Improving Health Care Data in California

SUMMARY

Technical appendices to
this report are available
on the PPIC website.

California policymakers are taking steps to create a health care payment database (HPD)—often referred to as an all-payer claims database—that would assemble comprehensive payment information on health care services provided to most state residents with public or private health insurance. Rising costs and a lack of transparency are key motivators of this effort, but an overarching goal is to make health care data available to a wide range of stakeholders—including insurers, employers, health care providers, consumers, state agencies, and researchers—in order to continuously monitor and evaluate health care use, expenditures, and outcomes.

A California HPD would cover a larger and more diverse population than databases in other states, and could be a critical resource for addressing some of the state's most pressing challenges, including homelessness, untreated mental illness, and the well-being of children. Not only could an HPD offer a crucial source of information about current spending patterns, but it would also be an essential tool to monitor the effects of policy changes.

This report offers examples of research that could be developed and/or enhanced by an HPD. It also reports our findings from in-depth interviews and an online survey to highlight insights and potential contributions of the California research community. There are several key takeaways:

- An HPD promises to provide better data to address questions related to health care cost drivers, including health provider consolidation and patient costs. Research using data from an HPD could also shed light on the continuity of health care coverage for California's children and how coverage lapses may impact use of preventive services.

- An HPD holds the potential to inform statewide policy by facilitating broader access to data required to evaluate local intervention and pilot programs. For example, it could enhance studies aimed at identifying successful housing interventions that lower costs and improve outcomes among low-income, chronically ill Californians or inform efforts to prevent child maltreatment.

- California's research community could serve as a valuable resource for developing, monitoring, and maintaining a successful HPD. California's many higher education and research institutions could serve as partners in organizing and vetting the data. Nearly all of the researchers we interviewed indicated they would apply to use data from a California HPD and would be willing to pay for access.

- Key features of an HPD that would ensure that it is a high-quality tool for policy researchers include the ability to follow individuals over time and across insurance plans, demographic information, and data on costs,

rebates, and alternate payments. Researchers also prioritize linkages to other health data, such as vital statistics, hospital discharges, and disease registries. Lastly, linkages to social safety net and other administrative data could benefit research in arenas—such as employment and child welfare—that may be affected by health or health care.

- In addition to the HPD, California policymakers are planning other large-scale databases to bring together state administrative data. Examples include a database to capture longitudinal education and employment information and a database to integrate information across multiple social safety net programs. The future may hold opportunities to link these data systems and further improve data for policy-relevant research.

As policymakers consider the future of health insurance and health care in California—including a single-payer system and other major insurance reforms—a reliable, timely, and comprehensive source of information on who pays how much for health care services holds the potential to drive evidence-based policymaking.

Introduction

As California's population grows, diversifies, and ages, it is imperative that policymakers have timely and comprehensive information on health care use, costs, and outcomes. Over the past decade, California has seen several efforts to increase transparency around the cost of health care. Various private entities have assembled claims and encounter data—detailed records for each medical service provided to patients and paid for by health insurance plans —and made them available to health care systems, policymakers, and researchers.[1] In addition, state lawmakers have considered several pieces of legislation to create cost transparency tools that consumers, purchasers, and policymakers could use to manage rising health care costs. Despite these efforts, there continues to be a dearth of information on health care in California.

To address this gap, the state legislature included funding in the 2018 budget trailer bill (AB 1810) for the development of a comprehensive health care payments database (HPD). The legislation allocated $60 million to convene a review committee, design technological and programmatic features, and submit a report with recommendations to the legislature by July 2020.

Eighteen states have created HPDs—also called all payer claims databases (APCDs)—and additional HPDs are under development in several other states in addition to California.[2] Although cost transparency is the primary goal, lawmakers have also signaled the importance of an HPD to efforts to improve health care delivery and patient outcomes and examining the impacts of social determinants of health. An HPD can also help researchers conduct rigorous research that expands the evidence base for a wider range of policy decisions. Indeed, if individual records could be linked to other state administrative data, the database could be a powerful tool for investigating a broader set of outcomes, such as employment or criminal justice involvement, in which health care may play an important role.

The goals of this report are, first, to provide examples of how the database could support high-quality research to enable more evidence-based policymaking in health and other policy areas; and, second, to outline priorities and insights from the California research community that should inform development of the database. In the first section, we offer examples of studies that could be conducted with an HPD and explain their relevance for California policymakers. We then outline the ways researchers can support the development and operation of the HPD. We conclude with a discussion of key insights drawn from our outreach to researchers and from the experiences of other states.

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[1] Integrated Healthcare Association (IHA), a nonprofit entity, incorporates commercial, Medicare, and Medi-Cal data. The nonprofit California Healthcare Performance Information System (CHPI) organized a voluntary database that is now defunct. Health Care Cost Institute, a national organization, collects claims from large commercial plans; conducts research, and makes data available for research purposes. FAIR Health, Truven MarketScan, and Optum are examples of private entities that assemble claims data from commercial insurance plans and make these data available for research at a cost.

[2] The 18 states that have APCDs are Arkansas, Colorado, Connecticut, Delaware, Florida, Kansas, Maine, Maryland, Massachusetts, Minnesota, New Hampshire, New York, Oregon, Rhode Island, Utah, Vermont, Virginia, and Washington.

Health Care Payments Data Review Committee

The legislature tasked the Office of Statewide Health Planning and Development (OSHPD)—a state agency that collects and publishes several data products related to health care—with planning the health care payments database. The authorizing legislation required a review committee composed of a broad range of stakeholders to guide the planning process. The members of the review committee have diverse and sometimes competing interests. For example, they represent entities who will need to submit data, such as health insurance companies and hospital systems, and groups that could be users of the data, such as employers, consumers, and researchers. The committee does include a representative from the research community; however, the wide-ranging charge for the group is to develop recommendations around data submission and quality, technology requirements, data security and storage, governance, and sustainability. Additional information about committee members is in Technical Appendix E.

The committee convened monthly public meetings between March 2019 and February 2020 to develop recommendations on questions such as which entities to require data submissions from and on what schedule, which data elements to require, where to house the data, to whom to permit access, and how to protect privacy. OSHPD will deliver a report to the state legislature in July 2020 detailing recommendations for the HPD design that take into account feedback from the review committee. The enacting legislation set a target date of July 1, 2023, for the database to be "substantially completed."

How an HPD Can Inform Policy in California

California's leadership has clearly signaled an interest in tackling rising health care costs. The governor's January budget proposed a new state office focused on health care affordability. Additionally, a new state commission, Healthy California for All, has been tasked with developing a plan that moves California toward a unified health care financing system and broadens coverage to all Californians; it recently held its first meeting. In order for these efforts to be successful, state policymakers need better information on what health care costs and how it varies across different health insurance plans, providers, and regions of the state. An HPD would be an invaluable source of information about current spending patterns; it would also be an essential tool to monitor the effects of policy changes.

