Framework for Data Access and Release

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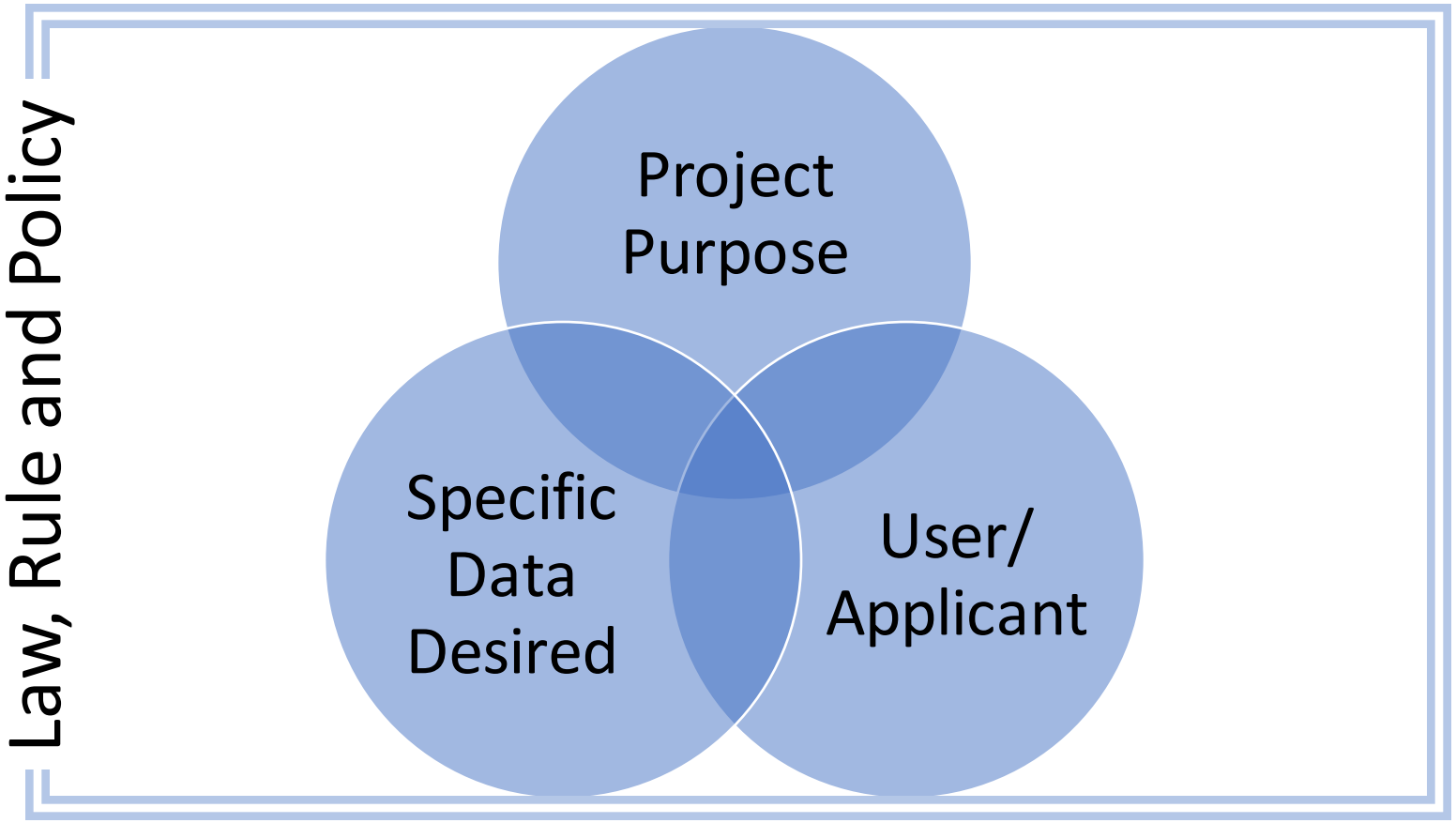
HCAi
Department of Health Care Access and Information

