

Data Release Committee: Role and Membership

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Data Release Committee: Role

For Today

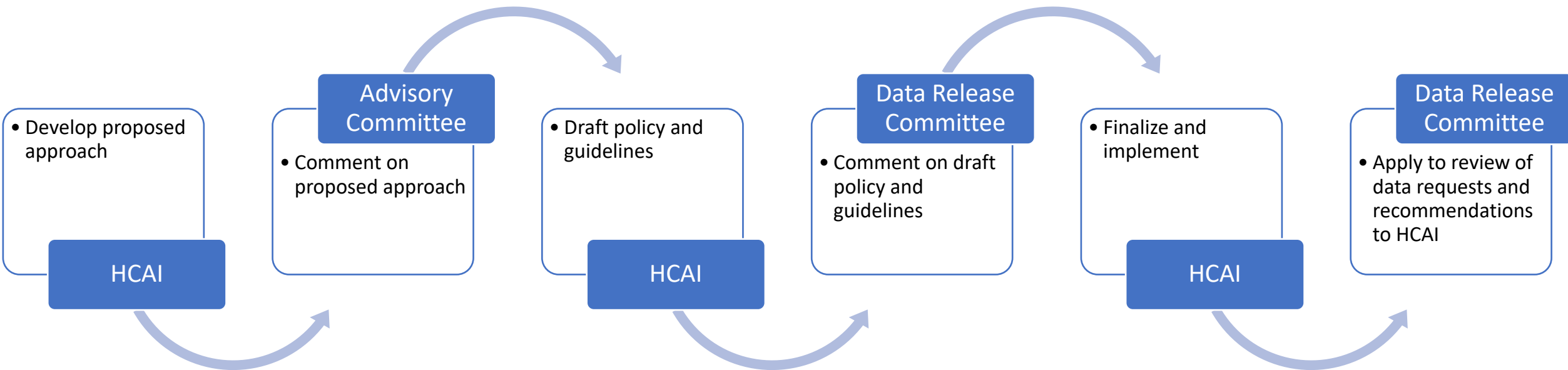
- Roles for HCAI, Advisory Committee, and Data Release Committee
- DRC's role in reviewing applications for non-public data

Typical Roles for HCAI and Committees

“Advise on criteria, policies, and procedures for access to and release of nonpublic data” HSC Section 127671-127674

Sample topics for input from AC and DRC:

- “Benefit” as a condition of non-public data access (AC input received January 2022)
- Standard limited dataset offerings (AC input received January 2022)
- Non-public access to payment data
- Non-public access to entity identifiers (i.e, payer and provider identifiers)



Data Release Committee's Launch

Ramp-Up

Onboarding and orientation – understand the HPD Program, program goals, data access objectives, the DRC's role

Provide input on **policies and procedures** related to non-public data

Provide input on **privacy and security** policies and procedures and data product offerings

Application Review

Review and make recommendations on all requests for **research identifiable data**

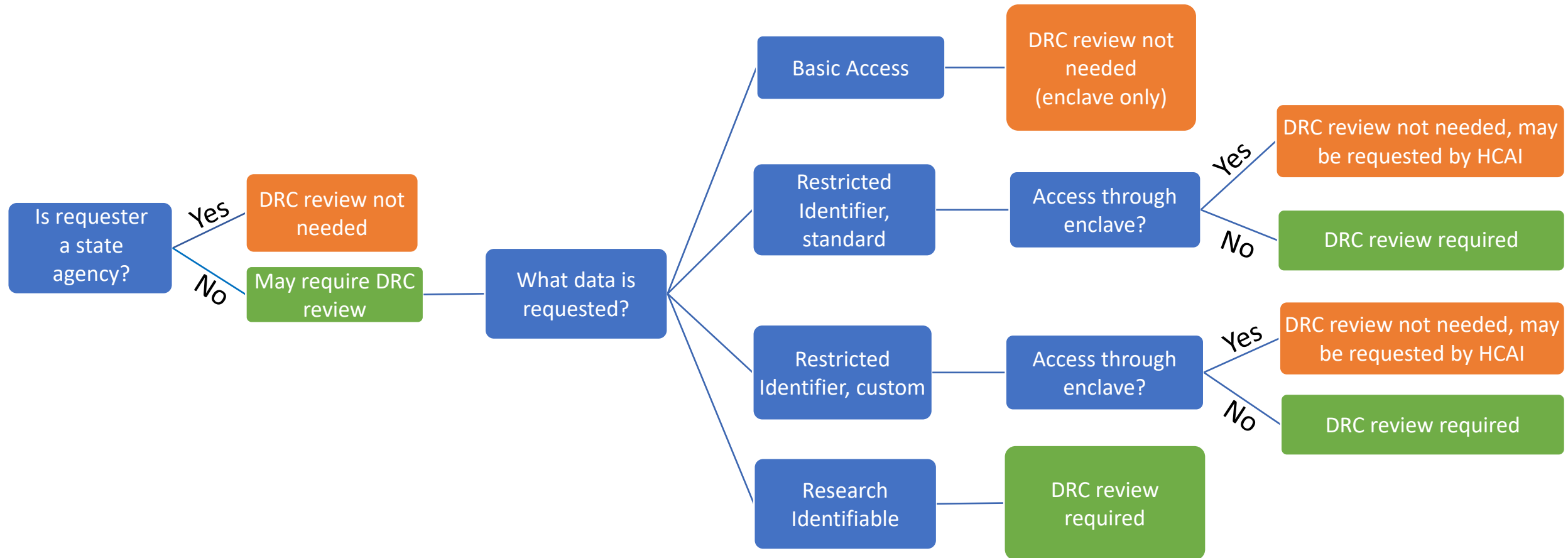
Review and make recommendations on all requests for **transmission of non public data outside the enclave**