Several states have created commissions that rely on HPDs to inform cost containment policies (Melnick and Maerki 2020). For example, Massachusetts relies on its HPD to establish an annual target for the growth rate of total health care expenditures across the state. This growth benchmark is calculated across all payers, including commercial/private plans, Medicare, and Medicaid, to address concerns of cross-subsidization.[3] Maryland—the first state to establish an HPD—has used its database to track and implement various cost control methods, including global hospital budgets (Zemel and Riley 2016). States are using HPDs in other innovative ways to inform policy. A 2018 state law in New Hampshire requires the use of their state HPD to monitor network adequacy standards and better evaluate whether health insurance plans contract with an adequate number of providers to ensure access to covered services across all regions of the state.

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[3] Cross-subsidization refers to the practice of health care providers charging commercial/private insurance plans more for health care in order to make up for low rates paid by public programs. While the evidence base is somewhat mixed on how prevalent cross-subsidization is, it is often raised in policy discussions around provider payment rates and rising insurance costs.

In addition, many states provide access to data extracted from their HPDs to researchers. Several recent studies published in peer-reviewed research journals have relied on state HPDs. Some of these studies examine relatively narrow research questions (e.g., disparities in breastfeeding based on insurance coverage) while others provide broader examinations of health care use (e.g., utilization patterns of telemedicine) (Hawkins et al. 2017; Yu et al. 2018).

Another broad category of research that could be substantially enhanced with a California HPD is evaluation studies of large and small pilot efforts to improve health care access and health care delivery—and ultimately outcomes (Reschovsky and Bradley 2019).[4] State and local governments, along with health care systems, invest millions of dollars each year in interventions designed to improve health outcomes and reduce costs for the Californians they serve, yet these interventions are not always evaluated as rigorously as they could be—or in as timely a fashion as policymakers and other stakeholders would wish.

While randomized control trials (RCTs) are the gold standard for conducting program evaluation, their high costs have led to discussions and development of lower-cost strategies to assess program effects. Typically, government agencies contract with large research organizations or academic research centers to conduct required evaluations of program changes to federally funded insurance programs including Medicaid and Medicare. These types of studies tend to be quite expensive in part because it takes time and effort—including securing data agreements and establishing protocols for data transfers—to obtain the necessary administrative data. The routinely collected health data in an HPD has been proposed as a means to construct low-cost RCTs (McCord et al. 2018; Choudry 2017). Not only could large-scale evaluations be made more efficient and/or cost-effective with an HPD, evaluations of small-scale pilot projects could become feasible. Examples of evaluations using data from HPDs include studying the effects of a medically tailored meal program on health care use, estimating the impact of a team-based primary care initiative on health care costs of chronically ill patients, and estimating the impact of medication-assisted therapy for opioid addiction on Medicaid costs (Mohlman et al. 2016; Meyers et al. 2018; Berkowitz et al. 2019).

Ideally, California's HPD can be harnessed to meet the informational needs of policymakers and support California's research institutions to study complex issues that can expand the existing knowledge base.

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[4] This is particularly true for studies seeking to evaluate interventions targeting patients' social and economic needs—often referred to as social determinants of health. A recent review of the existing research literature found that most evaluations addressing social needs were limited by poor study quality (Gottlieb et al. 2017). Few studies evaluating program interventions were able to examine measures of health care spending or outcomes, with most focused on process due to constraints on available data.

Based on the current recommendations of the HPD review committee, the set of information in the database will include four core files: medical claims and encounter data, monthly enrollment files, pharmacy claims, and provider information. Nearly all commercial health insurance and managed care plans operating in the state would submit these data monthly; state and federal government agencies would submit Medi-Cal and Medicare data. One notable exception is self-insured employer plans, which cover about 4.8 million Californians: due to federal regulations and a Supreme Court decision, these plans cannot be compelled to submit data.

A multiphase implementation is planned for the HPD to incorporate additional information over time and ensure a high-quality database. Unique identifiers for patients, providers, and payers are among the priority data elements, and are recommended for inclusion in the first phase of HPD implementation. A master patient identifier—unique to individuals and created from personal information but de-identified to meet privacy standards—is a key data element. The first phase is also slated to include geographic identifiers (such as ZIP codes or Census tracts) along with characteristics of these geographies (such as median income) from the Census.

Current plans for the second phase of implementation include collection of information on alternative payment models, pharmacy rebates, and dental claims, along with patient-level linkages to hospital discharge data (inpatient and emergency department) and vital statistics records (birth and death certificates). In later phases, the plan is to include data from disease registries (e.g., cancer surveillance) and clinical information (e.g., lab results), among others. It is important to note that none of these plans have been finalized.

Finally, some individuals and services will not be captured in the HPD. The largest potential exclusion will be individuals covered by self-insured employer plans, as their participation will be voluntary. Individuals who are not covered by insurance will not have their health care use or payments included in the HPD. Neither disability insurance, workers' compensation claims, nor information from several federal programs, including the Veteran's Administration and the Indian Health Service, are planned for inclusion.

California's HPD Could Enable or Enhance Research in Many Areas

In this section we present five "use cases"—policy research questions that could be addressed with an HPD. These examples are informed by existing research that uses health care payment data and information gathered from interviews and a survey of researchers that we conducted.[5]

For each use case, we highlight three key points:

? Research question that could be addressed with an HPD

database How an HPD could add value to existing research

California Relevance of findings to California policymaking

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5 We conducted a literature review of studies that used health payments data. Technical Appendix A provides additional detail and highlights select articles referenced in this report.

The first two use cases involve health care costs: how much Californians pay for health services and how market consolidation among physicians and hospitals affects costs, quality, and outcomes. The third use case focuses on the frequency of transitions across insurance plans—in particular, Medi-Cal and Covered California—and how these transitions may impact the use of preventive health care services. The fourth use case involves rigorous evaluation studies of pilot programs aimed at providing more integrated services, including housing assistance to low-income, chronically ill Californians. Finally, we highlight a broader research agenda that requires linkages of the HPD with other state administrative data, including child welfare reports, birth records, and potentially other social service program data to inform prevention efforts targeting children at risk of adverse childhood events.

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Health care market consolidation

? How does provider consolidation affect costs, quality, and patient outcomes?

database Existing research suggests consolidation increases prices, but there is limited information on quality or outcomes. Patient and provider IDs across all payers would facilitate more robust analysis.

Research examining implications of consolidation on quality and outcomes can inform state and federal regulatory actions.

Health care markets have become more concentrated in recent years. The consolidation of hospital systems, physician groups, and insurance plans has reduced the number of options in certain regions and raised concerns about consumers or purchasers being forced to pay higher prices. In California, a recent lawsuit brought by the state attorney general charged the Sutter Health system with anti-competitive practices that increased prices for consumers (California Office of the Attorney General 2019). There is also interest in the relationship between market consolidation and the fact that costs for insurance and hospital stays are much lower in Southern California than in Northern California (Eibner et al. 2020). Research in this area would benefit from an HPD.

