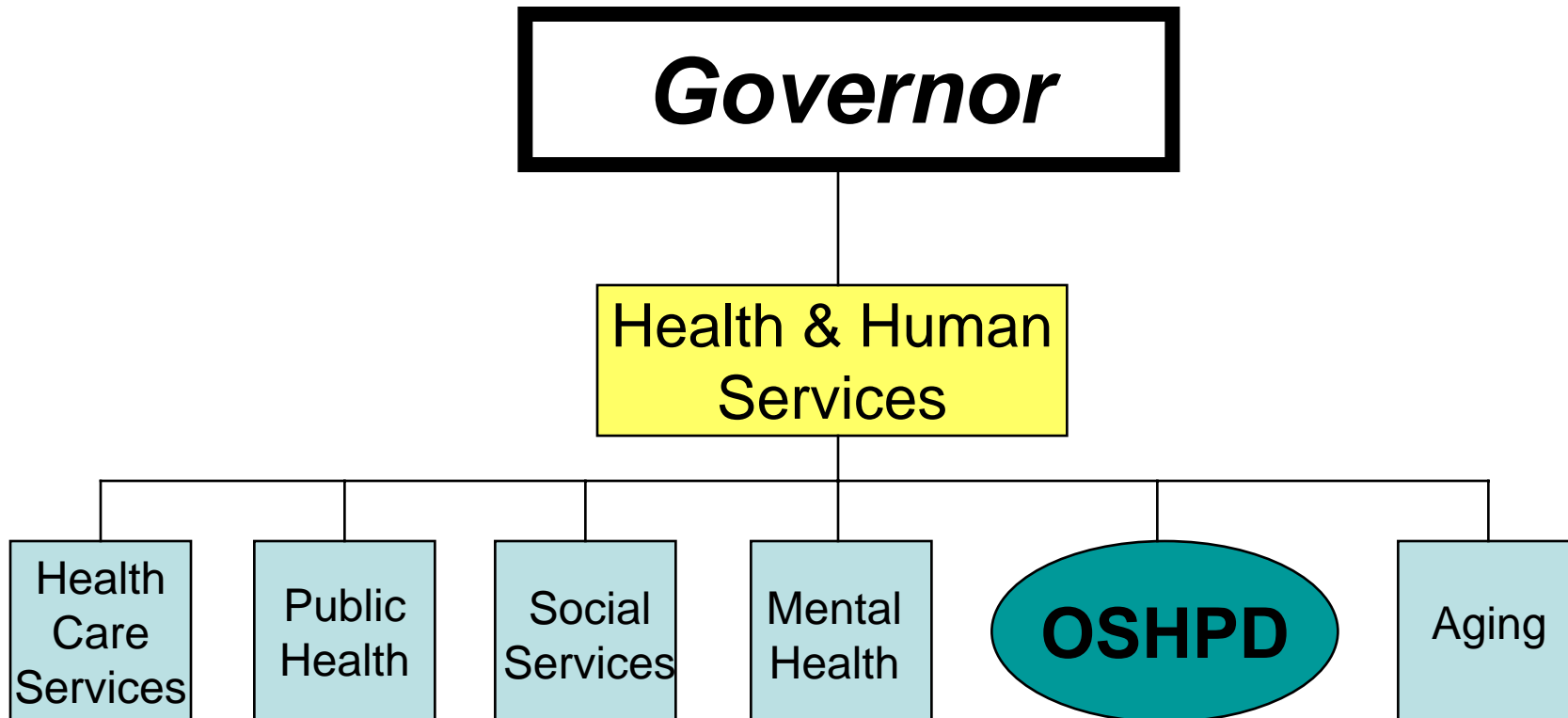# Presentation to the
National Committee on Vital and Health Statistics (NCVHS)
Ad Hoc Work Group on
Secondary Uses of Health Data

Dr. David Carlisle, Director
Office of Statewide Health Planning and Development
California Health and Human Services Agency
August 1, 2007

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OSHPD in the California Government Hierarchy

