The Perinatal Periods of Risk Approach

Vital Records Data – Access and Preparation

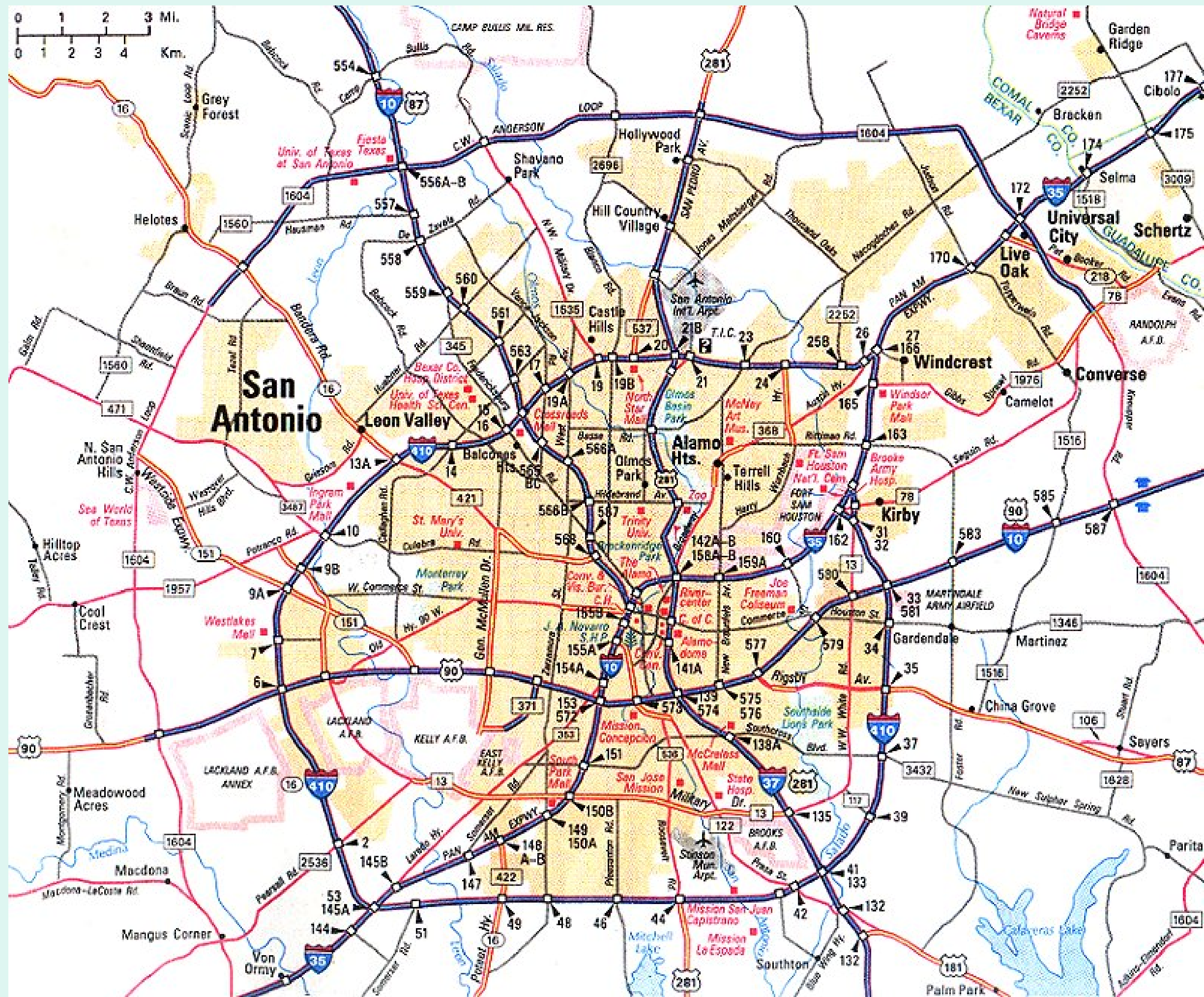
Preparation of Data

- 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)

Clearly Define the Study Population

- Agree on geo-political boundaries, racial/ethnic or other subgroup, timeframe

- Include infants and fetal deaths whose mothers were **residents** of the study area (City, e.g.) **at the time of the birth**



