# Agenda V: Overall HPD Data Release Process

*Jasmine Neeley, Research Data Analyst II, HCAI*
*James Yi, Attorney, HCAI*
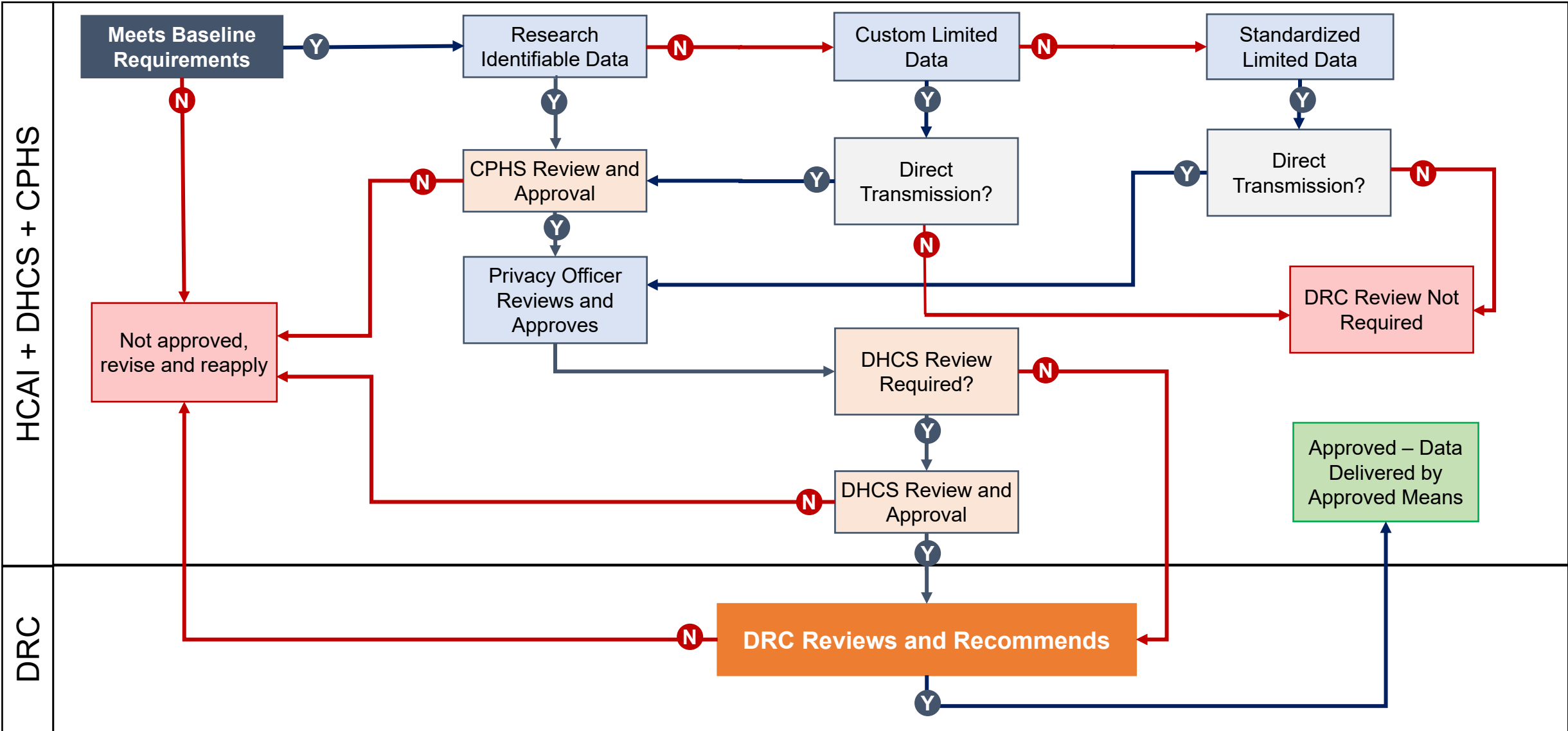*Terrence Nolan, Healthcare Data Request Unit Supervisor, HCAI*
*Wade Iuele, HPD Consultant, HCAI*

