opioids from two proprietary systems and several publicly available data sources (Butler et al., 2018; Butler et al., 2008; Butler et al., 2013; Cepeda et al., 2017; Coplan et al., 2016; Secora et al., 2014). Non-traditional data resources such as Twitter, web forum postings, Google trends, and cryptomarket forums on the Dark Web are also drawing attention as means to bolster public health surveillance, better understand opioid misuse and prescription drug diversion (Anderson et al., 2017; Chan et al., 2015; Katsuki et al., 2015), forecast state-level mortality or nonfatal overdose (Parker et al., 2017; Young et al., 2018), and assess emerging trends in new psychoactive substances (Van Hout and Hearne, 2017).

RADARS data on diversion has been used to examine illicit pharmaceutical opioid markets (Coplan et al., 2016; Dart et al., 2015; Inciardi et al., 2009), and NSDUH (Inciardi et al., 2009; Jones et al., 2014a) and NAVIPPRO (Cassidy et al., 2014) includes information on self-reported sources of prescription opioids for nonmedical use. While national data on drug seizures, drug testing, and illicit drug prices that could be used to examine trends and geographic variation in illicit opioid markets exist in the National Forensic Laboratory Information System (NFLIS) or System to Retrieve Information from Drug Evidence (STRIDE) (National Academies of Sciences Engineering and Medicine, 2017; Secora et al., 2014), we identified few empirical analyses using these measures (Rosenblum et al., 2014; Stein et al., 2015a), and found local or state law enforcement databases to be more common sources of drug seizures and arrest data (Bujojld et al., 2012; Piper et al., 2016; Ray et al., 2017).

While mortality microdata help monitor drug overdose mortality and polysubstance involvement in fatal overdose (Jalal et al., 2018; Kandel et al., 2017), concerns about its use for public health surveillance have been raised due to state variation in procedures used by medical examiners and coroners to record manner of death and specific drugs involved in overdoses (Davis et al., 2014b; Lucyk and Nelson, 2017; Ruhm, 2017, 2018; Warner et al., 2013). Alternative data sources that have been used to examine trends, geographic “hot spots,” and product-specific characteristics for opioid-related overdose include Drug Abuse Warning Network (DAWN) emergency department data (Bau et al., 2016; Secora et al., 2017), opioid-related toxic exposures through RADARS or the National Poison Data System (NPDS) (Bau et al., 2016; Coplan et al., 2016; Coplan et al., 2013; Davis et al., 2014b; Mowry et al., 2016), and detailed and timely information on fatal and nonfatal overdose through the Enhanced State Opioid Overdose Surveillance (ESOOS)/State Unintentional Drug Overdose Reporting System (SUDORS) (Mattson et al., 2018; Seth et al., 2018; Vivolo-Kantor et al., 2018), and information about opioid-related overdose from state hospital discharge databases (Cerda et al., 2017) or emergency department syndromic surveillance systems (Albert et al., 2011; Daly et al., 2017; Tomassoni et al., 2017). While containing less detailed information on specific products involved in overdose, the Healthcare Cost and Utilization Project (H-CUP) suite of inpatient and emergency department databases have also been used to assess temporal and geographic variation in nonfatal opioid-related overdose (Guy et al., 2018; Sakhuja et al., 2017; Tedesco et al., 2017; Unick et al., 2014; Unick and Ciccarone, 2017).

Much of the effort toward bettering data for public health surveillance involves state strategies to facilitate linkages of multiple data sources (Albert et al., 2011; Bau et al., 2016; Cepeda et al., 2017; Coplan et al., 2016; Davis et al., 2014b; Inciardi et al., 2009), across multiple state agencies. For example, with Chapter 55 of the Acts of 2015, Massachusetts’ Department of Public Health developed a data warehouse providing person-level linkages across ten datasets managed by five state agencies, including the state all-payer claims database; state PDMP; death certificate records and toxicology results; substance abuse treatment information; hospital, emergency department, and outpatient records; criminal justice incarceration and treatment records; and emergency medical service data (Massachusetts Department of Public Health, 2017). Maryland also is advancing efforts to link person-level data from the PDMP, drug use and alcohol treatment admissions, hospital admissions, fatalities, and criminal justice data (Lyons and Madison, 2017; Saloner, 2016).

