Agenda Item V: HPD Data Access and Release: Program Updates

Chris Krawczyk, Chief Analytics Officer, HCAI

Public Reporting Updates

2025 Program Priorities

Data Collection

- Continue to expand the database
- Continue to improve data quality and completeness

Public Reporting

- Continue executing public reporting priorities: Publish new reports, refresh existing reports with new data
- Expand use of public reports

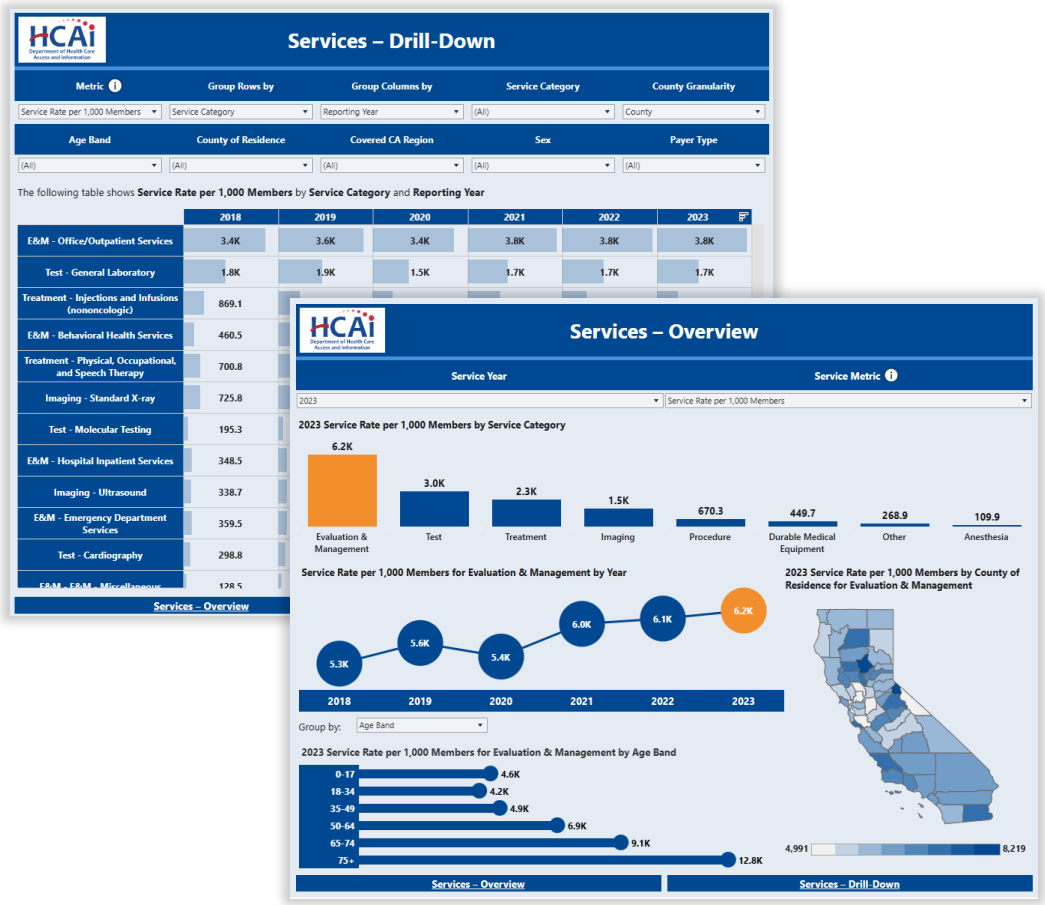
Data Release

- Monitor demand; adjust staffing, program policies, and pricing as needed
- Strategically partner with other state agencies

New HPD Public Reports: Services Report

Consists of 2 dashboards allowing users to explore the types of healthcare services provided to Californians each year.

