Agenda Item II: Data Access

Chris Krawczyk, Chief Analytics Officer, HCAI
Nuriel Moghavem, Neurologist, Los Angeles General Medical Center, DRC Chair
Wade Iuele, HPD Consultant, HCAI

Data Release Committee Updates

Nuriel Moghavem, HPD DRC Chair

Roles: Advisory Committee, Data Release Committee

HCAI

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 criteria, policies, and procedures for access to and release of HPD data**
- Provide input on establishing the user fee schedule and fee waivers

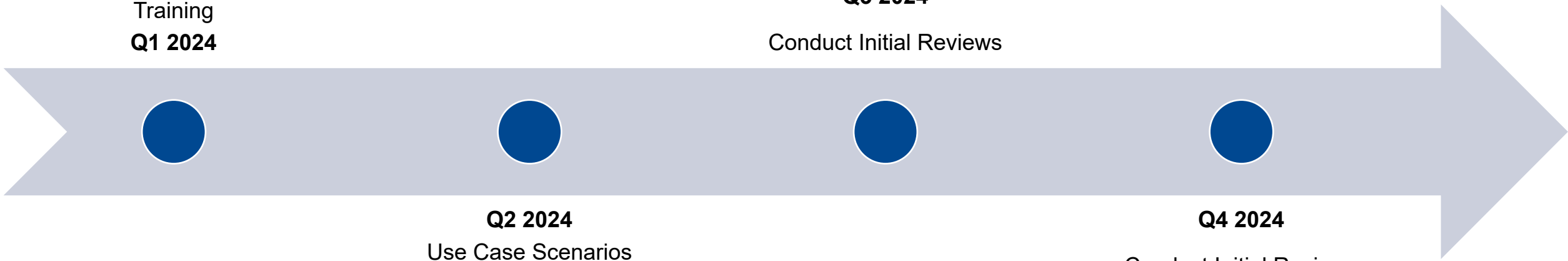
Data Release Committee

- **Advise on criteria, policies, and procedures for access to and release of HPD data**
- Make recommendations about applications for HPD data
- Consider whether the use of HPD data is consistent with the goals of the program, 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

