Agenda Item VI: HPD Data Access and Release: Funding, Data Quality, and Coordination of Review

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Requestor Questions and Engagement

- HCAI has regularly received questions from interested requestors prior to their applying

- Common themes in the questions indicate that requestors:
  - Want to make sure the data content, completeness, and quality will support their planned analysis
  - Want to secure funding to cover the cost of the data prior to applying

- To better understand potential requestors experiences, perspectives, concerns, and areas for improvement, HCAI conducted a survey

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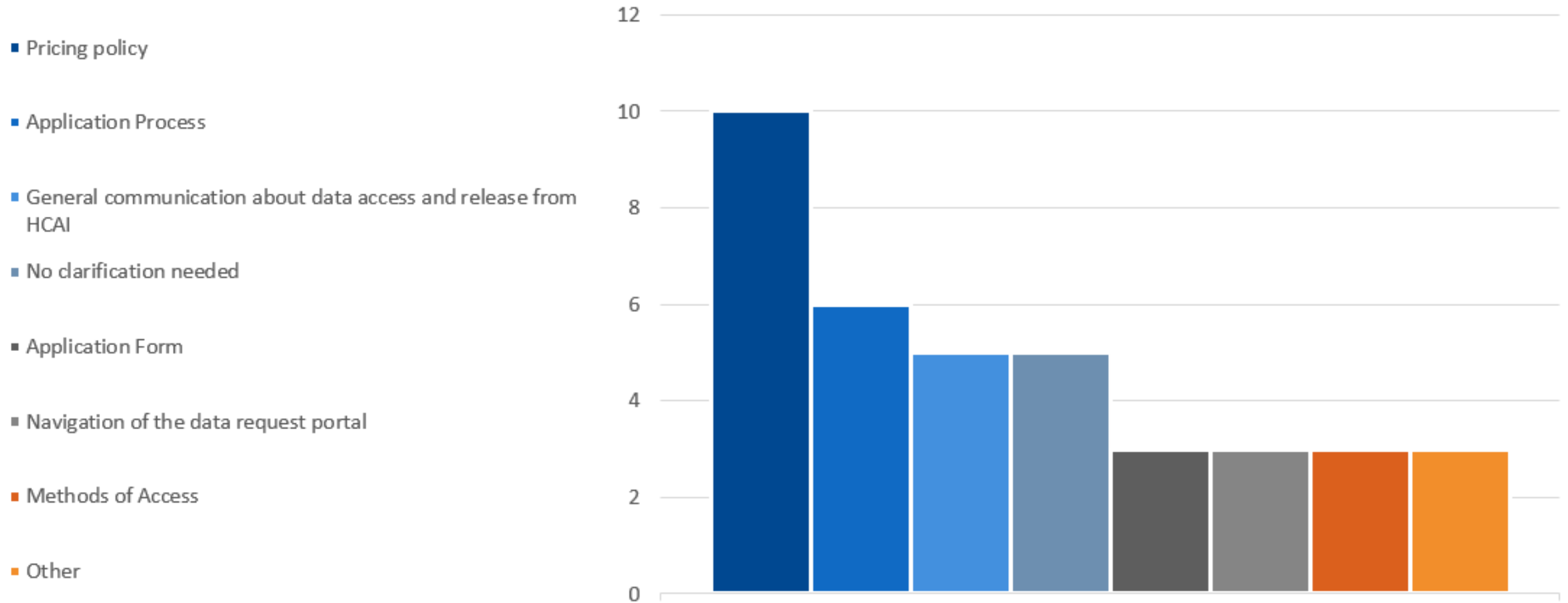Department of Health Care
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Researchers' Perspectives – Survey Results

- HCAI hosted the HPD Data Access and Release webinar in January and sent the survey to webinar participants.

- The survey was sent to all webinar registrants, regardless of whether they attended.
  - 24 responses were received
  - 21 of the responses were from webinar participants

