

Creating a robust coordinated data and policy framework for addressing substance use issues in the United States



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ABSTRACT

The ongoing opioid epidemic has been met with the inadequate use of data-informed approaches to respond to the crisis. Although data relevant to opioid and substance use do exist and have been utilized for research in the literature and practice, they have not been prepared for cross-sector coordination and for providing practical intelligence to inform policy planning directly. In this article, we share our views on how data can better serve the purposes of informing policy and planning to maximize population health and safety benefits. Based on our experience in advising state policymakers on developing settlement allocation strategies based on empirical data, we discuss several issues in the data, including coverage, specificity in drug types, time relevance, geographic units, and access, which may hinder data-informed policymaking. Following these discussions, we envision a coordinated data and policy framework as an ideal case to ensure access to meaningful and timely data and harness the full potential of the data to inform policy to combat the continuing epidemic.

Introduction

The lingering opioid crisis across the United States (US) of the past two decades has exposed how inadequately equipped states and sub-state municipalities in the US are with data for monitoring and responding to emerging public health crises related to substance use and misuse (Blanco et al., 2022; Volkow et al., 2022). While the current emphasis relates to issues associated with opioids, this will likely not be the final substance of focus nor the set of substance-related problems the US will face in the future. It is critical to ask what can be learned from the current opioid epidemic to help prevent the next one (Scanlon & Hollenbeck, 2019). The focus on the opioid crisis illustrates the significant limitations for informed policy intervention when a comprehensive data infrastructure for monitoring substance use-related outcomes, with ease of access and timely intelligence to inform action plans, continues to elude policymakers, regulators, healthcare providers, law enforcement, and academics, even after previous calls to address this

issue (Sevigny & Fuleihan, 2015). Effectively combatting the opioid and future substance use crises requires strategic decisions regarding the allocation of limited resources and deployment of interventions across communities, with the goal of abating the negative population health and safety impacts of substance use. Actionable intelligence to inform impactful implementation of interventions requires data that are *meaningful*, i.e., able to measure the issue(s) in the population of interest, and *timely*, i.e., relevant to the concurrent context. Without it, response strategies can be suboptimal, leading to both wasted resources and limited progress toward curbing any ongoing substance use epidemic. Practically, this suboptimality results in more deaths and human suffering.

Data relevant to opioid and substance use are not entirely lacking (Geissler et al., 2022; Jalali et al., 2021; Smart et al., 2020). However, historically, these efforts in collecting and using data have not been developed systematically or strategically across jurisdictions and organizations, nor is there clear cross-sector coordination between data

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collection and policy planning with the joint goal of maximizing positive impact on societal public health outcomes. There are many explanations for why this is the case, not the least of which is the federalist approach to governance in the US where coordination across states may be inhibited by state and sub-state policies. Absent a well-planned and thoughtful approach to working across sectors, states, and with the federal government, it is unclear how available data can provide practical and actionable intelligence to directly inform policies for comprehensively addressing the extant opioid crisis and future substance use-related issues.

As new threats in the current substance use crisis continue to emerge (Hall & Miczek, 2019; Kariisa et al., 2023), linking coordinated data collection efforts with the need for data-informed policy planning approaches is required more than ever. Furthermore, several large national opioid settlements may provide states and counties with financial resources to mitigate the harms of the opioid epidemic (Haffajee, 2020; Krawczyk et al., 2023), but the question remains how to most effectively utilize these and other limited resources for maximal positive impact on public health and safety outcomes now and into the future (Whaley & Sharfstein, 2023). In this article, we share our views on how data can best serve the purposes of informing policy and planning to maximize population health and safety benefits, in conjunction with key stakeholders in this public health crisis, including federal, state, and local policymakers; regulatory agencies (e.g., Substance Abuse and Mental Health Services Administration [SAMHSA], Centers for Disease Control and Prevention [CDC], Drug Enforcement Administration [DEA]); public health offices; law enforcement agencies; and the general public. Building upon the history of others noting data challenges around drugs and drug policies (Sevigny & Fuleihan, 2015), we discuss several common issues in existing data sources that may hinder data-informed policymaking at the national, state, and local levels from our experience with advising on the allocation policy of the opioid settlements in Pennsylvania (Rhubart et al., 2022). Following such discussions, we suggest a pragmatic framework with coordinated and strategically planned data and policymaking that works across political and geographic boundaries. Finally, we end with a call for a joint effort and committed investment in improving the data infrastructure for substance use-related measures to minimize societal burden and maximize population health and safety outcomes with a data-informed approach.

A coordinated data to policy creation model

Facilitating data-informed policy planning in combatting substance use crises requires access to data that provides timely, contextual information. Fig. 1 illustrates a conceptual framework of a coordinated data to policy model that can facilitate data-informed policymaking processes and enable continuous improvement iteratively, which are further detailed below.