Source: Committee roles described in HSC Section 127671-127674

Previous HPD DRC Meeting Topics

Anticipated 2024 DRC Topics



Q1 2024

Pricing Schedule

Adopt DRC Manual

Use Case Scenarios

Training

Q2 2024

Use Case Scenarios

Conduct Initial Reviews

Q3 2024

Conduct Initial Reviews

Q4 2024

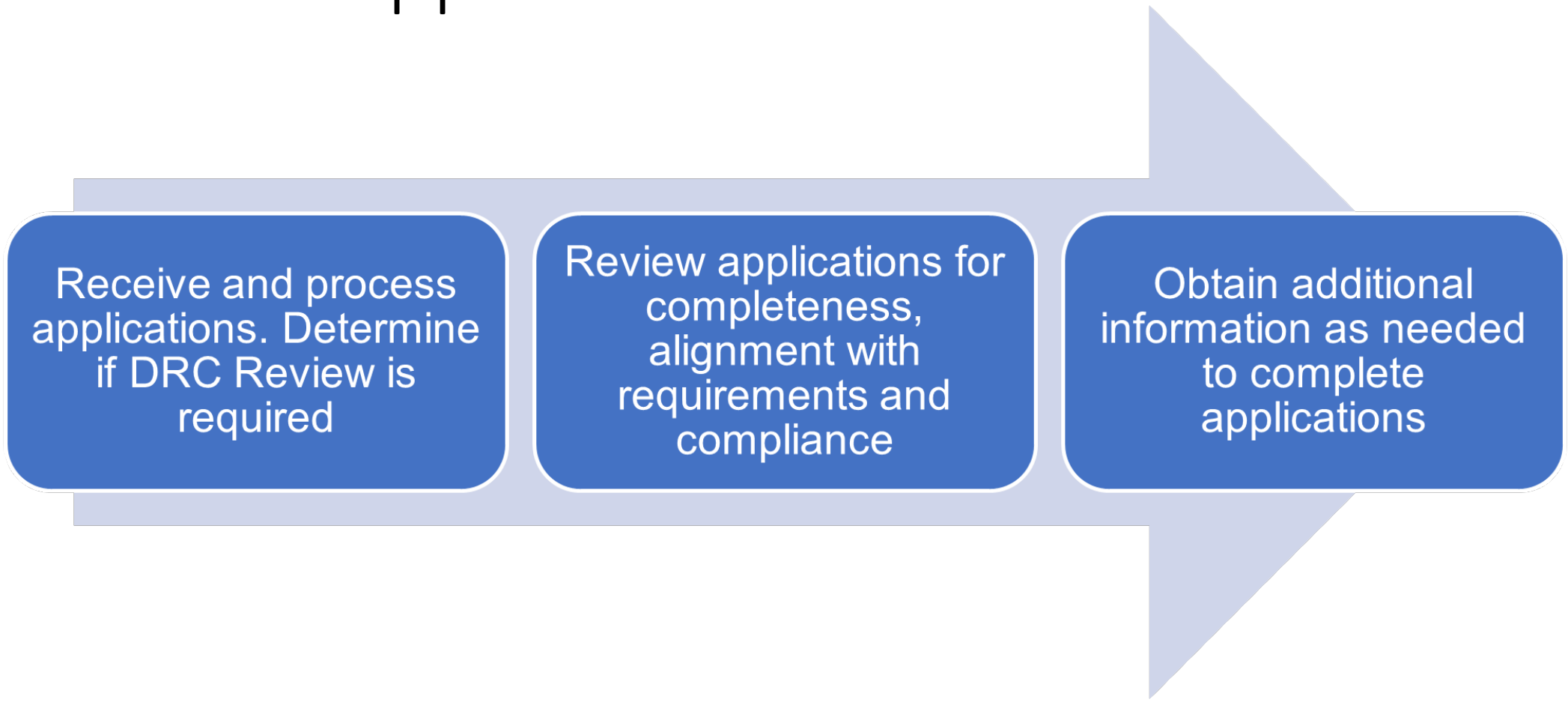
Conduct Initial Reviews

Conduct HPD DRC Evaluation

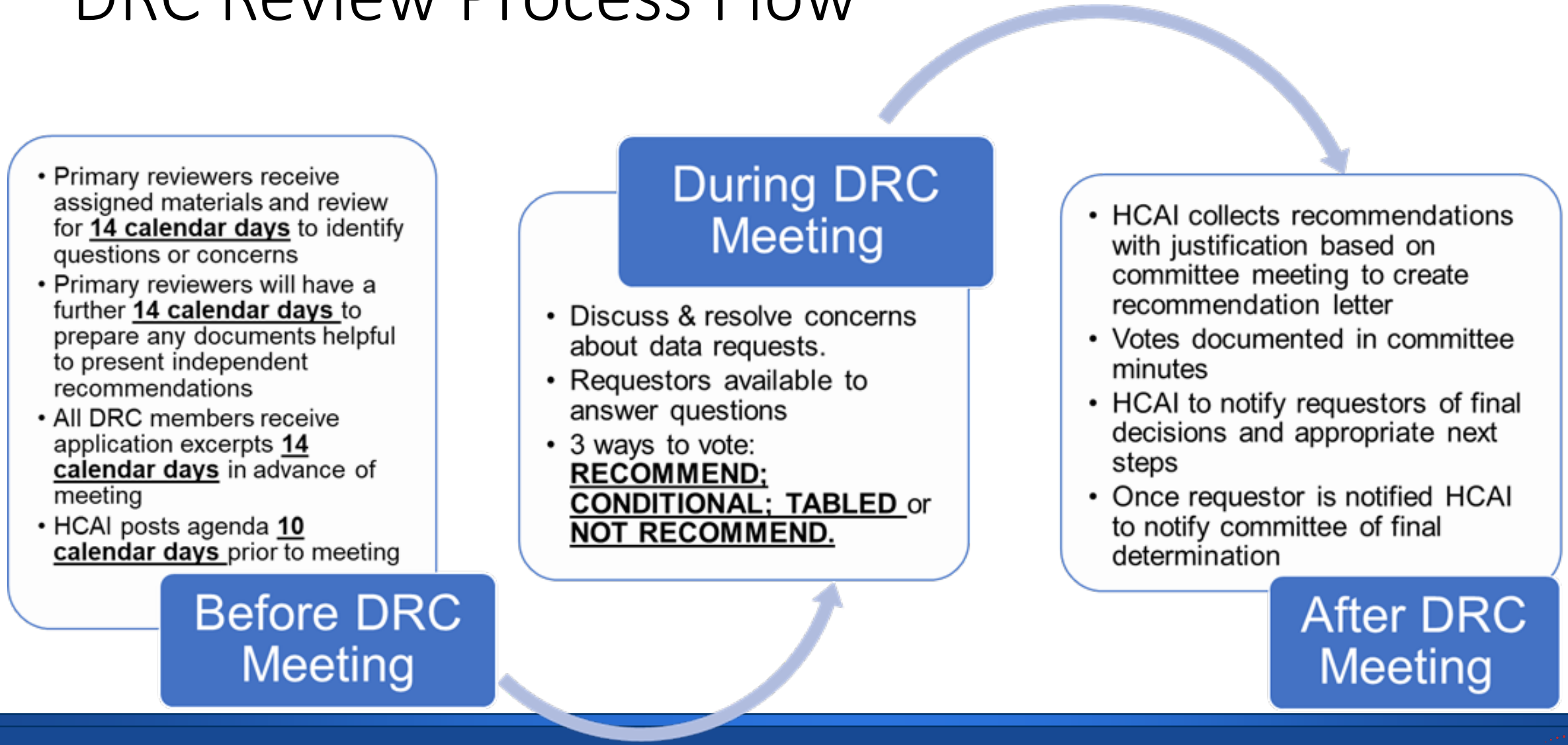
Proposed Next DRC Meeting Topics

- Review of Previous DRC Discussions
- Use Case Scenarios
- Application Excerpts
- DRC Considerations for Review

Initial HCAI Application Review



DRC Review Process Flow



Additional DRC Considerations

In addition to statutory and regulatory requirements, the DRC may consider other factors in the review of applications related to their experiences as health care payers, providers, purchasers, researchers, consumers, and other stakeholders.

The DRC may also consider whether the proposed use of the data is “consistent” with the goals; the requestor’s ability to balance the possible anticompetitive and/or commercial risks; and for requests that include direct personal identifiers, whether there are “significant opportunities to achieve Program Goals.”

Additional DRC Considerations (cont.)

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?

Additional DRC Considerations (cont.)

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?

Anticompetitive Use & Commercialization of HPD Data

- 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?

Proposed DRC Recommendation Options

Four recommendation options are available to the DRC:

- **Recommended:** The committee votes to recommend approval of the application. If recommended, HCAI will make a final determination and provide information on data user fees, the method of data access (Enclave, direct transmission), and the Data Use Agreement (DUA) with the written notification. However, even if the committee recommends approval, HCAI may still deny the application.
- **Conditional:** The committee can recommend conditional approval for applications that require additional information to address minor issues or deficiencies. In these cases, conditional approval letters listing the issues and deficiencies will be provided to the requestor and HCAI will work with the requestor to modify the application or obtain additional information to address the DRC's concerns. These applications will not need to return to the DRC for review.

