



The Perinatal Periods of Risk Approach

Vital Records Data – Access and Preparation



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Preparation of Data

- Define study population
- Obtain the “raw” data files
- Assess data quality
- Restrict study population by birthweight and gestational age (excluding extremely premature cases)
- Assure sufficient number of deaths (at least 60 deaths in at most 5 years)

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Place: occurrence vs. residence

- In the US, births and deaths are reported in the place (city, county, state) in which the event **occurs**
- Place of **residence** is also recorded
- If a birth mother resides in a state different from where she gave birth, a copy of the birth certificate is sent to mother’s state of **residence**
- Death certificates are sent to the decedent’s state of **residence**, if known

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Cause of Death

- Part I -- reporting a chain of events leading directly to death, with the immediate cause of death (the final disease, injury, or complication directly causing death) on line a and the underlying cause of death (the disease or injury that initiated the chain of events that led directly and inevitably to death) on the lowest used line.
- Part II -- reporting all other significant diseases, conditions, or injuries that contributed to death but which did not result in the underlying cause of death given in Part I.

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Underlying cause of death

- Underlying cause-of-death is coded by NCHS based on the conditions entered by the physician on the cause of death section of the death certificate
- Determined by the sequence of conditions on the certificate, provisions of the ICD, and associated selection rules and modifications
- Classified in accordance with the International Classification of Disease using the Tenth Revision (ICD-10)

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Infant Death Data

- Death certificates in a state are maintained by state vital statistics registrar
 - If a person dies in a state different from the one in which he / she resided, then a copy of certificate is sent to decedant’s state of residence\
- All infant deaths (less than 1 year) are linked to the baby’s birth certificate

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What does it mean to “link” the death record to the birth record?

- ◆ When a baby dies we find the birth information *for that same baby* and put the two records together into one “row” in a computer data file.
 - ◆ Most birth certificates are easy to find and match exactly (same mother, same birthday, same address etc.)
 - ◆ If the mother has moved or changed names or if the baby was adopted this can be more difficult but eventually almost all are found.

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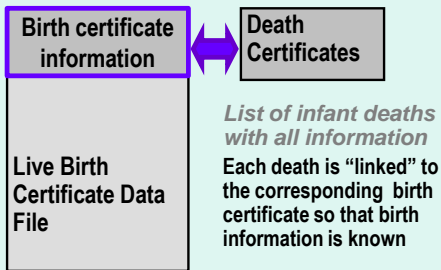
Why do we need to link the death record with the birth record?

- ◆ The death record tells us the cause of death and the age at death
- ◆ The birth record tells us birth weight
 - ◆ Baby’s health
 - ◆ Mother’s health history & demographics
 - ◆ Birth circumstances

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Creating the linked death file



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Data quality problems: Under-reporting

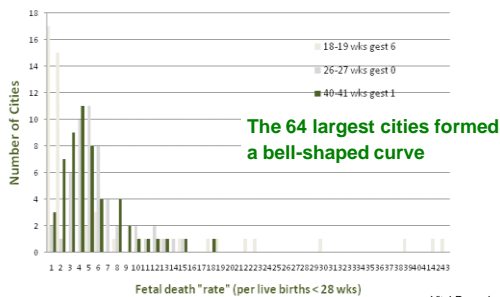
- Under-reporting is probably the largest source of bias, especially for fetal deaths
- Under-reporting can be difficult to detect
- Here is an example --- our investigation of fetal death certificates



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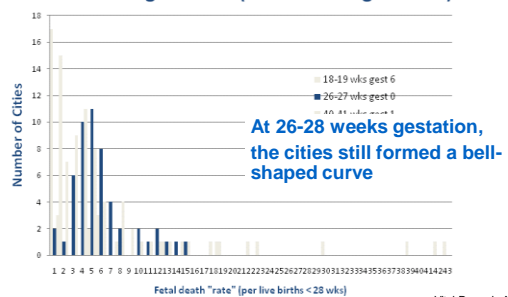
Distribution of fetal death “rates” in largest cities (40-41 weeks gestation)



