Agenda III: Considerations for Release of HPD Data

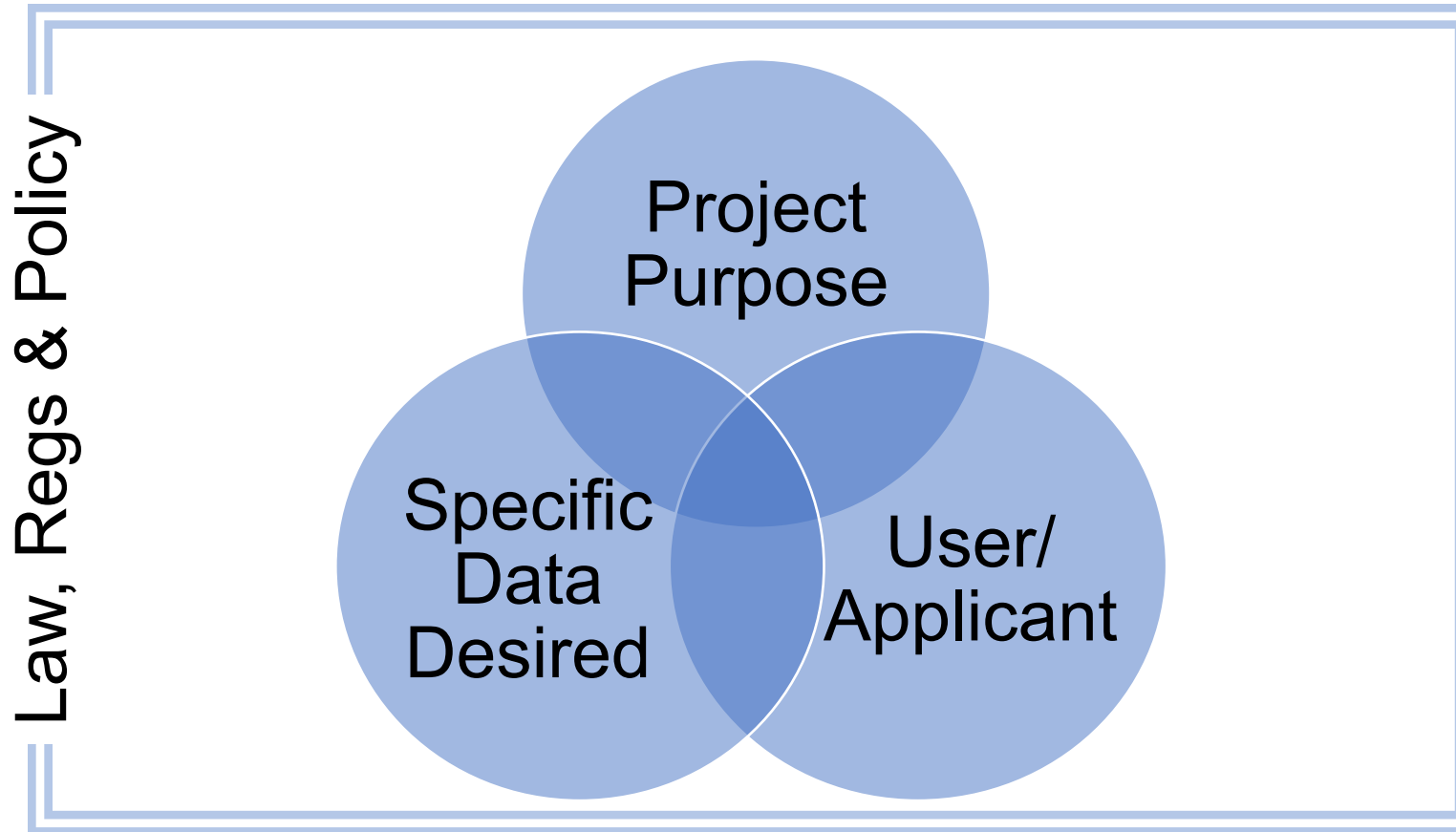*Chris Krawczyk, Research Scientist Manager, HCAI*

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.