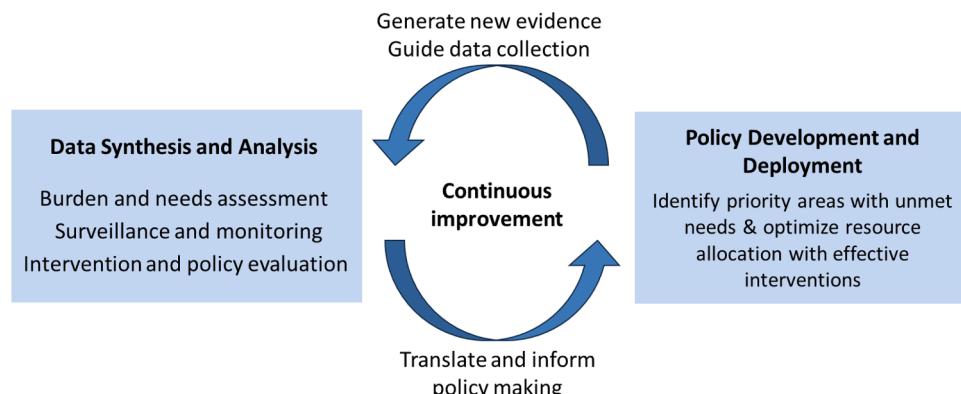


Fig. 1. A conceptual model of how a coordinated data system could enable data-informed policymaking processes to iteratively improve substance use policies for maximizing public health impact.

Data synthesis and analysis

Conducting data analyses to answer important questions and translate data insights to stakeholders can help to ensure that policy is data-informed. In the following, we summarize three common analyses using empirical data from various sources. With a coordinated data system, a stronger body of evidence and knowledge could be synthesized and drawn from more comprehensive and timely data sources to inform effective policy with maximal impact.

Retrospective assessment of disease burden and unmet needs: Analysis of contemporary data can better help understand the damages of substance use to facilitate future investment priorities. Researchers in this field have examined a variety of outcome measures to capture not only the cumulative losses in the health of the population such as mortality and disability (Bahji et al., 2020; King et al., 2014; Swartz & Beltran, 2019), but also the increased burden on the healthcare, public health, and public safety systems attributed to the opioid epidemic (Alsabbagh et al., 2021; Chen et al., 2022; Salzman et al., 2020; Suen et al., 2022). Economic burden has also been assessed for healthcare services (Leslie et al., 2019), loss in the labor market (Segel et al., 2019), criminal justice (Zajac et al., 2019), and child welfare services (Crowley et al., 2019), which have served as the basis of claiming and distributing compensation to remedy harms. In addition to examining the totality of burden by sector, it is also imperative to understand the disparity in the unmet needs across demographic subgroups (Barnett et al., 2023; Chang et al., 2022; Han et al., 2022; Siddiqui & Urman, 2022) or by social determinants of health (Hansen et al., 2022; Owens et al., 2006; Radic et al., 2022).

Surveillance and monitoring: Analysis of routinely and systematically collected data, such as administrative insurance claims data, syndromic surveillance data from electronic health records (EHR), and Emergency Medical Services (EMS) records can provide crucial insights into rapid changes and emerging trends (El Ibrahimi et al., 2020; Rock et al., 2021; Tehrani et al., 2018). In addition to using health-related outcomes for monitoring, there has also been increased use of drug-checking data, from seized drugs (Fiorentin et al., 2019) or based on community-based street drug-checking programs (Dasgupta & Figgatt, 2022; Singh et al., 2020; Tobias et al., 2022), to understand the emerging threats from the toxic adulterants in the street drug supply.

Intervention and policy evaluation: Published research utilizes various data sources to evaluate the impact of a broad array of policies in prevention, treatment, and harm reduction that aim to mitigate substance use-related issues (Lee et al., 2021; Schuler et al., 2020). In addition to policy evaluations at the federal and state levels, data are also used to help communities assess the real-world efficacy of evidence-based interventions since the clinical effectiveness of these interventions may not necessarily translate from the literature to practical implementation through the “translation pipeline” (Ducharme et al., 2016; Louie et al.,

2021). Further, to facilitate novel strategies and pilot programs for addressing the unmet needs in local communities (Hernandez et al., 2023; Wu et al., 2022), data are utilized to understand their effectiveness and cost-effectiveness and to guide the communities' planning for the wide rollout of such strategies if proven effective.

Policy development and deployment

Results from analyses of the coordinated data system could help policymakers better understand existing assets and deficiencies to determine the types and levels of effective intervention programs for implementation in communities (Tomko et al., 2023). Given the practical constraints of finite resources, policymakers may face challenges in choosing areas of priority or what to fund for optimizing their resource allocation for maximal health impacts, which the translational data analysis can help to inform. For example, data showing geospatial patterns of overdose deaths help to shed light on the need to improve access to treatment and harm reduction services varying by location and community (Anwar et al., 2022; Bonifonte & Garcia, 2022; Dodson et al., 2018). The policy development process can also inform what additional data are needed for analysis to address identified unmet needs or existing unanswered questions.