3.4.1. Common interview themes

Interviewees highlighted the need for surveillance efforts to consider the opioid crisis as a dynamic system with multiple agents and networks of interacting individuals and agencies (Burke, 2016; Wakeland et al., 2015), involving both licit and illicit markets. Linking
| Data Elements (by Topic) | Sources | Strengths and Limitations |
|-------------------------|---------|---------------------------|
| Detection of opioid misuse | State PDMP, PBSS | + Comprehensive data on prescribing (i.e., multi-payer) + Can be used to develop measures around patient, prescriber, and pharmacist risky behaviors |
| Mortality data | NDI, NVSS MCOD, CDC WONDER | + National data with information on opioid overdose mortality + CDC WONDER is readily downloadable and publicly available |
| Other national sources | HCUP (national and state inpatient and emergency department databases) | + Large collection of longitudinal data, nation-wide and state-level + State data is mapped to a standardized format |
| Toxico-surveillance | Poison Control, NPDS | + Product and drug specific information + Must be requested and purchased |
| Product-specific use & trends | Proprietary surveillance, RADARS, NAVIPPRO | + Multifaceted data collection including product and drug specific information + Can identify exposure among high-risk groups (e.g., pregnant women) + RADARS has information on product street prices |
| Toxico-surveillance | | |
| Nonfatal opioid overdose | | |
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opiodic prescribing or dispensing data with data about illicit opioid users and illicit drug markets, such as that available in the recently scaled back Arrestee Drug Abuse Monitoring System (ADAM; Table 4), could be used to systematically examine individuals’ histories associated with arrests, indicators of diversion, or movement between heroin and opioid analogous markets. Interviewees also commonly discussed the need for more rapid data collection and analyses of other data sources, such as nonfatal overdose or drug seizure data, that can complement mortality data (Ruhm, 2017; Warner et al., 2013) and allow timelier understanding of emerging trends and facilitate more appropriately tailored interventions (Houry, 2017). Rhode Island’s Opioid Overdose Reporting System (McCormick et al., 2017) and North Carolina’s Disease Event Tracking and Epidemiologic Collection Tool are examples of state efforts toward near-real time collection and analysis of statewide nonfatal overdose data (Ising et al., 2016). Many interviewees also mentioned other novel efforts to leverage novel data sources (e.g., social media, the Dark Web) combined with machine learning techniques to identify risks and emerging trends (Brownstein et al., 2009; Kalyanam et al., 2017; Kalyanam and Mackey, 2017), as well as the potential benefits of linking claims or PDMP data with social services data (e.g., child welfare data) to augment ecological analyses (Ghertner et al., 2018; Orsi et al., 2018; Quast, 2018; Quast et al., 2019; Quast et al., 2018) and better understand the consequences of opioid misuse and opioid use disorder treatment on child welfare outcomes.

4. Discussion

Many efforts to inform strategies to combat the opioid crisis rely on analyses of secondary data. To further these efforts, this study is intended to enhance researcher awareness regarding the many existing data sources that can be used to address key HHS strategies, identify ways in which data sources can be used together to address questions more effectively than is possible with a single data source, and highlight existing data source strengths and limitations, innovative uses of data and data linkages, and opportunities to use such data to address high-priority research questions.

We identified a broad range of available data resources that researchers are using to examine a range of issues related to the opioid crisis, as well as many of the combinations of data sources being used by researchers to examine how the community and policy context relates to opioid-related outcomes. The value and availability of HHS support for data collection, aggregation and dissemination in addressing the opioid crisis is highlighted by the frequency with which researchers are using federal data sources, including surveys, claims data, policy data, and data from the census and other federal agencies. Such federal investments, and the consideration of future investments to enhance the quality and availability of data, such as linking mortality data to federal claims data, supporting the development of and access to all-payer claims databases, and encouraging the integration of criminal justice and public health datasets, are highlighted by our findings as critical steps to enhance the quality of future opioid-related research.