APCD Data Access Programs' Product Components

Intersecting Factors in Data Access Approvals



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Project Purpose

- State law establishes umbrella criteria for data access policy and is further refined in rule
- Examples:
  - Proposed use will benefit the state and its residents (CO)
  - Supporting treatment and coordinating care among providers (one of two purposes in MA)
  - For the purpose of allowing review ….[of] such data as it relates to health care utilization, costs or quality of health care services (CT)

Data Users/Applicants

- Categories often identified in APCD statute or rule
- Characteristics considered during application/review process
  - Academic researchers' credentials
  - Experience performing claims data analysis
  - Capacity to conduct appropriate analysis
  - How/where the user plans to use/disseminate results

Type of Data (HIPAA Defined)

- Deidentified Data Set (two options):
  - The Safe Harbor Method removes all 18 categories of identifiers (PHI) identified in the HIPAA Privacy Rule.
  - Expert Determination requires hiring an expert to determine that the risks of patient reidentification are minimized.
- Limited Data Set – includes indirect patient identifiers, e.g., dates specific to individuals with day/month detail, 5-digit Zip Code.
- Identifiable Data – includes direct patient identifiers, e.g., name, street address, and other identifiers unique to individuals.

Variation in Products

Standard = single file format provided to all qualified applicants
Custom = project-specific combinations of data elements, e.g., provider names with allowed (paid) amounts

Product	Format	Type	AR	CO	DE	MA	MD	MN	NH	OR	RI	UT	VA	WA
Data Set	Aggregated & No PHI	Standard		✓	✓		✓	✓	✓	✓	✓	✓		✓
		Custom	✓	✓			✓			✓				✓
	Limited	Standard					*				✓	✓		
		Custom	✓	✓	✓	✓	✓		✓	✓	✓		✓	✓
	Research Identifiable	Custom		✓	✓				✓	✓		✓		

*Access process TBD based on recent regulatory action allowing a limited dataset.

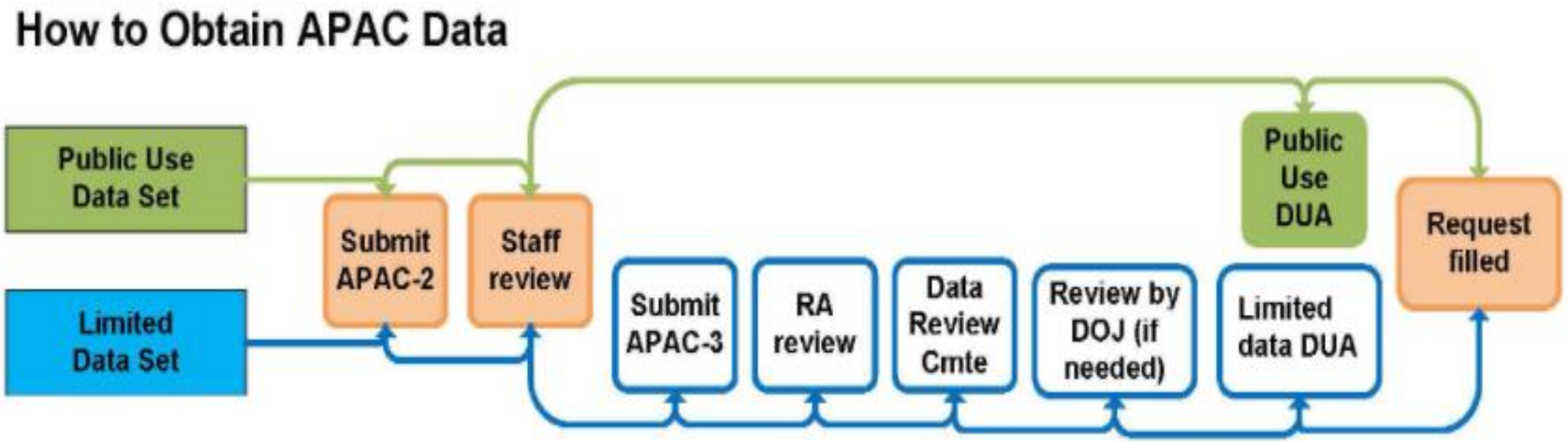
Requests for Entity and Financial Data

In addition to patient identifiers (direct or indirect), states often ask applicants to justify the need for:

