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NOTICE OF PUBLIC MEETING
HEALTH CARE PAYMENTS DATA PROGRAM (HPD)
DATA RELEASE COMMITTEE (DRC)

Date:

March 20, 2024
Draft Meeting Minutes

Members Attending: Paul Bouganim, Executive Director, Finance Operations; Miranda Dietz, Project Director, California Simulation of Insurance Markets (CalSIM); Genia Fick, Vice President, Quality; Cora Han, Chief Health Data Officer; Jan Hanley, Director of Research Programming; Terry Hill, Physician Consultant, Researcher, Writer; Barbara Koenig, Professor Emerita of Bioethics; Nuriel Moghavem, Clinical Instructor of Neurology; Daniel Ruiz, Vice President, Operations Quality; and

Members not in attendance: Janet Coffman, Professor, Institute for Health Policy Studies and Koh Kerd Sri, Vice President, Risk Adjustment, Compliance, and IT.

HCAI Presenters: Chris Krawczyk, Chief Analytics Officer; Tara Zimonjic, Chief Planning Officer.

Public Attendance: 68

Agenda Item I: Welcome and Meeting Minutes

Nuriel Moghavem, DRC Chair

Nuriel Moghavem, DRC Chair, welcomed the committee and members of the public. The committee members conducted a rollcall. The chair reviewed the meeting ground rules and Cora Han read the HPD program goals and statement from the committee. Genia Fick volunteered to read the statement at the next public meeting.

The committee reviewed and approved the meeting minutes from the January 17th, 2024, DRC Meeting with a minor edit to update the meeting end time. The motion to approve was made by Terry Hill and seconded by Cora Han.

The following members voted to approve the minutes: Miranda Dietz, Cora Han, Terry Hill, Barbara Koenig, and Daniel Ruiz.



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Genia Fick, Jan Hanley, and Nuriel Moghavem abstained from voting.

Paul Bouganim was absent from voting.

The motion to approve the minutes was carried by a vote of five in favor and three abstentions.

Questions and comments from the committee:

There were no questions from the committee.

Public comment:

There was no public comment.

Agenda Item II: HPD Program Updates and January Meeting Recap

Miranda Dietz, DRC Vice Chair

Chris Krawczyk, Chief Analytics Officer, HCAI

Miranda Dietz, DRC Vice Chair, gave a recap of the previous session, including the timeline for reviewing applications being delayed until the second half of the year due to ongoing regulations, the need for clarity and predictability in pricing decisions, the potential for foundation funding for certain projects, and issues regarding data use agreements and required signatories.

Chris Krawczyk, Chief Analytics Officer, HCAI provided updates on the upcoming HPD Advisory Committee meeting, which will focus on data release and pricing as well as recommendations for using HPD data for public health purposes.

Updates were also provided on the Bagley-Keene Open Meeting Act and the progress towards HPD data release, including the completion of various components and the need for additional staff hiring and training. The meeting also outlined anticipated topics for the DRC in 2024, including use case scenarios and evaluations.

Questions and comments from the committee:

The committee inquired about HCAI staff's ability to meet the technical demands of the project, with concerns raised about retention and competition in the job market. HCAI acknowledged the risk and emphasized the importance of hiring, training, and ensuring retention in roles.



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The committee expressed appreciation for the cautious approach in rolling out the project, highlighting the value of the data for policymaking and transparency. The committee also inquired about the recommendations to be discussed at the upcoming April 25th HPD Advisory Committee meeting, clarifying the DRC's role in the process. HCAI clarified that the recommendations focus on public health uses of the data and are more high-level in nature.

The committee mentioned the availability of reports to provide context to interested parties and encouraged committee members to participate in the upcoming Advisory Committee meeting.

Public Comment:

There was no public comment.

Agenda Item III. DRC Manual Review

Tara Zimonjic, Chief Planning Officer, HCAI

Tara Zimonjic, Chief Planning Officer, HCAI reviewed the process outlined in the manual, particularly section three, which covers the application review process. Tara Zimonjic, Chief Planning Officer, HCAI highlighted changes made based on previous discussions, such as clarifying the roles of primary reviewers and streamlining the review timeline to ensure concurrent review by both primary reviewers. Additionally, a draft template for preparing recommendations and an application excerpt for committee members were discussed to provide necessary information while safeguarding proprietary and security-sensitive data. James Yi, Attorney, HCAI emphasized the importance of protecting security-related information.

Questions and comments from the committee:

The committee appreciated the provision of a template to help prepare recommendations but suggested clarifying that it's a guide, not a requirement. HCAI proposed including language to indicate that the template is a flexible tool for committee members. The discussion also touched on whether the template should be provided to all committee members or just the primary reviewers. The committee raised concerns about the application excerpt that non-primary reviewers receive and suggested clarifying its content. The conversation also addressed the timeline for reviewing materials and preparing documents, ensuring clarity on the workflow. Other topics included the content of the application form and the consideration of personal identifiers.



