Department of Health Care Access and Information

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

April 25, 2024 **MEETING MINUTES**

Members Attending: Ken Stuart, California Health Care Coalition; Steffanie Watkins, Association of California Life and Health Insurance Companies; Anthony Wright, Health Access California; 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

Members not in attendance: Charles Bacchi, California Association of Health Plans; Amber Ott, California Hospital Association.

HPD Advisory Committee Ex-Officio Members Attending: Michael Valle, Department of Health Care Access and Information (HCAI); Dr. Linette Scott, California Department of Health Care Services (DHCS); Isaac Menashe, Covered California (CA)

Presenters: Elizabeth Landsberg, Director, HCAI; Michael Valle, Chief Information Officer and Deputy Director, HCAI; Christopher Krawczyk, Chief Analytics Officer, HCAI; Robyn Strong, Chief Data Programs Officer, HCAI; Tara Zimonjic, Chief Planning Officer, HCAI; Nitisha Patel, Research Data Specialist I, HCAI; Jasmine Neeley Research Data Analyst II, HCAI; Jill Yegian, HPD Consultant, HCAI; Wade luele, HPD Consultant, HCAI

Members in virtual attendance: William Barcellona, America's Physician Groups; John Kabateck, National Federation of Independent Business

Public Attendance: 62

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

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

The committee voted and approved the January 25, 2024, meeting minutes. The motion to approve was raised by Emma Hoo and seconded by Cheryl Damberg. The minutes were approved, 9-0.

No Questions and Comments from the Committee.

No Public Comments.

Agenda Item # 2: Department Updates

Elizabeth Landsberg, Director, HCAI

Presentation on department and program updates.

No Questions and Comments from the Committee.

No Public Comments.

Agenda Item # 3: Deputy Director Update Michael Valle, Chief Information Officer and Deputy Director, HCAI

Presentation on division policy and program activities of interest.

Questions or Comments from the Committee.

The committee inquired if HCAI's patient data included unique identifiers or more specific information, referencing the Change Healthcare cyber-attack. HCAI confirmed individual identifiers are collected, and that the department takes care to provide the least identifiable information needed to be used by data users as part of their standard limited dataset process.

The committee discussed the forthcoming pricing discussion, recognizing the difficulty in forecasting demand for the database. The committee emphasized the historical context of HCAI's limited resources and stressed the importance of accurate forecasting for financial sustainability.

No Public Comments.

Agenda Item # 4: HPD Data Collection, Use, and Release Updates Robyn Strong, Chief Data Programs Officer, HCAI

Update on data collection status and submitter outreach and engagement.

Questions and Comments from the Committee:

The committee had a robust discussion regarding the recently updated race/ethnicity categories from the Office of Management and Budget. There was discussion related to forthcoming updates to the X12 format for submitting and billing claims.

The committee inquired about historical race and ethnicity data collected during Medicare sign-ups, noting that earlier standards lacked detailed categories. The committee also inquired about the possibility of Medicare Advantage plans having updated data and HCAI added that in the current data layout, race and ethnicity data often reside in the eligibility file rather than the claim itself.

The committee asked about the hierarchy of data accuracy between plan eligibility and self-reported needs. HCAI explained that while self-reported data is preferred, HCAI lacks authority to dictate data collection methods. The committee informed HCAI that using race and ethnicity data from eligibility files, supplemented by claim data, if necessary, poses challenges in ensuring data integrity and meaning, highlighting various data collection processes across entities.

The committee also confirmed the timeframe covered by the dental claims data due by October. HCAI explained that they are collecting historical data, going back to 2017, as specified in the statute, with the precise date being June 29th, 2017. The committee raised concerns about the timeline for including non-claims data in the HPD and when it would be available, to which HCAI stated that the aim for the initial data submission is September 2025, with historical data possibly going back to 2018, though the feasibility of obtaining data from that time is uncertain.

No Public Comments.

Agenda Item # 5: Finalizing Recommendations on HPD and Public Health Data Tara Zimonjic, Chief Planning Officer, HCAI Jill Yegian, HPD Consultant, HCAI

Presentation on January meeting discussion, high level overview of additional input received and a vote on recommendations.

Questions and Comments from the Committee:

The committee inquired if health equity use cases are considered part of public health use or if they should be specifically called out. HCAI confirmed that health equity is included, explaining that recommendations are intentionally broad to encompass various intersections of health policy and public health data. HCAI emphasized that integrating public health and health policy data is crucial for enabling research on health disparities and equity

The motion to approve the recommendations regarding public health integration with the HPD was made by John Kabateck and seconded by Anthony Wright. The motion was approved 9-0.

No Public Comments.

Agenda Item # 6: Data Access

Christopher Krawczyk, Chief Analytics Officer, HCAI Nitisha Patel, Research Data Specialist I, HCAI Jasmine Neeley, Research Data Analyst II, HCAI Wade Iuele, HPD Consultant, HCAI

Overview of HPD Data Release Program progress including data access milestones updates on standard datasets, and a discussion on data access pricing and price reductions.