- Entity Data
  - Payer name
  - Hospitals and health systems
  - Specific facilities
  - Medical practices (no individual providers)
- Financial Data
  - Allowed amounts; data elements for plan paid and patient responsibility)

External Data Applicants – Process Overview

Oregon APCD Application Flow*



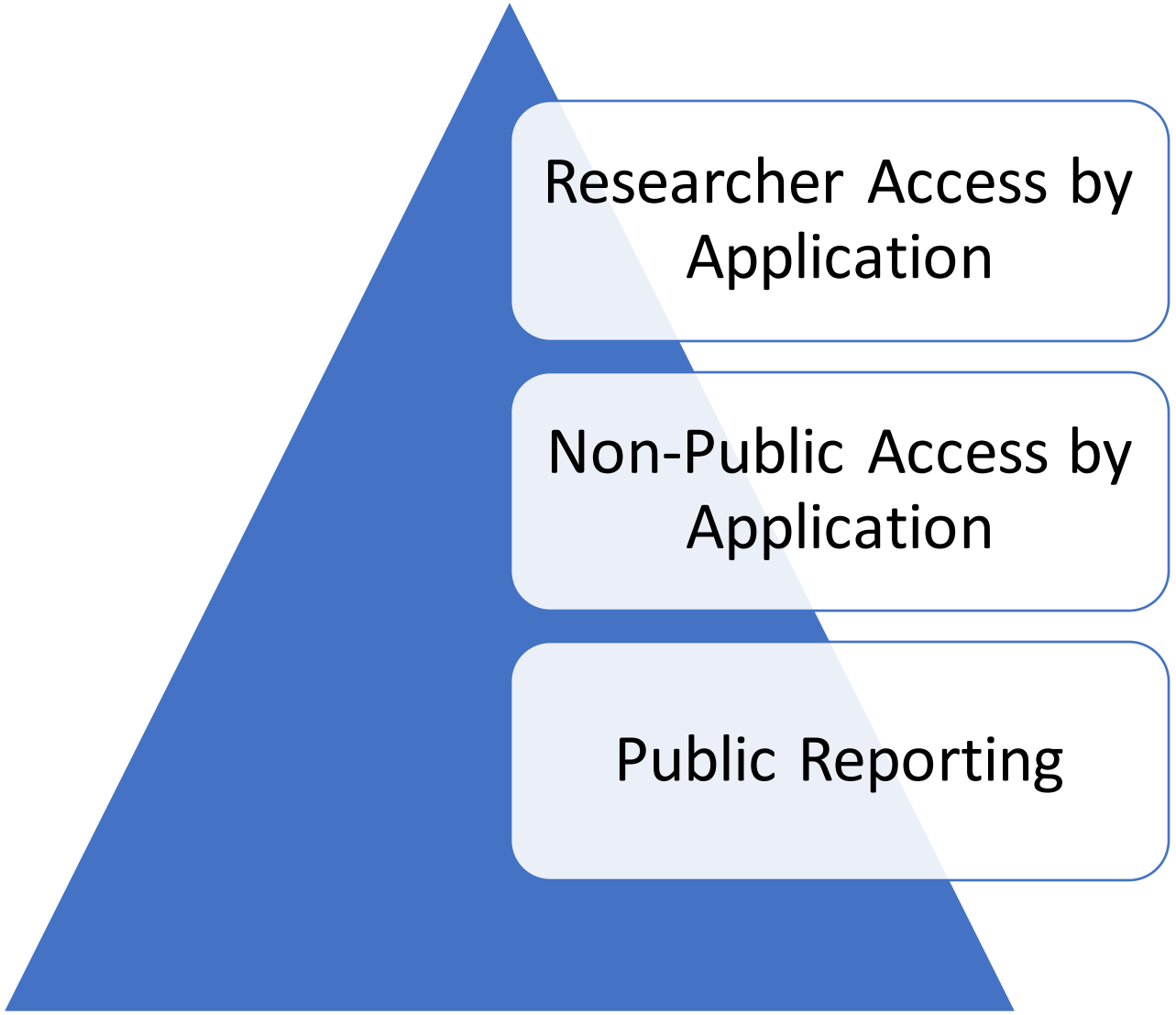
* Program is currently revising this diagram.