A more comprehensive analysis of hospital ownership of physician practices—known as vertical integration—would inform policymaking and regulatory efforts. While vertical integration raises concerns of anti-competitive practices (resulting in higher prices), pro-integration arguments can also be made about the ability of more integrated health systems to provide better care and improve patient outcomes. Comprehensive data drawn from multiple payers, along with the ability to link patients to providers over time, would help policymakers and state regulators to better evaluate the effects of consolidation.

The percentage of physicians in practices owned by a hospital in California rose from about 25 percent to 40 percent from 2010 to 2016 (Scheffler et al. 2018). Research focused on California has found that higher levels of integration among physicians and hospitals are associated with higher prices for physician services, hospital services, Covered California premiums, and total expenditures. (Scheffler et al. 2018; Baker et al. 2014; Robinson et al. 2014). However, due to data constraints these studies do not examine how increased costs may improve quality of care or patient outcomes. Researchers recognize the need to investigate these issues, and hospitals and other stakeholders criticize existing studies for these limitations (Baker et al. 2014; Coyle 2018).

A California HPD would allow researchers to conduct more robust research on the impact of increased consolidation of hospital and physicians groups on the quality of providers to whom patients have access, as well as health outcomes. Using patient and provider IDs, researchers can construct episodes of care by examining outpatient visits at a doctor's office with hospital admissions over a window of time, examine referral patterns, and connect those with hospital quality metrics. A study using Medicare claims performed a similar analysis and found that patients were more likely to receive care in high-cost, low-quality hospitals when their physician was in a practice owned by the hospital—contrary to the pro-integration hypotheses (Baker et al. 2016). Linking the HPD with hospital discharge data and vital statistics death records could extend these analyses to patient outcomes such as 30-day hospital readmission rates and mortality.

The state legislature has clearly signaled a desire to respond to increased consolidation in health care markets by enacting recent legislation that gives state agencies more power to approve or deny consolidations.[6] More detailed findings about the effects of consolidation and other health care market changes can inform policy decisions and regulatory actions.

Patient out-of-pocket costs

? How often do Californians overpay for prescription drugs, mental health, and hospital services?

database Limited evidence indicates high prevalence. An HPD could provide California-specific comparisons across payers and regions of the state.

A better understanding of patient costs across the state can inform the implementation and monitoring of state legislation.

Medical expenses that are not covered by insurance plans are a key facet of health care costs—and one of particular salience for policymakers. These expenses, often referred to as out-of-pocket costs, have increased considerably over the past decade for people enrolled in employer-based health insurance and for those covered by the Medicare program (Sawyer et al. 2017; Rae et al. 2019). While much of the existing research on out-of-pocket health care costs relies on national survey data, recent studies are using claims data to provide a more comprehensive and accurate accounting of these costs.

Prescription drugs—and their impact on health care costs—have become a policy focus for national and state lawmakers looking to control costs. Large increases in drug prices have led to nationwide efforts to gather information on costs, usage, and distribution channels. In California, these concerns have translated into mandatory reporting of wholesale drug prices and timely notification to drug purchasers of price increases.

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[6] For example, SB 932 (2016)—which did not pass—would have required that mergers or consolidations be approved by the Department of Managed Health Care and accompanied by public hearing to assess their effects. AB 595 (2017), which did pass, requires a review of the impact a merger would have on health care costs, access, or quality.

One important aspect of rising drug prices is their impact on how much patients pay for prescription medicine. Most insurance plans—both public and private—require people to pay set amounts for prescription drugs, which are referred to as co-pays. In addition, many insurers contract with pharmacy benefit managers (PBMs) to manage the purchase of prescription drugs for their enrollees.[7] Unfortunately, very little information is available on how this process works, or its impact on both overall drug spending and individual co-pays. One recent study found that for about a quarter of all prescriptions filled nationally, the consumer co-pay was higher than the drug's retail price (Van Nuys et al. 2018). This analysis, however, was based on a subset of commercial claims and provided no information for individual states. While it is unclear how widespread this problem is in California, lawmakers passed legislation in 2018 that requires pharmacists to inform patients of a drug's list price if it is lower than their co-pay.[8]

A state HPD would facilitate analysis of patient overpayment for prescription drugs in California and whether patients in some communities are likely to pay more than others. The analysis would draw on pharmacy claims data, including the national drug code (NDC), the prescribed dosage, supply, and amount paid. To assess differences across insurance plans and regions, pharmacy claims could be attached via master patient IDs to monthly enrollment information and geographic identifiers. In addition, researchers could obtain information on the retail prices of drugs available through various public and private sources via the NDC. Understanding how often Californians overpay for prescription drugs and by how much—as well as the impact of the new law—is essential to state policymaking.

Several other research studies examining out-of-pocket costs would be possible with an HPD. One recent study presents evidence on the effects of a 2017 California law that seeks to protect patients from "surprise bills" for care provided by providers that do not contract with their insurance plans. The study, based on a subset of commercial insurance claims, found notable declines in services delivered by specialty physicians who were not part of a patient's insurance network and were subject to the law. However, it acknowledged the limitations of using a select set of claims (Adler et al. 2019).

Another area in need of research is individual payments for mental health services. Federal regulations require mental health to be covered by insurance plans at the same level as physical health—this is often referred to as mental health parity. In addition, the ACA includes behavioral health as an essential benefit that must be covered by health insurance. Nonetheless, evidence drawn from national commercial claims indicates that patients pay more out-of-pocket for mental health care because these services are not covered by their insurance plans (Xu et al. 2019). A state HPD would allow researchers to assess the impact of these costs in California.

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[7] Pharmacy benefit managers negotiate rebates with drug manufacturers and contract with pharmacies to distribute prescription drugs. The rebates presumably result in lower payments for insurance providers but PBMs retain at least part of the rebates. There are concerns that the payment structure for PBMs may encourage the use of prescription drugs with higher prices. (Seeley and Kesselheim, 2019).

[8] The law (AB 315) also established a task force to determine what additional information/reporting will be required to monitor implementation.

Coverage changes and children's well-being

? How often do children transition between Medi-Cal, Covered California, and other sources of insurance coverage?

database Research suggests changes in coverage are prevalent, but little is known about how churn affects use of preventive services.

Improving access to care and use of preventive services among children in Medi-Cal is a policy priority.

Millions of Californians move between different health insurance plans each year. Changes in health insurance coverage, commonly known as churning, occur for a variety of reasons, including shifts in income, employment, and family circumstances. A recent analysis relying on survey data estimates that nearly 11 million Californians change coverage sources over the course of two years (Graves 2018). While coverage changes are not necessarily bad, churning has been associated with disruptions of care, increased emergency department use and hospitalizations, and worsening self-reported health status (Sommers et al. 2016; Bindman et al. 2008).

Coverage transitions may be particularly disruptive for low-income individuals. Two studies have found that churn among California Medi-Cal enrollees is quite prevalent among both adults and children (Bindman et al. 2008; Fairbrother and Schuchter 2008). However, these studies rely on data that are two decades old, and neither could determine whether individuals who lost Medi-Cal coverage transitioned to other coverage sources or became uninsured.