Survey Results
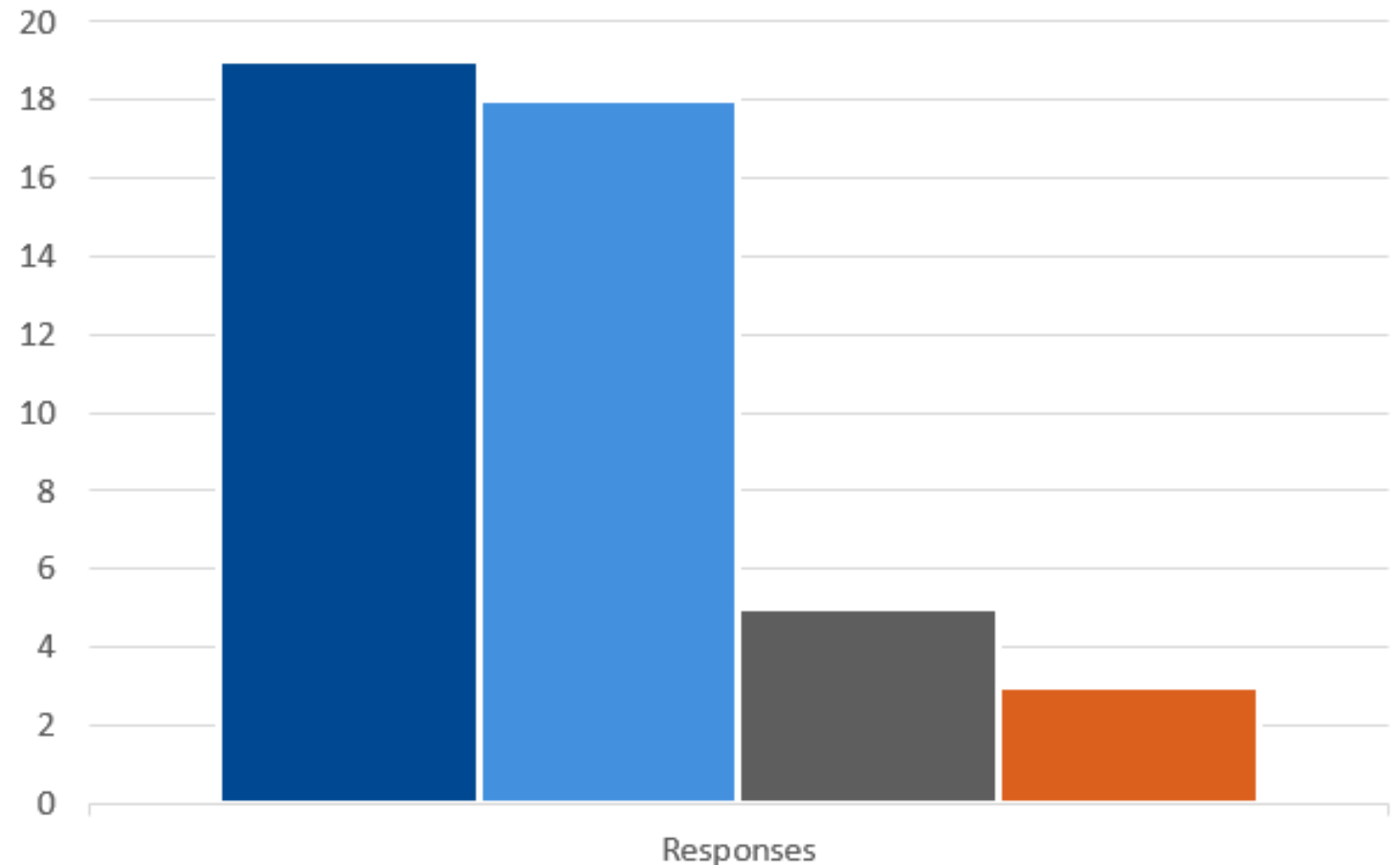
Researchers' Perspectives – Survey Results

When asked which areas of the HPD data request process could use clarification, survey responses indicated confusion with HCAI's pricing policy, followed by the application process and general communication.

Legend:
- Pricing policy
- Application Process
- General communication about data access and release from HCAI
- No clarification needed
- Application Form
- Navigation of the data request portal
- Methods of Access
- Other

Researchers' Perspectives – Survey Results

Survey results showed the documents on HCAI's website and the webinar held in January have been the most useful in providing information and guidance on the HPD data request process

