Agenda IV: Data Release Process - HCAI's Role

Merry Holliday-Hanson, Research Scientist Supervisor, HCAI
Jasmine Neeley, Research Data Analyst, HCAI

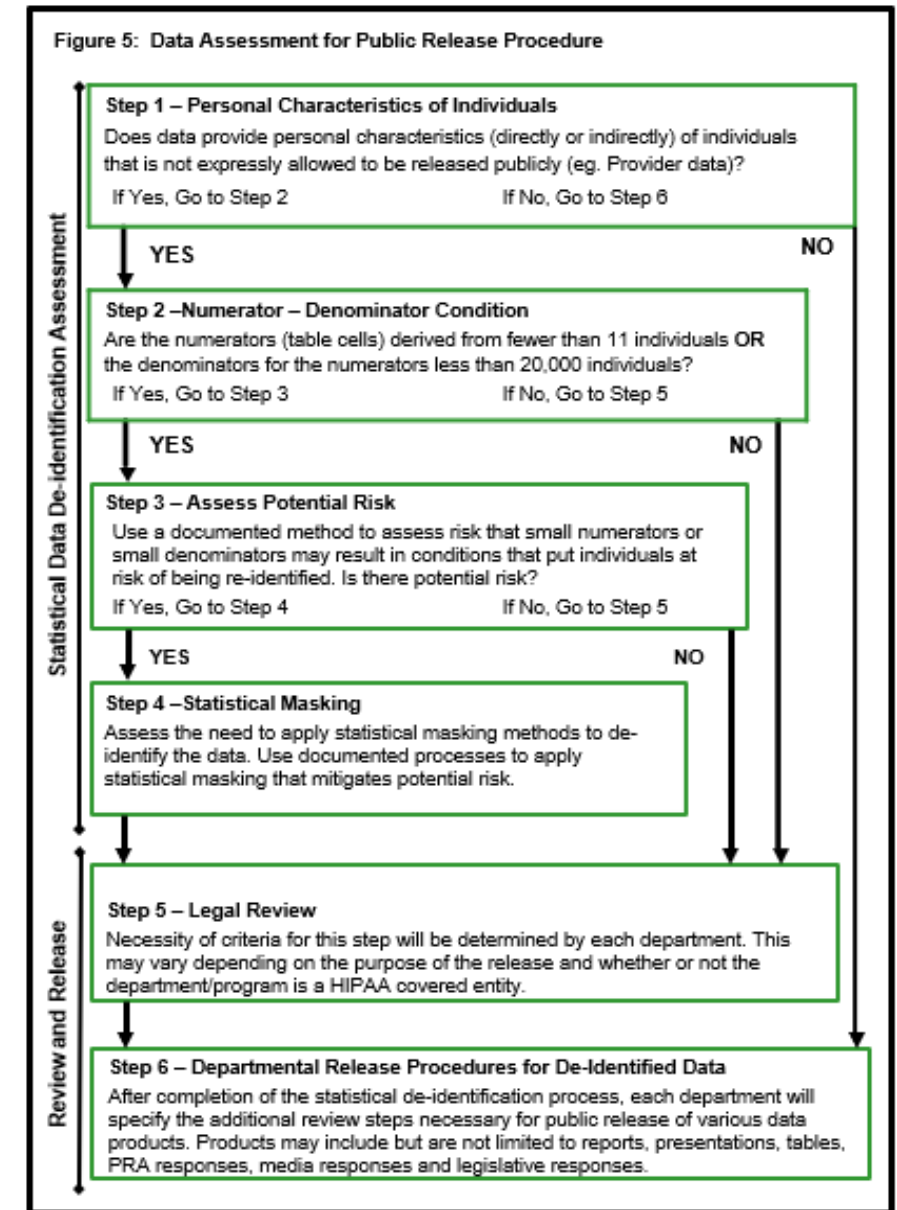# HCAI's Current Approach to Data Access Requests