Half of California's children receive health coverage through either the Medi-Cal program (43%) or Covered California (7%) (McConville and Cha 2020). Both programs cover preventive services such as routine screening, vaccinations, and well-child visits. Encouraging the use of preventive health services is a recognized way to reduce health care costs while improving children's health and development. However, gaps in coverage or transitions to new health plans could hinder a child's access to preventive health care services.

Currently, data limitations make it difficult to assess the prevalence and implications of churning. For example, the state's Medi-Cal administrative data cannot be used to determine whether a child whose program eligibility is not recertified has lost coverage or transitioned to other insurance. According to an analysis by Covered California, yearly turnover among its enrollees is nearly 40 percent, with about two-thirds moving to employer-based coverage (43%) or Medi-Cal (27%). While informative, these estimates are based on self-reported information from a small sample of members.

Research using data from other state HPDs yield insights that are applicable for California. For example, a recent Colorado study that relied on the state HPD identified predictors of early disenrollment from Colorado's ACA insurance marketplace and transitions to other coverage, including Medicaid. Results indicated that children and young adults experienced higher risk of disenrollment compared to older adults, as did living in a neighborhood with a greater proportion of Latino residents (Gordon et al. 2019). Other work using Massachusetts' HPD found that Medicaid enrollees who switched insurance plans had increased primary care and specialist physician visits after the coverage change, but also had higher rates of emergency department use (Barnett et al. 2017).

A California HPD would allow policymakers, along with managed care plans that serve Medi-Cal and Covered California enrollees, to better understand how often children change coverage.[9] Patient identifiers and monthly enrollment files would allow researchers to examine how children move across different insurance plans over time.

An HPD would also provide the necessary data to examine how churning affects children's use of recommended preventive services. A recent report from the California auditor found that usage of these services was low among children enrolled in Medi-Cal (California Auditor 2019). Health plan identification and type, available demographic characteristics such as age and sex, along with medical encounter and claim records, would allow researchers to model the likelihood of different groups of children receiving recommended preventive services. This can inform efforts by the Department of Health Care Services and Medi-Cal managed care plans to improve usage rates of preventive services among children and reduce geographic or demographic disparities. It can also inform policymakers about the impact of reporting requirements and recertification procedures.

Housing interventions for low-income, chronically ill

? What types of housing strategies are most effective for low-income, chronically ill Californians?

database Few studies are able to use robust analytic methods or link to other programs and services due to data constraints.

Addressing homelessness is a top priority among Californians, and Whole Person Care pilots offer an opportunity to evaluate what works.

Understanding how supportive housing investments can improve the health of chronically ill Californians, including those with behavioral health conditions, and also lower public expenditures has become a focus of local and state health agencies as well as hospital systems. Several local health departments (e.g., Los Angeles County's Housing for Health program) and hospital systems (e.g., Kaiser Permanente's Thriving Communities Fund) are investing in housing to help treat people with multiple chronic conditions—including mental health and substance use disorders—who are also struggling with housing instability.

California's Whole Person Care (WPC) pilot represents a statewide effort to test methods that provide supportive housing and increase coordination between medical and behavioral health services to Medi-Cal enrollees with complex needs, including those with serious mental illness and at risk of homelessness. As of 2017, 25 WPC pilot programs were operating in 26 counties, and the most recent state budget includes additional funds for these programs to invest in housing and other interventions.

The current WPC evaluation plan includes analysis of Medi-Cal claims and encounter data to examine changes in health care use and cost outcomes for program participants. Interim findings from the WPC evaluation suggest

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[9] Because self-insured large employers cannot be compelled to submit health payment data by states, it may not be possible to identify all instances of children changing sources of insurance coverage. However, other states with HPDs have created programs for voluntary submission among self-insured employers; as a result, many self-insured employers do submit claims.

that the program is reaching the high-need Medi-Cal enrollees it is targeting; nearly half of all WPC enrollees were homeless. While there were no significant changes in emergency department use or hospitalizations among WPC enrollees in the first two years of the pilot program, the final evaluation report will compare the package of interventions, including housing, to potentially identify specific services that improve outcomes (Pourat et al. 2019).

A California HPD could support evaluation efforts by providing more streamlined access to needed administrative data along with a defined process for linking this information to other public services and safety net programs. This could reduce the time it takes to complete formal, federally required evaluation studies and broaden access to the data required to conduct additional research studies with complex research designs. For example, a study of housing interventions in New York City that targeted homeless individuals with severe mental illness used the fact that the program had limited housing resources to randomly assign individuals to treatment and control groups in order to examine the program's effect on Medicaid costs (Lim et al. 2018). Using Medicaid claims data linked with administrative data from jails, homeless shelters, state psychiatric facilities, government housing, and food assistance programs, researchers were able to assess a broader range of outcomes and provide a more complete accounting of cost savings across a variety of areas.

A well-defined and timely process for linking Medi-Cal data to other administrative sources and to the HPD could improve and expand the evaluation of the WPC program. Data from county mental health plans, substance-use-disorder treatment programs, and social service programs (including nutrition assistance and in-home supportive services) would allow for a more complete examination of their effectiveness. It could also allow a broader group of stakeholders—including health care systems and county agencies—to conduct more studies on this crucial topic, either alone or in collaboration with research groups.

Some California counties already have integrated data systems that could allow researchers to conduct similar analyses. San Francisco County, for example, maintains an integrated client database that was recently used to assess how heavy emergency department users interact with multiple public systems including jails, housing shelters, and sobering centers (Kanzaria et al. 2019). Another recently released study uses an integrated data system maintained by Los Angeles County to assess the possibility of developing data-driven models to predict homelessness and better target prevention efforts (von Wachter 2019). But many counties do not have the capacity to integrate their data systems. A state-level data infrastructure would allow evaluations across more counties; this would strengthen the evidence base for policies aimed at addressing homelessness.

Preventing adverse childhood experiences

? How can California improve outcomes for children at risk of adverse childhood experiences?

database Research suggests that prevention and early intervention improves later life outcomes, but data constraints limit the evidence base.

Addressing child maltreatment is a top priority of the governor and many legislators.

An individual's physical and mental health can interact with a number of other areas that are of interest to policymakers, including educational attainment, employment and earnings, involvement with criminal justice and child welfare systems, and others. In addition, health care providers and systems often have contact with people when they are particularly vulnerable (i.e., during childbirth, mental health crises, or serious chronic illnesses); these encounters are probably underutilized as points of intervention and prevention.

Linking information from the health care payments database to other longitudinal administrative data sources could be a powerful tool for assessing and improving longer-term outcomes across policy domains. For example, an HPD could inform efforts to prevent and ameliorate the effects of early childhood trauma. Improving the lives of California's children is a primary goal of the current governor—his first two state budgets included several investments in early intervention and prevention services for children and parents. Perhaps the clearest example of the governor's commitment is his selection of a physician who has long championed efforts to improve children's well-being as the first-ever California surgeon general. A signature initiative of Dr. Burke-Harris is increased screening for adverse childhood experiences (ACEs): potentially traumatic events—such as violence, abuse, and neglect—that are associated with poor health, substance use disorders, and premature mortality, as well as reduced educational attainment and earnings.

