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

Date:

June 19, 2024
Approved Meeting Minutes

Members Attending: Paul Bouganim, Executive Director, Finance Operations; Janet Coffman, Professor, Institute for Health Policy Studies; Miranda Dietz, Project Director, California Simulation of Insurance Markets (CalSIM); Genia Fick, Vice President, Quality; Jan Hanley, Director of Research Programming; Koh Kerdsri, Vice President, Risk Adjustment, Compliance, and IT; and Nuriel Moghavem, Clinical Instructor of Neurology.

Members not in attendance: Cora Han, Chief Health Data Officer; Barbara Koenig, Professor Emerita of Bioethics; and Daniel Ruiz, Vice President, Operations Quality.

HCAI Presenters: Chris Krawczyk, Chief Analytics Officer and Jasmine Neeley, Research Data Analyst

Public Attendance: 52

Agenda Item I: Welcome and Meeting Minutes

Nuriel Moghavem, DRC Chair

Nuriel Moghavem, DRC Chair, welcomed the committee and members of the public and acknowledged that the committee was meeting on Juneteenth, a federal holiday commemorating the end of slavery in Texas. The DRC chair gave an overview of the discussion that he spoke at the April HPD Advisory Committee meeting. The chair also announced that Terry Hill has resigned from the committee. The committee members conducted a roll call of attendance. The chair reviewed the meeting ground rules, and Genia Fick read the HPD program goals and statement from the committee. Paul Bouganim volunteered to read the statement at the next public meeting.

The committee reviewed and approved the meeting minutes from the March 20th, 2024, DRC Meeting. The motion to approve was made by Genia Fick and seconded by Koh Kerdsri.



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The following members voted to approve the minutes: Miranda Dietz, Paul Bouganim, Janet Coffman, Genia Fick, Koh Kerdsri, and Nuriel Moghavem.

Jan Hanley was absent from voting.

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

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 March Meeting Recap

Nuriel Moghavem, DRC Chair

Chris Krawczyk, Chief Analytics Officer, HCAI

Nuriel Moghavem, DRC Chair, gave a recap of the previous meeting at which the committee voted to approve the DRC manual. The manual serves as a guide for reviewing applications. It is intended to be a living document, allowing for continuous improvements. The review then moved to a recap of use case scenarios related to Personally Identifiable Data (PII) presented by Chris and the team. The scenarios were evaluated based on program goals, privacy and security risks, and considerations for vulnerable populations.

Chris Krawczyk provided program updates, starting with the next Healthcare Payments Data Program Advisory Committee meeting scheduled for July 25th, 2024, from 9:00 AM to 12:30 PM. The agenda includes topics such as Non-Claims Payment Data Collection, Self-Funded Data Collection, Voluntary Submitters, and Core Data Collection across the areas of medical, pharmacy, and dental data. He also discussed the timeline for HPD data release regulations, noting that the regulations were submitted to the Office of Administrative Law (OAL) on May 28th, with a 30-business-day review period expected to conclude by the end of Q2 2024.

Questions and comments from the committee:

The committee inquired about the availability of materials necessary for submitting data requests. HCAI responded, explaining that while the application content is ready within the data request environment, supportive materials like data documentation and code



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books are still under staff review. HCAI mentioned that additional supportive documentation, including communication and training strategies as well as enclave supportive materials are being prepared and will be available in July. However, the exact timing of their release will depend on finalization of the regulations. The committee expressed their eagerness to start promoting the program and sharing information with partners and researchers, but they acknowledged the necessity of following the legal and technical processes to ensure a smooth launch. The committee reiterated their excitement and readiness to begin, appreciating the respect for the proper procedures to guarantee a successful and continuous process.

Public Comment:

There was no public comment.

Agenda Item III. DRC Review - Application Excerpts

Jasmine Neeley, Research Data Analyst, HCAI

Jasmine Neeley, Research Data Analyst, HCAI, presented the HPD application excerpt. She provided an overview of the data request application, which is a dynamic digital form accessible through the HCAI ServiceNow data request portal. The form adjusts its questions based on user selections, and Jasmine provided partially filled-out versions to illustrate its functionality. The primary focus of the discussion was not the form itself but the excerpt.

Jasmine explained that the excerpt consists of a collection of fields from the application, intended to be shared with committee members while ensuring that private or sensitive information is not made public. This is crucial as any materials provided to committee members must be posted on the website and made available to the public. The excerpt aims to facilitate informed discussions without compromising security or privacy.

