Iris Cantor – UCLA Women’s Health Center

REPRODUCTIVE HEALTH METADATA PROJECT
**Key Objectives of the Reproductive Health Metadata Project**

- To serve as a resource for students and researchers new to the field of reproductive health
- To build a constituency of students, emerging leaders, and scholars to support legislative actions to advocate for and defend the maintenance and continuation of these vital data sources
CURRENT STATE OF REPRODUCTIVE HEALTH DATA
Our Reproductive Health Data are in Danger of Heading in the Same Direction
CURRENT STATE OF REPRODUCTIVE HEALTH DATA

- California Birth Defects Monitoring Program: A cautionary tale or a trend?
  - Launched in 1982
  - Slowly expanded eventually collect from all of California’s 58 counties
  - Fiscal priorities shift and data collection has been reduced to 10 counties
  - Los Angeles County data have not been collected since 2004

- Current LA County political environment is uncertain
  - New County Supervisors
  - Integration of County Departments
PROTECTING REPRODUCTIVE HEALTH DATA

- Collecting Reproductive Health Data Is Not Enough
- We need alternative funding approaches to keep them vibrant and sufficiently supported
- We need a vocal constituency defending these data from the caprices of politics and shifting priorities due in part to diminishing public dollars
- #birthoutcomesmatter
So, what are we going to do about this?

Wonder Woman, Superman, and Batman. What are you going to do about it?
Reproductive Health Metadata Project

What is the Reproductive Health Metadata Project?

- Helps new researchers and graduate students learn more about reproductive health data in California and Los Angeles
- Increases their familiarity with some core bits of metadata for each dataset included so far
- Designed to facilitate data acquisition for research projects
- Intended to be responsive and current (wiki-esque)
- Will expand to include Environmental Health Datasets
REPRODUCTIVE HEALTH METADATA PROJECT

- The Reproductive Health Metadata Project is not
  - An institutional repository
  - Nor is it a compilation of data dictionaries for each included dataset
LIST OF REPRODUCTIVE HEALTH DATASETS

- California Birth Defects Monitoring Program
- California Health Interview Survey
- California Prenatal Screening Program (PNS)
- California Vital Statistics
- LA HealthDataNow!
- L.A. HOPE
- Los Angeles County Health Survey
LIST OF REPRODUCTIVE HEALTH DATASETS

- LAMB Project
- Maternal and Infant Health Assessment
- California Office of Statewide Health Planning & Development
- PHFE WIC Data Mining Project
- University of California Research eXchange
CORE METADATA

- General Description
- Background
- Data Collection Methods
- Data Coverage (Temporal and Spatial)
- Accessibility
- Funding
- Contact Information
Reproductive Health Metadata Project

Overview of the Project

Welcome to Iris Cantor UCLA Women’s Health Center Reproductive Health Metadata Project. This project was developed to help researchers and students learn more about available reproductive health data in California and Los Angeles County. We have compiled a list of administrative databases that researchers use to answer various research questions. To help you with your own investigations, we have included common bits of metadata so that you are more familiar with the procedures to acquire these data, frequencies these data are collected, agencies responsible for collecting and maintaining the data, and where you can visit them on the web to learn even more. In very short time, you should be prepared to take the first steps to gather the data you need to test your hypothesis!

If there are any errors in the metadata, suggestions for data collection websites, or if their respective administrators change protocols or methodologies, please do not hesitate to let us know. We will make every effort to keep these data links up to date.

For further information, follow these links:
- Glossary of Terms
- List of DataSets

For more information about the Reproductive Health Metadata Project, please contact:

Efrén Aguilar
Geographic Information Systems Unit Chief
UCLA Center for Healthier Children, Families and Communities
eaquilar@mednet.ucla.edu
Datasets

Reproductive Health Datasets

California Birth Defects Monitoring Program

The California Birth Defects Monitoring Program (CBDMP) collects and analyzes data to decrease the occurrence of birth defects and improving the health of babies. For more information, click here.

Website Link

California Health Interview Survey

CHIS is the nation's largest state health survey, giving a detailed picture of the health and wellbeing of the diverse and diverse population. For more information, click here.

Website Link

California Prenatal Screening Program (PNS)

The California Prenatal Screening Program (PNS) is one component of the California Genetics and Diagnostic Services Program (GDSP). Currently, the GDSP runs the largest screening program in the world and has designed, in collaboration with the GDSP, a high quality, cost-effective genetic services to all Californians. For more information, click here.

Website Link

California Vital Statistics

California Vital Statistics data files are compiled from the information reported on birth, death, and other vital events, including detailed demographic information related to the infant, mother, and father (for births and deaths), as well as medical data related to the vital event. For more information, click here.

Website Link

LA HealthDataNow!
California Prenatal Screening Program (PNS)

General Description
The California Prenatal Screening Program (PNS) is one component of the California Genetic Disease Screening Program (GDSP). Currently, the GDSP runs the largest screening program in the world and have set the standard in delivering high-quality, cost-effective genetic services to all Californians.¹ The activities of the PNS are directed toward detecting birth defects during pregnancy. PNS is working to assure prenatal screening services and follow-up diagnostic services, where indicated, are available to all pregnant women in California. Prenatal screening currently offers three types of screening tests to pregnant women in order to identify individuals who are at increased risk for carrying a fetus with a specific birth defect.

