

# Agenda VI: Sensitive Conditions and Vulnerable Populations

*Merry Holliday-Hanson, Research Scientist Supervisor, HCAI*

# Federal Privacy Requirements

- 42 CFR Part 2 – Confidentiality of Substance Use Disorder (SUD) Records
  - Prohibits disclosure (or redisclosure) of patient-identifying SUD treatment information held by a Part 2 (federally assisted) program without patient authorization
  - Legal exceptions are limited – many state APCDs do not collect Part 2 data
- Revised Part 2 Rule (2020)
  - Basic framework not altered – revisions facilitate better care coordination while maintaining patient record confidentiality safeguards
  - APCD impact – Aligns Part 2 research disclosure requirements with HIPAA Privacy Rule and Common Rule (re: Research on Human Subjects)
- The Veterans Administration must obtain written authorization prior to external disclosure if a Veterans' health record includes:
  - Diagnosis of HIV or sickle cell anemia
  - Diagnosis and treatment of drug and alcohol abuse

# Sensitive Health Information

- Sensitivity is subjective and varies depending on the particulars of an individual's situation and context, it is information that carries with it unusually high risks in the event of disclosure.
  - Genetics, Mental Health, Reproductive Care/Abortion, Substance Abuse, HIV/AIDS, STDs
  - Influenced by cultural and political norms, individual life circumstances, emotional and health status
  - *Protecting Sensitive Health Information in the Context of HIT*, Consumer Partnership for eHealth, June 2010
  - [http://go.nationalpartnership.org/site/DocServer/Sensitive-Data-Final\\_070710\\_2.pdf?docID=7041](http://go.nationalpartnership.org/site/DocServer/Sensitive-Data-Final_070710_2.pdf?docID=7041)
- Some laws and frameworks recognize that particular health conditions may put individuals at higher risk for discrimination and harm ... and require special treatment and handling of information relating to alcohol and drug abuse, genetics, domestic violence, mental health, and HIV/AIDS
  - *Guide to Privacy and Security of Electronic Health Information*, ONC HIT, V.2.0, April 2015
  - <https://www.healthit.gov/sites/default/files/pdf/privacy/privacy-and-security-guide.pdf>

# Sensitive Diagnoses, Procedures and Vulnerable Populations

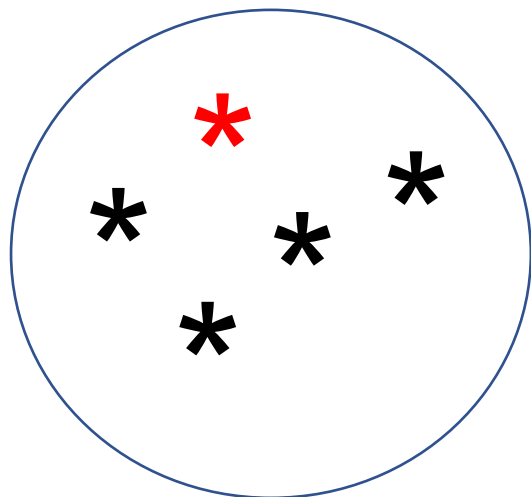
- Very little statutory and regulatory guidance
- State APCDs have taken a variety of approaches
- Stakeholder concerns are often state specific

# APCDs Limit Access & Release of Certain Data

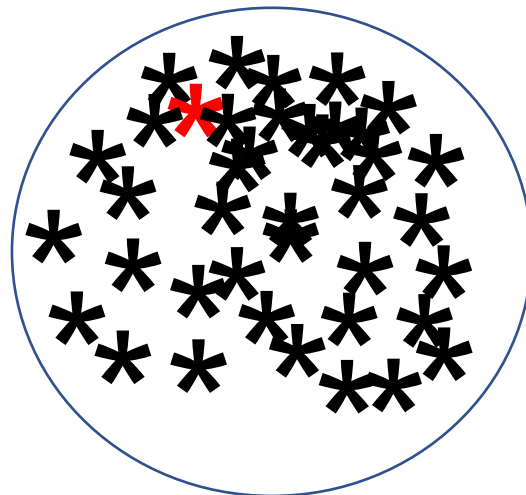
- HIV/AIDS
- Alcohol and Substance Use Disorder
- Reproductive Health – Abortion, Family Planning
- Mental and Behavioral Health
- Genetic Testing
- Sexually Transmitted Diseases (STDs)
- Gender Affirming Care
- Rare Diseases and Conditions
  - Tuberculosis
  - Hemophilia
  - Etc.