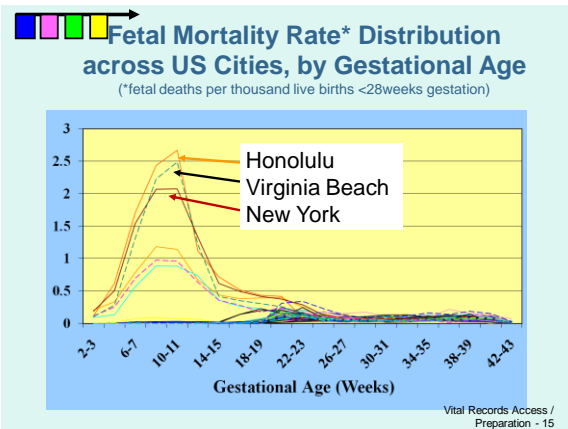
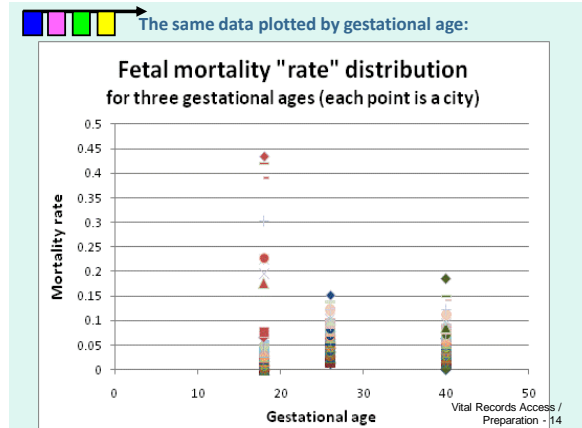
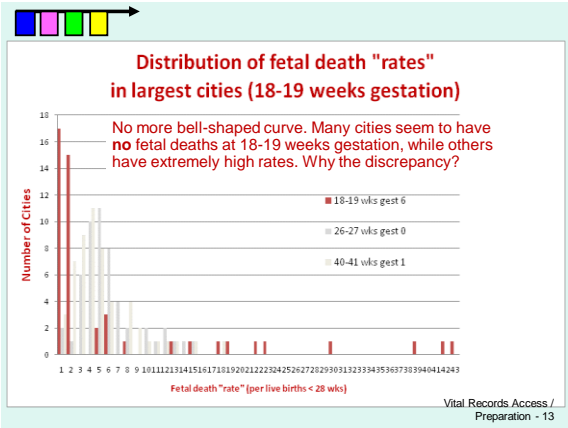
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Distribution of fetal death “rates” in largest cities (26-27 weeks gestation)



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- Solution: Restricting Birthweight and Gestational Age**
- FETAL DEATHS ≥ 24 WEEKS
AND ≥ 500 GRAMS
 - LIVE BIRTHS ≥ 500 GRAMS
 - Below these limits, reporting is NOT consistent between hospitals, among cities, and across states
 - Comparisons can be invalid
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- Missing data elements introduce bias**
- PPOR needs **maternal residence and infant weight at birth**
 - An infant death that has **not been linked** to the birth certificate **cannot be used in PPOR**, artificially decreasing the mortality rate
 - If a birth certificate is **missing the birth weight** data element, it cannot be used in the numerator or denominator
 - Often, higher percentages of necessary information are missing among infant deaths than among the births that survived, artificially decreasing the mortality rate
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- Implausible data elements should not be used (treat as missing)**
- Check for very large or very small values, the so-called "outliers"
 - Scan and sort data to check for 'curious' or potentially mis-coded data
 - E.g., birth weight entered as pounds and ounces instead of grams
 - Check for combinations of data elements that are impossible or "implausible"
 - E.g., a baby weighing 2900 grams at only 20 weeks gestation
 - Check for out-right errors
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Implausible birth weight and gestational age combinations are blacked out. There are other schemes; you don't have to use these limits.

