



Putting
the Pieces
Together

OSHPD's Non-public Data Request Process

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When Public Data Is Not Enough

- Some research requires access to the confidential file



OSHPD Non-public Data

- Hospital Patient Discharge Data (PDD)
- Emergency Department Data (ED)
- Ambulatory Surgery Data (AS)
- California Coronary (Artery Bypass Graft CABG) Outcomes Reporting Program (CCORP/PDD)
- Vital Statistics Birth and Death Master files linked to PDD
 - “Birth Cohort” file
 - PDD-Death Linked file
 - Other linked products under discussion

Access to Confidential Patient-level Information



OSHPD Non-public Data

- Patient level records, in non-deidentified data sets
- Specific legal requirements must be met to access this data
 - Information Practices Act (IPA) – CA Civil Code §1798.24 *et seq.*
 - Health Data Act – CA Health & Safety Code §128766
- IPA is legal avenue for university-sponsored researchers

AB 2876 Non-public Data Review

- Patient level records, in non-deidentified model data sets
- Specific legal requirements must be met to access this data
 - AB 2876 Hospitals and Public Health Departments means to access non-de-identified PDD, ED and AS data sets

OSHPD Data and IRB Review

- Committee for the Protection of Human Subjects (CPHS) is state IRB for California Health & Human Services Agency
- OSHPD policy: all IPA confidential data requests must have current approved CPHS protocol, to be maintained while data is in researchers' possession.

OSHPD Data and IRB Review

- CPHS also has statutory responsibilities for privacy protection under the Information Practices Act
- “Data only” projects can receive expedited review
- See: <http://www.oshpd.ca.gov/CPHS/index.htm> for forms and information

Statutory Requirements Applied to Data Requests

- Disclosures limited to “minimum necessary” data required to conduct the proposed research
- Data will be “sub-set” to achieve this
 - Reduce number of records to those actually required for research (including control/comparison groups)
 - Includes geographical, age, and gender subsets
 - Reduce suite of data elements in each record to those actually employed for research
- The more precise the subset, the easier to pass review

Statutory Requirements Applied to Data Requests

- Researcher cannot “re-identify” patient records, by linking to other data files or otherwise adding identifiers to the OSHPD file
- Persons with access to the data must be specified, including consultants
- Secure information environment for working with the data
- Products (publications, etc.) must not contain any patient level information
 - Address small cell sizes in presentation of research results

Requesting Non-public Data

- Two principal steps:
 - Approved OSHPD application for data
 - Approved CPHS Project Protocol
- The two must be consistent in terms of the data desired and purposes for which it is sought
 - Recommended to come to OSHPD first, to ensure that data specifications are consistent between OSHPD data request and CPHS project protocol

Requesting Non-public Data

- Data grid contains detailed justification for each element required
- Sensitive data elements will entail more scrutiny
- University (“non-profit educational institution”) must sponsor the data request
 - Signatures by PI(s) and Department Chair or equivalent university official, on Protocol
- OSHPD Chief Information Officer is final arbiter of requests for confidential data

Modes of Access to Non-public Data

- Typically data is made available to requestor as a time-limited data release on DVD
- OSHPD currently experimenting with on-site data availability
 - Similar to research data centers at CDC National Center for Health Statistics or the U.S. Bureau of the Census
 - Goal is minimization of risks of inadvertent disclosure of confidential information

Pricing of Non-public Data

- Data pricing policy: Most recent three years of data can be provided at no charge to eligible non-profit requestors (e.g., presently, 2005-2007)
- \$200/year for PDD other data years
- \$200/for half year for ED/AS other data years
- Linked data products (PDD/VSD or /VSB) require additional payment to Dept. of Public Health for their data files incorporated in the product files.
- OSHPD cannot discount the DPH portion of the data fees. This is \$200 per year of VSD or /VSB

For Non-public OSHPD Data

- Contact LOUISE HAND – OSHPD/HID/HIRC
- Telephone: (916) 326-3813
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Questions?