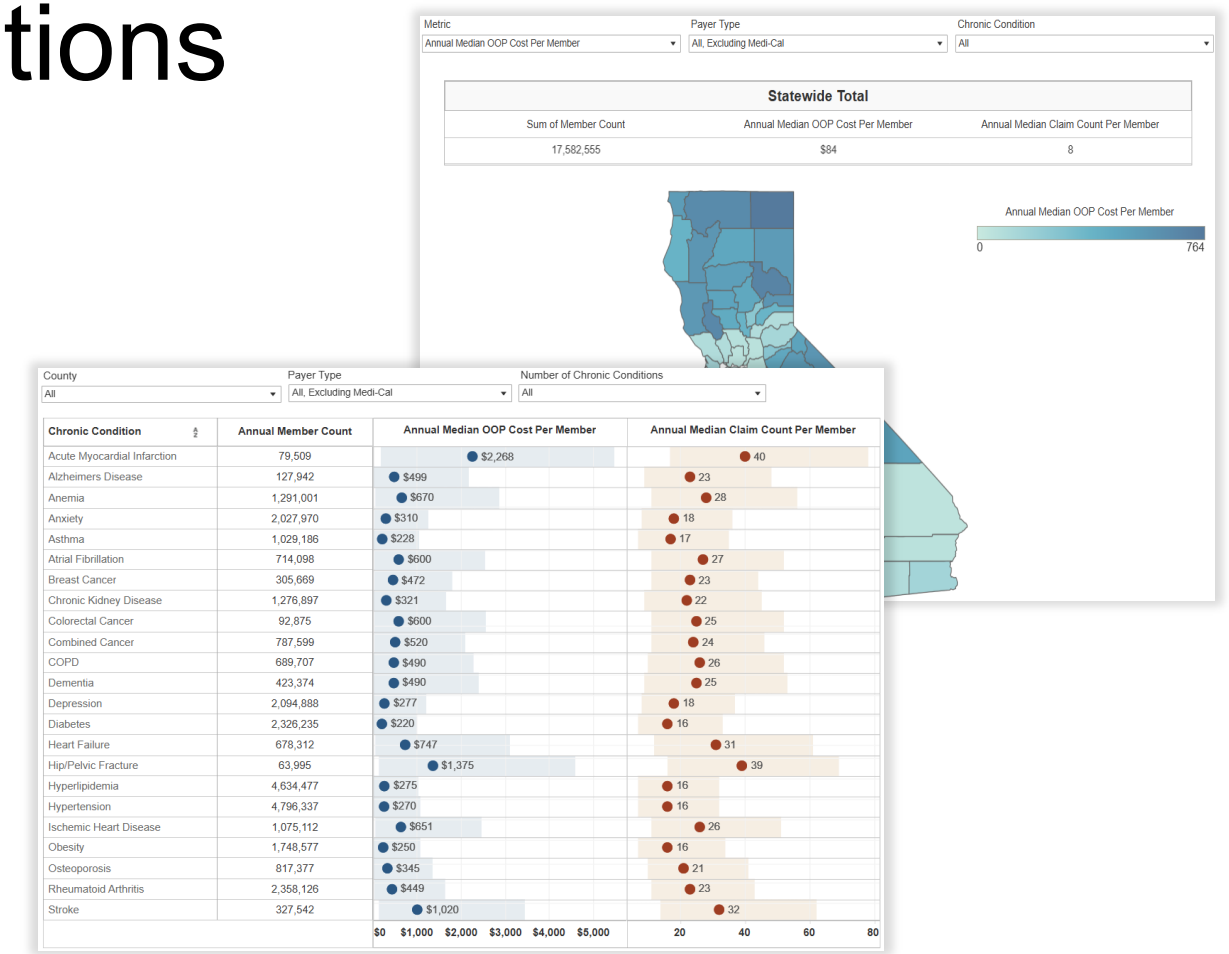
- **Overview visualization:**
  - Can be viewed by total number of occurrences, number of people who received the service, or utilization rate of the service category per 1,000 members/year.
  - Selecting a specific service category will highlight differences in utilization over time, by geographic region, and across age, sex, or payer type. Payer types are commercial, Medi-Cal, and Medicare.
- **Drill-Down visualization:**
  - Displays 8 service categories in their relevant subcategories
  - View by total number of occurrences, the number of people who received the service at least once, and the utilization rate per 1,000 members per year
    - Additional filters by year, age range, sex, Covered California region, and payer type.
  - County Granularity filter allows users to view Los Angeles County's data for the entire county or by one or more of its Service Planning Areas (SPAs).