# Workflow

# Standard HCAI Review

- Analyst

- Supervisor

- Privacy Officer

- Final Approver

- Science Advisor
  - As needed

# Data Request Decision Tree and Flow Diagram

# Request Form

# Application Sections (high-level)

**Data Security**

- Method of Data Access – Enclave or Direct Transmission
- Data User information – Contractors?
- Data Security Plan
- Description of how results and key findings will be shared
- Small cells

**Additional Information**

- Does the project offer significant opportunities to achieve HPD goals?
- All records vs. Subset of Records
- Minimum Data necessary
- Planned Data Products
- Applicant History, including with Breaches/Convictions/Civil Actions

# Application Sections (high-level)

**Overview**

- Data Applicant information, qualifications, and prior experience
- Alignment of request with HPD purpose, goals, requirements
- Submit data to HPD program?
- Requesting a Fee Reduction?
- New or Supplemental Request?

**Project Specific**

- Description of project purpose, goals, and data use/methods
- Requested HPD data product, timeframe of data, and desired delivery format
- List of data elements with justification/reason based on project purpose
- DHCS data requested?
- Proposed Linkages to other sources with justification/reason

# HPD Data Request Form
(external view)

## HPD Data Request

*Request Type ❓

Select *New* if this is a Research Data Request that has not been previously submitted in this Data Request Portal.

If you have submitted a Research Data Request before, and are requesting additional years, or are adding additional information to your existing request, select *Supplemental*.

❌

⦿ New    ◯ Supplemental

*Data Request Type
⦿ Limited Data    ◯ Research Identifiable Data

*Requested Limited Data Set
⦿ Standard Limited    ◯ Custom Limited

*Which method of data access are you requesting?
◯ Secure Data Enclave Environment    ⦿ Direct Transmission

Data Applicant Information

*First Name

[ ]

*Last Name

[ ]

*Title

[ ]

*Entity Type

[ -- None -- ▾ ]

*Organization Name

[ ]

*Department

[ ]

*Address

[ ]

*Phone number

[ ]

### Research Identifiable Data Product Selection Menu

*Requested Data Sources

☑ Claims Medical

☑ Claims Pharmacy

☐ Member Enrollment

☐ Provider Information

*Please indicate the timeframe of requested data for Claims Medical

[ ex. 2019, 2021 ]

*Please indicate the timeframe of requested data for Claims Pharmacy

[ ex. 2019, 2021 ]

*Are you requesting access to Medi-Cal variables?
◯ Yes    ◯ No

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# HPD Data Request Form

*Describe how use of the requested data aligns with the goals of the HPD Program. Identify the specific goals your request aligns with below.

[ ]

*HPD Program Goals

- [ ] Provide public benefit for Californians and the state while protecting individual privacy.
- [ ] Increase transparency about health care costs, utilization, quality, and equity.
- [ ] Inform policy decisions on topics including the provision of quality health care, improving public health, reducing disparities, advancing health coverage, reducing health care costs, and oversight of the health care system and health care companies.
- [ ] Support the development of approaches, services and programs that deliver health care that is cost effective, responsive to the needs of Californians, and recognizes the diversity of California and the impacts of social determinants of health.
- [ ] Support a sustainable health care system and more equitable access to affordable and quality health care for all.

## Data Access

*Please list all individuals who are anticipated to observe, use, or access confidential data, including yourself

| Add | Remove All |
| --- | --- |

| Actions | Data User Name | Data User Organization | Data User Email Address | Data User Phone Number | Dat |
| --- | --- | --- | --- | --- | --- |
| | | | | No data to displa | |

*Will a contractor be used for this project?

( ) Yes    ( ) No

## Project Security

*Have you previously requested HPD data?

( ) Yes    ( ) No

*Has the data applicant been involved in a data breach, or other similar issue, in which Personally Identifiable Information (PII) and/or Protected Health Information (PHI) was misused or improperly disclosed, within the last 7 years?