HPD Data Access & Release Objectives

1. Protect Patient Privacy

2. Support Program Goals

3. Ensure appropriate data users, uses, methodologies, and compliance with all requirements

4. Provide timely data access to qualified applicants and make decisions in a consistent manner

5. Enable & support diverse users, representing multiple audiences & levels of expertise

6. Complement the HPD public reporting program

7. Support sustainability through user fees that balance program support and affordability

Intersecting Factors in Data Access Approvals

Considerations for DRC in Making Recommendations

Statute requires consideration of:

- Whether and to what extent the data use will contribute to 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 use of the data 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
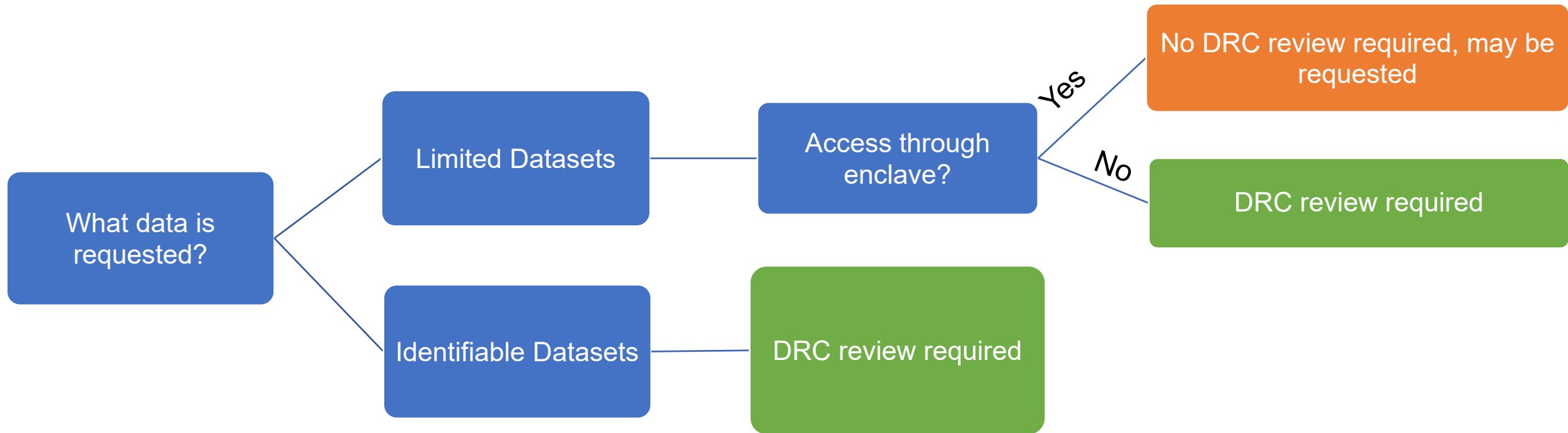
> **Exception:**
> data requests from other state agencies

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

Framework for HPD Data Access

	Non-Confidential Data	Confidential Data Limited Data - Indirect Identifiers	Confidential Data Research Identifiable Data
Standard	• Shortest approval process • Designed to meet needs of multiple applicant categories, use cases • Could rely on interactive tool that supports a query-based approach • DRC guidance on process; HCAI approves applications and handles permissions	• Shorter approval process • Designed to meet needs of multiple applicant categories, use cases • HCAI-defined dataset with no direct identifiers • DRC review required for transmission outside enclave • HCAI approves applications	
Custom		• Longer approval process • Requestor-defined dataset • Content of dataset negotiated during review, no direct identifiers • DRC review required for transmission outside enclave • HCAI approves applications (tailored dataset + purpose + requestor)	• Longest approval process • Requestor-defined dataset, content negotiated during review • Direct identifiers rarely released • DRC review required • HCAI, CPHS, & DRC approve applications (tailored dataset + purpose + requestor)

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Non-State Agency Data Requests: Review Process Flow

What data is requested?

Limited Datasets → Access through enclave? → Yes → No DRC review required, may be requested
Access through enclave? → No → DRC review required

Identifiable Datasets → DRC review required

What is the purpose of standard limited datasets?

- Protects patient privacy (based on HIPAA concepts)
- Standard, pre-made limited datasets easier to produce, while managing risk
  - Custom limited datasets and custom research datasets take more effort to produce
- In addition to being easier for HCAI to produce, standard datasets should be easier for users to analyze, with pre-loaded variables that are valuable for targeted uses
- HCAI already has experience routinely producing a standard limited dataset with hospitalization data
- HPD will also need to produce standard datasets for different payer passthrough requirements (for example, Medi-Cal data)
- HCAI expects to produce several standard limited data products for HPD
  - HCAI wants DRC's input on which to produce, with what variables in each
- HCAI will likely request DRC review for some limited data products, at least to start

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Build Over Time