Continuous improvement

Rather than considering data curation and analysis for supporting policy decisions as static isolated tasks, or as a sequential linear process, it is more realistic to consider the need for data and associated analysis as a *dynamic* and *iterative* process for continuous improvement. That is, instead of a one-time statistical exercise of acquiring, pooling, and analyzing data for policy development, a coordinated data and policy framework should be viewed as a continuous quality improvement process (Hoffman et al., 2012; Hunter et al., 2017) requiring sustained efforts and ongoing improvement. As new data are collected in parallel with intervention implementation over time, ongoing analysis can help reveal shifting patterns, allowing policymakers to reassess existing approaches and apply necessary adjustments to action plans moving forward. Feedback on policy development, deployment, and adjustment impacts at the federal, state, and local levels over time can help to reduce conflicting and competing substance use policy regimes.

While having identified several potential use cases for systematically coordinated efforts in data collection and analytical workflow for informing policy creation and decision-making, we acknowledge that it is by no means a simple goal to achieve. While each of these identified elements offers promise in theory, there are numerous practical challenges in the current landscape. In the next section, we highlight key data issues such as siloed datasets, policy restrictions, and jurisdictional limitations, and discuss how these have limited the implementation of effective policy solutions to substance use-related public health and safety issues, particularly in instances of emergencies and the need for an immediate response to address urgent needs.

Issues in the data

Despite a variety of data sources that have been utilized to address substance use-related research questions in the literature (Evans et al., 2010; Geissler et al., 2022; Jalali et al., 2021; Smart et al., 2018, 2020), these data may not be readily accessible for the analytic tasks necessary to facilitate real-time policy development in real-world settings. While there existed a large body of research assessing the quality and utility of drug data systems (Sevigny & Fuleihan, 2015), the challenges remained in bridging available data sources with policy development, which also became evident in our earlier work of providing analytic technical assistance to policymakers in developing a policy of allocating opioid settlement funds in Pennsylvania (Rhubart et al., 2022). To create an evidence-based and transparent approach for the intra-state distribution

of the settlement funds, we initially identified a wide range of empirical measures from diverse data sources for consideration (Appendix Table S1), but not all of them are ready for plug-and-use. Data sources and definitions of outcome measures were assessed for their relevance, limitations, and overall quality, which further underwent thorough deliberation with stakeholders from state and local communities to finalize the selection of empirical measures. In the final recommended formula, the share of the total settlement funds a county receives was calculated as a weighted sum of the county's share of overdose deaths from all drugs, adjusted amount of opioid dispensed, OUD-related hospitalizations, and EMS-administered naloxone (more details for the development of the allocation model can be found in Rhubarb et al. (2022).

Through this process of developing the allocation formula, we found several common challenges associated with existing data sources (Table 1), and we believe that these barriers are not unique to our experience. In the following, we summarize and discuss these issues in existing data that may have hampered policy development as informed by our experience, with the goal of identifying updated recommendations for changes and improvements that can lead to a more measured public policy response to prevent and address future emerging substance use crises beyond the opioid epidemic.

Coverage and representativeness of data

Understanding how data are collected is crucial for accurate interpretation of the findings from analyses. A simple characterization is that data could be broadly differentiated as systematically collected or voluntarily reported. Data that are systematically collected provide a more meaningful assessment of temporal and geospatial distributions of what is being measured. Such data can be collected in survey studies with carefully designed sampling strategies such that the collected data will be nationally or regionally representative, such as with the National Survey on Drug Use and Health (NSDUH) (Substance Abuse & Mental Health Services Administration, 2023). Systematically collected data could also be retrospectively and comprehensively extracted from existing registries or databases that had compiled data and records. For example, in Pennsylvania, Emergency Department (ED) visits for non-fatal drug overdoses are collected through the syndromic surveillance system, which covers all 171 Emergency Departments in the state (not including Veterans Affairs Medical Centers) (Pennsylvania Department of Health, 2023). Opioid-related hospitalizations can be identified from Inpatient Discharge Data in the Pennsylvania Health Care Cost Containment Council (PHC4) (Pennsylvania Health Care Cost Containment Council (PHC4), 2021), to which all licensed healthcare facilities in Pennsylvania are mandated to provide administrative data (similar to State Inpatient Databases from the Healthcare Cost and Utilization Project [HCUP] (Agency for Healthcare Research & Quality, 2023)). Other administrative processes may also generate comprehensive data at the transaction level, such as the amount of opioid and other drug distribution from the Automated Reports and Consolidated Ordering System (ARCOS) which mandates manufacturers and distributors to report the relevant transactions to the Drug Enforcement Administration (Drug Enforcement Administration, 2024), and the prescriptions of opioid and other controlled substances from the Prescription Drug Monitoring Program (PDMP) that have been implemented in many states (Fink et al., 2018; Tay et al., 2023). The Drug Abuse Warning Network (DAWN), which is currently being reestablished, also systematically captures electronic health records of emergency department visits based on substance use-related issues at a national scale (Substance Abuse & Mental Health Services Administration, n.d.).