She outlined that certain sensitive information, such as system security plans, home addresses, and internal pricing decisions, would be excluded from the excerpt to avoid potential risks. Jasmine showcased an example of what the excerpt would look like, emphasizing that the final document would only include fields selected by the committee members.

Questions and comments from the committee:

During the meeting, the discussion centered on refining the application process for project proposals. HCAI presented an example application format including the submitter's details, project title, goals, and compliance with HPD objectives. The



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committee was prompted to consider if this information was sufficient and if additional data types should be specified. The committee suggested including the type of data requested, and emphasized the importance of knowing the organization type and the dissemination plans for research results. The discussion also touched on whether to include the project's timeline and funding source, with HCAI noting potential privacy concerns of disclosing that information. The committee agreed on the need for efficiency and consistency in the application excerpts, with an emphasis on ensuring the inclusion relevant information like the requestor's previous approvals and any necessary information about data security protocols.

The motion to recommend to HCAI that the following fields be added to the application excerpt and that these fields be requested from all applicants, if possible, within privacy and legal limits was made by Nuriel Moghavem and seconded by Jan Hanley.

- Submitter and Co-PI names.
- Project title, purpose, and goals.
- Type of data requested.
- Project timeline.
- Organization type and name.
- Previous approvals, if any.
- How results will be shared or published.
- Funding source.

The following members voted to approve the recommendation: Miranda Dietz, Paul Bouganim, Janet Coffman, Genia Fick, Jan Hanley, Koh Kerdsri, and Nuriel Moghavem.

Public Comment:

The public inquired about the differences between ambulatory, emergency department, hospital discharge data, and HPD/all-payer data, and how to request each type. They also asked if visits to a general doctor were captured in the dataset. HCAI responded, explaining that the HPD request portal was not yet available but would be like the existing HCAI hospital data request process. HCAI clarified that data collection depends on whether the general practice visit falls under mandatory reporting requirements.

Agenda Item IV: DRC Review – Additional Resources for Review

Chris Krawczyk, Chief Analytics Officer, HCAI

Chris Krawczyk, Chief Analytics Officer, HCAI, discussed the development of additional resources requested by the DRC. These resources aim to assist reviewers in organizing



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their thoughts during the data request review process. The guide, titled "DRC Guide to HPD Data Use Access and Release Regulations," is a table with four main columns representing different types of HPD data and rows detailing regulatory considerations for approval or denial of data requests. The guide outlines mandatory and discretionary reasons for denial and maps these items to statutory and regulatory requirements. The second document, "DRC Considerations for Application Review," is an optional tool for committee members, especially primary reviewers, to use when evaluating data requests. It can help to organize reviewers' thoughts around statutory, regulatory, and additional considerations, such as privacy, data necessity, project goals, and public benefits. This tool also includes sections for reviewers to provide justifications for their recommendations. Chris emphasized the optional nature of this tool and its potential to be subject to Public Records Act requests.

Questions and comments from the committee:

The committee discussed the usefulness of the presented resources. They emphasized the flexibility in the review process, highlighting that primary reviewers are required to provide justified recommendations rather than follow a prescribed format. Questions arose about the need for documentation from primary reviewers, with clarification that verbal recommendations suffice, and formal documentation is generated by HCAI after discussions. The discussion also touched on the potential for public records requests regarding personal notes versus formal submissions. The committee emphasized the importance of having a clear process for data requests, noting that applicants often struggle to meet minimum data requirements due to a lack of understanding about how the data will be used. The committee agreed that to be flexible and supportive that if a request is denied, applicants should have the opportunity to reapply with a revised application addressing the committee's concerns. The committee emphasized the value of providing clear and actionable feedback to applicants, especially those with less experience, to help them improve their proposals.

The committee raised the question of whether commercialization resulting from research should be viewed negatively in all cases, or if there could be circumstances where it might be acceptable, especially if it aligns with program goals or provides a public benefit. HCAI clarified that commercialization alone is not a mandatory reason for denial if the proposed use also brings a public benefit. The committee expressed concern about the potential for entities to profit from data without any return to the state, suggesting the need for mechanisms similar to those used in universities, where patents and licensing can generate returns from commercialization. HCAI legal, mentioned that



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provisions could be included in data use agreements to prohibit the use of data for profit, thereby providing a safeguard against unauthorized commercialization. The discussion acknowledged that while not everyone may fully adhere to data use agreements, including such prohibitions can act as a deterrent and provide a basis for enforcement if necessary. Feedback on the review worksheet included minor suggestions for improvement, such as clarifying sections related to public benefit and commercialization risks.