Federal Price Transparency Rules & APCD Data Access

- Hospitals and providers are now required to display contracted amounts for procedures on public websites
  - Similar to APCD's "allowed amounts"
  - Other than price look up tools, limited applicability to APCD use cases
- Potential impact on APCD data access
  - Currently, some states limit access to entity and financial information or have special approval processes
  - Publication of contracted amounts on public websites weakens claims of confidentiality and anti-trust that have been used to curtail access

Data Access Framework

HPD Data Access



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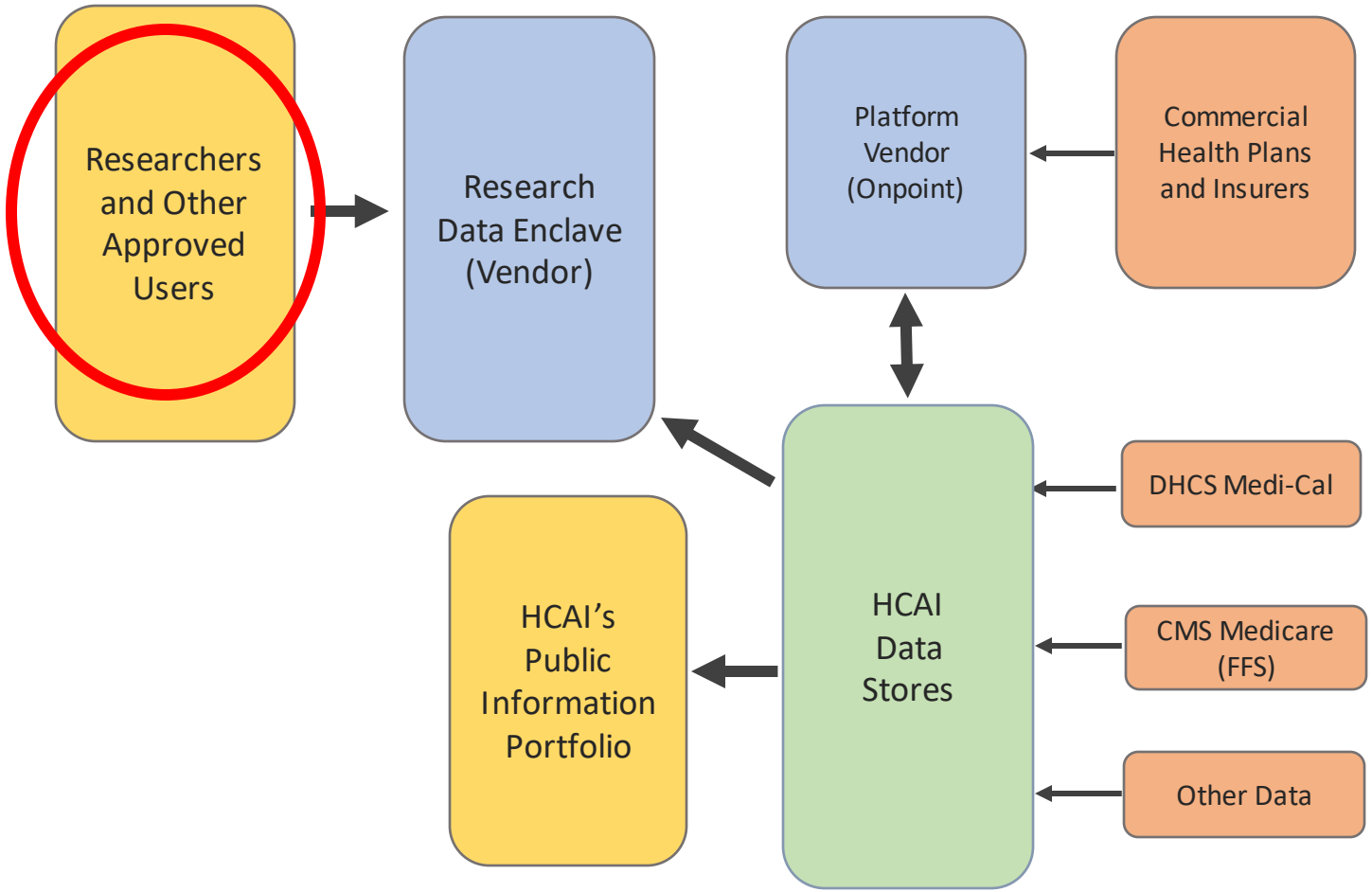
HPD Data Access