In contrast, for voluntarily reported data, the coverage may vary substantially or is simply not known. For example, the National Incidence-Based Reporting System (NIBRS) collects incident-level data on each crime incident, including detailed drug information if any drug

Table 1

Challenges with the use of existing data sources to inform practical public policy responses to address the public health needs related to the opioid and substance use crisis.

Issues in the data	Challenges faced in the development of opioid settlement allocation strategy in Pennsylvania (Rhubart et al., 2022)
Coverage and representativeness	<ul style="list-style-type: none"> There exist several publicly available datasets for opioid and substance use-related outcome measures, but many of them either have unknown or inconsistent geographic coverage across counties in the Commonwealth (e.g., suspected overdose incidents, ED visits, drug seizure, crime incidents). Some data sets are comprehensive in their coverages for specific subpopulations only (e.g., Medicaid population, incarcerated population) and may not be representative of the overall distribution of the opioid crisis burden in all counties, given the objective of allocating settlement funds across counties instead to specific target subpopulations. The NSDUH survey provides systematic estimates for the burden of substance use at county and state levels, but has limited samples for representing local (county) level disease burden. It is also known to be subject to underestimating the prevalence of substance use.
Specificity in drug types	<ul style="list-style-type: none"> Data quality about drug-specific overdose deaths may not be consistent across all locations and years in the CDC WONDER multiple causes of death database, likely due to the varying practice of toxicology testing by coroner's offices (subject to capacity and resource constraints). It is impractical to accurately distinguish opioid overdose deaths from other drug-caused overdose deaths in the CDC WONDER database, which limits the capacity to understand the evolving patterns and identify emerging new substances in local communities.
Time relevance and timeliness	<ul style="list-style-type: none"> Data from different data sources are available for various time ranges. Choosing a time range that is overlapped by all data sources, even if feasible, may significantly limit the amount of data to be included. Selecting a specific time range for each dataset may depend on the contextual background to ensure the data within the included time ranges remain relevant to what is intended to be captured. Substantial lags in available data (most with a lag of at least 1–2 years at the time of the conducted analysis), which limits the capability of understanding the concurrent burden and unmet needs in communities to inform resource allocation. Publicly reported data usually suppress data below a specific (small) value to prevent the identification of individuals, which makes county-level measures more often subject to data suppression, especially for rural and small counties. Some substance use-related health outcome measures may be more significantly affected by spatial spillover effects of the opioid epidemic. Not all counties have adequate access to healthcare services and resources such as Emergency Departments and Emergency Medical Services, which may affect the estimates of the actual burden in the community.
Geographic units	<ul style="list-style-type: none"> Only publicly available datasets are used in developing settlement allocation formulas due to limited time and resources, while other private or proprietary data might be useful. Publicly available datasets are used "as-is," with limited flexibility in tailoring the definitions of outcome measures for intended analysis. More detailed level data (e.g., at an individual level or a discharge level) could have finer granularity and do not have data suppression concerns, but access to such data (public or private) may require extra time for request, processing, and approval.
Data access, restrictions, and linking	

is involved, which could serve as a potential data source to understand the patterns of the local drug market and drug-related crime activities. However, it relies on law enforcement agencies that voluntarily contribute the data (US Department of Justice, 2022), and the agency participation rates and overall coverage vary by state and change over time. Using voluntarily reported data without closely examining its coverage level could lead to incomparable results between local regions. Another example is collecting naloxone administration information from multiple sources. In Pennsylvania, the Overdose Information Network (ODIN) initiative (Pennsylvania State Police, 2021) reports overdose responses and naloxone administration by law enforcement and other first responders (EMS, Fire, etc.) who voluntarily enter incident data (before the mandatory reporting required since 2022 (Pennsylvania General Assembly, 2022)). The representativeness of the data depends on the participation level and coverage of the program rollout across regions. An alternative dataset for naloxone administrations is from Emergency Medical Services (EMS) records; although not inclusive of events involving naloxone administered by other non-EMS first responders, the EMS records are systematically collected across the state, and are mandated for all EMS agencies by state law. As such, ODIN data may provide more complete naloxone administration information in certain regions with adequate coverage, while EMS records could be more comparable across the state though limited in its comprehensiveness.

Even systematically collected data may not always adequately measure targeted outcomes with representativeness at the desired level of granularity or scope. For example, the NSDUH, among the largest general population surveys for substance use in the US, can provide systematic estimates of opioid use disorder (OUD) prevalence at national and state levels, but given the limited samples for relatively rare events in each county, it may not be practically useful for characterizing the OUD burden and its variations at the county level. Moreover, because the NSDUH does not cover homeless and institutionalized (e.g., incarcerated) individuals and self-reported outcomes are likely under-reporting stigmatized behaviors like substance use (Reuter et al., 2021), previous studies have found that the OUD prevalence estimated from other data sources and statistical methods could be at least 3–5 times higher than the NSDUH estimates (Keyes et al., 2022; Mojtabai, 2022; Wang et al., 2023). An alternative data source could be health insurance claims (e.g., Medicaid, Medicare, commercial insurance, or all payers claims data), which can identify individuals based on the OUD diagnosis code and count them by patients' residence location to obtain the county-level prevalence of OUD estimates (Lindner et al., 2023). On the other hand, this approach has limitations considering that OUD diagnosis codes in claims data may not always be accurate (Lagisetty et al., 2021; Scherrer et al., 2023); caution is also needed when generalizing its estimates to the general population with a mix of diverse insurance types, given the known existing disparities in OUD prevalence by insurance types (Davenport & Matthews, 2023).