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Governor

Health & Human Services

Health Care Services	Public Health	Social Services	Mental Health	**OSHPD**	Aging

Other CHHSA Department-Level Units include: Rehabilitation, MRMIB, Alcohol &Drug, Education Development, Developmental Services, Emergency Medical Services, Data Bank, Community Development, but not Managed Care
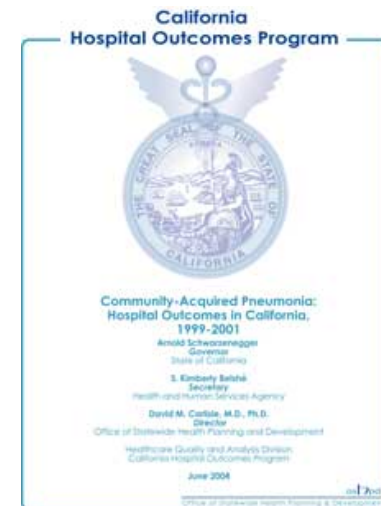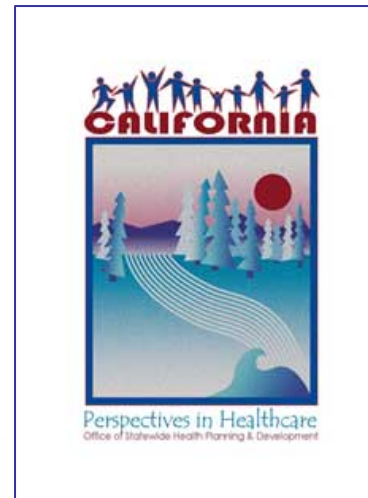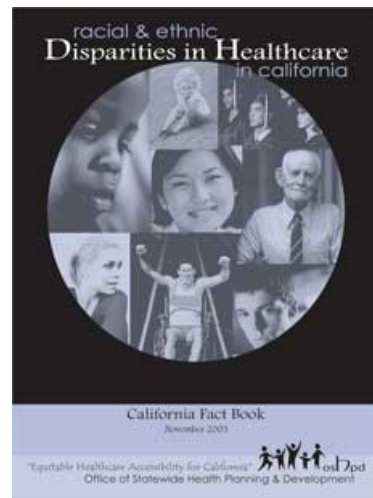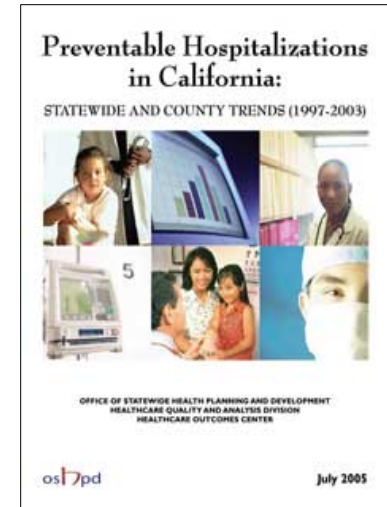
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OSHPD Outcomes Reports

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Healthcare Outcomes Center:

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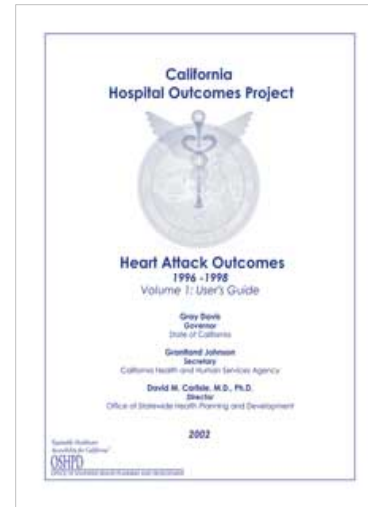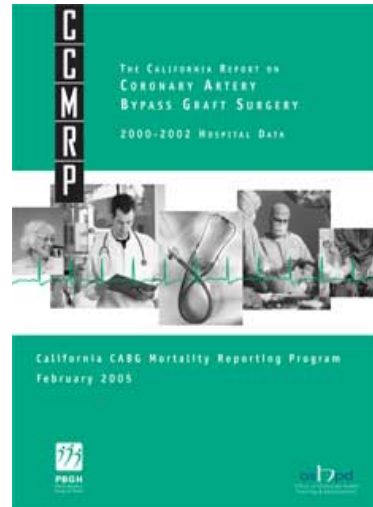
OSHDP Databases

	LTC	Clinics	Hospitals	EDs	Hospice/ HHA	ASCs
Financial	√-	√-	√-			√-
Utilization	√	√-	√-	√	√	√
Discharge			√	√		√
Clinical (CABG)			√ (public & Non-public)			

√- : Limited Database

# Patient-Level (Discharge) Datasets

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- 3.9 million hospital discharges/year

- 8.5 million ED discharges/year

- 2.9 million AS discharges/year

- Demographic Data (Age, Sex, Race/Ethnicity)

- Medical Data (Diagnoses, Procedures, E-Codes, MDC, DRG)

- Other Data (Patient ZIP Code, Record Linkage Number (SSN-based), Admission Source, Disposition, Payer, Charges, Hospital ID)

OSHPD Patient-Level (Discharge) Data

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Discharge Databases
(Hospital, ED, ASC)

