

# Agenda V: HPD Confidential and Non-Confidential Data

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# HPD Data Access & Release Objectives

1. Protect Patient Privacy
2. Support Program Goals
3. Ensure appropriate data users, uses, methodologies, and compliance with all requirements
4. Provide timely data access to qualified applicants and make decisions in a consistent manner
5. Enable & support diverse users, representing multiple audiences & levels of expertise
6. Complement the HPD public reporting program
7. Support sustainability through user fees that balance program support and affordability

# Sensitive HPD Information

- Personally Identifiable Information (PII)
  - The HPD System will collect Protected Health Information (PHI).
- Entity and Financial Information (EFI)
  - Payer and Provider identifiers
  - Detailed payment information, e.g., charges, allowed amounts, plan paid amounts, patient responsibility (copay, coinsurance, deductible)
  - FTC/DOJ Statement 6 provides guidance related to U.S. antitrust law.
- Substance Use Disorder & Treatment
  - SAMHSA 42 CFR Part 2 - may constrain what comes into the database and how it can be used.
- Other: Sensitive procedures/diagnoses, Vulnerable CA populations

# Framework for HPD Data Access

|              | Non-Confidential Data<br>Aggregated, De-Identified   | Confidential Data<br>Limited Data   | Confidential Data<br>Research Identifiable Data  |
|--------------|--|---|--|
| Standardized | <ul style="list-style-type: none"> <li>• Shortest approval process</li> <li>• Designed to meet needs of multiple applicant categories, use cases</li> <li>• Could rely on interactive tool that supports a query-based approach</li> <li>• DRC provides guidance on process</li> <li>• HCAI approves applications</li> </ul> | <ul style="list-style-type: none"> <li>• Shorter approval process</li> <li>• Designed to meet needs of multiple applicant categories, use cases</li> <li>• HCAI-defined, no direct identifiers</li> <li>• DRC review required for transmission outside enclave</li> <li>• HCAI approves applications</li> </ul>                               |  |
| Custom       |  | <ul style="list-style-type: none"> <li>• Longer approval process</li> <li>• Requestor-defined dataset</li> <li>• Content of dataset negotiated during review, no direct identifiers</li> <li>• DRC review required for transmission outside enclave</li> <li>• HCAI approves applications (tailored dataset + purpose + requestor)</li> </ul> | <ul style="list-style-type: none"> <li>• Longest approval process</li> <li>• Requestor-defined dataset</li> <li>• Content of dataset negotiated during review</li> <li>• Direct identifiers rarely released</li> <li>• HCAI, CPHS, &amp; DRC approve application (tailored dataset + purpose + requestor)</li> </ul> |

# Non-Confidential Data

- Aggregated, De-Identified Data Access
- No PII or patient record level data
- *Policies for other types of sensitive information are TBD*
- Process: Requestor submits an electronic application
- DRC Role: Review and provide input/guidance on criteria, policies and procedures
- HCAI Role: Review applications, implement criteria, policies and procedures, make final approval decisions, provide/monitor access.

# Confidential Data

- Standardized & Custom Limited Data, Custom Research Identifiable Data
- May include PII/PHI and patient record level data
- *Policies for other types of sensitive information are TBD*
- Process: Requestor submits a detailed electronic application
- DRC Role:
  - Review and provide input/guidance on criteria, policies, procedures
  - Review applications and make approval recommendations.
- HCAI Role: Review applications, implement criteria, policies and procedures, make final approval decisions, provide/monitor access.

# Reasons for Denial - Confidential Data

- Confidential Data Access (via Enclave):
  - Data is not needed to support the proposed use
  - The request is for more than the minimum necessary data
  - Data access is not limited to members of the requestor's approved project team.
- Obtaining Confidential Data (via direct file transfer):
  - The proposed use can be accommodated through the Enclave
  - Requestor IT infrastructure does not satisfy data security requirements
  - Confidential data would be stored outside of the U.S.

# Discussion Questions

- Specific to DRC's role, what should HCAI consider in developing the HPD data access framework?
- Are there types of sensitive information that you would like to learn more about?
- What questions or additional discussion items related to confidential and non-confidential data should HCAI address at future DRC meetings?



# Discussion Questions

- What are your reactions to the framework for access to confidential data? How do you see this affecting the DRC's role in making recommendations to HCAI?
- What questions or additional discussion items to the data access framework should HCAI address at future DRC meetings?