Data and measures with high and consistent coverage can more accurately reveal spatial and temporal patterns. In our experience of developing a settlement allocation formula in Pennsylvania, with the goal of characterizing the distribution of the opioid crisis burden across counties, we faced several barriers and challenges in identifying proper data sources for the analysis we sought to conduct to inform policy response. We prioritized data sources that had consistent coverage across all counties, as measures with poor and inconsistent coverage may distort the assessment in the distributions of the burden and need in the communities, leading to inequitable allocation of resources to help these communities address the ongoing crisis.

Specificity of drug types in the data

As the nature of the opioid epidemic has shifted towards stimulant and polysubstance use, which has been referred to as the "fourth wave" (Friedman & Shover, 2023; Segel & Winkelman, 2021), the inability to

differentiate outcomes by specific drug types may mask crucial changes and delay or reduce opportunities for timely interventions in communities. Common drug classifications by opioids, heroin, cocaine, and stimulants (methamphetamine) are available in some of the current data, but the specificity and accuracy of the involved drug types at this level may not be adequate. Likely, this will continue to be an issue as novel psychoactive substances are identified. In the CDC WONDER multiple causes of death database, the most commonly used source for overdose death-related outcome measures, drug types involved in overdose deaths are specified by ICD-10 codes (Centers for Disease Control & Prevention, 2023), which have limited drug types and cannot distinguish fentanyl and other specific synthetic opioids. Moreover, the quality of drug type information eventually relies on the accuracy and comprehensiveness of the death certificates. In other data related to drug overdose from ED and hospitalization records in healthcare settings, reported drug types may also be affected by the drug screening policies and workflows that may vary from one provider to another (Danda, 2022; Jin et al., 2020).

Being aware of such caveats in the data could help us avoid misinterpreting the results of drug-specific estimates. When analyzing county-level temporal trends of drug overdose deaths in Pennsylvania using the CDC WONDER data, we observed that in Philadelphia County, the number of opioid overdose deaths was only 4–11 % of the number of overdose deaths from any drug (identified by all ICD-10 codes T36-T50, including “other and unspecified” drugs) during the years 2007–2017, whereas this proportion increased drastically to around 80 % after the year 2018. While other neighboring counties, as well as other non-adjacent counties across the state, did not show similar drastic changes in drug overdose deaths and the prevalence of opioid misuse estimate for this region from NSDUH remained stable, such substantial changes are unlikely explained by the true increasing proportion of opioids involved in all overdose events. Previous studies have also suggested that opioid-specific deaths are underreported, which should be adjusted by utilizing the data on overdose deaths from the “other and unspecified” category (Ruhm, 2016).

As such, inaccurate drug-specific measures make it difficult for policymakers to separate the burden and damages resulting from different substances in the community, and can hinder the development of effective intervention strategies targeted at different at-risk populations, as well as the evaluation of the effectiveness of such programs if tracking the wrong outcome measures. Lacking proper documentation of drug type data also limits the surveillance capability to detect emerging changes in drug use activities in the community and for timely response to public health threats. Efforts are underway to improve the specificity of drug types. The National Forensic Laboratory Information System (NFLIS) provides detailed reports of drug types for each state from the substances seized by law enforcement through a public Data Query System (National Forensic Laboratory Information System, 2023). Localized efforts to test drug supplies have also emerged in the community setting to detect emerging trends (Public Health Drug Checking, 2024). However, such data sources with a more granular level of substance identification are mostly based on ad-hoc and voluntary samples and may lack representativeness; thus, they can be more useful to identify the latest drug threat as sentinel data, whereas the totality of these data may not necessarily represent the overall burden and its geographical distribution. In addition, these data can provide valuable information about the availability of detailed drug types on the street from the supply side, but the drug specificity of outcome measures from the demand side (e.g., healthcare visits, first responder encounters, urinalysis records) still remains less mature.

Time relevance and timeliness of data

Data vary in terms of when they are available and how frequently they are updated. For questions of evaluating the impact of implemented interventions or policies using pre-post analysis, data need to be

available for time periods both before and after the intervention is implemented; otherwise, the effects cannot be properly inferred from changes due to lack of pre-post comparisons.

