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**NOTICE OF PUBLIC MEETING:
HEALTH CARE PAYMENTS DATA PROGRAM (HPD) ADVISORY COMMITTEE**

**May 13, 2024
DRAFT MEETING MINUTES**

Members attending: Anthony Wright, Health Access California

Members in virtual attendance: Charles Bacchi, California Association of Health Plans; Amber Ott, California Hospital Association; Ken Stuart, California Health Care Coalition; Joan Allen, Service Employees International Union- United Healthcare Workers West; Janice Rocco, California Medical Association; Emma Hoo, Purchaser Business Group on Health; Cheryl Damberg, RAND Corporation

HPD Advisory Committee Ex-Officio Members attending: Michael Valle, Department of Health Care Access and Information (HCAI)

Members not in attendance: William Barcellona, America's Physician Groups; John Kabateck, National Federation of Independent Business; Steffanie Watkins, Association of California Life and Health Insurance Companies

Presenters: Michael Valle, Chief Information Officer and Deputy Director, HCAI; Christopher Krawczyk, Chief Analytics Officer, HCAI; Nitisha Patel, Research Data Specialist I, HCAI; Wade Iuele, HPD Consultant HCAI; Nuriel Moghavem, Neurologist, Los Angeles General Medical, HPD Data Release Committee Chair

Public Attendance: 61

Agenda Item # 1: Welcome and Meeting Minutes
Ken Stuart, Chair

Welcome and review of meeting ground rules and procedures. Review and approval of April 25, 2024, meeting minutes.

The committee voted and approved the April 25, 2024, meeting minutes. The motion to approve was made by Cheryl Damberg and seconded by Joan Allen. The minutes were approved, 6-0. Amber Ott and Charles Bacchi abstained from voting.

No Questions or Comments from the Committee.

No Public Comments.

Agenda Item # 2: Data Access

Christopher Krawczyk, Chief Analytics Officer, HCAI

Nitisha Patel, Research Data Specialist I, HCAI

Wade Iuele, HPD Consultant, HCAI

*Nuriel Moghavem, Neurologist, Los Angeles General Medical,
Data Release Committee Chair*

Continuation from the previous meeting of discussion on data access pricing and price reductions and an update on the status of the Data Release Committee (DRC).

Questions and Comments from the Committee about the status of the DRC:

The committee members expressed gratitude for the efforts of the data release team and discussed the review process and the need for a streamlined review process. They discussed potential use cases for the data, such as studying insurance transitions, and raised the potential scenario of large research centers with grants covering multiple projects, emphasizing the importance of collaboration amongst researchers to addressing broad research questions. The committee also noted consideration for the typical grant application cycle from large funders, such as the National Institutes of Health.

The committee thanked the DRC for their work and raised concerns about commercialization of data. The committee discussed the need to align with program goals and the importance of maintaining public trust and inquired about transparency regarding data users' funding sources.

The committee commended the DRC's work and highlighted the importance of privacy in data management. The committee inquired about the definition of specific terms used by the DRC, such as "minimum data necessary". The committee also asked about the process of accessing the enclave, whether applicants must join before or after approval. HCAI staff confirmed that there is no upfront fee for submitting an application, but an application fee is required, with the possibility of folding it into total costs later.

The committee expressed appreciation for the support and foundation provided by the HCAI staff, acknowledging their achievements in upholding privacy standards. The DRC Chair reciprocated gratitude, highlighting the collaboration between the committee and staff. The Advisory Committee members and the DRC chair emphasized the shared commitment to data privacy.

The committee inquired about conflict-of-interest policies regarding researchers on the DRC and how to manage potential conflicts. The DRC Chair mentioned the inclusion of conflict-of-interest policies in the DRC Board Manual and emphasized the importance of

transparency. They discussed considering the track record of institutions applying for data access, especially regarding data breaches, and how it factors into the decision-making process. The DRC Chair highlighted the need to assess the privacy and security capacity of requesters, including any risks for data reidentification, and mentioned potential considerations for applicants with a history of breaches.

The committee raised concerns about insurance requirements for data handling, particularly for non-profits, and asked if this was considered in the process. They also addressed the issue of the appeals process regarding requests that are not recommended for approval. The DRC Chair suggested the need for further discussion on insurance requirements. HCAI staff clarified that the DRC makes recommendations, but HCAI makes final decisions, and while there isn't a formal appeals process, rejected projects can be resubmitted for reconsideration.