Researchers' Perspectives – Survey Results

The most common concerns around requesting data were the cost of the data, the length of time required for the review process, and the approval process.
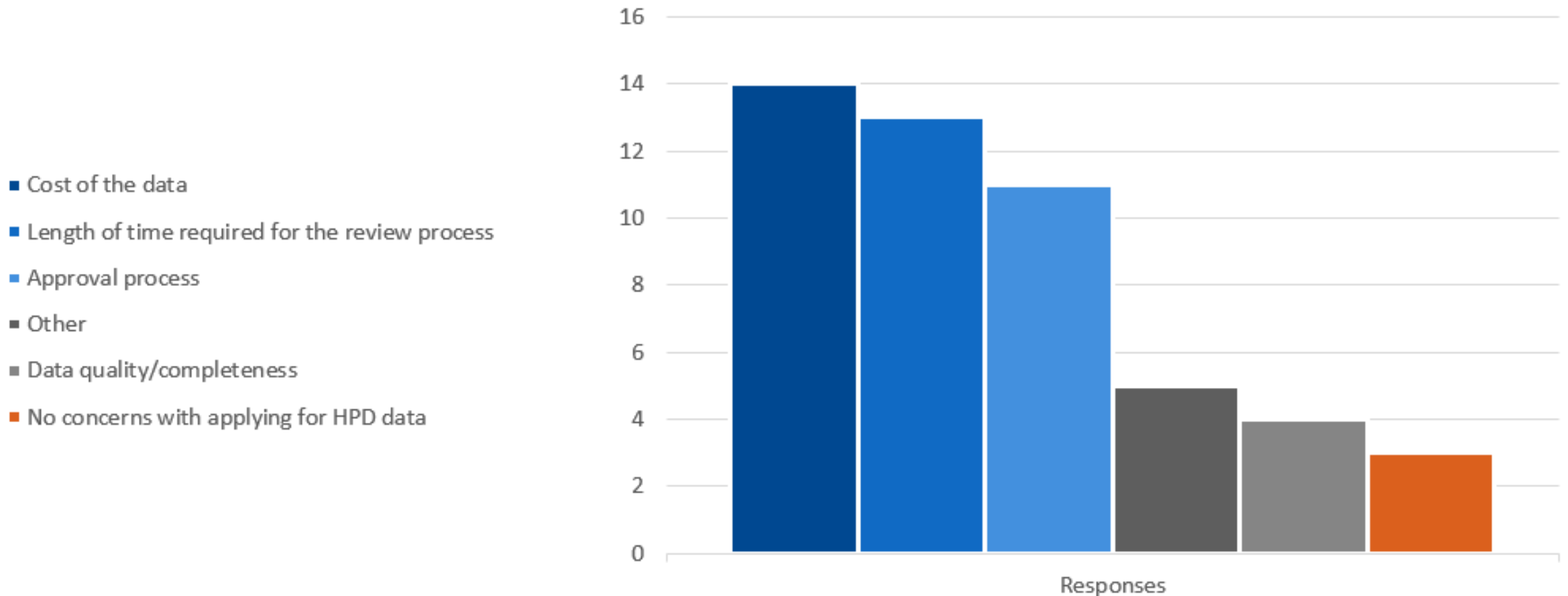
Researchers' Perspectives – Survey Results

- When asked what challenges potential requestors are facing when applying for data, almost all responses stated financial limitations, followed by several responses noting their own internal approvals/processes.

- Survey results also indicated top reasons preventing researchers from requesting data in the future were the cost of the data, complexity and length of time associated with the data request process, and the quality of the data.

Legend:
- Financial limitations
- Internal approvals/processes
- No limitations with applying for data
- Other