Questions and Comments from the Committee:

The committee clarified specific components for HCAI's data release process including the approach to data security plans, supplemental requests for updating data use annually, considering a parallel review process for other agency review, as well as proposing a printable PDF form that outlines the data request application to support users in gathering all the required information ahead of starting the online application. The committee clarified that HCAI does not evaluate scientific validity but ensures data feasibility and associated methodologies for proposed analyses, and also that HCAI does not evaluate the third parties data requestors work with but does require documentation for anyone who will be using the data including third parties.

The committee praised HCAI's impressive work and inquired about staff involvement, particularly regarding existing and additional hires for the process. HCAI confirmed ongoing expansion efforts, mentioning the recruitment of research scientists to bolster the HPD unit and enhance data understanding. The committee sought clarification on the data element justification grid, suggesting guidance to avoid lengthy responses. HCAI explained the structured document's purpose and encouraged concise justifications for applicants. The committee also raised concerns about the one-year timeframe, citing potential project extensions and the need for flexibility. HCAI noted efforts to streamline the annual review process and hinted at future adjustments based on project growth.

The committee discussed data availability in the standard limited data (SLD) set versus the standard limited data set plus (SLD+). HCAI clarified that while payer and provider codes are included in the SLD, the fully named identifiers are not. If a requestor wants direct identifiers, they can request an SLD+ which requires transmission within the HCAI Secure Research Enclave (Enclave). The committee also inquired about the level of provider information available in requested datasets, particularly whether individual physician data or only medical group data would be accessible. HCAI clarified that access to provider information is available, depending on the request and associated approvals, and can include both individual and non-individual providers. The department also clarified that projects requesting publishing results that include provider identifiers will be evaluated along with all other uses on a case-by-case basis. The committee emphasized the importance of identifying individual providers in public datasets for

specific valid use cases, acknowledging the need also for caution and scrutiny of such reporting.

The committee inquired about the ability to link data about related parties within the Enclave or through research identifiable requests, particularly regarding entities like individual physicians, hospitals, and health plans. HCAI emphasized assessing the nature of the request and the availability of different datasets. The committee clarified the distinction between the provider directory and the concept of mapping relationships within health systems and medical groups. The committee explained the need for understanding provider relationships for comparative analysis.

The committee expressed appreciation for the effort in navigating the complexities of the pricing structure. The committee sought clarification on the pricing differences between researcher and analyst seats, emphasizing the need for cost considerations in research planning and also raised concerns about the affordability of long-term projects due to escalating costs and suggested discussions with CMS to expand data access. The committee questioned the need for multiple licenses for a team and highlighted potential challenges with the current pricing model, especially for larger teams. HCAI emphasized the necessity to balance various factors, including functionality, security, and cost, in designing the pricing structure. HCAI acknowledged the complexity and variability in user needs and suggested revisiting the pricing model after gaining experience with the initial launch.

The committee inquired about the overall fixed cost of providing the Enclave service, expressing concern about potential price increases if demand does not meet expectations. HCAI clarified that only variable costs are being considered in the pricing structure, with close monitoring of the program's financial health. HCAI affirmed that any excess funds generated could be rolled back into the program's budget and future considerations to temper fees. The committee expressed concern about the affordability of the pricing structure, suggesting a reevaluation of the fee reduction frame and proposing alternative funding mechanisms, such as charging a percentage for data that is subsequently monetized, emphasizing the importance of ensuring public access to the data without overly burdensome costs. HCAI acknowledged the comments and highlighted the need to differentiate between direct transmission and Enclave costs, noting that the proposed pricing for the Enclave service is competitive in the space.

The committee suggested implementing a pre-screening process to provide some certainty to potential users about the possibility of fee reductions and emphasized the importance of establishing clear expectations regarding fee reductions for the first year, suggesting a need-based aid approach similar to scholarships. The committee cautioned against creating uncertainty for applicants and compared the situation to other scholarship programs, prompting a discussion on the fairness of the current approach. The committee expressed concern about the potential reputational damage if the pricing structure discourages users upfront proposing starting with a lower initial price to attract users and adjusting in the future based on program success. HCAI

acknowledged the complexity of the issue and emphasized the need to balance various considerations.

The committee highlighted the potential for increased utilization of the Enclave to offset fixed costs, with HCAI clarifying that only variable costs are currently being passed through. The discussion touched on the scalability of variable costs with increased users, with HCAI agreeing to provide more information on this aspect. The committee emphasized the importance of demonstrating early use of the data to demonstrate the value of the program and to support long-term funding and budget advocacy. The committee noted it is a common business practice of underpricing initially to build market share, suggesting a similar approach for the Enclave.

The committee was not able to complete the discussion around pricing reductions and agreed to re-convening as a special 2-hour meeting to complete this discussion and hear from the data release committee chair regarding updates from the data release committee.

No Public Comments.

Agenda Item #7: Public Comment for Items Not on the Agenda

No Questions and Comments from the Committee:

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

No Public Comments.