Department of Health Care Access and Information
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NOTICE OF PUBLIC MEETING

HEALTH CARE PAYMENTS DATA PROGRAM (HPD)

DATA RELEASE COMMITTEE (DRC)

Date:

May 2, 2023
Approved Meeting Minutes

Members Attending: Miranda Dietz, Project Director, California Simulation of Insurance Markets microsimulation model (CalSIM); Genia Fick, Vice President, Quality; Cora Han, Chief Health Data Officer; Jan Hanley, Director of Research Programming; Koh Kerdsri, Vice President, Risk Adjustment Operations, Compliance & IT; Barbara Koenig, Professor Emerita of Bioethics; Nuriel Moghavem, Clinical Instructor of Neurology; Daniel Ruiz, Vice President, Operations Quality.

Members not in attendance: Janet Coffman, Professor, Institute for Health Policy Studies; Larry deGhetaldi, Vice President Government Medical Affairs; Terry Hill, Physician Consultant, Researcher, Writer.

Presenters: Merry Holliday-Hanson, Research Scientist Supervisor, HCAI; Chris Krawczyk, Chief Analytics Officer, HCAI; James Yi, Attorney, HCAI; Jonathan Mathieu, Freedman HealthCare; Jasmine Neeley, Research Data Analyst I, HCAI; Larry Dickey, MD, MPH, MSW, CPHS Vice Chair; Tara Zimonjic, Chief Planning Officer, HCAI.

Public Attendance: 86

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; Jan Hanley, Barbara Koenig, and Daniel Ruiz were absent from roll call but joined the meeting later; and the chair reviewed the virtual meeting ground rules.

The committee reviewed and approved the meeting minutes from the March 7th, 2023, DRC Meeting. The motion was made by Miranda Dietz and seconded by Koh Kerdsri.

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The following members voted to approve the minutes: Koh Kerdsri, Nuriel Moghavem, Cora Han, Miranda Dietz, Jan Hanley, Daniel Ruiz.

Genia Fick abstained from voting.

The following members were absent from voting: Larry de Ghetaldi and Barbara Koenig.

Questions and comments from the committee:

There were no questions or comments from the committee.

Agenda Item II: HPD Program Updates & March Meeting Recap
Nuriel Moghavem, DRC Chair
Chris Krawczyk, Chief Analytics Officer, HCAI

The chair provided a brief overview of the topics discussed at the March meeting, including the considerations for release, privacy, entity and financial information, and sensitive conditions and vulnerable populations.

The chair also discussed the follow-up items presented at the March meeting, provided an update regarding NIH requirements, and addressed when other follow up items will be discussed.

Chris Krawczyk, Chief Analytics Officer at HCAI, set the framing for the day by reviewing the HPD program goals, objective, role, review process flow, and anticipated topics. He also prefaced the meeting topics by discussing the partner organizations and committees that will be involved with the HPD and gave an overview of the standard limited datasets (SLD).

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Questions and comments from the committee:

The committee inquired if the decisions regarding types of released datasets will be made available to the public. The committee was informed that the public meetings will serve as a forum for public engagement for the HPD program, and the public will have the opportunity to engage with the DRC to get an understanding of how the data is being used and what types of requests are being approved for release. The committee was advised that the public will be informed about the "crawl, walk, run" approach for what datasets are accessible. The committee was informed that HCAI will be analyzing the requests using business intelligence for elements such as number of requests and audiences for file types and the time span from submission to approval to determine how the data request process may be improved.

The committee expressed interest in discussing the process for obtaining Medicare fee for service (FFS) data, as was discussed in the April 27th HPD Advisory Committee meeting. The committee was informed that HCAI attempted to appeal the decision from the Center for Medicare & Medicaid Services (CMS), regarding the data only being available to state entities, but CMS was clear about the restrictions. HCAI is continuing to work with CMS on the issue.

The committee asked about the process for taking data analysis from SLDs out of the enclave. The committee was told that when a user wants to extract data out of the enclave, the data will need to be de-identified per the Data De-identification Guidelines (DDG) prior to extraction. HCAI will review the aggregated data products and will confirm that it meets the DDG prior to being authorized for release outside of the enclave.

