

Goals for Data Access and Release

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For Today

- Shift from public reporting (discussed in July/October) to non-public data access
- Goals for HPD Program (based on legislative intent)
- Key statutory provisions related to data access and release
- Discussion and input

Roles: Advisory Committee, Data Release Committee

Advisory Committee

- Assist and advise HCAI director in formulating program policies regarding data collection, management, use and access, and development of public information to meet the goals of the program
- Provide a forum for stakeholder and public engagement
- Provide input on priorities for the public information portfolio
- Advise on development of criteria, policies, and procedures for access to and release of nonpublic data
- Provide input on establishing the user fee schedule and fee waivers

Data Release Committee

- Advise on development of criteria, policies, and procedures for access to and release of nonpublic data
- Make recommendations about applications for non-public data
- Consider whether the use of the data is consistent with the goals of the system, whether it provides greater transparency regarding health care costs, utilization, quality, or equity, or 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
- Advise the HCAI director about privacy and security matters related to the program
- Provide feedback on the program's data application review processes and other matters

HSC Section 127671-127674

Data Release Committee Membership

- At least 7 members and no more than 11
- Appointed by HCAI Director
- Term of two years
- Members shall have knowledge and experience with health care data, privacy, and security

Representation from health care:

- Payers
- Providers
- Suppliers
- Purchasers
- Researchers
- Consumers
- Labor

High-Level Framework for Data Access

Publicly Available

- Data products (analyses, reports) posted on HPD website
- Process to request custom analysis and reports to be developed

Non-Public Access by Application

- Potentially identifiable data (no direct patient identifiers)
- Intention to create a data enclave to facilitate access through a secure environment
- Requires formal application/review, data use agreement

Researcher Access by Application

- Identifiable data (could include direct patient identifiers)
- Intention to create a data enclave to facilitate access through a secure environment
- Requires approval from CHHS IRB and formal application/review, data use agreement

HPD Program Goals

1. Provide public benefit for Californians and the state while protecting individual privacy.
2. Increase transparency about health care costs, utilization, quality, and equity.
3. Inform policy decisions on topics including the provision of quality health care, improving public health, reducing disparities, advancing health coverage, reducing health care costs, and oversight of the health care system and health care companies.
4. Support the development of approaches, services and programs that deliver health care that is cost effective, responsive to the needs of Californians, and recognizes the diversity of California and the impacts of social determinants of health.
5. Support a sustainable health care system and more equitable access to affordable and quality health care for all.

Data Release Provisions in Enabling Statute

- Develop comprehensive program for data use, access, and release
 - Qualified applicants
 - Data Release Committee
 - Access to data in a secure research environment
- Protect privacy, security, and confidentiality of consumers' individually identifiable health information
- Prohibition of use of data for individual patient care or treatment, or individual coverage or eligibility decisions, or similar purposes

“To meet the research and policy goals of the program, controlled access to nonpublic data by outside data analysts, researchers, and other qualified applicants is necessary.”

HSC 127673.82(c)

Qualified Applicants for Non-Public Data

- State agencies
- Mandatory submitters
- Established non-profit research institutions
- University of California
- Non-profit educational institutions
- Providers (e.g., hospitals)
- Suppliers (e.g., physician organizations)
- Labor unions
- Self-insured multiple employer plans that submit data to HPD
- Consumer organizations certified by the Consumer Participation Program that have been awarded reasonable advocacy and witness fees in a proceeding of the Department of Managed Health Care

“The office shall, with the advice of the advisory committee and the data release committee, develop criteria, policies, and procedures for access to and release of nonpublic data.”

HSC 127673.82(e)

Health and Safety Code Section 127671

Alignment with Relevant Provisions in DOL Report

- State All Payer Claims Databases Advisory Committee convened by the Department of Labor in spring 2021
- [Report](#) released 10.19.21 includes several recommendations related to data privacy, security, and release
- Planning for HPD data access aligns with these recommendations

- **Recommendation 7:** Existing State APCDs should maintain, and new State APCDs should develop and implement, **rigorous privacy and security protections** for the health information they receive, maintain, and release, including comprehensive administrative, technical, and physical safeguards.
- **Recommendation 8:** Where permissible under state laws, APCDs should develop an infrastructure and implement a process that is adequately resourced to **ensure timely release of data** to approved data requesters.
- **Recommendation 9:** While individual State APCDs have their own data dissemination processes, states should explore establishing a secure, privacy-protective, **multi-state data aggregation and dissemination model** that would permit wider use of the data.

Discussion Questions

- How should the department think about benefit to Californians as a condition of access to non-public data?
- What kinds of users and uses should HPD ensure are able to apply for non-public data?
 - What kinds of users and uses might be inappropriate or should be excluded?

Context:

- All access to non-public data is permissive (i.e., no one is entitled to data)
- Data Release Committee will make recommendations to HCAI director