- HCAI will release public data products (reports, interactive visualizations)
- Access to non-public HPD data for approved users is expected to rely on a data enclave



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Objectives for Access to Non-Public Data

1. Protect patient privacy
2. Support program goals
3. Ensure appropriate data users, uses, and methodologies
4. Provide timely data access to qualified applicants
5. Enable and support a diverse group of data users
6. Complement the HPD public reporting program
7. Contribute to HPD Program sustainability

Program Goals (Abbreviated Version)

1. Provide public benefit while protecting individual privacy.
2. Increase transparency.
3. Inform policy decisions.
4. Support 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.
5. Support a sustainable health care system and more equitable access to affordable and quality health care for all.

Discussion Questions

- Any additional objectives that should be considered?
- Any objectives that don’t belong on the list?

Based on Statute:

- Only Qualified Applicants will be eligible to apply
- Access to non-public data will occur primarily through a secure data enclave with role-based permissions
- Access to personal identifiers will be restricted to protect privacy, may be granted if justified

Access to entity (payer, provider) and financial information is not addressed in statute.

- Principles are in place to guide public reporting
- Advisory Committee and Data Release Committee will inform decision-making

Framework for Data Access to Non-Public Data

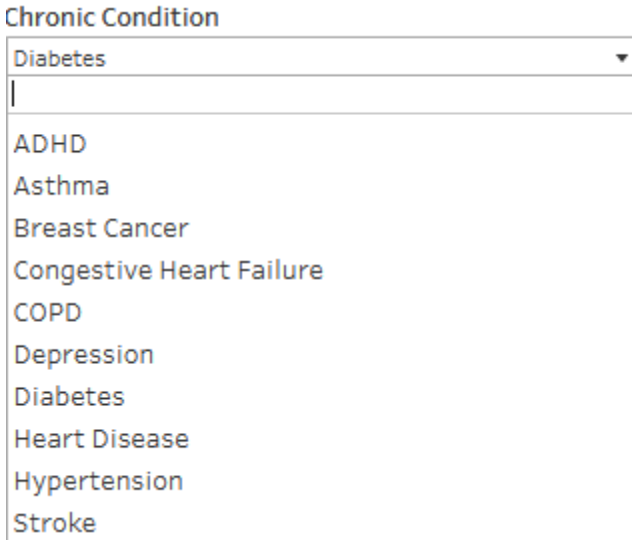
	Basic Access	Restricted Access to Identifiers	Research Identifiable Data
Standard	• Shortest approval process • Designed to meet needs of multiple Qualified Applicant categories, use cases • Could rely on interactive tool that supports a query-based approach • DRC guidance on process; HCAI approves applications and handles permissions	• Shorter approval process • Designed to meet needs of multiple Qualified Applicant categories, use cases • HCAI-defined dataset with no direct identifiers • DRC recommendation for approval may be required • HCAI approve application	
Custom		• Longer approval process • Requestor-defined dataset • Qualified Applicants eligible to apply • Content of dataset negotiated during review, no direct identifiers • DRC recommendation for approval may be required • HCAI approve applications (tailored dataset + purpose + requestor)	• Longest approval process • Requestor-defined dataset • Content of dataset negotiated during review • Direct identifiers rarely released • HCAI, CPHS, & DRC approve application (tailored dataset + purpose + requestor)

