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NOTICE OF PUBLIC MEETING

HEALTH CARE PAYMENTS DATA PROGRAM (HPD)

DATA RELEASE COMMITTEE (DRC)

Date:

January 17, 2024 Draft Meeting Minutes

Members Attending: Miranda Dietz, Project Director, California Simulation of Insurance Markets (CalSIM); Cora Han, Chief Health Data Officer; Terry Hill, Physician Consultant, Researcher, Writer; Koh Kerdsri, Vice President, Risk Adjustment, Compliance, and IT; Barbara Koenig, Professor Emerita of Bioethics; Daniel Ruiz, Vice President, Operations Quality; and Janet Coffman, Professor, Institute for Health Policy Studies.

Members not in attendance: Paul Bouganim, Executive Director, Finance Operations; Nuriel Moghavem, Clinical Instructor of Neurology; Genia Fick, Vice President, Quality and Jan Hanley, Director of Research Programming.

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

Public Attendance: 70

Agenda Item I: Welcome and Meeting Minutes

Miranda Dietz, DRC Vice Chair

Miranda Dietz, DRC Vice Chair, welcomed the committee and members of the public. The committee members conducted a roll. The chair reviewed the meeting ground rules and read the HPD program goals and statement from the committee. Janet Coffman volunteered to read the statement at the next public meeting.

The committee reviewed and approved the meeting minutes from the November 7, 2023, DRC Meeting. The motion was made by Terry Hill and seconded by Barbara Koenig.

The following members voted to approve the minutes: Janet Coffman, Barbara Koenig Miranda Dietz, Terry Hill, and Koh Kerdsri.

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Cora Han abstained from voting.

Daniel Ruiz was absent from voting.

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

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 November Meeting Recap

Miranda Dietz, DRC Vice Chair Chris Krawczyk, Chief Analytics Officer

Miranda Dietz, DRC Vice Chair, gave a recap of the previous session, highlighting discussions on the application's appearance in the data enclave, pricing schedule, committee roles, statutory criteria, and workflow logistics.

HCAI then provided updates on Bagley Keene Open Meeting Act requirements, emphasizing the need for in-person meetings per statute.

The next segment covered the regulations package progress, with a second 45-day public comment period closing on February 1. HCAI aims to finalize the regulations package by Quarter Two (Q2) of 2024, allowing for HCAI to formally begin accepting applications requesting the release of non-public data.

The anticipated 2024 topics for the DRC were outlined, including discussions on the pricing schedule, committee manual, and simulated use cases in Quarter One (Q1) and Q2. Simulated use cases will involve trial discussions with a science advisor's feedback to prepare for actual requests in Q2 to Quarter Three (Q3).

HCAI explained that the timeline will be dependent on the request's nature and processes, involving committee reviews, human subjects review, and departmental assessments. Initial reviews are expected to begin in Quarter Four (Q4) and an evaluation of data release operations and processes will be scheduled for the end of the year.

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Questions and comments from the committee:

The committee raised a question about potential delays of the regulations package from the Office of Administrative Law (OAL). HCAI explained that the OAL does not provide definitive responses until they receive the final package, but efforts were made to address their criteria.

The committee recapped key information for potential data applicants, highlighting the expected availability of the HPD application in the second half of the year. HCAI suggested signing up for the HPD's listserv for quick updates on the go-live date.

The discussion touched upon the intersection of the responsibilities of the DRC and that of the HPD Advisory Committee (AC). HCAI mentioned an upcoming January AC meeting will be focused on the potential for the HPD to integrate with public health functions and that the April AC meeting will be focused on the status of the data release program, including the pricing schedule.

The committee expressed interest in hearing about substantive matters from the AC meetings closely related to data release. HCAI explained the AC's scheduled cadence, with specific themes for each quarterly meeting, such as strategy, data release, data collection, and public reporting. Chair Nurel Moghavem has been invited to join the April AC meeting for the discussion of the data release program.

Public Comment:

There was no public comment.

Agenda Item III: Pricing Schedule

Chris Krawczyk, Chief Analytics Officer, HCAI

HCAI provided an update on the planning for the pricing schedule, expressing gratitude for feedback received during the November meeting. The presentation summarized the initial proposal, shared the intended direction for future revisions to the proposal, and discussed upcoming steps.

The presentation also summarized the feedback received at the November meeting, including the overall price of the data, the definitions for criteria for price reductions, and the issues with a first-come, first-served approach to applying reductions.

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HCAI discussed the challenges and trade-offs in managing the available budget for data enclave price reductions, especially when projects extend over multiple years. HCAI emphasized the need to monitor expenses, cost recoveries from data access prices, and the impact of carrying price reductions forward on future budgets.

The presentation concluded with HCAI describing how it intended to revise the pricing schedule proposal based on DRC and stakeholder feedback. HCAI intends to present the pricing schedule at the April HPD AC meeting.

Questions and comments from the committee:

The committee asked why the Centers for Medicare & Medicaid Services (CMS) data could not be accessed within the HPD, and speculated whether CMS imposes restrictions for revenue-generation. HCAI clarified that discussions are ongoing with CMS about data availability and that other states face similar challenges.