The committee inquired about which of the two committees, the HPD Advisory Committee, or the DRC, will have final approval recommendations and determine what is included in the SLD. It was clarified for the committee that although input from both committees is welcome and considered, HCAI will be the final approver. The committee inquired on potential expansions to the SLD—using the crawl-walk-run approach—and if there will be a roadmap shared with the public that shows the growth of the SLD over time. The committee was informed that the DRC public meetings and the HCAI website will be the mediums used to inform the public of all improvements to the HPD datasets.

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The committee inquired about the statutory guidelines for misuse and was informed that HCAI has operations in place for its existing data programs and products and will work with the DRC to develop any further operations specifically for HPD, if needed.

Public Comment:

There was no public comment.

Agenda Item III: Use Cases for HPD Data Product, e.g., Standardized Limited Data, Custom Limited Data, and Research Identifiable Data
Chris Krawczyk, Chief Analytics Officer, HCAI
Jonathan Mathieu, Freedman HealthCare

Chris Krawczyk, Chief Analytics Officer at HCAI, and Jonathan Mathieu at Freedman HealthCare, gave an overview of the kinds of use cases HCAI observes for current data products and the use cases for other All Payer Claims Databases (APCDs) using various data products.

Questions and comments from the committee:

The committee inquired if data from the California Cancer Registry (CCR) will be available for linkage to the HPD data or if a crosswalk will be made available to link identifiers. The committee was informed that since HPD will be managed by a different entity than CCR that it will require coordination to link the two, and that the conversation around linkage with the DRC is planned for September. The committee encouraged the HPD team to work with other state entities who have access to other highly requested data points for linkage to support building out a comprehensive approach to data linkage.

The committee inquired about the potential use of artificial intelligence (AI) for data analysis. The committee was informed that since HCAI is currently in the crawl stage of the development of the HPD program, that HCAI will be reviewing requests on a case-by-case basis to evaluate the intended use, the appropriateness of use, and how the use will contribute to the HPD goals.

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The committee commented that payer and provider information is going to be highly sought after by requestors and that not including this information in the standard limited dataset will affect timeliness, cost for researchers, and committee workload. The committee suggested that this information be included in the SLD or be available at a reduced cost and expedited basis. The committee was thanked for the suggestion and informed that similar feedback was provided by the HPD Advisory Committee. HCAI is in the process of reviewing the feedback received and determining how to finalize the approach to the SLDs. The committee asked whether they could advise requestors on which datasets would better accompany their requests and were informed that both HCAI and the DRC would have the ability to guide requestors to an approved request, based on their intended use case.

The committee asked about the level of granularity included in the data visualizations shared with the committee, and if the application review process will include vetting for data used and shared in potentially public forums. The committee was informed that part of the application process will include what types of public information will be generated using the data and where it will be presented. Once the visualizations are completed, they will need to be submitted to HCAI and adhere to the DDG. The committee was also informed that with other APCDs small cell sizes are suppressed in visualizations.

The committee inquired about metrics related to data completeness; metrics will assist requestors in determining if the data available will meet their needs. The committee was informed that as HPD moves forward, the data completeness and quality will continue to mature over time. The committee commented that the visualizations that HCAI currently provides can be thought of as another form of public engagement and raised the importance of obtaining the public input in the selection for which topics to create visualizations.

Public Comment:

There was a public comment inquiring if the record linkage numbers currently utilized in the inpatient and emergency department datasets will match the identifiers used for patients in the HPD. The public was informed that there will be no direct match between HCAI's current datasets and the HPD data and that linkage will be part of a future discussion as HCAI is interested in the use cases that would involve HPD data and other databases.

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Agenda Item IV: Data Release Process: HCAI's Role
Merry Holliday-Hanson, Research Scientist Supervisor, HCAI
Jasmine Neeley, Research Data Analyst I, HCAI

Merry Holliday-Hanson, Research Scientist Supervisor at HCAI and Jasmine Neeley, Research Data Analyst I at HCAI, gave an overview of HCAI's current approach to data access requests and HCAI's role in data release.