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The committee approved the DRC Manual with updates to Nuriel and Genia's places of employment and updates to the review process flow graphic to include the 14 calendar days the primary reviewers receive for their initial review and the additional 14 days they receive to prepare any helpful documentation that may be needed to make a recommendation. The motion to approve was made by Genia Fick and seconded by Jan Hanley.

The following members voted to approve the manual: Paul Bouganim, Miranda Dietz, Genia Fick, Cora Han, Jan Hanley, Terry Hill, Barbara Koenig, Nuriel Moghavem and Daniel Ruiz.

The motion to approve the minutes was carried by a vote of nine in favor.

Public Comment:

There was no public comment.

Agenda Item IV: Pricing Schedule

Chris Krawczyk, Chief Analytics Officer, HCAI

Chris Krawczyk, Chief Analytics Officer, HCAI outlined the purpose of the presentation, which was to discuss and review various use cases for data release. The aim was to familiarize the committee with different topics and stimulate dialogue to understand the considerations and requirements for data release. The presentation covered statutory requirements and optional considerations for data release, emphasizing privacy, transparency, and benefit to California. The importance of context and the uniqueness of each request was also discussed, highlighting the need for iterative learning in the review process. Specific considerations regarding personally identifiable information (PII) and indirect identifiers were addressed. The first use case reviewed concerned the prevalence and treatment of asthma in adolescent patients. Discussion questions were provided to guide the conversation around statutory mandates, privacy concerns, and program goals.

Questions and comments from the committee:

Regarding the first use case, the committee inquired about the necessity of personally identifiable data, suggesting that indirect identifiers like census track could suffice for geographic variation and socioeconomic factors. HCAI acknowledged this point, pointing to the question of whether the researcher needed a dataset with direct identifiers. The committee emphasized the importance of aligning data requests with the research goal and minimizing the release of unnecessary information.



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The committee highlighted the need for individual-level data to analyze treatment patterns and access to care and asked about the necessity of personally identifiable information for tracking patients across different healthcare providers. The committee emphasized the importance of understanding the specific definition of PII to make informed decisions about data requests.

The discussion also touched on the sensitivity of pediatric data, potential commercialization concerns, and the need for clarity on terms like Protected Health Information (PHI) and PII. The committee suggested having a reference sheet for committee members to ensure consistency in their approach. The committee raised the point that requesting Medi-Cal data could indicate the need for additional scrutiny due to the rigorous vetting process.

The committee agreed on the importance of understanding the research question and ensuring that data requests align with the stated objectives. The committee expressed interest in examples of commercialization concerns, prompting a discussion about targeted marketing and commercial exploitation of healthcare data.

The committee discussed a request for direct transmission of data for the second use case regarding care variation for adults with diabetes. The purpose aligned with program goals, focusing on transparency for healthcare cost utilization, quality, and equity, as well as informing policy discussions and improving public health. Concerns were raised about the amount and specificity of the data requested, as well as the motivations and capacity of the requesters, particularly advocacy groups potentially allied with commercial interests. Security and privacy risks associated with direct transmission were highlighted, with emphasis on the need for thorough vetting of requesters' systems and adherence to data use agreements to prevent re-identification. Consideration was given to the potential benefits of direct transmission for innovative analysis but with caution due to the data privacy security implications. The committee emphasized the importance of clear justification for direct transmission requests and robust controls to ensure data integrity and privacy.

HCAI facilitated a discussion regarding the third proposed use case involving the linking of a disease registry with HPD data for research purposes. Nuriel Moghavam, DRC Chair presented the use case, outlining the hypothetical requester's intent to combine data sources to analyze patient care and treatment costs, with a focus on comparing matching algorithms. The committee engaged in discussions addressing program goals, privacy concerns, collaboration with state agencies, and potential uses of the data. Concerns were raised regarding privacy, direct data transmission, and the potential for



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nefarious use of the data. The committee emphasized the importance of understanding the requester's motives, particularly regarding performing healthcare cost analyses. The committee also highlighted the potential benefits and risks of creating a more complete patient record. The committee provided a perspective on analyzing healthcare costs and cautioned against unnecessary data sharing. The committee discussed the complexities of using cost data and the challenges in discerning motives. The committee also inquired about the lifecycle of the data and its distribution. HCAI addressed concerns regarding data transmission and the difficulty in monitoring data usage once it leaves the organization's control.

Public comment:

There was no public comment.

Agenda Item V. Next Meeting Topics

Nuriel Moghavem, DRC Chair

Nuriel Moghavem provided a preview of the next DRC meeting agenda, including:

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

The April 17 meeting has been cancelled and the next meeting is scheduled for May 15 from 1:00 p.m. to 4:00 p.m. and will be an in-person meeting at the Sacramento (2020 West El Camino Ave, Conference Room 1237, Sacramento, CA 95833) and LA offices (355 South Grand Avenue, Conference Room 1901, Los Angeles, CA 90071).

Questions and comments from the committee:

There were no comments from the committee.

Agenda Item VI: Public Comment for Items Not on the Agenda

Nuriel Moghavem, DRC Chair

There was no public comment.

Agenda Item VII: Adjournment

Nuriel Moghavem, DRC Chair

The meeting was adjourned at 3:48 p.m.