- Research Request
  - Researcher must follow DUA, which includes CalHHS DDG
  - Example requests for sensitive conditions/vulnerable populations
    - Hate crimes and ED visits – stressors associated with hate crime in a community
    - Suicide/attempted suicide – morbidity and mortality in ED/inpatient settings
- Custom Data Analysis Request
  - HCAI staff perform analysis and use CalHHS DDG
  - Balance usefulness with re-identification risk
  - Example requests for sensitive conditions/vulnerable populations
    - Legal intervention injuries and hospitalizations/ED visits
    - Abortions in ED/Ambulatory surgery setting by county (vs. facility)

APCDs Limit Access & Release of Certain Data

- HIV/AIDS
- Alcohol and Substance Use Disorder
- Reproductive Health – Abortion, Family Planning
- Mental and Behavioral Health
- Genetic Testing

- Sexually Transmitted Diseases (STDs)
- Gender Affirming Care
- Rare Diseases and Conditions
  - Tuberculosis
  - Hemophilia
  - Etc.

CalHHS Data De-identification Guidelines

1. Personal Characteristics of Individuals

2. Numerator – Denominator Condition

3. Address Potential Risks

4. Statistical Masking

5. Legal Review

6. Departmental Release Procedures for De-Identified Data

Figure 5: Data Assessment for Public Release Procedure

Step 1 – Personal Characteristics of Individuals
Does data provide personal characteristics (directly or indirectly) of individuals that is not expressly allowed to be released publicly (eg. Provider data)?
If Yes, Go to Step 2   If No, Go to Step 6

YES   NO

Step 2 –Numerator – Denominator Condition
Are the numerators (table cells) derived from fewer than 11 individuals OR the denominators for the numerators less than 20,000 individuals?
If Yes, Go to Step 3   If No, Go to Step 5

YES   NO

Step 3 – Assess Potential Risk
Use a documented method to assess risk that small numerators or small denominators may result in conditions that put individuals at risk of being re-identified. Is there potential risk?
If Yes, Go to Step 4   If No, Go to Step 5

YES   NO

Step 4 –Statistical Masking
Assess the need to apply statistical masking methods to de-identify the data. Use documented processes to apply statistical masking that mitigates potential risk.

Step 5 – Legal Review
Necessity of criteria for this step will be determined by each department. This may vary depending on the purpose of the release and whether or not the department/program is a HIPAA covered entity.

Step 6 – Departmental Release Procedures for De-Identified Data
After completion of the statistical de-identification process, each department will specify the additional review steps necessary for public release of various data products. Products may include but are not limited to reports, presentations, tables, PRA responses, media responses and legislative responses.

Statistical Data De-Identification Assessment

Review and Release

HCAi
Department of Health Care
Access and Information

HCAI HPD Release

HCAI's Role

- Receive and process applications in the Data Request Portal
- Categorize applications, determine if DRC review is required
- Review applications for compliance with HCAI standards and minimum data necessary
- Produce decision letters, collect fees, fulfill approved requests
- Review project outputs for compliance with requirements
- Disable access/ensure data is destroyed at project completion
- Coordinate Communication between DRC and applicant

HCAI Roles

- Analyst
  - Assess application completeness – perform initial reviews and obtain additional information, if needed
- Supervisor
  - Confirm application completeness – check attached documents and signatures for compliance, confirm project is feasible given requested data
- Privacy Officer
  - Review request form compliance with HCAI Security Guidelines
- Final Approver - HCAI Leadership
  - HCAI positions designated with approval power