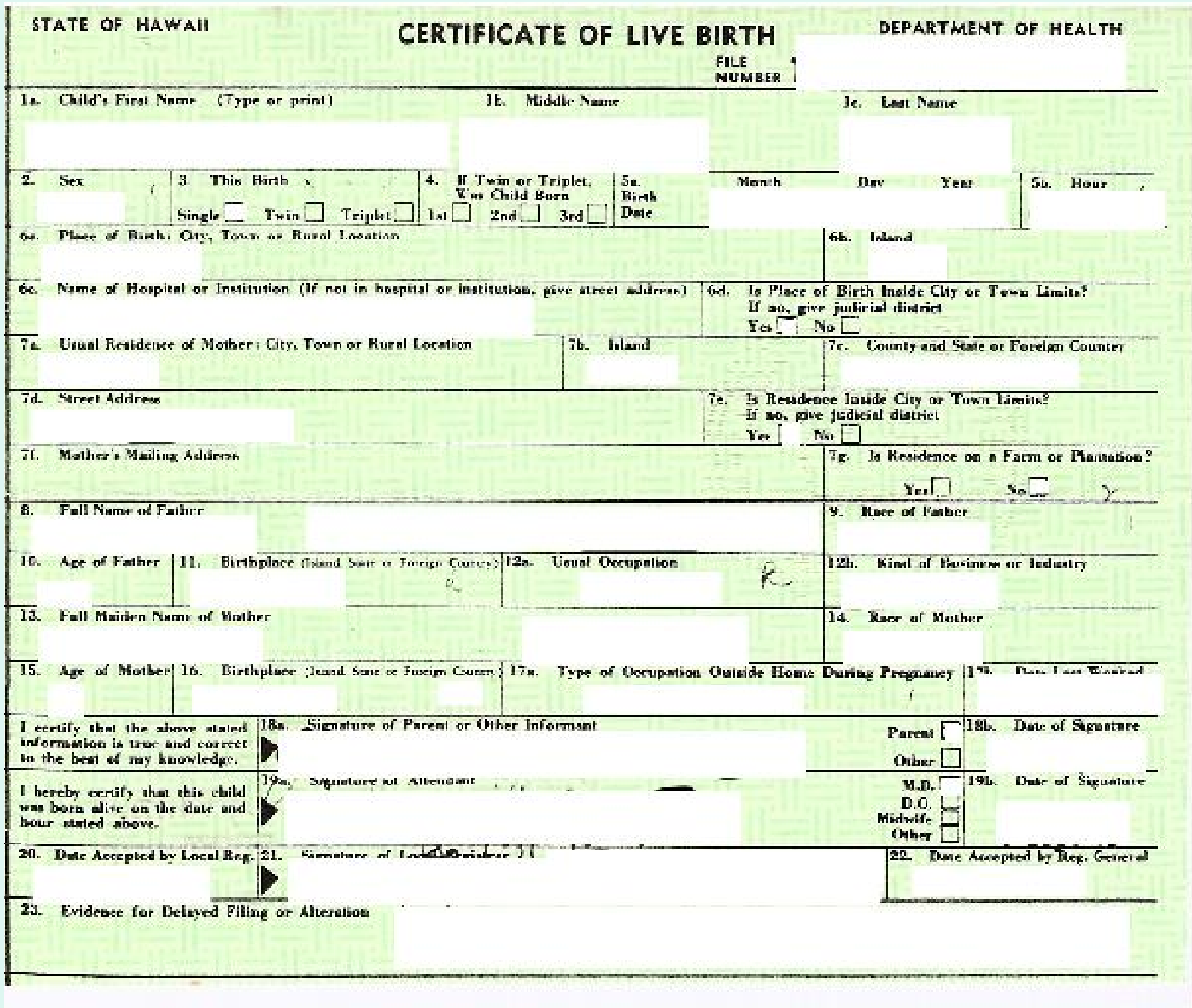
What vital records data are needed for the PPOR *MAP?*

1. Live births
2. Fetal deaths
3. Infant deaths, linked to birth records

ALL are produced by every state, but they are sometimes difficult for local health departments to obtain

Note: Spontaneous and induced abortions are NOT included!