Kaiser Permanente recently announced a multi-million dollar research initiative for the study of ACEs and their effects on life trajectories. In addition, starting in 2020 California's Medi-Cal program will reimburse health care providers for the screening of enrolled children for ACEs in order to target preventive services and better address the social determinants of health (California Department of Finance 2019). Information from an HPD that is integrated with other administrative data could enhance these efforts. Below we provide a specific example focused on informing efforts to reduce child welfare involvement among children whose mothers suffer from behavioral health conditions.

A recent study documented the prevalence of behavioral health conditions (mental illness and/or substance use disorder) among all women giving birth in California and examined the likelihood that these new mothers would be reported to the state's child welfare system for abuse or neglect of their infants within the first year of their life (Hammond et al. 2017). The findings are stark: among the 2 to 3 percent of women with mental health conditions recorded on their hospital birth records, more than a third were reported for child maltreatment within one year of the birth, most often in the first month.[10] Many of these mothers also had documented substance use disorders.

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[10] The study used all first reports of maltreatment regardless of whether the allegation was investigated or substantiated.

Even after race, age, type of insurance, prenatal care, and other factors were accounted for, mothers with any maternal mental health condition were nearly three times more likely to be reported to child welfare services than were mothers without mental health issues; among mothers with both mental health and substance use conditions, the risk was nearly six times as great (Hammond et al. 2017).

The research team arrived at these findings after linking three sources of administrative data: hospital discharge records, vital statistics birth records, and child welfare records. But they could not identify a broader group of mothers whose mental health conditions were not identified when they gave birth. A state HPD would add that information, which, combined with the other three sources of data (birth, hospital discharge, and child welfare records), would create a crucial policy tool to inform and evaluate prevention efforts.

As the state explores the creation of other integrated databases, it may be possible to examine additional outcomes. For example, a study using linked administrative data from Washington State assessed how adverse childhood experiences including child abuse and parental criminal justice involvement impacted future behavioral health issues in adolescence (Lucenko 2015). In the case of interventions targeting children and their families, such as home visiting programs or intensive support for parents with behavioral health conditions, assessing their role on children's educational outcomes would be an obvious extension. If the state creates the longitudinal student-level database that is currently under discussion, these types of connections may be possible in the future.

California's Research Community Can Support the Development and Maintenance of an HPD

California is fortunate in having a vast network of researchers with current, deep knowledge of using the data that are planned for a California HPD. Many California researchers have extensive experience using claims and encounter data, often from commercial insurance plans or the Medicare program. Through interviews and an online survey we engaged 60 of these researchers to inform the use cases presented in the previous section; we also solicited their input on the HPD planning and development process. In this section, we highlight insights provided by this group on HPD design, the types of policy research they would pursue, and the technical database features they would need.

Collecting researcher feedback on a California HPD

We collected information from 60 researchers: 9 participated in-depth interviews and 51 responded to a short online survey. Most of our participants are at academic institutions, including UCLA, UC Berkeley, UCSF, University of Southern California, and Stanford University, but some represent research organizations such as the RAND Corporation. We sought out participants with a range of research backgrounds, including economics, epidemiology, health services research, medicine, and social welfare. Most are experienced with claims data, but we also included scholars who conduct quantitative research in other policy areas, but who are not necessarily familiar with claims. Technical Appendices B, C, and D have details, including the interview protocol, survey instrument, and full survey tabulations.

The researchers we spoke with are enthusiastic about the potential of the HPD. In the words of one, "The CA HPD would be a FANTASTIC and IMPORTANT resource. It can be used to improve the health care market for millions of Californians" (emphasis in original). The overwhelming majority (over 90%) of all survey respondents are "likely" or "very likely" to submit a proposal to use HPD data in research (Figure 1).
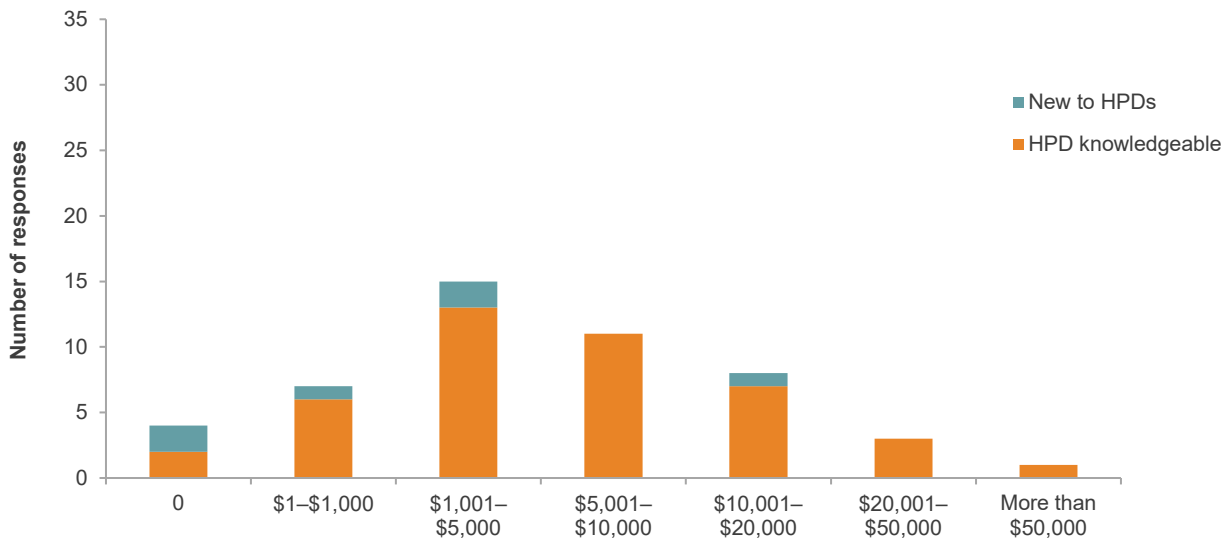
Researchers are likely to submit proposals to use the California HPD
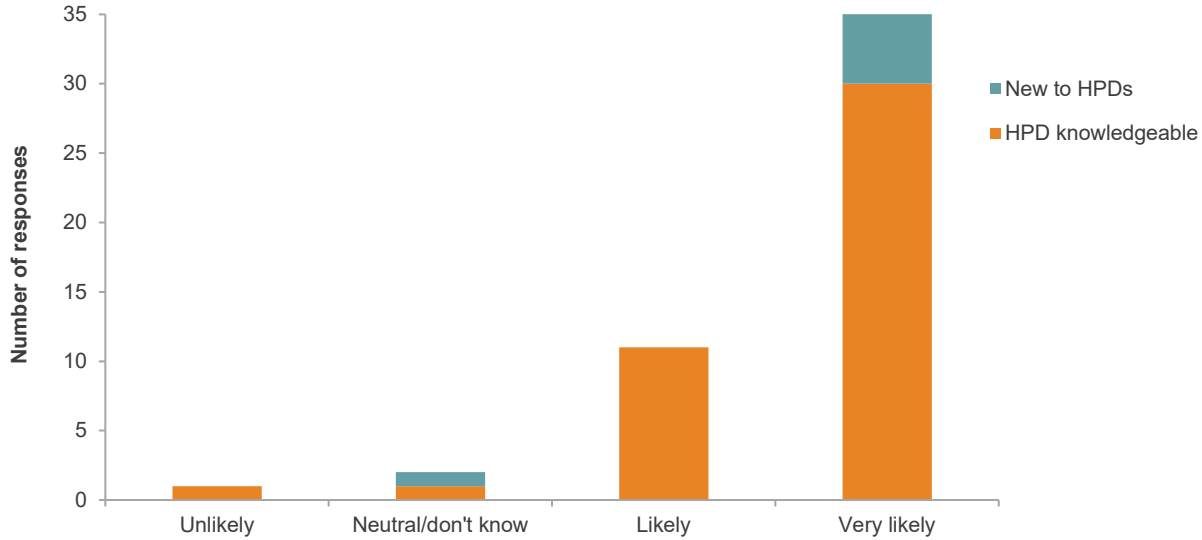
SOURCE: PPIC online survey of researchers. See Technical Appendix C for more details.
NOTE: The survey offered the option of viewing a short primer on HPDs, which allowed us to separate respondents into two groups: an "HPD-knowledgeable" group, and a "new-to-HPDs" group. There were 51 total respondents (43 HPD-knowledgeable and 8 new-to-HPDs); 1 did not answer this question.