Questions and comments from the committee:

The committee asked for the rationale behind requiring special justification when requesting Entity and Financial Information (EFI). The committee was informed that special justification is required for EFI to minimize the risk of anticompetitive or antitrust behavior. HCAI is still in the process of developing the standard limited dataset file specifications, and the inclusion of EFI information, pursuant to the crawl-walk-run approach. HCAI will be reviewing each request on a case-by case basis to determine the purpose of the request and ensure that it is meeting HPD goals.

Re-identification of individuals is a prohibited use of the HPD data, and the data in the HPD system is exempt from Public Records Act (PRA) requests. The committee inquired if Committee for the Protection of Human Subject (CPHS) review is required for requests not involving a standard limited dataset and were informed that per statute CPHS review is required only for research identifiable data.

The committee discussed their role in the data access process coming after CPHS and the Department of Health Care Services (DHCS). Given the fact that their review comes after other reviewers, the committee suggested that one way to operationalize their review of requests would potentially be to form a small subcommittee to preview applications that will later come to the committee for approval recommendations, to ensure that the committee is comfortable with the revisions made during the review process.

Public Comment:

There was no public comment.

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Agenda Item V: Data Release Process: Other Reviewer's Role
Jasmine Neeley, Research Data Analyst I, HCAI
Larry Dickey, MD, MPH, MSW, CPHS Vice Chair

Jasmine Neeley, Research Data Analyst I at HCAI, and Larry Dickey, MD, MPH, MSW, CPHS Vice Chair, provided an overview on the DHCS and CPHS role in the data release process.

Questions and comments from the committee:

The committee asked how CPHS evaluates projects to determine if they are research or quality improvement. The committee was informed that CPHS evaluates applications using the federal definition of research found in the Common Rule, which is the systematic investigation for the purpose of creating generalizable knowledge; for instance, if a project is for program evaluation or improvement, CPHS would not consider it research and their review and approval would not be required. It is common for departments to reach out to CPHS prior to submitting a request explaining the intent of their study so that CPHS can advise on whether the study could be considered research.

It was clarified for the committee that HPD has its own statutes and requirements outside of the IPA that require CPHS review for certain data requests, and each requester may have their own requirements that may also require an Institutional Review Board (IRB) review.

The committee confirmed that only requests that could be defined as research using the federal Common Rule would need CPHS review and approval, however, requests for custom limited datasets will need to be reviewed on a case-by-case basis. The committee inquired about institutions using their own IRBs as the sole reviewer of studies and were informed that CPHS can delegate reviews to other institutions.

Public Comment:

There was no public comment.

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Agenda Item VI: Data Release Process: DRC's Role
Tara Zimonjic, Chief Planning Officer, HCAI

Tara Zimonjic, Chief Planning Officer at HCAI gave an overview of the DRC's role in reviewing applications, discussed the administrative process of other public data review committees, and presented proposed approaches for the DRC process.

Questions and comments from the committee:

The committee asked if the consent calendar used by the Vital Statistics Advisory Committee (VSAC) could allow for discussion on one of the projects on the calendar only, or if the projects had to be voted on as a whole. The committee was informed by a member of VSAC, Chris Krawczyk, that with the consent calendar approach a project can be removed from the calendar to discuss it individually through a motioned vote.

The committee inquired on CPHS' public discussion of research requests that may contain proprietary information about the research project. The committee was informed that although CPHS is subject to Bagley Keene, the committees does not publish the research requests and their materials online. The posted agenda contains the title of the proposals and the name of the principal investigator and their institution. If a member of the public wanted copies of the research requests, they would need to submit a public records request and then CalHHS's lawyers would determine how the request could be fulfilled.