Public comment:

The public inquired about distinctions between limited datasets and research identifiable datasets, particularly regarding patient identifiers and geographic granularity. They asked whether limited datasets include dummy identification numbers for record linkage and if geographic data below zip code level will be available. HCAI responded that detailed data documentation, including these specifics, will accompany the dataset's launch.

Agenda Item V: Use Case Scenarios

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

Chris Krawczyk provided a brief overview and framing for the discussion, referencing previous documents and discussions related to legal requirements for DRC reviews under the HPD statute. He highlighted considerations such as alignment with program goals, transparency, and informing policy decisions are central to the review process, with these elements reflected in the review worksheet. Emphasizing the broad and interpretive nature of these criteria, Chris underscored the DRC's reliance on the collective expertise of the members to evaluate each request based on its unique characteristics and potential impacts. Following the overview, detailed use case scenarios were presented, starting with one focused on Entity and Financial Information (EFI) for a commercial health plan in California. This application aimed to develop value-based insurance products, potentially benefiting consumers by enhancing market competitiveness and choice.

Questions and comments from the committee:

The committee evaluated whether the presented use cases aligned with program goals, considering factors such as transparency, health quality improvement, and cost reduction, while also addressing concerns about anti-competitive implications raised by committee members.



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The committee expressed concerns regarding the potential misuse of data, while emphasizing that transparency is crucial for public benefit. They discussed the need for clear public benefits versus potential anti-competitive risks. The committee highlighted concerns about data confidentiality and the potential for market manipulation through the release of detailed provider and payment information. The committee also asked about data accuracy and reporting standards, particularly in relation to the healthcare service provider market dynamics. The committee explored alternative scenarios and conditional approvals to mitigate risks while supporting legitimate research and policy development. They emphasized the importance of aligning data requests with public interest and program goals, such as improving healthcare access and cost transparency across California.

The committee raised concerns about the necessity of EFI, suggesting it might not always be essential for analytical purposes. They highlighted the importance of understanding the applicant's intention to share findings publicly and their commitment to transparency, voicing support for a minimized datasets that maintain analytical rigor without compromising privacy.

The committee also discussed a use case involving direct data transmission outside the HCAI secure research enclave. HCAI outlined stringent criteria for such requests, emphasizing the need for requestors to have expertise in data security and compliance with state and federal regulations. The committee proposed a hybrid solution where researchers could construct analytic files within the enclave, mitigating risks associated with direct data transmission.

Throughout the meeting, the committee underscored the importance of aligning data requests with the public interest and program goals, emphasizing the need for transparency, data security, and methodological rigor in all approved applications. The discussion concluded with a consensus on the need for thorough evaluation and careful consideration of privacy implications in future deliberations.

Lastly, the committee discussed a use case involving a nonprofit policy research organization seeking direct transmission of detailed, identifiable datasets for studying healthcare access and outcomes. Committee members expressed cautious support, recognizing the potential public benefit but also highlighted privacy risks associated with the request. They deliberated on the necessity of including sensitive data elements and discussed alternative approaches to achieve research goals while safeguarding patient confidentiality.



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Public comment:

The public gave feedback, emphasizing the importance of understanding how an Institutional Review Board (IRB) or Committee for Protection of Human Subjects (CPHS) review processes intersects with the HPD.

A public comment was received expressing the importance of promoting the HPD as a widely recognized utility. They expressed concern with focusing on the identity of the data requester, whether a provider, researcher, or purchaser, rather than the data itself. They cautioned against restricting access to the HPD dataset, as this could lead organizations to seek alternative data sources, such as commercially available datasets like Milliman. The speaker urged the committee to focus on broadening access to the HPD dataset and enhancing its utility within the marketplace.

The committee acknowledged the comment and suggested that they could benefit from education on price transparency and understanding where similar data is publicly available. The committee proposed discussing price transparency guidelines at a federal level in future meetings and requested additional reference materials on standard elements to support the committee's work.

Agenda Item VI. Next Meeting Topics

Nuriel Moghavem, DRC Chair

Nuriel Moghavem provided a preview of the next DRC meeting agenda, which will focus on data requests requiring DRC review.

The next meeting is scheduled to be held on September 18th from 1:00 p.m. – 4:00 p.m. More details will be provided closer to the meeting date. There will be trainings on ServiceNow for committee members on July 17th and August 21st.

Questions and comments from the committee:

There were no comments from the committee.

There was no public comment.

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

Nuriel Moghavem, DRC Chair

There was no public comment.



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Agenda Item VIII: Adjournment

Nuriel Moghavem, DRC Chair

The meeting was adjourned at 4:02 p.m.