The state has allocated funds for the database design process, but ongoing state funding to support the database is not ensured. Annual operating costs for the HPD are estimated at $15 million (OSHPD 2020). Research data fees could cover part of the cost of ongoing maintenance. We asked researchers to estimate how much they would be willing to pay for HPD data for a single research study. The most common response was $1,000 to $5,000 (Figure 2). Some states do have user fees in this range, but prices of $10,000 and above are common (OSHPD 2020). Several respondents indicated that the availability of grant funds would be key to their willingness and ability to pay more. Many researchers suggested tiered pricing to reflect the amount of data requested; for example, higher prices could be charged for more years of data. Others cautioned that high barriers to data access are discouraging for students or early-career researchers, potentially narrowing the pipeline of HPD researchers long-term, and suggested institutional pricing or discounts for new investigators.

FIGURE 2
Researchers are willing to pay for HPD data, especially if grants can be secured

SOURCE: PPIC online survey of researchers. See Technical Appendix C for more details.

NOTE: The survey offered the option of viewing a short primer on HPDs, which allowed us to separate respondents into two groups: an "HPD-knowledgeable" group, and a "new-to-HPDs" group. There were 51 total respondents (43 HPD-knowledgeable and 8 new-to-HPDs); 2 did not answer this question.

Some of the earliest state claims databases were developed in small states like Maine; a California database would be the largest state HPD in the country. Colorado's HPD, which offers datasets starting at $10,000 and has application information listed on its website, had 69 paying data users in 2019 (OSHPD 2020). Interest in using the California HPD for research purposes is likely to be much greater. Because California's population is racially and ethnically diverse, its HPD data may allow rigorous quantitative research on some minority groups for the first time. Finally, California has a mature managed care environment. Research using California's HPD could inform other states and countries that are transitioning from fee-for-service to managed care systems.

Researcher Input Can Help the State Take Full Advantage of its HPD

While an HPD has enormous potential to improve the evidence base for policymaking, the state government's current resources and analytic capacity may not allow it to take full advantage of the data. California's many higher education and research institutions could serve as partners in maximizing this resource. The state already reaches out to its research community to inform some aspects of policymaking. For example, the California Health Benefits Review Program (CHBRP), which analyzes the effects of proposed changes to mandated health insurance benefits for the state legislature (University of California, Berkeley 2019), is comprised of University of California faculty and staff.

First and foremost, researchers we surveyed cautioned HPD designers not to underestimate the complexity of claims data. A claim payment is not necessarily finalized after a single transaction. Following the initial payment, a reconciliation process between a payer and a provider can result in payment adjustments. The adjusted payments, which could have negative values, need to be associated with the original claim. Additionally, multiple lines of billing can be associated with a single visit: for example, an exam, an x-ray, and a blood test. If these billing lines are bundled, it can be difficult to determine the array of services rendered. As one of the researchers we contacted put it, "There's a lot of work that goes into getting the balance sheet right for a particular claim."

One of the most frequently cited difficulties in using claims data was the incomplete accounting of patients and payers in available data resources. Here, a California HPD will represent a marked improvement. Most researchers currently rely on subsets of commercial claims from private vendors, or on Medicare data, which only includes seniors and those with qualifying disabilities.

The HPD Can Be a High-Quality Resource for Policy Research and Evaluation

The review committee and OSHPD have discussed HPD variables, potential linkages to other data sources, and the timelines for these features. Current plans are to use existing reporting formats for Medicare and Medi-Cal, along with a widely used format known as the APCD common data layout (APCD-CDL) for other payers (APCD Council 2019).

Because final decisions about the HPD's variables and linkages to other data have not yet been made, we asked survey respondents to identify their top research priorities. Respondents named studying the effects of health care policies on health outcomes as a top priority for HPD-related research (68% ranked this as priority 1 or 2). Health services (43%) and the social determinants of health (45%) are other research priorities.

One theme that emerged across several of the types of studies researchers proposed was an interest in evaluating programs. An HPD could provide access to records on individuals who participate in specific programs or pilots. It could also allow researchers to identify comparison groups of similar individuals who did not participate. The Centers for Medicaid and Medicare Services (CMS) provides an example: the agency has a secure process for researchers to submit what are known as "finder files," which identify specific participants and can be matched to Medicare and Medicaid records.[11] If California similarly allows researchers to submit finder files to match to HPD records, this would broaden opportunities for researchers to conduct more rigorous evaluation study designs. Notably, this functionality could also allow smaller entities such as counties, hospitals, and health systems to produce evidence on their program investments at relatively low cost.[12]

We also asked researchers to describe the variables and linkages they would need. Their responses overlap substantially with current database development plans (OSHPD 2019a). Below we provide more details of the types of information researchers identified as being essential to conducting high-quality studies.

Identifiers are the most requested variables

Research datasets usually produce their own identifiers to ensure uniqueness and protect sensitive information. Nearly 95 percent of those we surveyed, including 100 percent of the HPD-knowledgeable group, said that a patient identifier would be essential for assembling coverage characteristics for patients with more than one type of insurance. Identifying providers across multiple plans (86%) and dates of service (84%) also ranked high on the list of desired elements; 65 percent said that a payer identifier was essential for their research. Beyond constructing patient histories within the HPD, an individual identifier could support linkages to other administrative datasets, which we discuss in more detail below. The current plan is for the HPD to provide these identifiers in its first tier.