# Risk of Reidentification and Uniqueness

Aggregate Data File  
 $n < 11$



Aggregate Data File  
 $n \geq 11$



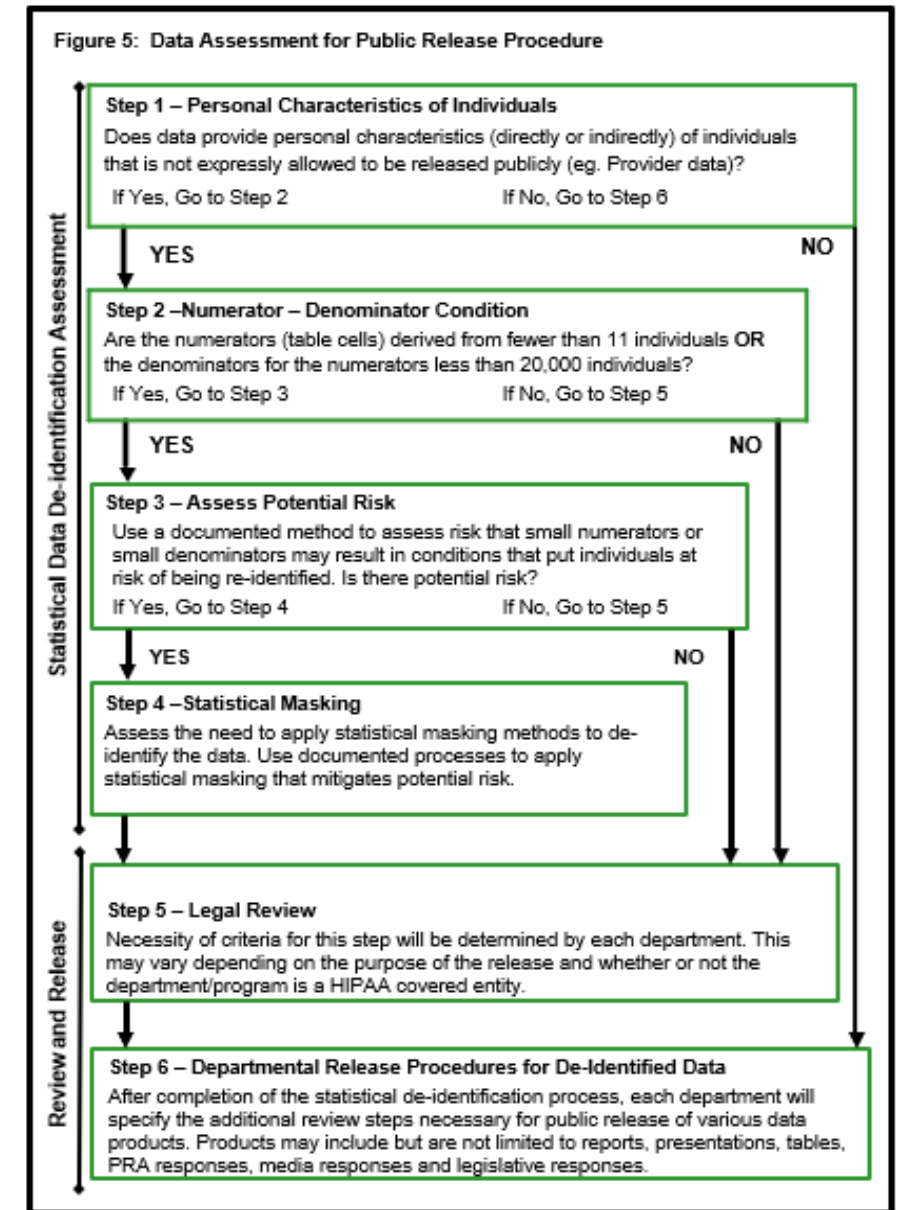
# Knowledge About an Individual (data in the world)

The collage illustrates the concept of 'Knowledge About an Individual' through various data sources and agencies. It features a newspaper labeled 'DAILY NEWS', a thought bubble containing a red asterisk, and two stick figures shaking hands. Below these are numerous logos of California state agencies, including:

- EMSA (Emergency Medical Services Authority)
- DHCS (California Department of Health Care Services)
- Department of State Hospitals
- CDPH (California Department of Public Health)
- CDSS (California Department of Social Services)
- DOR (Department of Rehabilitation)
- HCAI (Department of Health Care Access and Information)
- Center for Data Insights and Innovation (California Health & Human Services Agency)
- CSO (California State Office of the State Auditor)
- Department of Managed Health Care
- Department of Developmental Services
- Department of Aging

# 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



# HPD Approach

- Use CalHHS DDG
- Conservative
- Case by case basis
  - May need recommendations from DRC