Our discussions with experts also emphasized a range of actions that do not require a substantial investment but appear likely to enhance the quality, availability, and usability of existing data. These include establishing standards for determining opioid-related cause of death, making overdose data available in a timelier manner, and ensuring available data is provided in formats that facilitate incorporation into analytic software. Even in the short time period since our interviews took place, some progress has been made to fill the identified gaps in research. Researchers have increasingly leveraged information from state APCDs – linked or as a standalone data source – to understand the intersection of patient conditions, opioid use, non-opioid therapies, and opioid-related harms; and to better estimate state-level population prevalence of opioid use disorder (Barocas et al., 2018; Bartels et al., 2018; Larochelle et al., 2018; Malon et al., 2018; Whedon et al., 2018). Recent funding for the Enhanced State Opioid Overdose Surveillance (ESOOS) system has allowed for the collection of more timely and comprehensive data on fatal overdoses from over 30 states; however, to our knowledge, these data have not yet been made widely available to researchers for use beyond in the creation of reports by state health departments and the CDC (Goldschmidt et al., 2018; Mattson et al., 2018; O’Donnell et al., 2018; Schilke et al., 2019; Vivolo-Kantor et al., 2018). Making such data available to a broader array of researchers, and facilitating their linkage with other data sources, such as those with information on prescription drug use or criminal justice history, is one potential opportunity that could greatly enhance the value of these existing data sources.

5. Limitations

There are a number of limitations of this work that merit discussion. There is a tremendous amount of research being done related to the opioid crisis, with new papers being published in high quality journals weekly. Furthermore, the scoping study should not be considered a structured systematic literature review, thus there are studies and data sources not captured in this document and many of the key questions identified are ones that we expect investigators are already examining. Furthermore, we recognize that categorizing data sources and research questions by HHS strategy is somewhat arbitrary, and that the most influential research often crosses these categories.

Finally, while this review has taken an expansive perspective to highlight the breadth of potential resources available to researchers studying opioid policy, a deeper dive into any one area may yield further insights and challenges. The opioid crisis is complex, and there is a need to better understand the expected time course of a given policy’s effect, determine the role of heterogeneous policy implementation in differentially influencing outcomes, understand how the adoption of multiple policies may interact to enhance or diminish any given policy’s impact, and determine how a variety of important outcomes may be impacted by policy even if not the intended target of the intervention. Existing ecological research has highlighted the need to monitor multiple datasets simultaneously, and further research that can leverage individual-level record linkages and longitudinal information on individual outcomes will enhance our understanding of ecological associations in order to guide more informed policy design.

5.1. Conclusions

Given the human and societal toll of the opioid crisis, efforts to create and make available improved data assets to support more informed efforts to address the opioid crisis are a public health imperative. Overall, there are a variety of areas in which resources and time may be invested to enhance use and linkage of existing secondary data sources for opioid research. A tremendous amount of work is being done at the federal, state, and local levels to combat the opioid crisis. There has also been a substantial increase in research that has improved our understanding of the complex and multi-dimensional nature of the opioid crisis, as well as advanced the evidence base regarding the effectiveness of opioid policies and initiatives toward reducing opioid-related harms. While significant resources for the use and analysis of secondary data exist, not all are being optimized. This work serves to enhance awareness of existing data resources relevant to opioid research, describe the scope of research leveraging these datasets, and highlight some key research gaps, data limitations, and data linkage needs that future research can address to further efforts to combat the opioids crisis.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.
Acknowledgements

The authors would like to thank Brendan Saloner, Christine Eibner, and Paul Koegel for their assistance as reviewers. We also thank Amanda Meyer for her valuable research assistance and Hilary Peterson for assistance in manuscript preparation.

Funding

This work was supported by the following grants from the National Institutes of Health: R21 DA045950-01, (Smart, PI) and P50 DA046351 (Stein, PI), and Assistant Secretary of Planning and Evaluation of HHS: HHS/23320095649WC, HPHQ031. The content is solely the responsibility of the authors and does not necessarily represent the official views of NIDA or the National Institutes of Health.

Author contributions

Author RS managed the literature search, assisted with data extraction for all documents included, conducted interviews with key informants, and wrote the first draft of the manuscript. Authors CAK and EAT co-wrote the draft, checked the full text of identified documents and conducted data extraction activities, and conducted interviews with key informants. Author BDS oversaw environmental scan activities, conducted interviews with key informants, and contributed to writing the manuscript. SL and SRS helped formulate the research questions and contributed to drafting the manuscript.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pmedr.2019.101015.

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