HCAI
Department of Health Care
Access and Information

Data Request Decision Tree and Flow Diagram
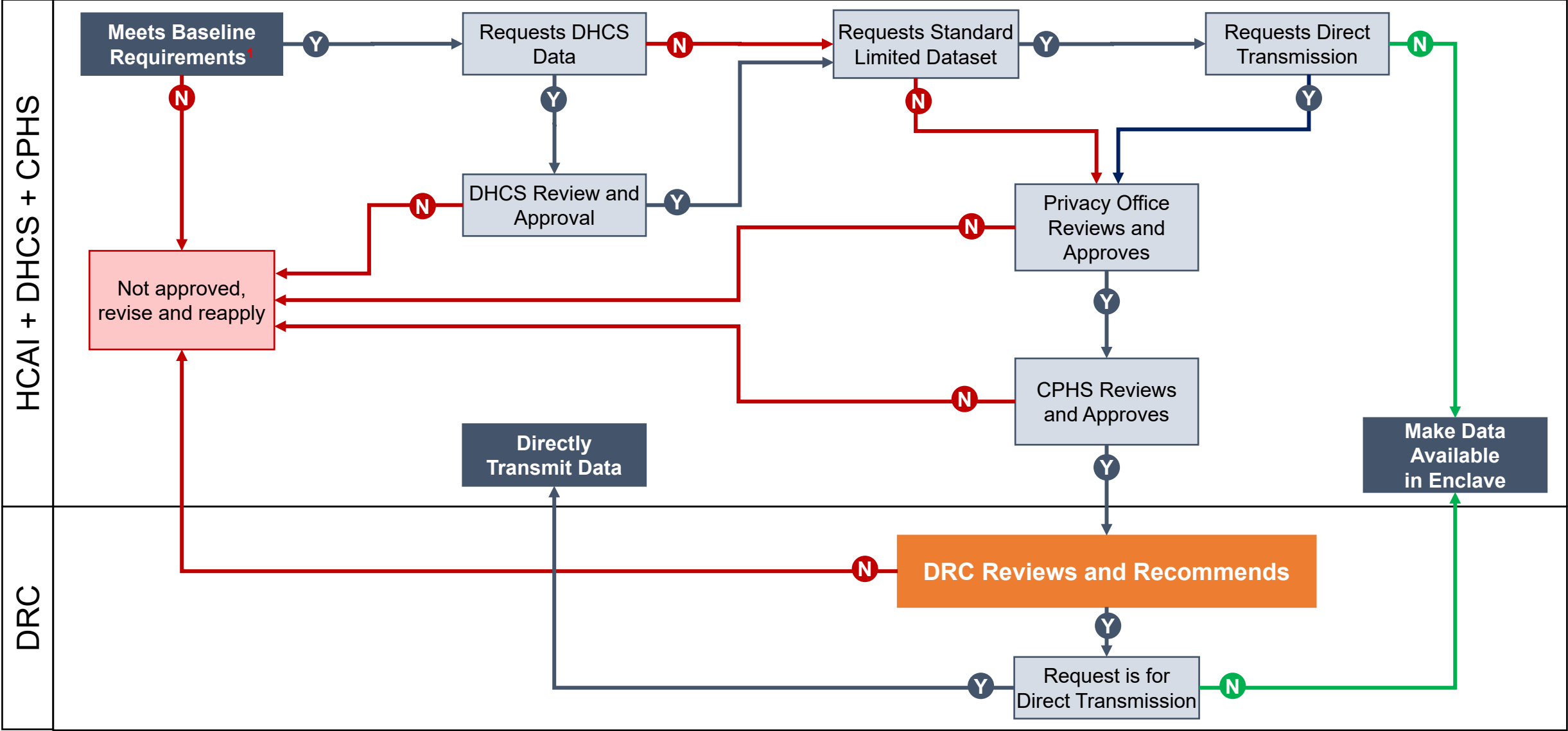
Considerations for Application Review

Statute requires consideration of:

- Whether and to what extent the data use will contribute to program goals:
  - For all requests, whether the use of the data is "**consistent with the goals"**
  - For requests that include direct personal identifiers, the bar is higher: access may only be provided for research projects that offer "**significant opportunities to achieve program goals**"
- Whether the use of the data provides **greater transparency** regarding health care costs, utilization, quality, or equity, or
- How the information may be used to **inform policy decisions** regarding the provision of quality health care, improving public health, reducing health disparities, advancing health coverage, or reducing health care costs

HSC Section 127673.83(b)(2), 127673.84(d)(2)

Considerations for Application Review

- Further considerations for request review:
  - How does the project meet minimum data necessary standards?
  - Will the research be made available to HCAI?
  - Does the project provide a public benefit for Californians?
  - Does the request involve creating something for commercialization or marketing?
  - If the project involves developing software, is it in partnership with the state?

Considerations for Application Review

- Elements requiring justification (on a per element basis):
  - Direct Identifiers
  - Indirect identifiers (dates, 5-digit zip code)
  - Entity & Financial Information (EFI)
  - Sensitive diagnoses and procedures