Questions and Comments from the Committee about the pricing schedule and price reductions:

The committee inquired if changes to the state's 2024-2025 budget will impact HPD's year-one price schedule. HCAI replied that the proposed price schedule and reductions are not directly impacted by the 2024-2025 state budget, as the HPD is still operating under the 2018 general fund appropriation. The committee inquired if the proposed price schedule was per-applicant or per-project. HCAI clarified that the pricing is per project.

The committee proposed enhancing transparency by informing applicants upfront about the availability of price reductions, aiming to clarify their likelihood of obtaining one. The committee also recommended a streamlined pre-approval process based on organization rather than individual projects, which would assist applicants in better budget planning. HCAI inquired whether fee reductions after budgeting for the full project amount might pose challenges; the committee indicated it would not but acknowledged that budgeting at full price could influence project funders' decisions. Some members advocated for revising the pricing structure to move beyond a basic pricing model with potential deductions, favoring instead a sliding scale or tiered pricing approach that considers the applicant organization's characteristics to determine the appropriate pricing tier.

The committee emphasized the importance of fair distribution of reductions, cautioning against a first-come-first-serve approach which could disadvantage later applicants. The committee suggested implementing a quarterly allocation system to ensure reductions are available consistently throughout the year. The committee reiterated their commitment to transparent price reduction guidelines to ensure equitable evaluation processes, aiming to eliminate any ambiguity regarding the criteria for granting reductions to projects.

Committee members cautioned against implementing across-the-board price reductions without first assessing demand, citing concerns over potential financial instability. The

committee highlighted that strong demand for the HPD public service could justify requests for additional funding and improve prospects for future funding opportunities. Some members of the committee advocated for a selective approach to price reductions, favoring adjustments on a case-by-case basis rather than universal reductions for all users, stating that offering discounts below cost could necessitate future subsidies, which are not yet guaranteed.

Several committee members advised against HPD's proposed high prices, stating that they would be prohibitive for many users, potentially restricting access to the system and diminishing its overall value to California. Other committee members contended that the proposed pricing structure is manageable for frequent users of the HPD system, particularly those with substantial resources and advanced teams and suggested that these organized teams are well-positioned to benefit the most from initial HPD price reductions in the first year.

The committee concurred with the state that the current approach prioritizes enclave access over direct transmission of the data to a user's system and reiterated the importance of establishing clear and transparent criteria on how to qualify for a price reduction in order to prevent a complex and lengthy decision-making process for each application. The committee proposed that establishing clear pricing tiers could accommodate various types of institutions without necessitating trade-offs, provided the tiers are transparent and predictable. The committee also recommended introducing an initial price reduction gating process based on the applicant organization's characteristics, aiming to inform applicants early on whether pursuing a reduction would be beneficial.

The committee discussed the impact of data access costs on research grants, emphasizing that projects where these costs consume a significant portion of the grant are deemed impractical and likely to be rejected. They proposed a below-cost pricing model for HPD in the first year to enhance funding opportunities for such projects. Additionally, the committee acknowledged that while this approach could facilitate participation in one-year projects, it may not provide substantial advantages for multi-year projects.

The committee raised concerns regarding the \$60 million general fund appropriation designated for operations through July 1, 2025, questioning whether implementing a below-cost pricing strategy in the first year would potentially lead to a deficit in HPD's operational budget. HCAI assured the committee that the HPD operating funds would remain secure under this approach. The committee emphasized the importance of sustainability, suggesting that the HPD user access price should be adjusted to cover a portion of the program's operating expenses.

The committee proposed focusing the program's initial year on a select group of experts using the system, citing concerns about potential initial data or system issues and the critical need for producing trustworthy results from the database. They endorsed treating the first year of HPD data as a "beta test", underscoring the value of

collaborative efforts with expert users to enhance database functionality. The committee recommended implementing price reductions for users who engage in activities aimed at improving the database, such as evaluating data quality or developing open-source analytic code beneficial to HCAI and other analysts.

The committee inquired about the possibility of using revenue generated from direct transmission costs to fund reductions in data access fees. HCAI explained that the more user fees collected, the more money would be available to the data release program.

Public Comments:

A member of the public expressed interest in learning more about the application process for state public health departments to access the data, particularly in becoming beta testers for the secure enclave environment. They also inquired about the possibility of prepaying for multiple years of access to the enclave.

Agenda Item # 3: Public Comment for Items Not on the Agenda

No Questions or Comments from the Committee.

No Public Comments.

Ken Stuart thanked the committee and HCAI staff and adjourned the meeting.