→ **Public***

Non-public

→ Standardized

→ Project-Specific
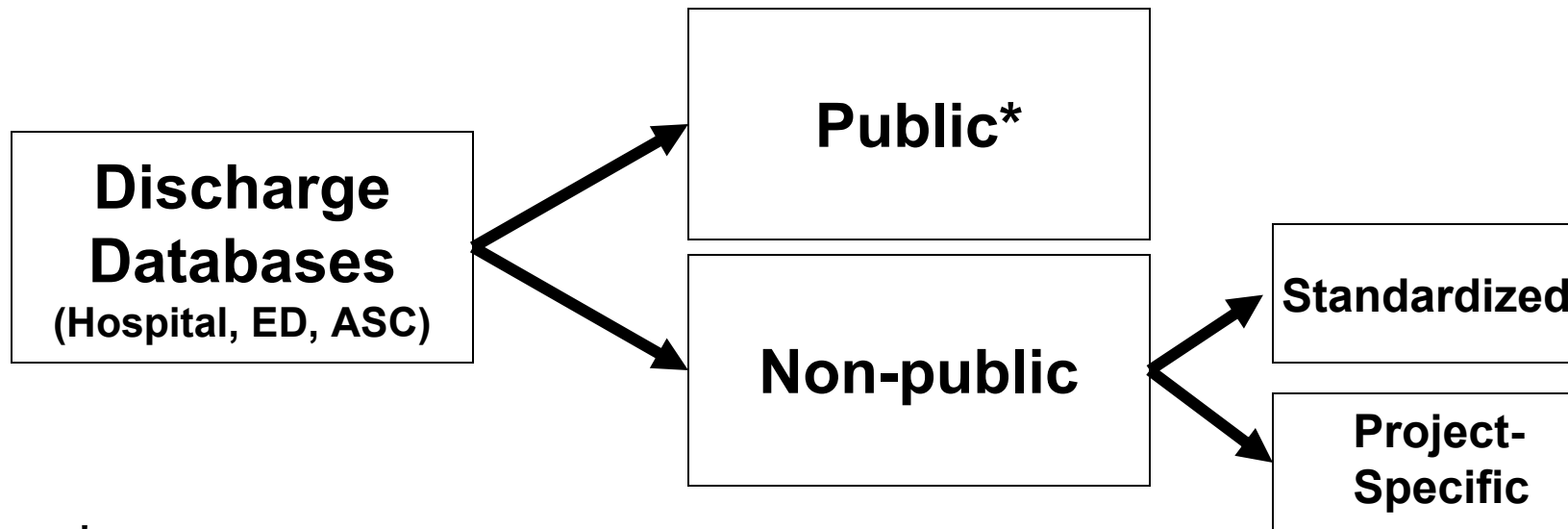
*****Public version of datasets – de-identified**

> Includes all records in confidential datasets, but not all elements
> Uses Age categories
> Includes 5-digit Zip Code
> Uses "masking" of specific data elements (race, diagnosis, procedure)

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Public Awareness of Uses of Patient-Level (Discharge) Data

- Administrative datasets collected from hospitals and ambulatory surgery clinics
  - It is expected that the individuals whose data are being used are not typically aware of this
    - No consent/authorization is obtained
  - Hospitals and medical researchers who are also providers request this data themselves and hence are aware of its secondary use
  - Strict security measures to keep data confidential or de-identified

Legal Constraints on Disclosure of Non-Public Patient-level Data

- California Information Practices Act
  - For research purposes, by non-profit education institutions (universities)
- California Health Data and Advisory Council Consolidation Act
  - extends to local and federal public health agencies and California hospitals
- H&S Code: OSHPD provides data to the CA Dept. of Public Health
- National Centers for Health Statistics or other unit of the Centers for Disease Control and Prevention
- The Agency for Healthcare Research and Quality

  …for statutorily authorized activities

Non-Public Patient Level Data: Content & Conditions

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- Designated users may have <u>limited data sets</u>
  - Complying with HIPAA data disclosure rules:
    - No direct identifiers (e.g., SSN)
    - The dataset must be the minimum required to fulfill the purpose
    - Must be for specified purposes of research, public health, or health care operations
    - With a data use agreement that will establish
      - The permitted uses
      - Who is permitted to use the data

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Non-Public Patient Level Data: Content & Conditions, cont'd

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Recipient agrees to:

- Use data only as specified
- Use appropriate safeguards to prevent misuse or disclosure of the data
- Report to OSHPD any disclosure not provided for in the data use agreement
- Ensure agents or subcontractors agree and comply with same conditions and restrictions
- Not identify or contact individuals

Non-Public Patient Level Data: Content & Conditions, cont'd

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- Research uses require approved protocol, in compliance with the Common Rule
- CHHSA's Internal Review Board – the Committee for the Protection of Human Subjects (CPHS)
  - Requests for confidential OSHPD data for research must include a CPHS-approved project protocol
  - Protocol must be kept current (annually) while researchers are in possession of patient-level data
  - Covers research by state agencies, public & private universities
    - Includes OSHPD's own Outcomes Reports
  - De-identified descriptive statistical reporting not included (e.g., data products such as Perspectives in Healthcare)

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Protecting Confidentiality of Data

- OSHPD maintains a secure IT environment
  - 128 bit encryption used on all removable media
  - SAS datasets held on a secure server with restricted access
  - Data collection systems maintain strong security; processing occurs in a locked facility, with servers in locked area behind firewalls.
- Primary personal identifiers (SSN) are not disclosed
- Other primary identifiers (e.g., names) are not collected
- Data Use Agreements with all users outside of statutory data recipients (OSPHD & DPH)

OSHPD Data Stewardship

- OSHPD's Patient Data Section collects and performs initial quality testing of the data

- OSHPD's Data Management Office has overall responsibility for maintaining the OSHPD Data Warehouse, a secure data repository.

- OSHPD Healthcare Information Resource Center reviews data requests, runs custom statistical analyses for requestors where data cannot itself be released.

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OSHPD Healthcare Information Resource Center

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