The committee emphasized the importance of predictability in pricing for researchers seeking funding. They suggested a tiered-pricing structure to accommodate different budgets and clear criteria for price reductions to ensure fairness. The committee raised concerns about the first-come, first-served approach, suggesting considerations for prioritizing projects based on public health goals and funding availability for researchers, especially early-career investigators. The committee emphasized the need to account for the complexity of data requests, including scenarios where additional time or resources are required to complete analyses or add variables, which may extend beyond a license's calendar year.

The committee proposed the idea of external philanthropic foundations contributing funds for specific high-priority research areas.

Public Comment:

There was no public comment.

Agenda Item IV. DRC Manual Review

Tara Zimonjic, Chief Planning Officer, HCAI

Prior to the start of this agenda item, the committee raised a procedural question regarding the allocation of time in the agenda to discuss travel reimbursement for the committee. HCAI offered to address questions after the meeting and send out broader email clarifications.

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The committee also expressed confusion about the discussion on the approval of minutes regarding who needs to sign actual data use agreements (DUAs).

The committee explained that there was an email exchange regarding the understanding of how institutions handle DUAs. The standard practice at institutions like University of California, San Francisco is to have an institutional official sign DUAs rather than individual investigators. The committee highlighted the importance of involving institutional officials in signing DUAs, especially when liability for the use of information data is involved. The committee raised the issue of potential challenges if the signature of one faculty member is deemed insufficient, leading to difficulties in obtaining campus signoffs.

The committee requested HCAI to follow up on ensuring clarity for users, including those outside the University of California system, about the requirement for institutional officials to sign DUAs. The committee suggested discussing the issue with other state agencies and possibly consulting with individuals to understand the requirements.

HCAI presented the DRC Manual, soliciting feedback and comments from the committee.

Questions and comments from the committee:

Proceeding to section one of DRC Manual, HCAI reviewed the two minor changes: alignment of program goals language and removal of HPD emergency regulation reference.

The committee raised a concern about the figure identifying the Request Process Flow and suggested moving the figure to section three. The committee also noted that a prior version of the DRC board manual had more details on the specifics of the data types that will be available for release and discussed that since that information was moved out of this final version it would be helpful to incorporate some regulatory definitions into the document glossary. The committee suggested quoting regulations in the document for clarity and emphasized the importance of supportive documentation for data types.

Proceeding to section three, the primary topic was the review timeline and process for primary reviewers and the rest of the committee members. The committee raised a concern about potential confusion regarding the 14-day review period. There was a discussion about whether there should be two sets of 14-day reviews or just one. Eventually, it was clarified that primary reviewers would have 14 calendar days to

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review an application, followed by an additional 14 days to prepare necessary documents and for the rest of the committee to review the application excerpts.

The conversation then shifted to the sequential review process and whether concurrent reviews by two primary reviewers would be possible. The committee expressed a preference for simultaneous independent reviews.

HCAI acknowledged the committee's feedback and committed to exploring technological solutions or manual workarounds to allow for simultaneous independent review rather than sequential. The committee suggested looking into systems used by other organizations that allow for concurrent reviews.

The discussion also touched on whether the two primary reviewers should meet and come up with a joint recommendation before the meeting or review independently. The committee determined that it would be easier to not require the primary reviewers to meet in advance of the meeting, but that it would be helpful to have a template for primary reviewers to structure their recommendations was suggested.

HCAI summarized the key takeaways, including the desire for concurrent reviews, the preference for not requiring primary reviewers to meet before the meeting, and the potential use of a template to organize thoughts. The discussion concluded with an affirmation of the 14-day review timeframe and a commitment to refining the application review process based on the feedback received.

The committee sought clarification on whether choosing "not recommended" means having veto power or just a recommendation. HCAI confirmed that the DRC has veto power, meaning that if the DRC does not recommend an application to receive data HCAI is not able to provide that data for the requestor. If the DRC recommends an application for approval, HCAI may still deny the application.

A question arose about the appeal process in case of denial, and it was clarified that there is no appeal process outlined in the regulations. The committee suggested including a sentence or reference to make it clear that once denied, there is no appeal process.

HCAI expressed gratitude for the engagement and feedback and outlined the next steps, focusing on refining the data release process portion in the manual and clarified that the final decision-making authority for application approval rests with the HCAI director or their delegate.

Public comment:

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There was no public comment.

Agenda Item V. Next Meeting Topics

Miranda Dietz, DRC Vice Chair

Miranda Dietz provided a preview of the next DRC meeting agenda, including:

- Review of previous DRC discussions
- Application Review Simulation
- DRC Manual Review

The February 21 meeting has been cancelled and the next meeting is scheduled for March 20 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).

HCAI addressed the complexity of virtual participation under the new Bagley-Keene rules. HCAI mentioned ongoing discussions about the option for virtual participation, which is allowed if physical presence guidelines are met. The committee suggested assuming all future meeting will require in-person attendance.

Questions and comments from the committee:

There were no comments from the committee.

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

Miranda Dietz, DRC Vice Chair

Public comment:

There was no public comment.

The meeting was adjourned at 1:05 p.m.