As requested by HCAI, review and make recommendations on other requests, e.g., for custom limited datasets within the enclave

Framework for Data Access to Non-Public Data (Updated)

	Basic Access	Restricted Access to Identifiers	Research Identifiable Data
Standard	<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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 approve application 	
Custom		<ul style="list-style-type: none"> • Longer approval process • Requestor-defined dataset • Content of dataset negotiated during review, no direct identifiers • DRC review required for transmission outside enclave • HCAI approve applications (tailored dataset + purpose + requestor) 	<ul style="list-style-type: none"> • Longest approval process • Requestor-defined dataset • Content of dataset negotiated during review • Direct identifiers rarely released • HCAI, CPHS, & DRC approve application (tailored dataset + purpose + requestor)

Data Release Committee Role in Review of Requests for Non-Public Data



Discussion Questions

- Is the role of the DRC clear for:
 - Policy, procedure, guidelines and regulations
 - When requests will be reviewed – required and HCAI requested
 - When DRC recommendation is required

Data Release Committee: Membership

For Today

- Member requirements and expectations
- HCAI's planned approach to member identification

DRC Member Expectations

- Meeting frequency: monthly
- Time commitment: significant, will depend on request volume
 - Early in the process, review will take additional time
- Attendance and participation
 - Quorum: one fewer member than one-half of full membership
 - Cannot designate substitute to attend in member's place
- Subject to Bagley Keene, open meeting rules apply
- Required expertise for DRC members: Knowledge and experience with health care data, privacy, and security

Initial priority:

as requested by HCAI, provide input on policies, and procedures related to non-public data

Ongoing central task:

vote on recommendations to HCAI regarding dispensation of data requests

Conflict of Interest / Recusal

- Definition of COI: a conflict between a person's private interests and public obligations
- DRC members will need to:
 - Disclose potential conflicts by completing a Statement of Economic Interest ([Form 700](#))
 - Recuse when appropriate "[to avoid actual bias or the appearance of possible improprieties](#)" (CA Fair Political Practices Commission)
- Examples of relevant policies
 - Other state APCDs, e.g., Colorado, Delaware
 - California's Committee for the Protection of Human Subjects (State of California's Institutional Review Board) – blue box

Committee for the Protection of Human Subjects – Conflict of Interest Policy

A member shall not participate in the review process for any project, except to provide information requested by the CPHS, in which he or she has a present or potential conflict of interest, including any personal, professional, or financial conflicts. The member should notify the Chair of the conflict of interest and should be absent from the meeting room during the discussion and voting phases of the deliberations, except to provide information requested by the CPHS.

Data Release Committee Member Identification

- HCAI Director will appoint Committee members
- HCAI to invite applications for:
 - Each of the 7 representative seats identified in statute (separate application pools)
 - Up to 4 at-large seats (one application pool)
- HCAI will actively distribute the application and encourage qualified candidates to apply
- Chair to be selected from among the members
 - Chair will partner with HCAI staff responsible for application intake and processing
 - Substantial amount of work for the Chair – high time commitment

Representation from health care:

- Payers
- Providers (facilities)
- Suppliers (clinicians)
- Purchasers
- Researchers
- Consumers
- Labor

Plus up to 4 At-Large Members

Advisory Committee member support in distributing the application and identifying qualified candidates is requested

Representative Seats on DRC

Sector	Sources for Data Release Committee Members – Partial List
Payer	<ul style="list-style-type: none"> • Health plans and insurance companies • Trade/member associations
Provider (Facilities)	<ul style="list-style-type: none"> • Hospitals and hospital systems • Trade/member associations
Supplier (Clinicians)	<ul style="list-style-type: none"> • Clinicians, e.g., clinician researchers • Trade/member associations
Purchaser	<ul style="list-style-type: none"> • Public purchasers, e.g., Covered CA, CalPERS, University of California • Private purchasers (voluntary submitters) • Trade/member associations
Researcher	<ul style="list-style-type: none"> • University of California • Other California-based academic institutions • Non-profit California-based research institutions
Consumer	<ul style="list-style-type: none"> • Consumer advocacy organizations • Patient advocacy organizations • Members of the public
Labor	<ul style="list-style-type: none"> • Labor unions and federations • Experts on labor, e.g., UCB Institute for Research on Labor and Employment

Typical Titles:

- Director, Health Informatics
- Privacy Officer
- Director, Data and Analytics
- Data Management Lead
- Senior Researcher
- Clinician Researcher

Discussion Questions:

- What other suggestions do you have for sources of DRC member candidates?
- Input on whether HCAI should allow (or require) letters of support or references?

At-Large Committee Members

- Required expertise for DRC members: Knowledge and experience with **health care data, privacy, and security**

Discussion Questions:

- What input do you have on additional subject matter expertise that should be represented on the DRC?
- What are the top priorities for the (up to) 4 “At-Large” DRC members?
 - Areas of expertise
 - Stakeholder perspectives

Select relevant areas of expertise:

- Analysis of claims/encounters
- Patient privacy
- Research methods
- Health economics, health care markets, payment
- Health care cost & utilization
- Health care quality
- Health equity
- Epidemiology
- Medi-Cal data
- Medicare data
- Prescription drug data