birthwt	gestational age (weeks)						47-up
	0-10	11-20	21-23	24-27	28-31	32-35	
0-500	Black	Black	Black	Black	Black	Black	Black
500-999	Black	Black	Black	Black	Black	Black	Black
1000-2000	Black	Black	Black	Black	Black	Black	Black
2000-2999	Black	Black	Black	Black	Black	Black	Black
3000-3999	Black	Black	Black	Black	Black	Black	Black
4000-7999	Black	Black	Black	Black	Black	Black	Black
8000-9999	Black	Black	Black	Black	Black	Black	Black

If plurality is greater than 1, the combinations in BLUE become plausible

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SAS code for implausible combinations of gestational age and birthweight

```

if ((gest_lmp<20 and grams>=500)
or (gest_lmp>=20 and gest_lmp<24 and grams>=2000)
or (gest_lmp>=24 and gest_lmp<28 and grams>=3000)
or (gest_lmp>=28 and gest_lmp<32 and grams>=4000)
or (gest_lmp>=32 and gest_lmp<47 and grams<1000 and plur=1))
then gest_lmp=99;

```

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Procedures for Assessing Data Quality

- Count missing data elements and unlinked deaths
- If the fetal and infant mortality rates calculated from your data files do not match published rates, you should find out why
- Test for implausible values (such as very high birth weight with very low gestational age)

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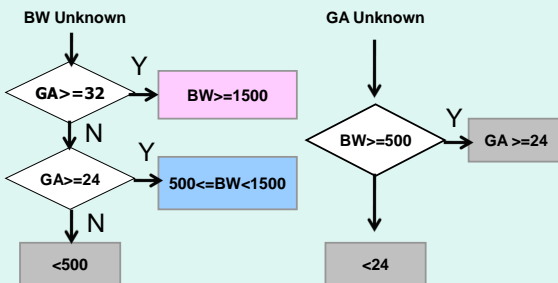
Imputing missing data elements

- If more than 5-10% of births, deaths, and fetal deaths are *missing key data items* (such as birth weight, gestational age, maternal residence, age at death), then imputation is recommended
 - e.g. estimating birth weight based on gestational age

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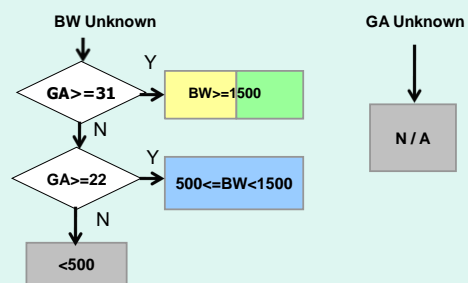
Imputation Algorithm for Fetal Deaths



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Imputation Algorithm for Live Births



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How do we measure gestational age?

- Physician estimate of gestational age takes into account LMP, ultrasound, physical exams
 - Last menstrual period estimate of gestational age requires error checking
- ***use whichever is best***
- Imputing gestational age from birth weight (and vice versa) is reasonable

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Strengths and Limitations of Vital Records

- Strengths
 - Electronic availability
 - Completeness for births, deaths
 - Linkage possible
 - Expansion of surveillance systems – e.g., PRAMS, BRFSS, YRBS
- Limitations
 - Timeliness of vital records
 - Access to local level data
 - Completeness, adequate response rate
 - Changes in vital records systems
 - Small numbers

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Limitations of Mortality Data

- Underlying cause of death may exclude information pertaining to the immediate cause of death, contributory causes, and intervening causes
- Quality of data
 - Validity studies of death certificates compared with hospital and autopsy records generally find higher validity for certain diseases
- Differences in ICD coding categories and regulations

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Special Considerations for Phase 2 Analysis

- Vital records and other data sources should be used
- How to set up a dataset for regression modeling and other examination of the relationship between risk factors and outcomes
- Data quality concerns