The screening tests include:
1) **Quad Marker Screening** - One blood specimen drawn at 15 weeks - 20 weeks of pregnancy (second trimester test).

2) **Serum Integrated Screening** - Combines a first trimester blood test screening result (10 weeks-13 weeks 6 days) with a second trimester blood test screening result (15 weeks-20 weeks).

3) **Sequential Integrated Screening** - Combines first and second blood test results with Nuchal Translucency (NT) ultrasound results. This type of ultrasound is done by clinicians with special training. It measures the back of the fetus' neck. This measurement helps screen for Down syndrome (trisomy 21). (Note: the Screening Program does not pay for NT ultrasounds).

The Prenatal Screening Program provides pregnant women with a risk assessment for open neural tube defects (NTD), Down syndrome (trisomy 21), trisomy 18 and SLOS (Smith-Lemli-Opitz Syndrome) through one or two blood tests. The screening test indicates risk, but does not diagnose fetal birth defects. For women with screening results indicating a high risk for a birth defect, the Program provides free follow-up diagnostic services at State-approved Prenatal Diagnosis Centers (PDCs) (PDF). Services offered at these Centers include genetic counseling, ultrasound, and amniocentesis. Participation in the screening testing and follow-up services is voluntary. The cost of the testing through the Prenatal Screening Program is $207.

Background
The California Prenatal Screening Program was developed by the Genetic Disease Screening Program, a division of the California Department of Public Health. The Program began in 1986 and it is linked to both the California Birth Defects Monitoring Program and California Biobank Program.

¹ [http://www.cdph.ca.gov/programs/GDSP/Pages/default.aspx](http://www.cdph.ca.gov/programs/GDSP/Pages/default.aspx)
Data Collection
Data are collected through blood samples and ultrasounds on an ongoing basis

Data Coverage
Data are collected for the entire state of California. Additional geographic information will be determined by California State IRB CalProtects.

Accessibility
Data released to researchers must be approved by an IRB. Terms of use and data restrictions to be determined by IRB.

Data Link

Funding
The PNS is funded as part of the CGSP. The California Department of Public Health, Center for Family Health administers the GDSP and is 100% fee supported.

Contact
Genetic Disease Screening Program
850 Marina Bay Parkway
Suite 175, MS 8200
Richmond, CA 94804
Voice: (510) 412-1502 / Fax: (510) 412-1548
Glossary of Research Terms

- We have also included a glossary of Research Terms (such as)
  - Institutional Review Board
  - Cohort
  - Surveillance
  - Institutional Repository, etc.
Reproductive Health Metadata Project

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Glossary of Terms
List of DataSets

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Glossary of Terms

Aggregate Data is data not limited to one participant, which is tracked across time, organizations, populations, and usually multiple and/or repeated variables. (Source: National Center for Biotechnology Information)

Asset Mapping is a visual representation of a location’s resourceful sites and services to its community. It is used to identify a community’s unmet needs for certain resources, which is useful in determining how to build upon existing assets or creation of new ones. Asset mapping promotes community empowerment, partnership, and involvement. (Source: National Center for Health Policy Research)
Glossary of Research Terms

**Aggregate Data** is data not limited to one participant, which is tracked across time, organizations, populations, or other variables. (Source: National Center for Biotechnology Information)

**Asset Mapping** is a visual representation of a location’s resourceful sites and services to its community. Asset mapping allows one to identify a community’s unmet needs for a certain resource, which is useful in determining how to build upon already existing assets or creation of new ones. Asset mapping promotes community empowerment, partnership, and involvement. (Source: UCLA Center for Health Policy Research)

**Cohort** is a set of people studied over a period of time. People within a cohort embody certain shared characteristics and are examined for investigation on a certain outcome like disease, death, etc. (Source: National Center for Biotechnology Information)

**Cohort Study/ Panel Study** is a type of epidemiological study in which sets of a certain population are identified to have, at one point, been exposed or unexposed to a certain factor that is hypothesized to influence the occurrence of a certain outcome. (Source: UCLA School of Public Health)

**Datasets** are a collection of data that is organized for studying. Most commonly, a single database table with a single statistical data matrix is used. (Source: Wikipedia)

**Demographics** are the statistical characteristics or qualities (such as age, sex, income, etc.) of populations used as identifiers. (Source: Wikipedia)

**Environmental Scanning** is a tool for obtaining and organizing data of an organization that allows the study for certain events and trends; environmental scanning helps plan the initiation and future of a project, provide evidence of the directionality of an organization, or raise awareness of issues. (Source: National Center for Biotechnology Information)
How to Access the Reproductive Health Metadata Project

- Google: The Reproductive Health Metadata Project
- Follow me on twitter @altruisticnerd
- Search twitter #birthoutcomesmatter
- Visit URL www.womenshealth.ucla.edu
You can be a Contributor to the Reproductive Health Metadata Project

- Submit an email to me at eaguilar@mednet.ucla.edu
- Tweet me @altruisticnerd