A prolonged time lag in data availability presents a critical barrier to surveillance and monitoring, which is intended to identify emerging threats in the community and thus inform real-time responses. The final data of multiple causes of death in CDC WONDER are updated annually and typically delayed by 1–2 years; in the provisional data that is more up-to-date, deaths from drug overdoses still have a delay of 4–6 months (Ahmad et al., 2024), much longer than other cause of deaths in the same dataset that can be updated to the last calendar month. Delays of 1–2 years are typical in other national data sources such as the HCUP databases (Healthcare Cost and Utilization Project (HCUP), 2024) and Center for Medicare and Medicaid (CMS) claims data (Research Data Assistance Center (ResDAC), 2024). Data collected within a state may be released sooner but still with a delay of 3–6 months (e.g., PHC4 hospitalization discharge data, ED visits for drug overdoses, and overdose deaths in Pennsylvania). Thus, when trying to inform decisions at an operational level, such as deploying interventions to address emergency responses to outbreaks or shifting patterns in substance use in the local community, data with a 6-month or longer lag may not be as relevant and informative.

In addition, a data source that is deemed relevant may evolve over time. For example, for drug-related crime statistics that measure supply-side activities to disrupt the illicit drug market, the reporting of crime data by law enforcement agencies has transitioned from the Uniform Crime Reporting Summary Reporting System (UCR SRS) Program with aggregate-level information to the more robust National Incident-Based Reporting System (NIBRS) with details at incident-level since 2021 (Lantz, 2022), which makes recent data of higher quality and not necessarily comparable with results in previous years. Designs and questions in national surveys could also change over time. The NSDUH revised the questionnaires and definition for measuring misuse of prescription drugs in 2015 (Center for Behavioral Health Statistics & Quality, 2015), which has changed the availability of certain outcome measures and the comparability between the estimates in more recent vs. previous years.

Geographic units

Geographic units are important in many measures but are not always present at a consistent level across data sources. Evaluating the impact of policies and interventions or assessing community needs often involves datasets from more than one single data source. When these data sources measure outcomes at different geographic units that are not in hierarchical levels, such as city, township, county, 3-digit or 5-digit zip code levels, among others, merging these datasets poses a significant challenge, as the mapping between different geographic units is nontrivial due to the complicated overlaps.

In addition to the issue of incompatible geographic units across datasets, how the location is defined in the data and its implication on assessing community burden and needs can often be mismatched. At an overdose event, a location (e.g., county) can be recorded as the overdose incident location in the EMS data, or as the involved individual's resident location. If an individual receives medical care in the ED or is discharged from the hospital, the location information could be recorded either for the patient's residence location or the location of the healthcare facility. These locations are not necessarily the same; as a result, the estimated geographic distribution of the burden should be interpreted accordingly. The location of the overdose incident or the healthcare facility could be more relevant to understanding the unmet need for resources to enhance acute care in healthcare settings, whereas the resident location could be more useful to quantify the need for harm reduction resources and treatment access.

There are also spatial spillover effects of the opioid epidemic across the municipality and county boundaries when estimating and

interpreting the geographic distribution of outcome measures, which could directly affect the assessment of needs for these communities. While outcome measures are distributed by physically separated counties in the calculation, the past damages and burdens are not contained by the county lines. For instance, “pill mill” pharmacies did harm far beyond their own counties. A resident of one county may acquire drugs, have an overdose incident requiring EMS, be admitted to an ED, receive substance use treatment, require assistance from child welfare services, and have an overdose death all in different counties. Such an effect is more severe in rural areas (Monnat, 2019; Rigg et al., 2018) with less access to necessary first response and healthcare resources, as not all counties are equipped with EMS and hospitals with ED nor are recovery services available in all locations.

Data access, collection, analysis, and linking

Policies limiting access to data provide necessary protections for individuals' rights and safety, reducing the ability for the identification of individuals within data to protect their anonymity. These protections are necessary and important for reducing nefarious and unintended negative consequences. Protections vary across data types and purposes, geographic jurisdiction, and agencies. Access policy is hierarchically devised and granted according to user type and intended use. An application and review process typically exists to gain access to a dataset held by an agency or organization. These processes can be nearly immediate or they may require months or more before access is granted to the requested data, if permitted. Therefore, when aiming to use a restricted access dataset for the first time, this may pose significant delays in analysis and results for informing policy.

There are also policies that limit access to specific data to only a specific set of personnel or entities. For example, in Pennsylvania, the Criminal History Record Information Act (CHRIA) (Office of Attorney General, Commonwealth of Pennsylvania, n.d.), restricts criminal justice data, and reduces the ability of any non-law enforcement agency to gain access to granular data for analysis. Interpretation of these policies can, therefore, limit the ability to share data, even among governmental stakeholders, who would require access to data for policy development and deployment of resources.

Due to existing restrictions, different datasets are often guarded by their owner agency. Although these agencies can generate analytical files and summary statistics from their own data, their data reporting does not necessarily conform to the same standard, resulting in challenges to harmonize and integrate data from different sources for further analysis. Data collection can be limited to the needs of an agency with agency-specific data collection guidelines, restricting universal awareness of the methodologies and data limitations. There is also a lack of adequate resources and infrastructure for collecting and consolidating useful data from various data sources across sectors, despite the joint mission of addressing the substance use crisis. Given the “fragmented” landscape of substance use-related data, anyone who wants to use such data must go through a treasure hunt to identify these scattered datasets, many of which require lengthy application processes to obtain access if the granular level data are not publicly available. Without a coordinated data collection and analytic infrastructure, such efforts will be repeated and duplicated each time, wasting valuable limited resources. Additionally, entities with limited capacity for data analysis face a significant barrier to accessing results that could help to drive decision-making in a data-informed way. The burden of cost to partner with an external entity (e.g., an academic or research institution) for conducting analyses can be prohibitive, particularly for jurisdictions with limited financial resources.