Released February 2025, explore at: [HPD Services Report]

New HPD Public Reports: Medical Out-of-Pocket Costs and Chronic Conditions

- Purpose: understanding chronic condition prevalence and medical out-of-pocket cost
- Focuses on 3 metrics: member count, annual median out-of-pocket cost, annual median claim count per member
- Can display the data for the entire state, by county or for specific chronic conditions
- Data can be filtered by county, payer type, and the number of chronic conditions



Released March 2025, explore at: [HPD: Medical Out-of-Pocket Costs and Chronic Conditions]

Data Access and Release Updates

HPD Data Access and Release Webpage

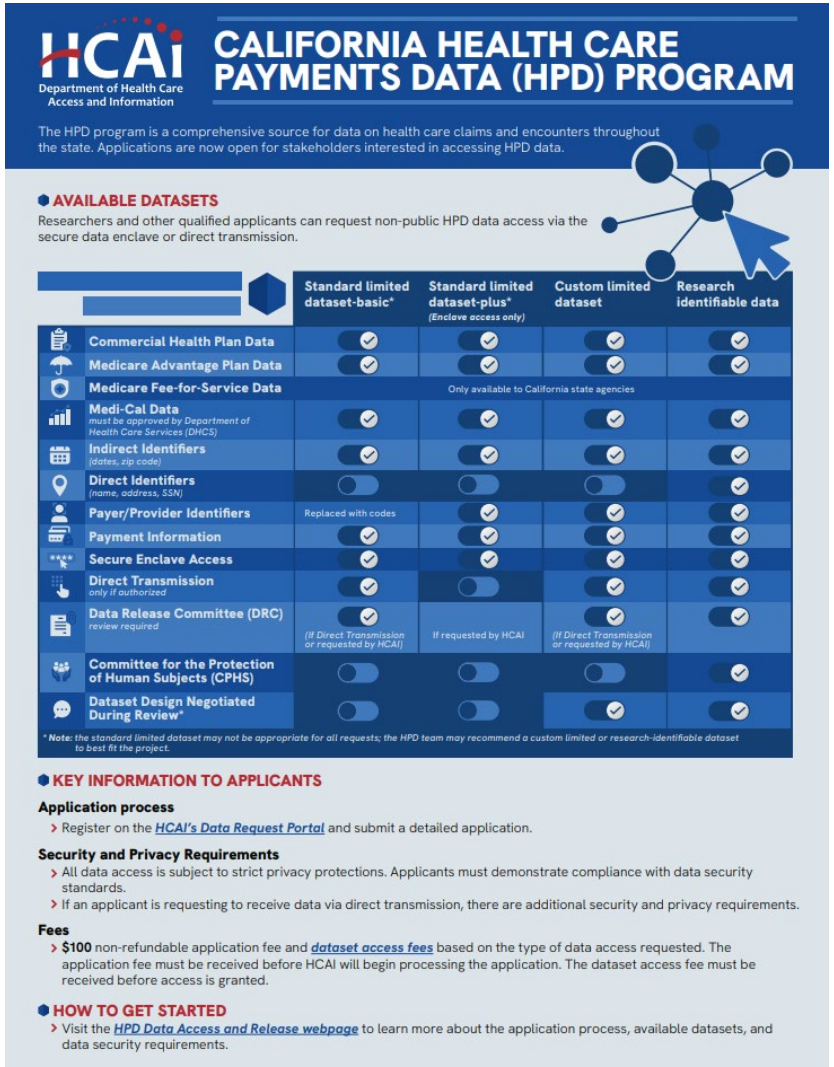
Launched publicly on December 17, 2024

HCAI's HPD Data Access and Release Informational webinar held on January 15, 2025

- provided information to researchers, state agencies, and other qualified applicants to hear from HCAI staff about the HPD data request process
- The agenda, presentation, and Q&A summary from the webinar are available on HCAI's site.

Information on HCAI's HPD Data Pricing Policy can be found on the HPD Data Access and Release page organized by method of access:

1. Secure Data Enclave Requests
2. Direct Transmission Requests

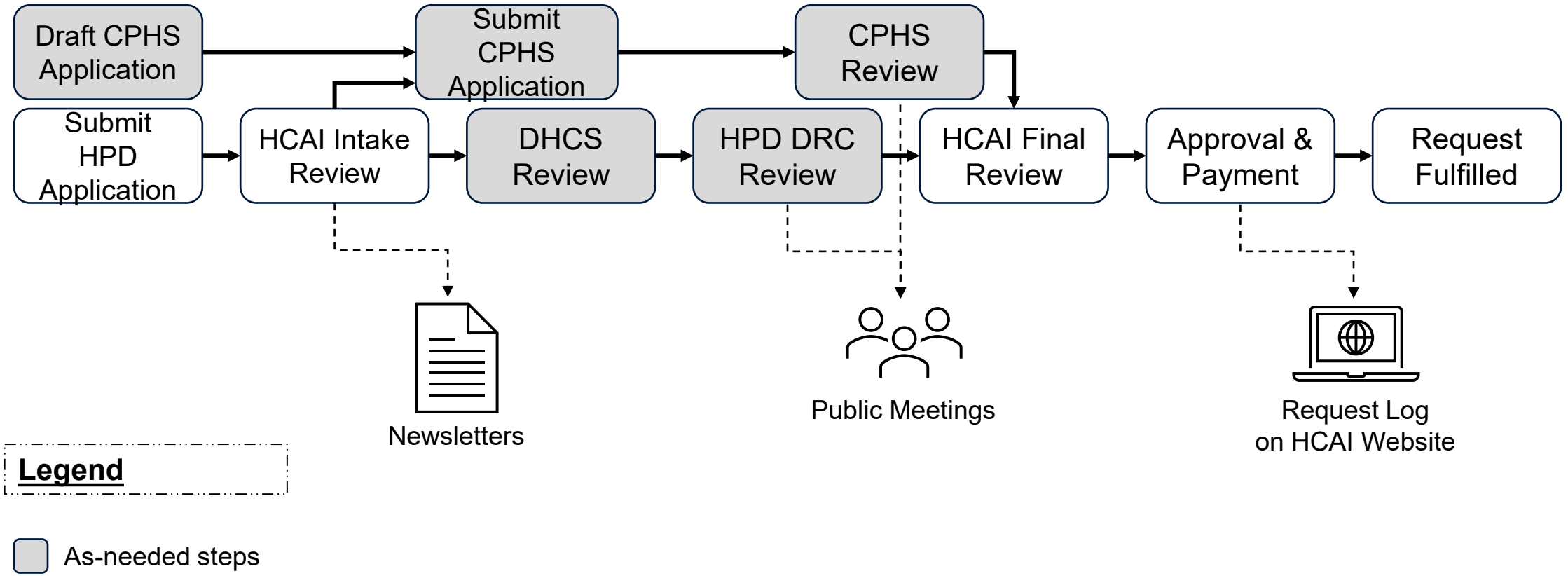


HPD Data Release Infographic

HPD Application Requests

#	Application Fee Paid?	Organization Type	Data Type	Medi-Cal Data?	Access Type	Request Summary
1	Yes	University	Standard Limited	Yes	Enclave	Analyze health impacts of water and air pollution.
2	Yes	University	Standard Limited +	Yes	Enclave	Assess the impact of the facility-centered discount drug program and model a person-centered version.
3	Yes	University	Custom Limited	Yes	Enclave	Identify disparities in access and outcomes among at-risk populations with a diagnosis of COVID.
4	Yes	Research	Standard Limited +	Yes	Enclave	Understand what drives shortfalls in access, value, and quality of healthcare in California.
5	N/A	State Agency	Research Identifiable	Yes	Direct	Supplement mandated communicable disease surveillance activity.
6	Yes	University	Research Identifiable	Yes	Direct	Analyze variations/disparities in cancer care, costs, and outcomes.
7	Not yet	University	Standard Limited	Yes	Enclave	Analyze hospital markets, financing, and prices in California.
8	Not yet	Business	Standard Limited	No	Direct	Mapping the HPD dataset to improve interoperability.
9	Not yet	Research	Standard Limited	Yes	Enclave	Analyze variations/trends in preventable ED visits by geography.
10	Not yet	Student	Standard Limited	Yes	Enclave	Study how differences in hospitals affect costs and pricing.
11	Not yet	Business	Standard Limited +	Yes	Enclave	Obtain data about providers to better sell them medical products.
12	Not yet	University	Research Identifiable	Yes	Direct	Estimate the national incidence rate of a condition by combining HPD information with data from other states.

DRAFT: Data Release Flowchart



HPD Data Sets: Following Approval

Once your data request has been approved:

DUA

Data applicants will need to sign the Data Request Form and Data Use Agreement (DUA) and pay for their data. The requestor will be invoiced based on the HPD pricing schedule.

Accepted forms of payment are credit card and check. Payment instructions are provided in the data request portal.

Data Access

Enclave accounts and data access will be granted through the HCAI Secure Data Enclave within 2 weeks of final approval.

Direct transmission instructions will be provided for this method if selected.

Data Due Date

After a request has been approved, HCAI issues a Data Due Date, upon which the HCAI patient-level data must be destroyed or returned to HCAI.

Data Due Dates can be extended annually, to align with the requestor's CPHS protocol expiration date.

Request Changes

If there are changes or date extensions requested, requestors must notify HCAI of changes to the project.

Supplemental Requests

If a requestor wishes to make changes to their request such as adding additional data users, or requesting additional years of data, they will submit a Supplemental Request.

