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NOTICE OF PUBLIC MEETING

HEALTH CARE PAYMENTS DATA PROGRAM (HPD)

DATA RELEASE COMMITTEE (DRC)

Date:

June 6, 2023 Draft Meeting Minutes

Members Attending: Nuriel Moghavem, Clinical Instructor of Neurology; Janet Coffman, Professor, Institute for Health Policy Studies; Miranda Dietz, Project Director, California Simulation of Insurance Markets microsimulation model (CalSIM); Genia Fick, Vice President, Quality; Cora Han, Chief Health Data Officer; Terry Hill, Physician Consultant, Researcher, Writer; Barbara Koenig, Professor Emerita of Bioethics; Daniel Ruiz, Vice President, Operations Quality.

Members not in attendance: Jan Hanley, Director of Research Programming; Koh Kerdsri, Vice President, Risk Adjustment Operations, Compliance & IT.

HCAI Presenters: Chris Krawczyk, Chief Analytics Officer; James Yi, Attorney; Jasmine Neeley, Research Data Analyst I.

Public Attendance: 70

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 roll call and reviewed the virtual meeting ground rules. It was announced that due to extenuating circumstances, Larry deGhetaldi resigned from the committee, HCAI is in the process of recruiting his replacement.

The committee reviewed and approved the meeting minutes from the May 2, 2023, DRC Meeting. The motion was made by Genia Fick and seconded by Janet Coffman.

The following members voted to approve the minutes: Janet Coffman, Miranda Dietz, Genia Fick, Cora Han, Barbara Koenig, Nuriel Moghavem.

Terry Hill abstained from voting.

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Daniel Ruiz was absent from voting.

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

Questions and comments from the committee:

The committee complimented the quality of the minutes.

Public comment:

There was no public comment.

Agenda Item II: HPD Program Updates and May Meeting Recap

Nuriel Moghavem, DRC Chair Chris Krawczyk, Chief Analytics Officer, HCAI

The chair provided a brief overview of the topics discussed at the May meeting, including the use cases for HPD products and the roles of HCAI and the DRC in the HPD data release process.

The chair also discussed the follow-up items presented at the May meeting and included dates when these items will be discussed.

Chris Krawczyk, provided an overview of the data release program updates, reviewed the HPD access and release objectives, statutory provisions, HCAI and the DRC's role, and anticipated topics, and outlined the "crawl, walk, run" approach to building out the HPD Program.

Questions and comments from the committee:

The committee asked if the regulations, which are currently out for public comment, and the HPD Snapshot public report, when released, could be shared and reviewed by additional stakeholders. The committee was encouraged to share the regulations and information about the HPD Snapshot whenever possible and to let HCAI know what assistance they can provide to make information easy to share. HCAI confirmed that the first product released to the public will be the HPD Snapshot. The interactive data measures product, to be released in the late third or early fourth quarter of 2024, will include visualizations displaying chronic conditions, utilization, and demographics, allowing users to explore the care and characteristics of Californians within the database. The first cost product to be released will be associated with prescription drug costs. HCAI will be accepting feedback from users on how the products are being used

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and what elements the users feel could be incorporated into future generations of the product.

The committee asked if more information will be provided for users who want to apply for use of the data through the enclave or obtain Standard Limited Datasets (SLDs). The committee was informed that HCAI is developing the aggregate and deidentified products available in the enclave – currently SLDs, custom limited, and research identifiable data – and are scheduled to be available in the first quarter of 2024 upon receipt of the initial applications. HCAI noted that the applications for SLDs may be evolved into requests for custom limited data, which will allow HCAI to determine how the SLDs can be modified for the future to meet the greatest use.

The committee noted the term "data product" from a patient's perspective, may be problematic as it connotes patients' data may be a commodity.

The committee was informed that there will be a fee waiver process for those who may want the data but do not have the means to pay for it included in the regulations package. The committee encouraged the public to give feedback on the regulations package.

Public Comment:

There was no public comment.

Agenda Item III: Standard Limited Data Sets

Chris Krawczyk, Chief Analytics Officer, HCAI

Chris Krawczyk provided an overview of the purpose and approach to the HPD SLDs, which was revised based on stakeholder feedback.

Questions and comments from the committee:

The committee was encouraged to provide feedback on the SLD approach. The committee expressed appreciation for the revision to the previously presented SLD approach, which now includes the SLD+ option, in addition to the SLD. The SLD+ includes entity identifiers and financial information.