Live Births



STATE OF HAWAII — CERTIFICATE OF LIVE BIRTH — DEPARTMENT OF HEALTH

FILE NUMBER

1a. Child's First Name (Type or print) | 1b. Middle Name | 1c. Last Name

2. Sex | 3. This Birth: Single ☐ Twin ☐ Triplet ☐ | 4. If Twin or Triplet, Was Child Born 1st ☐ 2nd ☐ 3rd ☐ | 5a. Birth Date: Month Day Year | 5b. Hour

6a. Place of Birth: City, Town or Rural Location | 6b. Island

6c. Name of Hospital or Institution (If not in hospital or institution, give street address) | 6d. Is Place of Birth Inside City or Town Limits? If no, give judicial district. Yes ☐ No ☐

7a. Usual Residence of Mother: City, Town or Rural Location | 7b. Island | 7c. County and State or Foreign Country

7d. Street Address | 7e. Is Residence Inside City or Town Limits? If no, give judicial district. Yes ☐ No ☐

7f. Mother's Mailing Address | 7g. Is Residence on a Farm or Plantation? Yes ☐ No ☐

8. Full Name of Father | 9. Race of Father

10. Age of Father | 11. Birthplace (Island, State or Foreign Country) | 12a. Usual Occupation | 12b. Kind of Business or Industry

13. Full Maiden Name of Mother | 14. Race of Mother

15. Age of Mother | 16. Birthplace (Island, State or Foreign Country) | 17a. Type of Occupation Outside Home During Pregnancy | 17b. Date Last Worked

I certify that the above stated information is true and correct to the best of my knowledge. | 18a. Signature of Parent or Other Informant | Parent ☐ Other ☐ | 18b. Date of Signature

I hereby certify that this child was born alive on the date and hour stated above. | 19a. Signature of Attendant | M.D. ☐ D.O. ☐ Midwife ☐ Other ☐ | 19b. Date of Signature

20. Date Accepted by Local Reg. | 21. Signature of Local Registrar | 22. Date Accepted by Reg. General

23. Evidence for Delayed Filing or Alteration

- Birth certificate required by state law for every birth
- Hospital or birth attendant is legally responsible for completing and filing with the state
- NCHS compiles data for all births in the U.S.

What PPOR Needs from Birth Certificate

- **Phase 1**
  - Maternal residence
  - Birth year of infant
  - Birth weight
  - (Gestational age for imputation of BW)
- **Reference Group**
  - Maternal age, education, race, ethnicity
- **Phase 2**
  - Everything

Schematic of Birth Data File

ID	Maternal Residence	Mother's Race / Origin	Maternal Age	Estimated Gestational Age	Detail Birth Weight
BC001	Peoria	8	17	29	798
BC002	Peoria	6	34	41	2,537
BC003	Peoria	8	22	38	3,511
BC004	Peoria	8	25	32	2,314
BC005	Peoria	8	21	32	1,757
BC006	Peoria	2	20	40	3,459
BC007	Peoria	1	26	24	680
. . .	. . .	. . .	. . .	. . .	. . .

Infant Deaths

- A certificate of death is required by state law for every death in the United States
- Physicians or medical examiners / coroners are required to pronounce death and to complete the “cause of death” portion of the death certificate
- NCHS compiles data for all deaths in the U.S.


STATE OF CALIFORNIA
CERTIFICATION OF VITAL RECORDS
COUNTY OF LOS ANGELES
DEPARTMENT OF HEALTH SERVICES
JUL - 7 2009

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.