(x-axis: Responses; y-axis: 0 to 20)
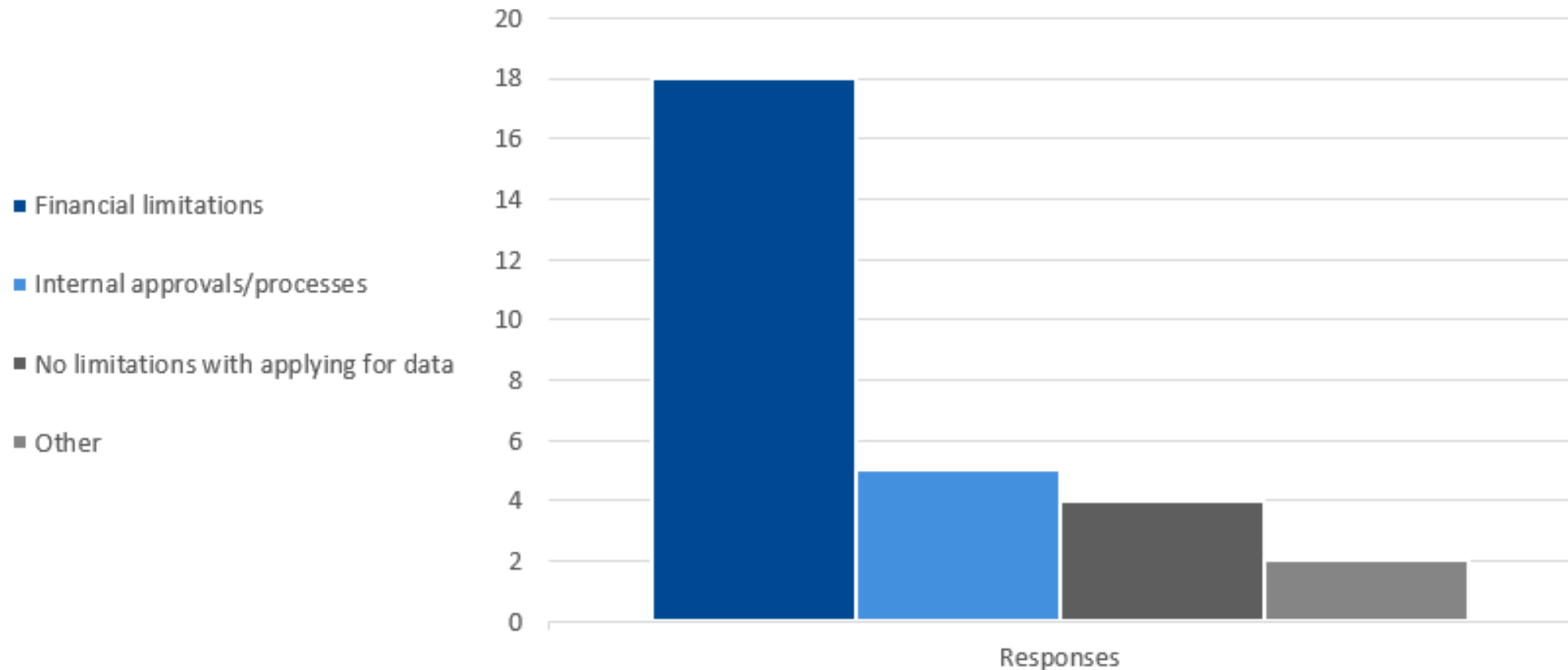
Researcher Feedback

Many questions received regarding HPD Data can be divided into the following categories:

- Data/concept-related questions

  - Requestors seeking more information regarding the data available to understand whether it will fulfill their visualization/linkage/funding/proposal writing objectives.

- Enclave related/Direct Transmission questions

  - Requestors seeking more information regarding what technology or apps we provide, ways the user(s) can interact with the data, and how to provide access to multiple users in Enclave.

- Cost-related questions

  - Requestors seeking more information regarding methods of payment, calculation of the cost, and what type of request they should consider to be more efficient, both application-wise and cost-wise (renewal and costs associated with it at the end of the first year).

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Researchers' Perspectives and Survey Results

Areas of improvement identified include:

Pricing Policy for HPD data	• Provide additional focus on HPD Data Pricing Policy resources and highlight funding opportunities.
Responsiveness of HCAI staff and the length of time required for the request/review process	• Hiring efforts continue to expand available staff and analysts available for HPD data requests.
Data request process and Application Form	• Include examples of appropriate and unacceptable answers for application sections.
Data quality and completeness	• Develop a Fact Sheet that provides information about key variable data completeness and quality