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[11] See resources for researchers on the CMS website.

[12] For more information on small-scale, quick turnaround, randomized control studies, see for example Rapid Cycle Evaluation and the recommendations in Zickafoose (2019).

Patient characteristics are important to advance equity

A large majority (75%) saw individual-level race and ethnicity variables as essential to their research; respondents were also interested in using demographic information such as age, sex, and marital status in their research. Respondents also mentioned income and housing status as key patient characteristics to inform their work. The difficulty is that these variables are not usually part of claims data because they are not factors in billing, which is the central purpose of a claim. If these variables are available at all, they often have missing or incorrect values. An alternative route is to link the HPD to other state data assets, for example vital statistics and tax records, that routinely include some of this information. An alternate route would be to use Census household survey data to provide geographically aggregated data on income, housing, commuting, and demographic characteristics of the areas in which patients live. Ninety percent of respondents requested information about where individuals live; census tract, county, and ZIP code were the most requested levels.

The tier 1 plan for the development of the California HPD is to link to Census information on county or neighborhood data, which can be used as proxies for individual-level characteristics such as race or income level. The review committee and OSHPD are evaluating ways to add other information, including missing data on individuals' racial/ethnic background. There has been some progress in this area: Covered California has begun to require plans to collect data on race/ethnicity (Covered California 2019). In addition, statistical methods that have been developed to impute race/ethnicity using information in claims data could be helpful (Elliott et al. 2008).[13]

Data on costs, rebates, and alternate payments are also key

Seventy-three percent of respondents requested the amount paid on a claim, including the allowed or negotiated price the provider has reached with the insurance plan, as well as the patient liability or cost-sharing amounts. The plan is to include information in the HPD as part of the monthly submissions by insurance plans.

In addition, several respondents expressed an interest in other types of health care payment information that are not part of claims or encounter data. In particular, alternative payment models and pharmacy rebates are common in California, but there is very limited information on their prevalence or how they factor into costs. While it will be more challenging to incorporate non-claim payment information into an HPD structure, OSPHD and the Review Committee recognize their importance in accounting for the total costs of health care and are planning to integrate them in the second tier of implementation.

Linkages with other administrative and survey data are also priorities

We asked researchers to suggest linkages to data assets that could increase the utility of the HPD. We describe only the linkages requested by at least 80 percent of respondents here, but full results are included in Technical Appendix C.[14] Commonly requested administrative health data linkages included hospital discharge data (86% requested it, and 59% deemed it essential), disease registries (80% requested it, 37% deemed it essential), and vital statistics—birth and death certificates (80% requested it, 65% deemed it essential). Researchers in interviews mentioned various health surveys, and many of our survey respondents wished to connect the HPD to the California Health Interview Survey (82% requested, 20% deemed essential). OSHPD and the review committee are planning to link the HPD to vital statistics and hospital discharges in the second tier of the database, and to disease registry data in a later tier.

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[13] One method under consideration is Bayesian Surname and Geocoding, a statistical imputation method to estimate individual and population race/ethnicity developed by researchers at the RAND Corporation in collaboration with federal data agencies.

[14] Researchers could indicate that a linkage would be essential, beneficial, nice to have, or not select the linkage at all. Only linkages selected—at some level—by 80 percent of respondents are reported here. We list both the total percentage requesting the linkage at any level, as well as the percentage citing it as essential.

Links to relevant non-health data resources would facilitate the study of the social determinants of health. As described above, many of the individual-level characteristics important in this area of research will be difficult to collect from claims. Researchers can partially fill this need using characteristics at small geographical levels. Apart from a geographical identifier that researchers can use to do their own linking (92% requested), the most common request was to have Census demographic characteristics pre-linked by geography by the HPD managing agency (90% of survey respondents requested this).

There was also strong interest in linking to non-health administrative data. Social safety net program data were most frequently mentioned among researchers' requests for non-health data linked to the HPD (three interviewees and 88% of survey respondents requested it). While it is unknown whether this linkage will be included in OSHPD's plan, it would be similar to linking that OSHPD is already planning.[15] For some populations, information on program participation, level or type of benefit accessed, and other details in the department data would add help researchers study the relationships between health and program participation. Other priorities include linkages to data from the Employment Development Department (82%); this could help researchers study the relationships between health and income and evaluate the effects of the Earned Income Tax Credit on health.

Leadership and Expertise Are Essential to a Successful HPD

Several of our participants highlighted the importance of organizational leadership in ensuring the HPD's success. One person with experience collecting health care data noted that leadership is a primary driver of data quality. Another expert warned that the HPD leadership role will be difficult to fill: "Having a lot of knowledge and sophistication of knowing how to sort claims into entities that make them easily searchable and usable is not a minor feat. And there's not a lot of people in the world who actually have a lot of those skills." Partnering with experienced researchers to support the HPD could be a valuable strategy.

Data Users Should Be Part of the HPD's Structure

California's research community can help with validating data quality, completeness, and consistency over time. Several researchers suggested that the HPD incorporate data users into its structure. Specific suggestions included establishing a group of "super users" who could provide quality checks and feedback, and test new data products for the managing agency, and an online user forum for researchers to share information and resources such as statistical code, pre-cleaned versions of the data, and fixes for known issues. Regardless of the specific form it takes, the user group should be treated as a resource.

There are examples of past and current collaborations between state agencies and California's research community that can provide important lessons. The California Medicaid Research Institute (CAMRI) once operated under a data-sharing agreement between the University of California and the California Department of Health Care Services, but this ended due to divergent priorities (University of California at San Francisco 2019). Although promising collaborations such as CAMRI have not always survived in their original form, the state and researchers can learn from these past ventures. California policymakers can get the most out of the relationship

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[15] The Record Reconciliation Project is a collaboration between the California Health and Human Services Agency and the University of Southern California Children's Data Network. The project has created individual-level, encrypted identifiers for certain agency records, enabling individual-level linkages between Medi-Cal records and administrative data for CalFresh; CalWORKS, Child Protection; Developmental Services; Family Planning, Access, Care and Treatment (Family PACT); In-Home Supportive Services; and WIC.

with the research community by creating incentives for researchers to investigate policy issues that align with their research priorities but also inform state decisions. Researchers seem eager to test new data products and give feedback regardless of what form the HPD takes, but incorporating their highest-priority features in the final HPD development plan will go a long way toward establishing a bidirectional, mutually beneficial relationship.

The HPD could serve as data access point for researchers, potentially easing the burden on individual agencies of responding to one-off requests and streamlining the research process. In this way, the HPD would resemble current partnerships between agencies and researchers that are proving to be mutually beneficial. For example, the California Policy Lab at the University of California is engaging researchers and state agencies on shared priorities (University of California at Los Angeles and University of California at Berkeley 2019). And the Children's Data Network at the University of Southern California conducts policy research using data assets from a wide range of state agencies and also provides technical assistance (University of Southern California 2019).