HPD Data: Methods of Access

Secure Data Enclave

- Centralized service for 24/7 remote access to sensitive data.
- Houses the data in a secure environment, protected in accordance with state and federal security and privacy rules, where it can be accessed via a virtual machine launched from the user's computer.
- Comes equipped with a suite of statistical tools and provides scalable computing power to perform analysis on a high volume of data.
- Datasets can only be downloaded from the Enclave after they have been properly de-identified and after HCAI administrator review and approval is granted.

Direct Transmission

- Direct Transmission is a method where HCAI sends copies of program data outside the secure data enclave directly to an individual or organization.
- Request for Direct Transmission of data will only be provided after a recommendation of approval by the HPD Data Release Committee.

Data Release Committee (DRC) Activity Updates

Miranda Dietz, DRC Vice Chair (or designee)

HPD Stakeholder Governance

Ken Stuart, Chair
California Health Care Coalition

HCAI
Office of Information Services

Nuriel Moghavem, MD, Chair
Los Angeles General Medical Center

Advisory Committee

- Advises in formulating program policies regarding data collection, management, use, and access
- Provides input on priorities for public reporting
- Provides a forum for stakeholder and public engagement

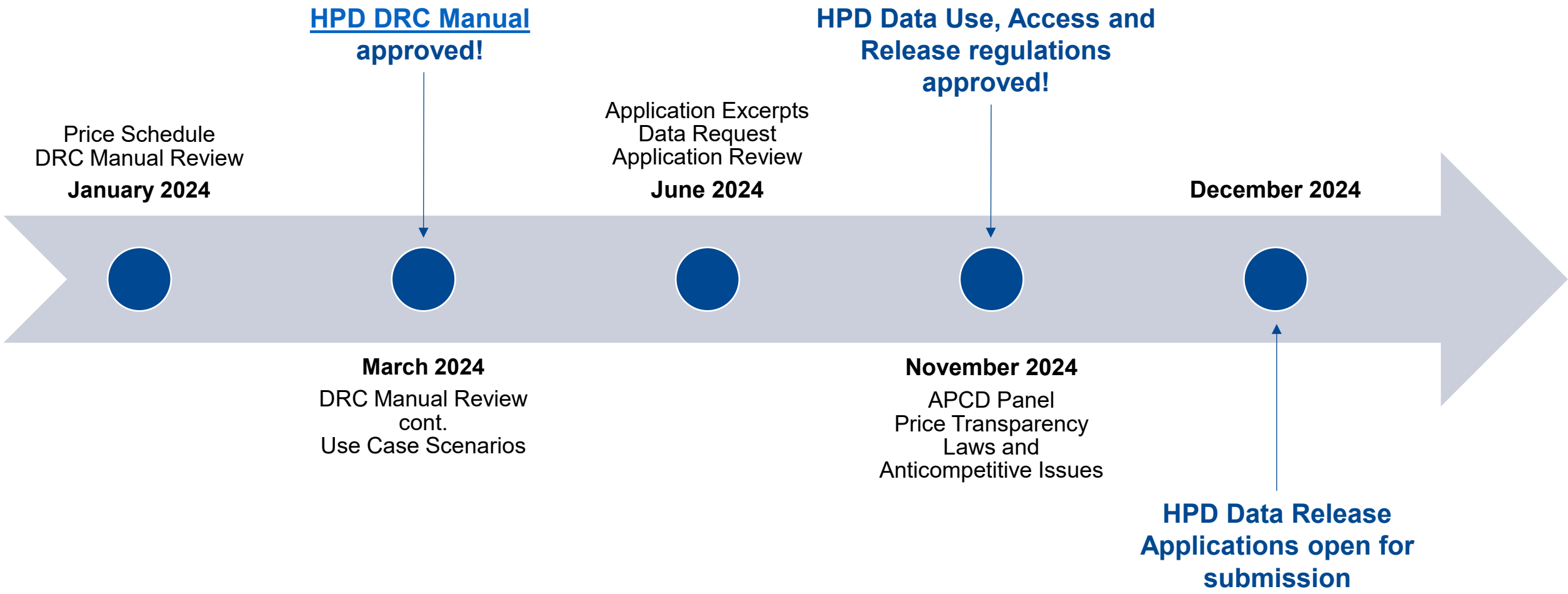
Data Release Committee

- Advises on specific criteria, policies, and procedures for access to non-public data
- Reviews requests to access non-public data
- Considers whether use of the data is consistent with the goals of the program
- Advises the program on privacy and security matters