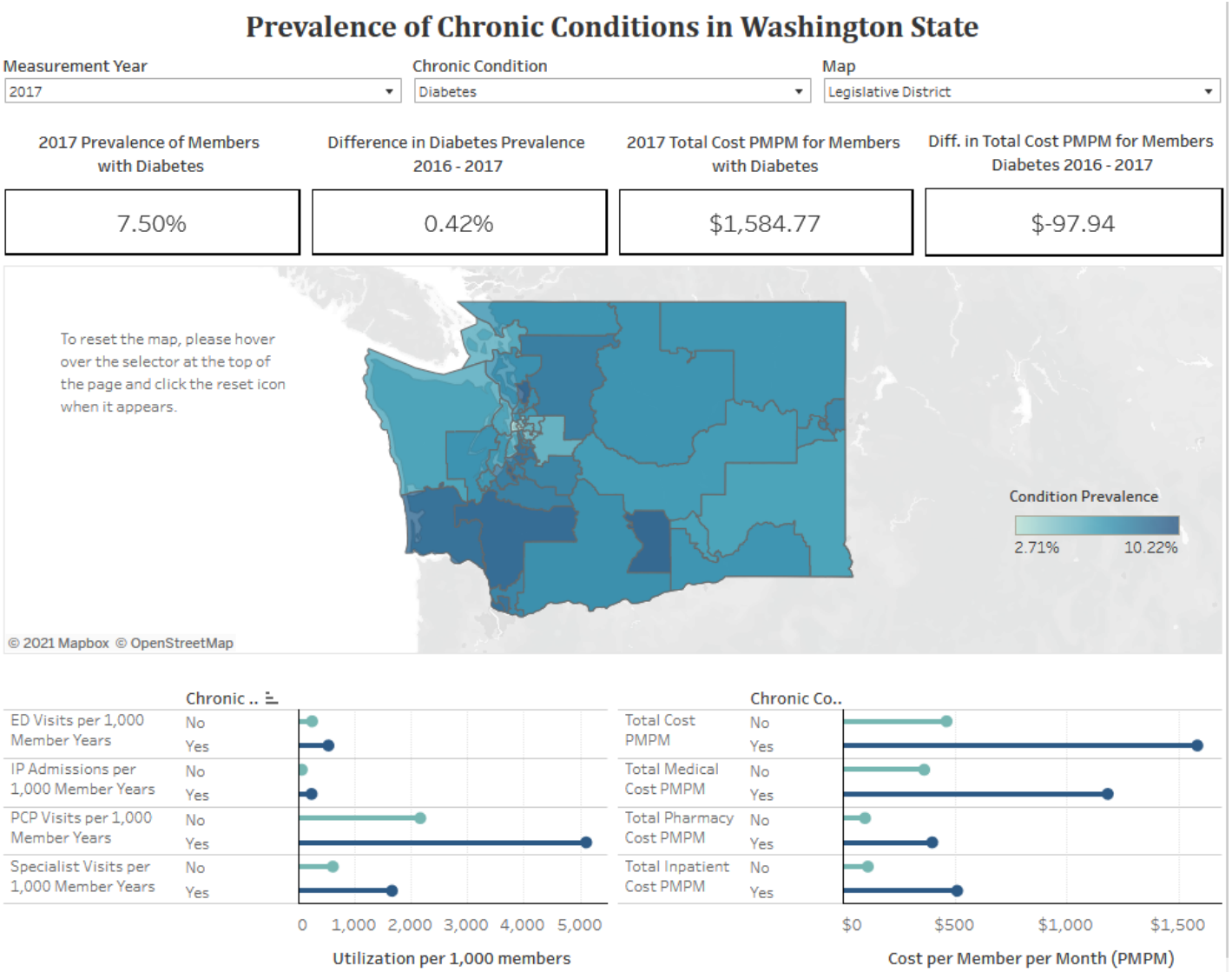
Illustrative Example – Understanding Chronic Conditions