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Data Quality

Data Quality

Available resources and information based on questions HCAI has received regarding data quality:
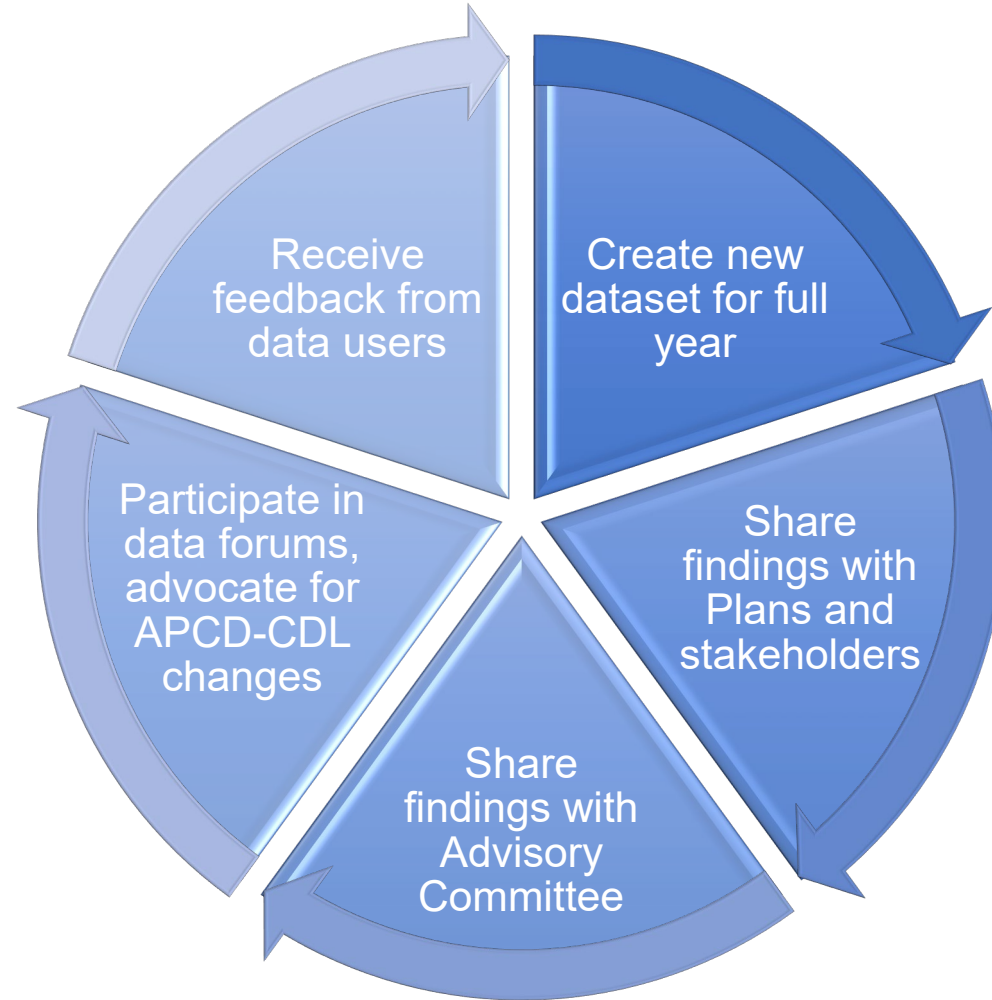
- Available variables such as age, gender, SSN, ZIP code, preferred language, NPIs for providers, family or employee linkages, etc.:

  - Refer to the [All-Payer Claims Databases Common Data Layout (CDL)](#) specifications, which include all demographic information that is collected for members, such as race, ethnicity, and Hispanic indicators. HCAI also collects members' primary language, along with other fields.

  - Some data are limited, such as SSN, ZIP_Code_Ambulance_Pickup or ZIP_Code_ambulance_Drop_Off, which are available only to state agencies, while others such as employee identifier are not available elements due to privacy concerns. Use of the Insured Group or Policy Number or Group Name may tie employees together.

  - NPIs are included as an option in the data element [justification grids](#) that must be completed when creating a custom research identifiable dataset. NPIs are also available in the Standard Limited Dataset Plus.

  - Research identifiable HPD datasets include both member and subscriber information which allows the user to locate the members under the same family or multi-person plan

- Regarding non-claims data:

  - Non-claims payment amounts (including capitation payments) are not yet in the system.

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Data Quality

Available resources and information based on questions HCAI has received regarding data quality:

- Years of data available:
  - Data requests can currently be submitted for service dates in years 2018-2023.
- Additional Information on HPD data quality and completeness:
  - The March 2024 HPD Legislative Report (Chapter 5) discusses the HPD data collection and validation processes, as well as quality and completeness. The legislative report also includes discussion of data completeness of key fields by submitter type (Medi-Cal, Medicare Fee-for-Service, and Commercial/Medicare Advantage).
  - The March 2024 HPD Legislative Report (Chapter 3) provides a general comparison of data represented in the HPD system to HCAI's emergency department and inpatient data. The data population and methodologies between these sources differ thus the evaluation provided is for initial evaluation purposes only. The comparison does not evaluate the missingness of hospital discharge claims by payer. However, Chapter 5 of the HPD Legislative Report provides an overview of completeness rates for key fields within the HPD as well as known data quality issues.