Again, the plan being developed by OSHPD and the review committee recommends that the governing agency for an HPD include advisory groups comprised of experts and stakeholders to inform decisions around access and use of the database. Perhaps more importantly, current recommendations also recognize the importance of developing processes that would allow secured access to confidential, individual-level data that is necessary for many rigorous research studies (OSHPD 2020).

Other States Offer Examples of How HPD Data Can Be Shared with Researchers

The state has not made final decisions about a number of HPD governance issues that will affect researcher access, including: how HPD data will be housed, what kinds of user fees may be collected, or what other data resources will be linked to the HPD. Perhaps the most important question for researchers is whether they will have access to individual-level data. Many important studies, including most of the research use cases outlined in this report, would require restricted, individual-level variables such as unique patient identifiers, dates of service, and patient characteristics. Patient privacy and secure data protocols are serious considerations in how to share protected health data with researchers.

Fortunately, California can learn from the experiences of states that have successfully implemented sharing of individual-level data with external researchers (Figure 3). About half of the 18 states that currently have HPDs allow eligible researchers to access individual-level data (OSHPD 2019b). Kelley and King describe how some of these states maintain data security while allowing access to their HPD for policy research (Kelley and King 2017). Sensitive data on patients and providers will require storage, transport, and usage protections. OSHPD and the review committee are developing protocols to fulfill these requirements that are informed by other states' expertise and experience.

FIGURE 3
States are in different phases of HPD development

Existing
In implementation
Strong interest
Voluntary effort
No activity
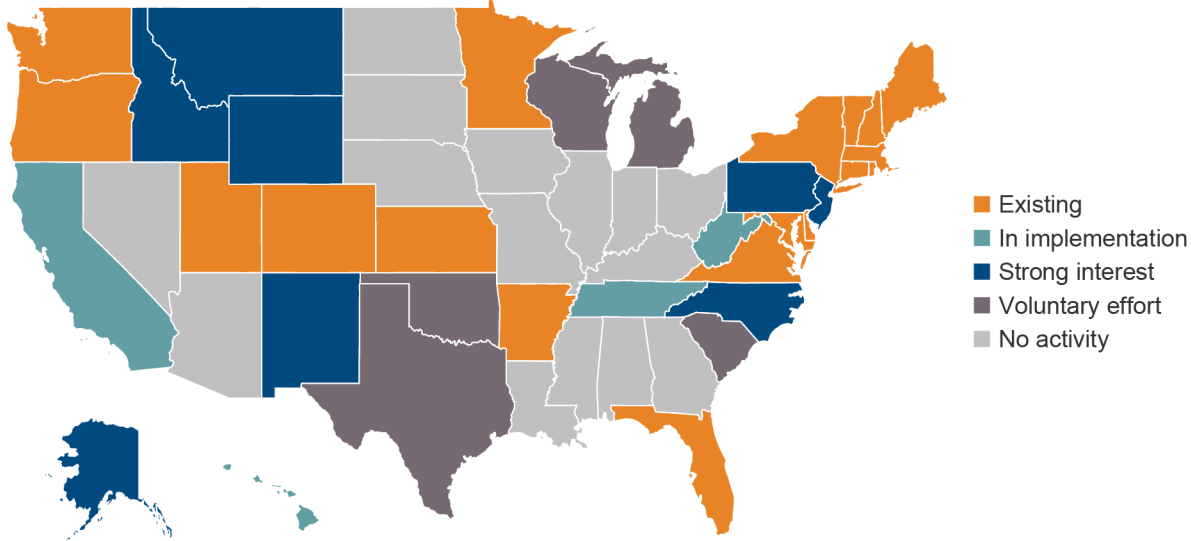
SOURCE: APCD Council, National Association of Health Data Organizations, University of New Hampshire, 2019 and Virginia Health Information.

California's HPD Can Tap into the State's Evolving Data Ecosystem

It is important to note that the state is currently developing data resources in multiple areas. The state is planning for a longitudinal data resource that would link K–12, higher education, and employment data. In addition, the California Health and Human Services agency has collaborated with researchers from the University of Southern California to develop a method for securely linking individual-level data across multiple social safety net programs.[16] The HPD's leadership could envision a future in which the HPD is integral to a growing statewide data ecosystem. In the words of one expert, "[t]here can be several parallel efforts to pull together data that can then converge at some future endpoint… Think about the relative ease with which [integrated social safety net data and the HPD] can be connected because we've already done all the internal work." This level of connection is still several years or more in the future, but visionary strategic leadership can help make it a reality.

There are many challenges associated with building this data ecosystem. Establishing robust procedures and standards for accurately linking information across individuals is crucial, as is routinely assessing the quality of the matches. The OSHPD agency does have considerable experience that can inform these efforts (OSHPD 2019a). There are also additional privacy protections that apply to certain types of information that will need to be considered. For example, treatment for substance use disorders have additional federal privacy protections, as do student education records. While these are serious considerations, other states have successfully navigated these issues and as a result have better data resources to inform policymaking.

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[16] See previous footnote about the Record Reconciliation Project for details.

Conclusion

California is considering major health policy reforms, including building a state single-payer health financing system, leveraging Medi-Cal as a tool to address complex issues like homelessness, and increasing the focus on prevention and screening for children. Timely, reliable, and comprehensive health care payments data, together with an experienced community of researchers, hold the potential to drive evidence-based policymaking in this important time.

In its forthcoming report, OSHPD will outline recommendations for a California HPD to the legislature and the administration. Our compilation of use cases, along with the valuable feedback we received from the research community, leads us to make three key recommendations:

Include patient and provider identifiers. A master patient ID that would allow individuals to be followed across different sources of insurance coverage over time and be connected to the providers who deliver their care would allow researchers to better examine the impacts of market consolidation or assess potential consequences of changing coverage. Other state HPDs have established protocols and procedures to create these identifiers that maintain privacy protections.

Use the HPD as an additional opportunity to streamline and manage access to linked administrative data. As we have outlined throughout this report, there are a multitude of administrative data sources that would enhance the types of studies and policy insights that could be facilitated by an HPD. For example, linkages with social safety net data would provide a more holistic picture of supports available to Californians at risk of homelessness and assist researchers in studying the social determinants of health. There are multiple, concurrent efforts to harness administrative data to inform policymaking across different domains.

Consider collaborations with California's research community to assist in developing, monitoring, and maintaining a successful HPD. California's many higher education and research institutions could serve as partners in organizing and vetting the data. Researchers would be valuable members of advisory groups given their experience using health payment data, and could also provide technical expertise and assistance to state agencies who are looking to do more with the data they collect.

A health care payments database is a resource that already exists in a number of states. They are the product of political will, technological expertise, and state investment. California policymakers will need to make a number of decisions related to database design and data user access that will have important implications. Leveraging California's research community as a resource can help maximize the value of an HPD to inform policy.

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ACKNOWLEDGMENTS

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