( ) Yes    ( ) No

*Has the data applicant been involved in any criminal convictions or substatiated violations of California, or other state, or federal laws regarding fraud, theft, data breach, data misuse or related offenses in the past 7 years? This includes civil or admistrative penalties, civil judgements, or disciplinary actions.

( ) Yes    ( ) No

*Please describe your experience with data security and the protection of large sets of confidential information.

[ ]

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# Additional Documents

**During Review**

- Variable Justification Grids

- CPHS Protocol

- Data Requestor CV*

- Contract*

**Final Approval**

- CPHS Approval letter

- Data Use Agreement (DUA)

- Signed Request Form

# Data Request Portal

# Data Request Portal - Dashboard

# DRC Request Task

# DRC Request View

# DRC Request View

# Request Notes and Communications

# Data Use Agreement (DUA)

# DUA Process

Currently, it is planned to have a DUA form consisting of a cover sheet and exhibits with standard provisions based on the type of data request.

The approved application will be incorporated as an exhibit into the DUA. The DUA will have additional provisions about termination, amending/supplementing a data request, data destruction, liability, and enforcement provisions.

HCAI anticipates requiring some DUA provisions by regulation. Other standard provisions may be altered based on the circumstances of the data applicant or data use.

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# Pricing Schedule

# Pricing Schedule Overview

- Pricing schedule is based on market research and historical experience

- Pricing schedule for **Data Enclave** use is based on cost to the state, not value of the data

- Pricing schedule for **Direct Transmission** is based on (a) value of the data, (b) incentivizing data enclave use, and (c) providing funding contribution to ongoing program operations
  - Ongoing HPD Funding Report contemplated as much as 5% ($1m) of program funding coming from data user fees

- HCAI will need to monitor actual demand, but *rough* estimates are:
  - Up to 50 project requests per year
  - **Data Enclave** projects will be at least $17,000 and up to $25,000 per year
  - **Direct Transmission** projects can range from $75,000 to $200,000 or more (one-time fee)

- HCAI plans to charge a nominal ($100) non-refundable application fee, which can be applied to the final data costs

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# Price Reduction Overview

- HCAI will plan to have a minimum of $600k available annually for **Data Enclave** price reductions
  - This amount may increase or decrease in the future, based on program funding

- **Data Enclave** price reductions will be granted on a first come, first served basis.

- At between $17k and $25k for a typical **Data Enclave** project, HCAI could fully subsidize between 24 and 35 projects annually.
  - A larger number of projects could be subsidized for partial pricing reductions.

- Any **Data Enclave** project can apply for consideration for a full price reduction but will need to provide sufficient justification for the full reduction and may be asked to provide additional supporting documentation.

- Proposed price reduction categories:
  - Financial Hardship
  - Data Innovation
  - High Priority Areas

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# Price Reductions by Category

| Category | Sub-Category | Proposed Reduction Amount |
|---|---|---|
| **Financial Hardship** | Student Requestors | High |
| | Academic Fellows | Low |
| | Government Organizations | Low |
| | Consumer Group | High |
| | Other non-profit organization | Medium |
| | Data Provider/Submitter (experiencing financial hardship) | High |
| **Data Innovation** | Open-sourced code or code sharing with HCAI | Low |
| **High Priority Area** | Equity, Workforce, Behavioral Health | High |