To examine prevalence of risk factors

- To examine prevalence of risk factors, the data source should be *representative* of the population at risk (e.g. all live births plus fetal deaths etc. are at risk for premature birth)
- The data source should include information needed to define the study and reference populations (i.e. mother's race, ethnicity, age, education, and place of residence at time of the baby's birth)



To examine the relationship between risk factors and outcomes

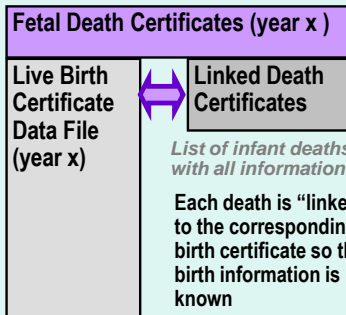
- To examine the relationship between risk factors and outcomes (death, age at death, cause of death) the data source needs to be linked to the mortality record so that the outcome of each individual pregnancy is known.
- The analyst must create an analysis file that includes all live births (and maybe fetal deaths), not just those that resulted in death.
- Since there are thousands of births, this is done with computer software such as SAS.



Creating a birth cohort file

for births and fetal deaths occurring in year x

Fetal file is "stacked" on birth file



SAS code for merging births with linked deaths by matching birth certificate numbers

- (both datasets previously sorted by birth certificate number)


```
data merged;
merge births linked;
By bcert;
run;
```



SAS code for stacking the merged file on top of the fetal death file

```
data all; set merged fetal; run;
```

- Assure that variables named and formatted consistently, e.g.
 - For birth weight, "grams" will not stack on top of "bwt"
 - Don't stack a character variable on top of a numeric



Creating a birth cohort from linked death files

Linked Death File	Year Born	Year Died	
2009	2008	2009	Omit
2009	2009	2009	Keep
2010	2009	2010	Keep
2010	2010	2010	Omit



Phase 2 Data Preparation: Schematic of Data File

ID	Outcome	Birth Certificate		Death Cert.	
		Birth-weight	Maternal Age	Age at Death	Cause of Death
Fet01	Fetal	798	17	Fetal	Infection
Fet02	Fetal	2537	34	Fetal	Cong. Anomaly
LB01	Survive	3511	22		
LB02	Death	2314	25	132 days	SIDS
LB03	Survive	1293	21		
LB04	Death	631	26	3 days	Infection



PPOR is not intended to be a research method, results may vary. (May common sense prevail.)

- Observational data
- Reporting inconsistencies
- Dependence among cases
- Models often do not fit the data well. The limitations of models should be carefully assessed.



Vital Statistics Resources

- National Center for Health Statistics – VitalStats
 - Collection of vital statistics products including tables, data files, and reports
 - US, state, county, MSA, and city level data
 - Allows users to access and examine vital statistics and population data interactively
 - Use prebuilt tables and reports for quick access to statistics
 - Use the data files to create your own tables--choosing from over 100 variables
 - <http://www.cdc.gov/nchs/VitalStats.htm>
- CDC -- WONDER
 - An easy-to-use, menu-driven system that makes the information resources of the CDC available to public health professionals and the public at large
 - <http://wonder.cdc.gov/>

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Local MCH Data Sources

- CDC, DRH, Reproductive Atlas
 - Web-based interactive geographic information system (GIS) dedicated to reproductive health issues, such as infant mortality, fertility, and low birth weight
 - US, state, and county level data
 - <http://www.cdc.gov/Features/AtlasReproductiveHealth/>
- March of Dimes - PeriStats®
 - Maternal and infant health-related data (e.g., preterm birth, infant mortality, tobacco use, cesarean section rates, and health insurance coverage)
 - US, state, county, and city level
 - Updated throughout the year
 - Useful for multiple tasks, including fact-finding, health assessments, grant writing, policy development, lectures and presentations
 - <http://marchofdimes.com/Peristats/>

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