Proposed DRC Recommendation Options

- **Tabled:** The committee can recommend tabling applications that require substantive changes or if a recommendation does not receive a majority vote. In these cases, tabled letters listing the substantive changes will be provided to the requestor and HCAI will work with the requestor to modify the application to address the DRC's concerns prior to the application returning to the primary reviewers and subsequently the committee.
- **Not Recommended:** The committee does not recommend approval of the application. In these cases, denial letters listing the reasons for denial will be provided to the requestor.

There is no appeal process for recommendations. HCAI will make a final determination on approval on all applications and shall notify the DRC of its final determinations.

2024 HPD DRC Committee Meetings

- Meetings occurring monthly on the third Wednesday from 1 – 4 pm

Wednesday, June 19	Wednesday, July 17	Wednesday, August 21
Wednesday, September 18	Wednesday, October 16	Wednesday, November 20
	Wednesday, December 18	

Data Access Pricing Recap

Recap: Price Schedule

Enclave: requires space + seat(s)	Annual Price
Project space with SLD or SLD+	$5,000
Project space with custom/research dataset	$14,000
Analyst seat	$5,000
Researcher seat	$6,000

Enclave options (per seat)	Annual Price
SAS Viya License	$5,000
Stata/MP License	$1,100
Tableau Creator License	$930

Direct Transmission: SLD	1 Year of Data
Commercial (includes Medicare Advantage)	$20,000
Commercial + Medi-Cal	$22,000

Direct Transmission: Custom	1 Year of Data
Medical Claims	$8,500
Pharmacy Claims	$7,000
Dental Claims	$7,000
Member Eligibility	$4,000
Provider Information	$3,000
All Tables	$29,500

What we heard during the April price reduction discussion

- On managing uncertainty in the price reduction program:
  - Clarify who is eligible for a reduction.
  - Be transparent about how much money is in the price reduction pool.
  - Anyone who is eligible should receive a discount; if too much is spent in current year, adjust next year's pool downward to compensate.
- On balancing affordability and sustainability for the program:
  - High prices may discourage prospective users; launch with a low price.
  - Low prices help build demand, and prices can increase over time.
  - High demand makes a clear case for long-term HPD funding.