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# Data Enclave

# HPD Enclave

- Secure environment for accessing potentially identifiable information

- Has controls so users can only access the data they are approved to see

- Protects against unapproved use of personal information
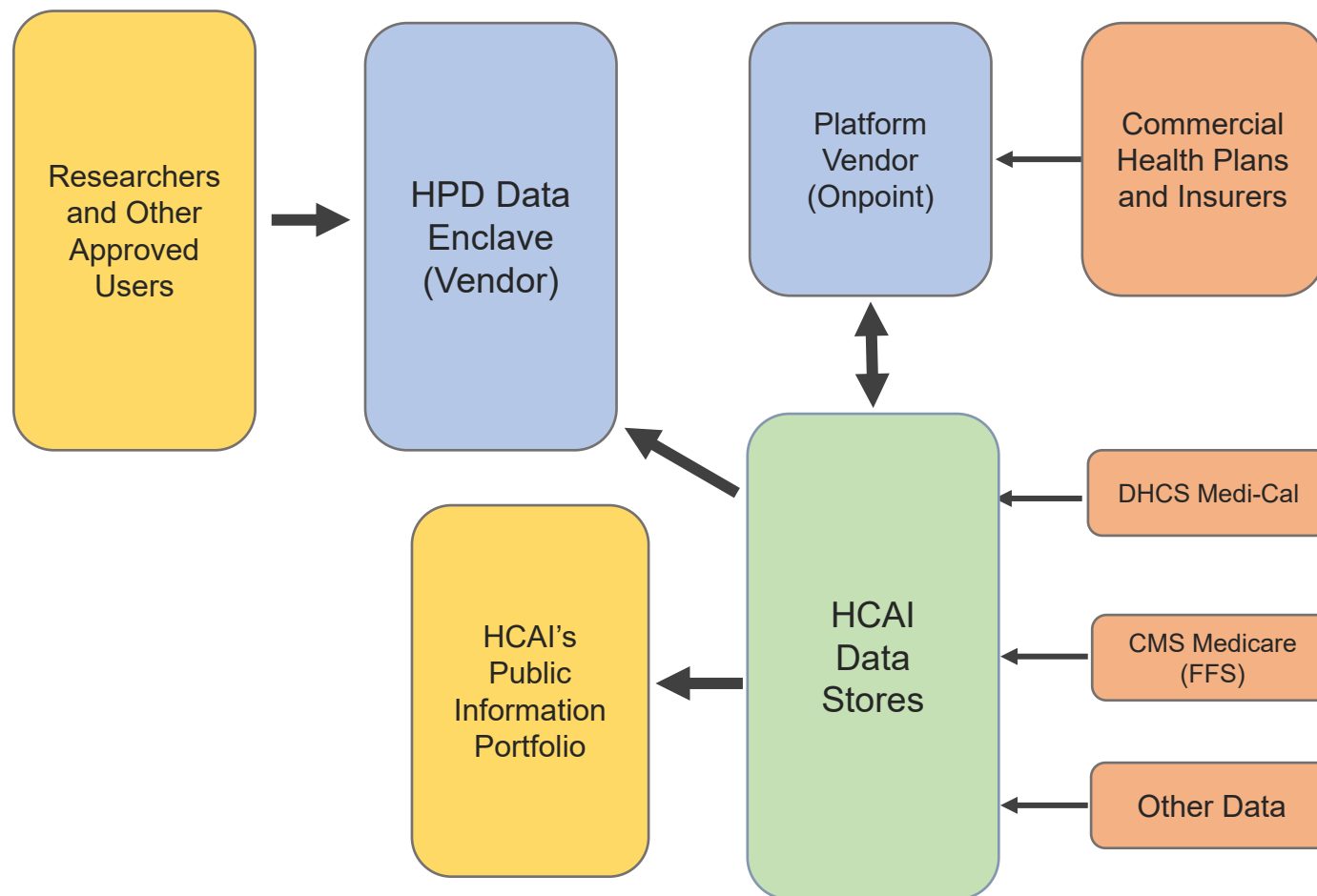
# What is an Enclave?

- Centralized service to remotely access sensitive data
- Houses data in a secure and scalable environment
- Protects data in accordance with state and federal security and privacy rules
- Data is accessed via a virtual machine launched from the user's computer
- Virtual machine operates on a remote server and is controlled by Enclave administrator
- Data products can only be downloaded to user's computer with administrator authorization

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# How is an Enclave Used?