Such isolated data sources also make it difficult or impossible to link datasets at the individual level, which may be relevant for identifying opportunities for targeted interventions. For example, to understand patient outcomes associated with treatment practices in Pennsylvania, we can find the treatment records within Medicaid or Medicare claims if

the patient receives state-based support for treatment; but if they then move to private insurance-paid treatment, no current dataset is available for connecting their care. This limits the ability to track individuals' longitudinal outcomes across the continuum of care, even if deidentified, reducing the ability to evaluate the effectiveness of treatment and other intervention supports. In addition, if an individual is justice-involved and moves into private insurance-funded treatment, there is no way of systematically tracking outcomes, including recidivism, treatment effectiveness, relapse, or overdose death. The lack of connection across datasets limits the ability to identify needed interventions.

Creating a coordinated data and policy framework for addressing substance use issues

In the previous section, we discussed several commonly encountered issues in the current datasets related to substance use. While this list was developed based on the authors' experience with developing metrics to inform the fair distribution of opioid settlement funds in Pennsylvania, these issues in the data are also likely to be critical for other policy-making settings (Smart et al., 2018) and mirror other previously identified issues (Sevigny & Fuleihan, 2015). If we are to realize the full potential of the use of data to address substance use issues in the US, we must overcome these limitations and develop a more robust and facile data infrastructure that could allow for readily available, meaningful, and timely analyses to inform policy making and implementation. We present a framework below that envisions such an ideal scenario (Fig. 2), where the components of the framework should help to mitigate the issues in existing data sources that were described above to better support the operations of the coordinated data to policy model that we previously presented (Fig. 1).

Coordination across local, state, and federal levels for data collection, archiving, and access

Data collection, archiving, and access would require federal-level coordination. However, state coordination of locally derived data would also be necessary.

Data collection

Coordinating data at the federal level implies a need for data collection and coordination from the local to state levels. This requires that a state agency coordinates local uniformity of data collection. It also requires the modification and development of reporting systems to ensure data collection can move from siloed datasets to federally coordinated systems. The results of this uniformity and collation will allow for representativeness and coverage that ensures all areas have complete and standardized data.

Data archiving and access

Ideally, one federal agency would develop a portal that provides unified access across agencies and datasets related to substance use-related health and safety outcomes. Memoranda of understanding and data use agreements would ensure data sharing enables use by stakeholders. Legacy data would be integrated into the new portal. The agency would develop access protocols according to user needs, data restrictions, and individual protections. This standardized access process would clearly delineate timelines associated with access across levels of restrictions for planning purposes. Emergency options would be available for immediate need for data access and analysis. This local-to-federal system could enable near real-time universal access if granted.

To ensure the efficacy of data, coordination would occur regarding data standardization, geographic compatibility, and database management. The data coordinating agency would ensure the universality of data availability across all localities. State-based data that is not universally relevant will be coordinated at the state level, and made

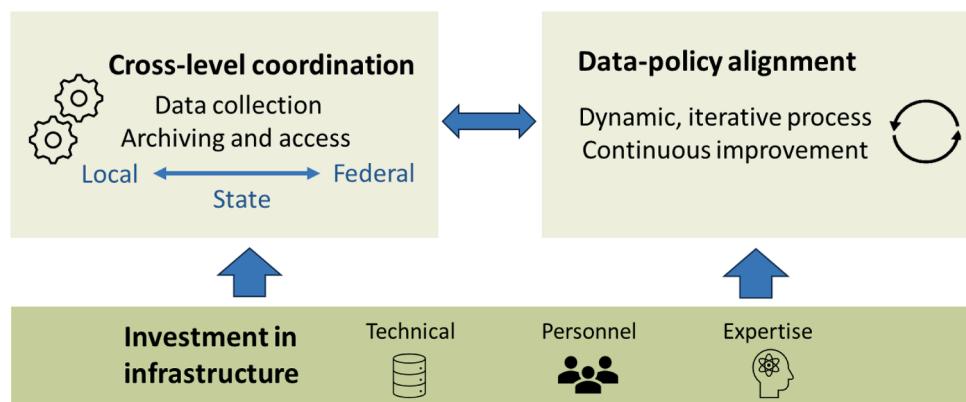


Fig. 2. Keys to creating a coordinated data and policy framework to inform the responses to address substance use issues.

available to stakeholders in a similar fashion as the federal portal; these portals would be compatible and users could translate access and data across systems through linking mechanisms. Datasets would be curated with developed data manuals to ensure ease of access for incorporation into statistical packages. Publicly available and non-restricted data would have clear instructions for use and interpretation. Linking between relevant administrative and proprietary datasets would be seamless. Unique identifiers would connect individuals across datasets, and, according to access, could be tracked across dataset types, with careful development of controls for protecting individuals' privacy rights.