The committee asked whether provider identifiers could be accessed using the SLD+ and was informed that data released outside of the enclave will need to adhere to the Data Deidentification Guidelines (DDG). The committee commented that there should be a distinction between protecting the privacy of people using health care services and the privacy of health plans and providers. The committee suggested identifying plans

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and providers may be necessary to satisfy analytical use cases intended to contain health care costs. The committee made comment that it may be appropriate for the DRC in particular to render its review and recommendation to HCAI on the SLD+ datasets, since they include the more detailed information.

It was noted that HCAI will be working with stakeholders to establish initial criteria for how the requests for provider and payer identifiers will be evaluated, including if there are any potential concerns of anticompetitive behavior, and noted that the criteria will be refined as use cases are received and as HCAI better understands what anticompetitive behavior is possible.

The committee reiterated their concern regarding patient confidentiality, sensitivity of data for patients, and those providing gender affirming care or other sensitive procedures, however, the committee does not consider provider spending data sensitive. HCAI and the DRC will work as partners to ensure that provider spending data is not being released for nefarious reasons that may relate to antitrust. The committee agreed that caution should be used when releasing provider level data, however, using caution when releasing plan and delivery system level data may not be consistent with HPD program goals.

The committee inquired about lessons learned from other states with All Payer Claims Databases, and how HPD might use the experiences of others to determine what should be released. The committee was informed that HCAI has been engaging with stakeholders about potential use cases and has found that other states have been conservative in their process for data release. The committee clarified that California should be more ambitious than other states given the political pressures and awareness of the cost of medical care.

The committee commented that Employee Retirement Income Security Act of 1974 (ERISA) data and Medicare fee for service (FFS) data will be missing from the HPD data and researchers may choose to link that data with the HPD data themselves. The committee asked if there are plans to provide guidance on that process or to create products in the future that will do the linkage for the researchers. The committee was informed that linkage discussions will take place in the future, and that HCAI would be interested in hearing approaches from potential users on how they would incorporate that data with the HPD data.

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The committee was informed that the SLDs include Covered California data and the exchange population, the Covered California information will be received through the commercial plans and insurers.

Public Comment:

There was no public comment.

Agenda Item IV: HPD Data Application Outline

Jasmine Neeley, Research Data Analyst I, HCAI

Jasmine Neeley provided an outline of the content included in the HPD data request application.

Questions and comments from the committee:

The committee asked about HCAI's history with data breaches, given that larger institutions may have a history of data breaches that individual research teams are unable to control. The committee was informed that there is no exclusive basis for approval or denial based on the researchers answers regarding data breaches, the questions are to determine if the researchers had any involvement in the breaches, and if so, their requests in totality would be considered on a case-by-case basis. The committee inquired about large organizations that may be international and have branches of the organizations in countries where data is less regulated and if requestors within those organizations will be required to disclose information about data breaches and fines paid internationally. The committee was informed that requestors are asked to voluntary disclose history of data breaches from the last seven years and convictions or civil action information, which could encompass international law. Additionally, the regulations state that the HPD data must be housed in the United States.

The committee was informed that multi-project applications will be considered in the future.

The committee commented that the distinction between research and non-research, such as for program evaluation, may begin to muddle as HPD grows and that this will be an important consideration going forward.

The committee was informed that the data request form is not a part of the regulations package, however, it is based on the regulations. The committee will receive a copy of

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the application once the regulations are finalized. The committee inquired on the gualifications and prior experiences for researchers that may be new to research. The committee was informed that the qualifications will be used differently based on the types of data that are being requested. For research identifiable data the qualifications will be used to ensure the requestor meets the definition of researcher and for SLDs accessed in the enclave, the qualifications are used more as contact information. For the more sensitive types of data, experience will be used to determine the requestors history with working with secure datasets, however, not having experience would not be a reason for denial. The committee was informed that when the data request form asks about linkages it is inquiring what the requestor plans to do with the linked dataset and that the linkage questions are more applicable to research identifiable datasets. The committee inquired whether funding source is required on the request and was informed that funding source is only asked on the application for requests involving DHCS data, but some requests will include questions that ask the researcher who the research is being done for. Per the regulations, HCAI has the flexibility to request additional information. The committee expressed interest in having funding source as a required field for each request.