Enclave Price Reductions

Wade Iuele, Consultant, HCAI

Price Reduction – Statute and Regulations

HPD Statute HSC 127674(f)(2):

"The department shall work with the advisory committee to make considerations for state agencies, data submitters, and consumer organizations…"

HPD Data Use, Access, and Release Regulations §97414:

"The Department may reduce program data prices…if it determines there is good cause for reduction, supported by documentation. Good cause includes, but is not limited to:

(1) the financial hardship of data applicants, such as students with needs-based financial aid working toward completion of required academic milestones, or government or nonprofit organizations whose funding sources for their projects do not cover data fees prices; or

(2) whether reduction will encourage the use of program data in high priority areas, or will lead to innovations that will benefit the public at large."

"Price reductions will be considered on a per project basis."

"Price reduction requests will be considered in the order received until available funds for price reductions are exhausted or price reductions are no longer compatible with program sustainability."

Starting Place - Assumptions

1. An annual price reduction program is contingent on long-term funding for the HPD program.
2. A finite pool of funds will be available to HCAI each year to pay for data access projects.
3. HPD project costs will vary substantially, so a fixed discount percentage regardless of project price may not be compatible with program sustainability.
4. Price reduction requests must be considered on a per-project basis, in the order received, as stated in the regulations.
5. The price reduction program can be refined over time as HCAI gains experience with the level of demand and requests for reductions.

Recap: Feedback on Price Reductions

Advisory Committee:

- Purpose of the request is important to consider; greater public benefit = more worthy of price reduction
- Assessing purpose could rely on program goals or HCAI could identify priority topics (e.g., Oregon's identification of disparities research)
- Incorporating purpose as a criterion should not create undue burden for review staff
- Consider budget size of requester alongside other criteria
- Broaden eligibility for consumer organizations beyond those with DMHC designation
- Consider actionability of the project results – academic research can take years

Data Release Committee:

- Discussed the need for clear criteria for eligibility for a price reduction and reduction amounts
- Use price reductions as a way to have more equity in access.
- Emphasized the importance of predictability in pricing for researchers seeking funding, particularly for graduate students and fellows.
- Identified limitations with first come, first serve reductions.
- Suggested prioritizing projects based on public health goals, funding availability for researchers, especially considering early-career investigators.

Consideration #1: Managing Uncertainty

Decisions about price reductions must be made on a case-by-case basis in the order received. While the HPD prices are publicly available, applicants who request a price reduction will not know in advance:

a) if they will be granted one, or
b) how large the reduction will be

Discussion:

- How can HPD help grant writers and other applicants manage the uncertainty of the price reduction program?

Consideration #2: Balancing Affordability and Sustainability

HPD Enclave access prices have been set as low as possible while maintaining program sustainability. While HPD prices are competitive, the cost to access HPD data is high enough to create a challenge for some applicants, which will reduce initial demand and limit the variety of HPD use cases.

Discussion:

- What guidance do you have for HCAI on striking a balance between affordability of data access and sustainability of the program?

Consideration #3: Direct Transmission Price

The price reduction program only applies to Enclave access; direct transmission prices are not planned to be reduced.

HPD's data access program takes an Enclave-first approach to best control and protect the data. Direct transmission prices are set above-cost, and not incentivized with price reductions, to help mitigate the privacy and security risks direct transmission adds to the program.

Discussion:

- Tradeoffs around adding direct transmission requests to the price reduction program, and prioritizing these factors: sustainability, data release program expansion, privacy/security, statutory requirements to promote enclave use.

Consideration #4: Length of Review Time

In the first year of the data access program, multiple unknowns will affect application review times, including:

- How many data access applications will HPD receive in the first month, quarter, and year?
- How complex will the applications be? (custom datasets? direct identifiers? DHCS data?)
- How many applications will require the evaluation of a price reduction request?

After a couple of years of experience, HCAI will be in a better position to predict and manage the flow of applications and the review process timeline.

Discussion:

- Given these multiple unknowns, would you prioritize a more streamlined and predictable review timeline or lower prices and more reduction opportunities?

Could Below-Cost Pricing in Year One Address the Considerations?

- What if HPD had 50% lower prices for all year-one applications, ensuring the widest possible user pool in the first year?
- Further price reductions could be requested, and would consider:
  - Documented cause for reduction
  - The purpose of the request
  - The total cost of the request
  - The remaining funds available in the price reduction pool

Components: choose space + seat(s)	50% Price First year only
Project space with SLD or SLD+	$2,500
Project space with custom/research dataset	$7,000
Analyst seat	$2,500
Researcher seat	$3,000

Additional Options (per seat)	50% Price First year only
SAS Viya License	$2,500
Stata/MP License	$550
Tableau Creator License	$465

Discussion: Would below-cost pricing in Year One address the considerations in a meaningful way?

Additional Thoughts?

Advisory Committee feedback on the HPD price schedule and price reduction program is welcomed.

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Public Comment