- Makes approved data available to approved users for approved projects
  - Each project's data are segregated from other projects
  - Will allow users to upload and link their own datasets
- Will include access to:
  - Standard tools (Python, SQL, R, Microsoft Office)
  - Additional tools (SAS, Stata, Tableau)
- Provides scalable computing power to perform analysis on a large volume of data

# Additional Enclave Info

- Will support single-user and multiple-user projects
- Multi-user projects include access to shared drive space to exchange code, reports, and tables with other team members
- Users will be able to create tables within the project space that contain data they import, and/or the output from their queries
- Users will receive training and technical assistance from the Enclave vendor, including information on system enhancements and any changes to the HPD datasets

# HPD Enclave Access Process
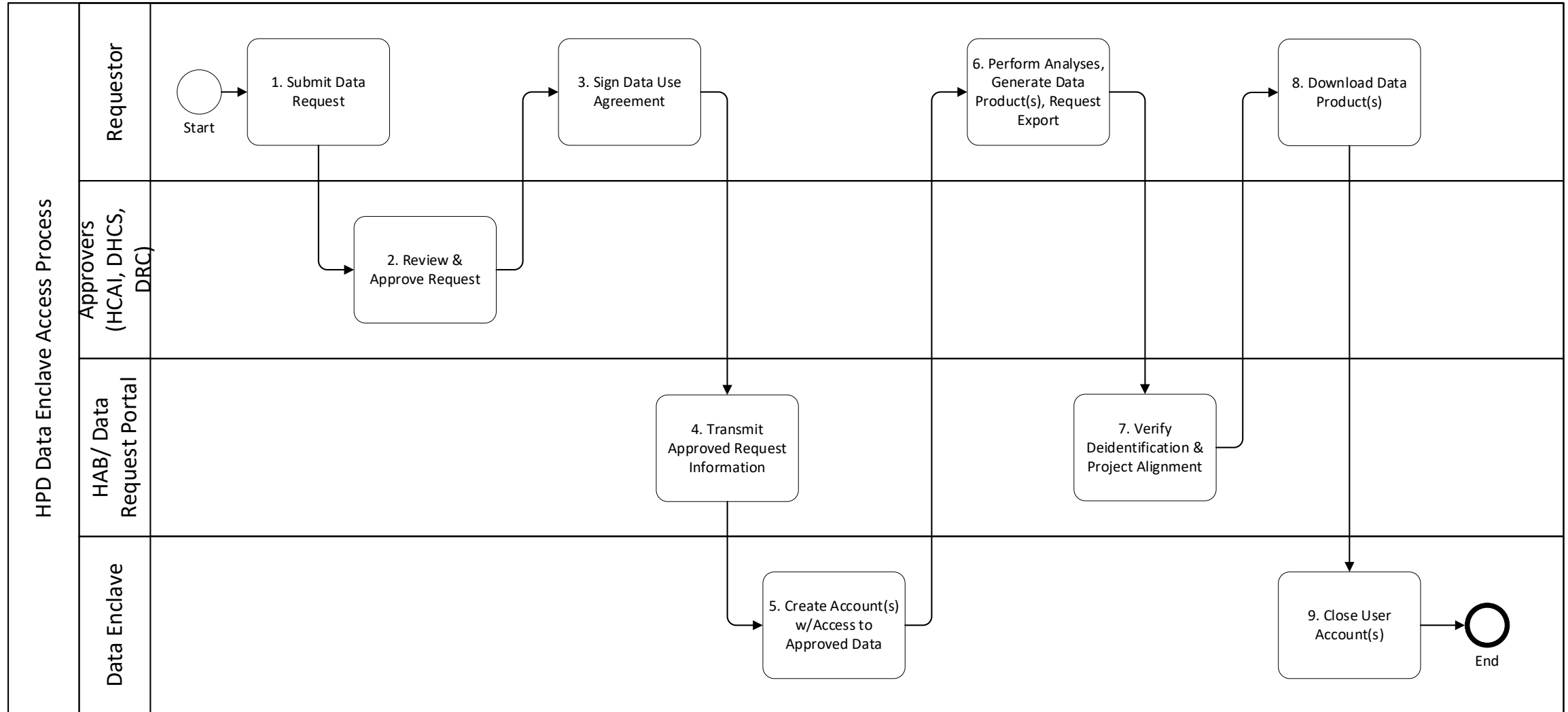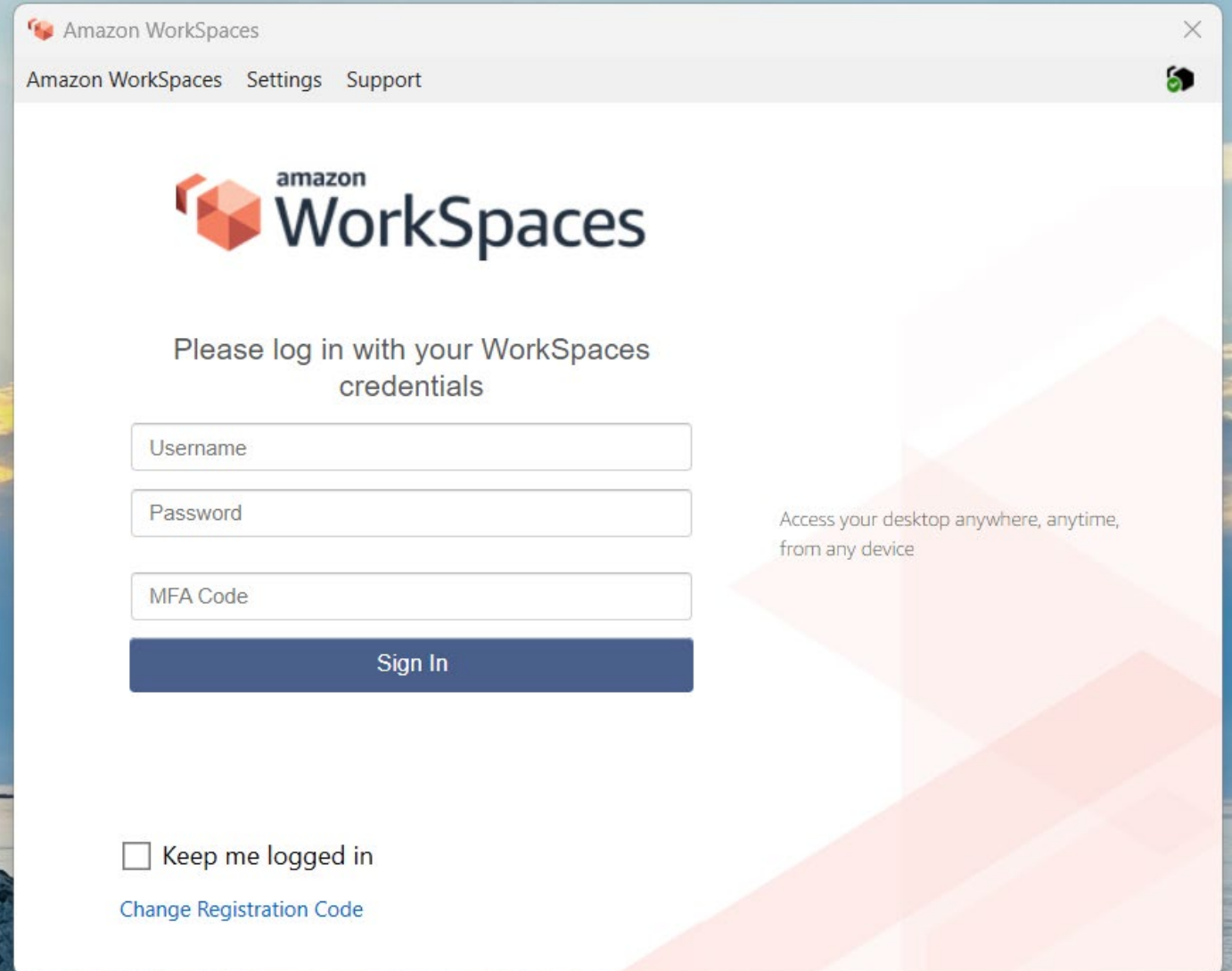
# Draft Enclave Screenshots