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Approach for Ongoing Data Quality Collaboration

- Create new dataset for full year
- Share findings with Plans and stakeholders
- Share findings with Advisory Committee
- Participate in data forums, advocate for APCD-CDL changes
- Receive feedback from data users

HPD Data Completeness: Fact Sheet

- Data completeness is an important aspect of data quality.
  - A high percentage of data completeness does not measure accuracy of the submitted data
  - Represents the degree to which specific fields are populated with values under expected circumstances (numerator) across all records (denominator) for the expected circumstances
- Data is submitted to HPD monthly and at the service line level.
  - There is an eligibility record for every month a member was enrolled with a plan, and a service line record for every non-denied service line on a claim

The HPD Data Completeness Fact Sheet can be found in the resources section of the HPD Data Access and Release Page:
HPD Data Access and Release Resources

Field	Commercial Range	Commercial	Medicaid	Medicare FFS	Medicare Advantage
Total Records Available	N/A	2,079,481,159	2,119,192,710	349,652,231	538,126,258
Samples	0%-100%	76.0%	98.0%	99.0%	87.0%
Member ID (masked)	100%	100%	100%	100%	100%
Coverage Type Code	100%	100%	100%	100%	100%
Product Code	100%	100%	100%	100%	100%
First Name *	98.9%-100%	100%	100%	100%	100%
Last Name *	98.9%-100%	100%	100%	100%	100%
Physical Address *	97.1%-100%	98.6%	96.7%	0% **	98.7%
Zip Code (5)	99.3-100%	99.9%	99.1%	100%	100%
Member Sex	100%	100%	100%	100%	100%
Member SSN *	0%-100%	94.3%	97.5%	100%	49.6
Date of Birth *	100%	100%	100%	100%	100%
Age in Years	99.7%-100%	99.9%	99.9%	100%	100%
Race (Actionable)	0%-99.4%	33.5%	89.7%	96.6%	49.8%

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Pricing Policy and Funding

Pricing Policy and Funding

- Requestors are concerned about the cost of the data and ability to get extramural funding, particularly researchers
  - Factors for consideration are that HCAI does not have permanent funding to support the HPD Program
  - There are costs to HCAI for administering the data release program – direct costs for the Enclave, for creating custom data sets
  - HCAI is to maximize use of the Secure Data Enclave and minimize direct transmission of the data
  - HCAI has reduced the cost for the first year of data release
  - HCAI does have a price reduction request process and has budgeted to provide reductions
  - Concerns among requestors of reduced availability of extramural funding, notably from federal funders
- Requestors would like an estimate of the cost of their project early in the application process
  - HCAI has implemented a project cost estimate step that immediately follows receipt of the application and paid application fee

Funding Opportunities: CHCF Grant

- The California Health Care Foundation created a $1 million affordability research funding pool for researchers interested is using HPD.

- Up to $500,000 of this funding will be awarded in spring 2025 and up to $500,000 will be awarded in Spring 2026.

- Awards may be used to offset HPD data use fees and grantee research time.

- CHCF received nearly 50 applications and made 5 initial award decisions for 2025.

- Award is contingent upon independent review and approval by HCAI and the HPD Data Release Committee.

- CHCF will open a separate application process for 2026 funding.

- More information: https://www.chcf.org/rfp/request-for-proposals-california-healthcare-payments-database-affordability-research-fund/

The California Health Care Foundation is an independent, nonprofit philanthropy that works to improve the health care system so that all Californians have the care they need. We focus especially on making sure the system works for Californians with low incomes and for communities who have traditionally faced the greatest barriers to care.

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Coordination of Review – Status

Coordination of Review – Status

Department of Health Care Services (DHCS)

- Data requests that include Medi-Cal data need to be reviewed by DHCS.
- DHCS's regular data request review process has been built within the HPD data request review process.
- DHCS can work directly with the requestor on changes/clarifications. This will need to be coordinated with HCAI's review team.
- After DHCS review and approval, the request moves to DRC review (as needed).
- Current Status: DHCS is reviewing the HPD Data Use Agreement to confirm it will suffice for requests that include Medi-Cal data.

California Committee for the Protection of Human Subjects (CPHS)

- Research identifiable requests and direct transmission of custom limited requests need to be reviewed by CPHS.
- Requestors will work with HPD analysts to ensure their application to CPHS remains in synch with their HPD application.
- HCAI will not approve requests until the CPHS approval letter (if required) is attached to the HPD application form.
- Current Status: CPHS is reviewing HPD database policies and procedures, per the Common Rule. HCAI is working with CPHS on specific review criteria and further coordinating processes.

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Public Comment