Public Comment:

There was no public comment.

Agenda Item V: Application Review Process

Chris Krawczyk, Chief Analytics Officer, HCAI James Yi, Attorney, HCAI

Chris Krawczyk and James Yi discussed the review process for HPD data requests to be conducted by HCAI, including the DRC, and the scope of the DRC's reviews.

Questions and comments from the committee:

The committee was informed that data will only be released to requestors that have physical servers in the United States. The committee was informed that the 120-day timeline for requests is the upper limit of the turnaround time and may be more applicable for research identifiable datasets as opposed to SLDs. The committee recommended that the public be informed that SLD requests are not expected to take up the 120-day timeline. The committee requested that evaluations be completed regarding the turnaround time and other metrics for applications in the future.

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The committee inquired about the length of DRC review within the 120-day timeline and was informed that various factors will determine how long each review is, and the factors will remain unknown until the HPD begins accepting data requests. The 120-day timeline was selected based on historical experience for HCAI's other administrative datasets.

The committee asked whether there is a possibility of concurrent reviews involving partner organizations such as DHCS and the Committee for the Protection of Human Subjects (CPHS). The committee was informed that HCAI is in discussion with partner organizations regarding the potential for concurrent reviews, however, the partner organizations have their own guiding statutes and regulations that will need to be adhered to as well.

The committee discussed the current proposed process of review, including the duties of the primary and secondary reviewers and having applicants available to answer questions. The committee confirmed that HCAI would be doing an extensive review prior to the applications going to the subcommittee and asked that there be a way for members to provide their availability for accepting reviews and a different subcommittee be assigned to each project instead of one subcommittee being assigned to all the projects at the meeting.

The committee had a robust discussion regarding how to determine the members of the subcommittee for review of projects, including developing expertise in subject matter and how applications should be assigned while the review process is evolving. The committee agreed that applications should be assigned at random while the review process is under development. The committee recommended a cap on reviews each month once the factors for review, such as volume of applications and committee availability, have been determined.

The committee noted that conflicts of interest will also take precedent when choosing reviewers and that HCAI will need to determine what is considered a conflict to counteract bias. The committee was informed that HCAI's formal conflict of interest policies relate to financial conflicts, personal interests in the outcomes or reviews, and incompatible activities. The committee recommended that HCAI gather conflict of interest policies from other entities to create a DRC conflict of interest policy within the HPD DRC Board Manual.

Public Comment:

There was no public comment.

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Agenda Item VI: HPD Data Use Agreement

James Yi, Attorney, HCAI

James Yi gave an overview of Data Use Agreements (DUAs) from HCAI and other entities and discussed potential HPD DUA provisions and subject areas.

Questions and comments from the committee:

The committee confirmed that statute limits the public release of HPD data to only deidentified aggregate data.

The committee had a robust discussion about the requestor vs. the institution being the responsible party for upholding the requirements stated in the DUA. The committee noted that having the requestor responsible for indemnification if the DUA is broken may not lead to any action by the requestor to the responsible member of their group. The committee was informed that HPD statute requires that every person who accesses the confidential data will have to sign the DUA, which will encompass the possibility of downstream misuse.

Public Comment:

There was no public comment.

Agenda Item VII. Next Meeting Topics

Nuriel Moghavem, DRC Chair

Nuriel Moghavem provided a preview of the September DRC meeting agenda. Topics for the September meeting include:

- Review of Previous DRC Discussions
- Data Quality and Completeness
 - HPD Linkages to Other Data Sources
- DRC Policies and Rubric for Review
- DRC Board Manual Review

The committee also included additional follow up items, which include:

- A follow up from the meeting with the advisory committee members who represent patient advocacy groups
- Information on conflicts of interest

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The next meeting will be held on September 5 from 9:00 a.m. to 1:00 p.m. and will be held in person.

It was also noted that at the next HPD Advisory Committee meeting on July 27, there will be a demonstration of the HPD Snapshot Dashboard and preview of the Measures Dashboard.

Questions and comments from the committee:

There were no comments from the committee.

Agenda Item VIII: Public Comment for Items Not on the Agenda Nuriel Moghavem, DRC Chair

Public Comment:

There was a comment from the Nor Cal Carpenters Union expressing concern about premium rate increases for their Kaiser Permanente health plan.

The meeting was adjourned at 12:46 p.m.