Currently in development and testing

# Logging In

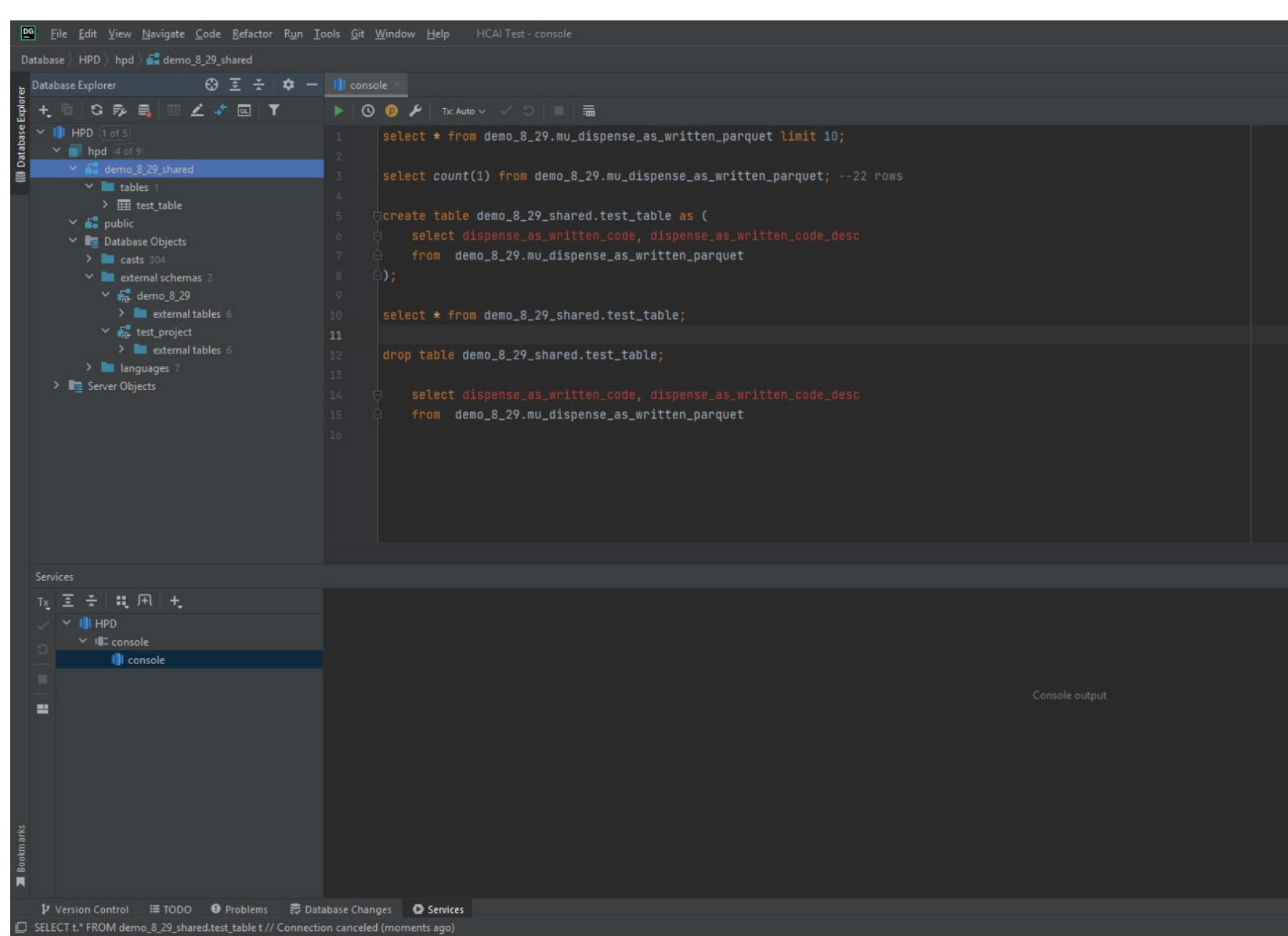This shows the user logging into the virtual machine they will use to access the HPD Enclave.

# Virtual Machine

This shows the desktop of the virtual machine on which they will use tools like DataGrip, R, Tableau, and SAS Viya.

59

# Writing Code

This is an example of DataGrip, where users can write SQL to analyze the data. Data sources are on the left. Queries are written in the top-center box.