Aligning data with policy and policy with data

The collection of data would be aligned with policy development needs, addressing issues similar to those we have identified. Assessment of existing datasets and collection mechanisms would occur to identify additional needs for policy creation. As policy development needs emerge, the connection between policymakers and the data coordinating agency (from local to state) will ensure timely access to data and that policy can respond to emerging and persistent trends. Existing data collection routines could be revisited regularly to assess needs or to be further augmented with additional data elements or granularity, such as emergent drug types, to support new policy development. Value of information (VOI) analysis, as a formal quantitative method (Eckermann et al., 2010; Fenwick et al., 2020), can also be employed to help identify data sources and measures of high priority and guide data collection efforts to better inform decision making. Translational analyses of state and local data to appropriate agencies will ensure syndromic surveillance, enabling local-to-state response strategies in a timely manner. Key indicators of substance-related public health and safety outcomes will be monitored over time, and the deployment of resources can be modified to meet localized needs. Modeling of policy implications on outcomes through the use of analytical support would inform policy and intervention development and implementation. Intentionally developed data collection will enable continuous quality improvement of both policy and intervention modification as evaluation of impact on outcomes over time occurs.

Investment in infrastructure for effective data collection and use

Data collection and coordination require a robust technological, technical, and personnel infrastructure. Existing inefficiencies across organizations would be reduced to realize infrastructure investment costs. However, federal funding to develop this infrastructure would likely be required. Investment in technical assistance and training mechanisms that can help guide data collection (e.g., survey designs, sampling strategies) will enhance data efficacy. External checks on data

efficacy and accuracy will provide validity measures to reduce the likelihood of data input and transfer errors. Principles of data collection by the coordinating agency and its subsidiaries would require consistent evaluation to ensure that individuals are protected and that data protocols are ethically guided.

In addition to investing in the data collection infrastructure, it is also important to build the personnel infrastructure with stakeholders and policymakers who would be equipped with domain knowledge and analytical expertise to effectively inform policymaking. Information sessions, training courses, or workshops can be organized through an extant and expanded technical assistance infrastructure to help these stakeholders and policymakers stay informed with relevant data sources and guide them in data interpretation. Understanding the nuances in the analytical processes would empower them to better translate the analytical results to practical implications and effectively use data to inform policy responses. These efforts may require access to relevant experts, e.g., from higher education or research institutions, for agencies and organizations that may lack internal data analysis and interpretation capacity.

The coordinated data and policy framework as envisioned above would be a substantial undertaking, requiring significant investment, time, and effort. Such an idealistic system may be unrealistic, particularly given the local control of data, jurisdictional issues, and the interplay between federal and state governments in the US. However, as we demonstrated in our experience with our assistance in determining the allocation of opioid settlement funds in Pennsylvania, the current structure and processes are untenable and broken, mirroring the historical issues associated with data analysis and translation for addressing substance use-related outcomes. If the US is unable to address the current status quo, we will continue to perpetuate the loss of lives, the harm experienced by individuals, families, and communities, and the increased expenditures on public resources required to address the devastation and damage caused by the ongoing opioid epidemic and any emerging and future substance use issues.

Conclusion

If we are serious about addressing substance use issues and abating the current opioid epidemic and future public health and safety harms of emergent substance use issues, we must reconsider the way we currently harness data for policy creation and intervention implementation. In this article, we have identified key data issues that arose in our efforts to develop an allocation of opioid settlement funds in Pennsylvania. Based on those issues, we have proposed a framework that would help address these data challenges, built upon historical, similar calls for a data infrastructure transformation. While this framework is idealized, it provides direction for future efforts that are interested in ensuring access to *meaningful* and *timely* data and analyses. At a minimum, it could serve

as a revised call for more deliberate conversations about a feasible plan for constructing a more data-informed approach to addressing substance use issues. Doing so will help us to better align policy and data for maximizing positive impact on substance use-related public health and safety outcomes.

Ethics approval

The authors declare that the work reported herein did not require ethics approval because it did not involve animal or human participation.

CRediT authorship contribution statement

Qushi Chen: Writing – review & editing, Writing – original draft, Visualization, Validation, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Glenn Sterner:** Writing – review & editing, Writing – original draft, Resources, Methodology, Investigation, Funding acquisition, Conceptualization. **Danielle Rhubarb:** Writing – review & editing, Writing – original draft, Visualization, Data curation, Conceptualization. **Robert Newton:** Writing – review & editing, Investigation, Data curation. **Bethany Shaw:** Writing – review & editing, Project administration, Investigation. **Dennis Scanlon:** Writing – review & editing, Writing – original draft, Supervision, Resources, Methodology, Investigation, Funding acquisition, Conceptualization.

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.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.drugpo.2024.104629](https://doi.org/10.1016/j.drugpo.2024.104629).

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