	Basic Access	Restricted Access to Identifiers	Research Identifiable Data
Standard	Purpose: understand prevalence and cost of chronic conditions by county, age group, and payer; visualize trends over time	Purpose: analyze prevalence, utilization, and cost of chronic conditions by 5-digit ZIP code for benchmarking against own patient population	
Custom		Purpose: understand chronic conditions as a predictor of readmission	Purpose: analysis of cancer clusters based on patient location (geo-coded)

Chronic Conditions

- Select chronic conditions for reporting
- Build on prevalence by adding utilization and cost





Source: Washington State APCD

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Discussion Questions

- What are your thoughts on the data access framework?
- What types of standard datasets would be most useful?
  - What use cases might be met by an interactive tool that supports a query-based approach?
  - What use cases might require access to some patient-level data?
  - What use cases might require access to payment data such as allowed amounts?
  - What use cases might require access to entity identifiers?

Program Goals (Abbreviated Version)

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Build Over Time

Basic/Standard

- Query-based tool
- Standard datasets
- Custom analytics (HCAI analysis, deidentified data product) – simple requests
- Basic linkages (e.g., finder files)

Custom

- Custom datasets
- Research identifiable datasets
- Custom analytics (HCAI analysis, deidentified data product) – complex requests
- Linkages to HCAI in-house datasets, simple requests

Enhancements

- Linkages to HCAI in-house datasets, more complex requests
- Linkages to additional datasets (e.g., SDOH)
- Develop approach to access and custom analytics for supplemental data

Operationalizing the Data Access Program

2022-2023

Policy and Process

- Data Release Committee stood up, onboarded, staffed, and operational
- Data application process, data use agreement established and posted
- Data enclave operational
- User fees established, integrated with application process

2023-25

Applications and Use

- Applications accepted for non-public datasets
- Provide consultation with applicants re whether HPD data meets their needs and the best pathway for data access
- DRC reviews applications and approval recommendation process is established
- Approved data users able to access data enclave
- Data Users Group launched

Options to Prioritize Users/Uses

Research Innovator Partners

- Create a priority pathway for eligible applicants to apply for research identifiable data early in the process
- Allow HCAI to learn through a “beta” test, in partnership with researchers; build capacity over time to create an efficient process for ongoing access
- Reduce time to first use of HPD data for research purposes

Accelerated Access for Equity Analysis

- Develop an accelerated review process for applicants using the data to reduce disparities
- Example: Oregon’s APCD offers “incentives” such as priority application processing if the project “will identify concrete actions to eliminate health inequities”
- Approach could be applied to other priority areas to reduce time for first use of HPD data

Discussion Questions

- What is your reaction to the initial thinking on phasing in data access functionality over time?
- What input do you have on opportunities to prioritize users and uses?
  - Research Innovator Partners
  - Accelerated Access for Equity Analysis
  - Other ideas?
- What additional input do you have for HCAI in design and development of access to non-public HPD data?