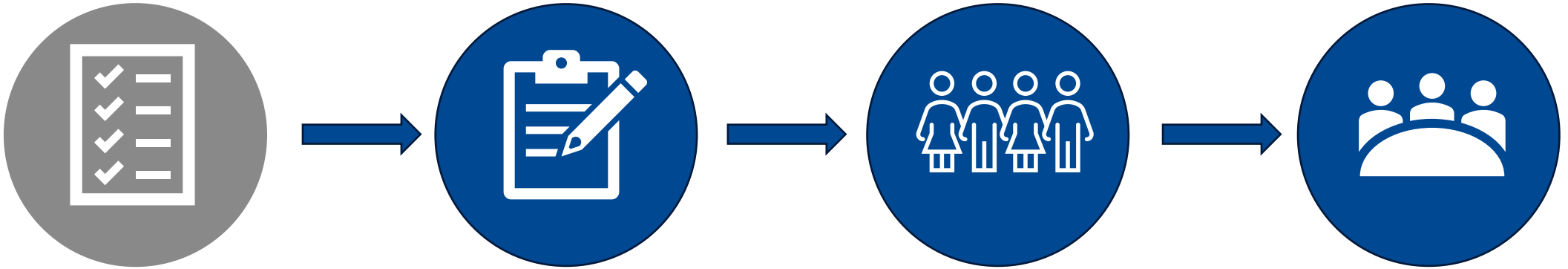
Committee roles described in California Health & Safety Code Sections 127671-127674

HCAI
Department of Health Care Access and Information

Previous HPD DRC Meeting Topics



Example: DRC Review & Public Meeting Timeline



Application Submission Deadline
Date TBD– contingent on internal review, data requested, and method of access

May 21st – 28 calendar days prior to the meeting
Primary Reviewers begin reviewing the full application

June 4th – 14 calendar days prior to the meeting
The remaining committee members receive the Application Excerpt.
Primary Reviewers have an additional two weeks to review prior to the meeting

June 21 - HPD DRC Public Meeting
DRC votes to recommend approval, conditional approval, not approved, or tabled

Data Release Committee - Review Process Flow

Before DRC Meeting

- Primary reviewers receive assigned materials and review for **14 calendar days** to identify questions and concerns
- Primary reviewers will have a further 14 calendar days to prepare any documents helpful to present independent recommendations
- All DRC members receive application excerpts **14 calendar days** in advance of meeting
- HCAI posts agenda 10 calendar days prior to meeting

During DRC Meeting

- Discuss & resolve concerns about data requests.
- Requestors available to answer questions
- 4 ways to vote: **RECOMMEND; CONDITIONAL; TABLED** or **NOT RECOMMEND.**

After DRC Meeting

- HCAI collects recommendations with justification based on committee meeting to create recommendation letter
- Votes documented in committee minutes
- HCAI to notify requestors of final decisions and appropriate next steps
- Once requestor is notified HCAI to notify committee of final determination

Considerations for DRC in Making Recommendations

Statute requires consideration of:

- Whether and to what extent the data use will contribute to HPD program goals:
  - For all requests, whether the use of the data is "**consistent with the goals"**
  - For requests that include direct personal identifiers, the bar is higher: access may only be provided for research projects that offer "**significant opportunities to achieve program goals**"
- Whether the proposed use of the data provides **greater transparency** regarding health care costs, utilization, quality, or equity
- How the information may be used to **inform policy decisions** regarding the provision of quality health care, improving public health, reducing health disparities, advancing health coverage, or reducing health care costs

Exception: data requests from other state agencies

HSC Section 127673.83(b)(2), 127673.84(d)(2)

Additional Considerations for DRC Review

Privacy

- What are the reasons or justifications provided for all confidential or sensitive data elements requested? These include direct identifiers, indirect identifiers (dates, 5-digit ZIP), and sensitive diagnoses and procedures.
- How does the request meet minimum data necessary standards?

Anticompetitive Use and Commercialization

- What are the risks for commercialization or marketing created by this request? And what is the state's involvement if any?
- What are the risks for anticompetitive use of the data?

Results and Information Products

- What are the expected findings/outputs? Will they be made available to policymakers or the public? What level of aggregation will be applied to reports, presentations, and other information products intended for public dissemination?
- How does the proposed project generate a public benefit for California?

Anticipated 2025 DRC Topics

- HPD DRC Recommendation Letter and Resolutions
- Continue refining the review process
- Data Request Reviews

Public Comment