The committee inquired about how the DRC would be informed if a request that they recommended for approval received final approval. The committee was told that if a request needed changes those changes would need to be fulfilled prior to DRC review. In the case of VSAC, all requests that have made it to the committee have received approval. HCAI encouraged the committee members to make suggestions about how the final status of requests can be best communicated to them.

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The committee asked when meeting materials would be assigned to committee members for review, suggesting a hard date, such as five business days prior to the meeting. The committee was informed that the time frames will be determined once HCAI is able to ascertain the volume of applications that will need to be reviewed. The committee voiced concern that with a greater the amount of time that the committee has to review a request, such as two weeks prior to the meeting, there would be increased pressure on staff to complete an adequate preliminary review and the requestors to provide all the necessary information and may cause a significant delay in the review time. Currently, the DRC is set to meet monthly in 2024, which may change dependent on the volume of requests. The committee suggested that application review be conducted by grouping so that several members are responsible for reviewing applications during one period of time while others are responsible for other time periods, which gives members flexibility if they must miss a meeting. This approach would require that HCAI and the chair be notified immediately if a member must miss a meeting. The committee also suggested all requests have a primary and secondary reviewer who will give a high-level overview of the request to the rest of the committee.

The committee discussed whether the requestors should be available to answer questions as opposed to being required to provide a presentation to the committee. The committee agreed that having the requestors available and not presenting at the meeting was adequate. The committee suggested that an informational agenda item be added detailing the outcome of the recommendations on data requests made at the previous meeting.

The committee expressed appreciation for the presentation showing what information other APCDs publish about data requests. The committee expressed interest in releasing the applications received, so that the public could see what is being requested and why. The committee also liked the idea of posting public comments, fees, and the final decisions for requests.

The committee inquired about what parts of the request application should be made public versus redacted. The committee was informed that redaction is often a concern of the research community, researchers may be proposing novel methods or research questions that they may not want to expose to the public prior to the start of the study. HCAI has restrictions on what can be redacted or withheld under the PRA and Bagley Keene. Anything included in the discussion can be disclosed but it is dependent on the exemptions provided in the PRA or Bagley Keene whether something is able to be kept confidential.

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The committee would be interested in knowing the past history of the requestors' experience handling sensitive data. It was noted that CPHS vets requestors by requiring them to submit a resume, budget, and name a responsible official, which is someone in a supervisory position who will be responsible for the project if anything goes wrong.

The committee commented that requestors from established organizations with good histories of use could submit multi-project applications that include a general purpose and how the projects meet HPD goals, which could expedite the vetting of requestors. The committee is interested in the funding for projects, to ensure projects are not being funded by industry organizations but being conducted by researchers. It was noted by the committee that HPD does not want to discourage new and young investigators from utilizing the database.

The committee also noted that researchers must often get approval from multiple institutions and find that the institutions have procedures that contradict each other, so it is important that the HPD make sure we are engaging with the public to streamline the process. It was noted that CalHHS is in development of a unified data application which would streamline the data request process upon completion.

The committee expressed interest in the creation of a board manual. The committee suggested that subject matter experts be invited to present to the committee as appropriate. The committee was encouraged to invite experts to the meetings to be available for questions. The committee may also ask applicants to suggest an expert to speak to the committee. It was noted that the DRC is missing specific patient-oriented and marginalized voices, such as those representing specific diseases groups.

Public Comment:

There was no public comment.

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Agenda Item VIII. Next Meeting Topics & Discussion
Nuriel Moghavem, DRC Chair

Nuriel Moghavem, DRC Chair, provided a preview of the June DRC meeting agenda. Topics for the June meeting include:

- Application Review Process Overview
- Provisions of the Data Use Agreement
- Review of data products – including limited data set offerings

The June meeting will be held on June 6th from 9:00 – 1:00 and will be fully virtual via Microsoft Teams.

Questions and comments from the committee:

The committee expressed interest in linkage, which will be discussed at the September meeting, and the relationship with CMS, the California Department of Public Health (CDPH), and other databases.

Public Comment:

There was no public comment.

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

Public Comment:

There was no public comment.

The meeting was adjourned at 12:39 p.m.