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)

What PPOR Needs from Death Certificate

- Phase 1 :
  - Date of death
  - Linkage to birth certificate to obtain age at death
- Phase 2:
  - Cause of death
  - Anything that could be a risk factor

Creating the linked death file

Birth certificate information

Live Birth Certificate Data File

Death Certificates

List of infant deaths with all information

Each death is "linked" to the corresponding birth certificate so that birth information is known

Fetal Death

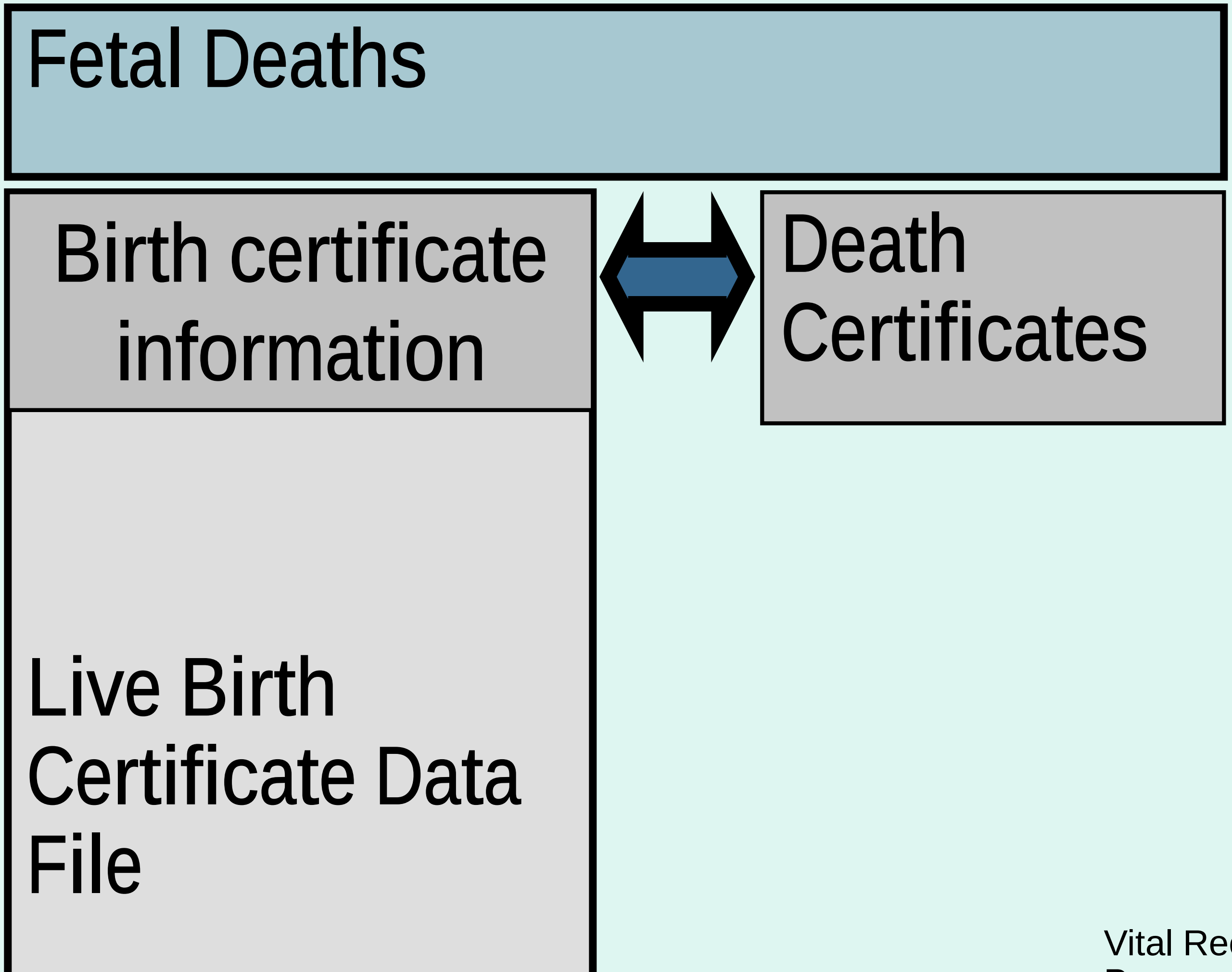
- Death prior to the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy
- Reporting requirements vary from state to state

What PPOR needs from the fetal death certificate

- Phase 1
  - Maternal place of residence
  - Year of delivery
  - Birth weight and gestational age
- Reference Group
  - Maternal age, race, ethnicity, education
- Phase 2
  - Cause of death
  - Everything

Fetal deaths are additional “cases”

(data elements related to birth *and* death)



Preparation of Data-- Assess Data Quality

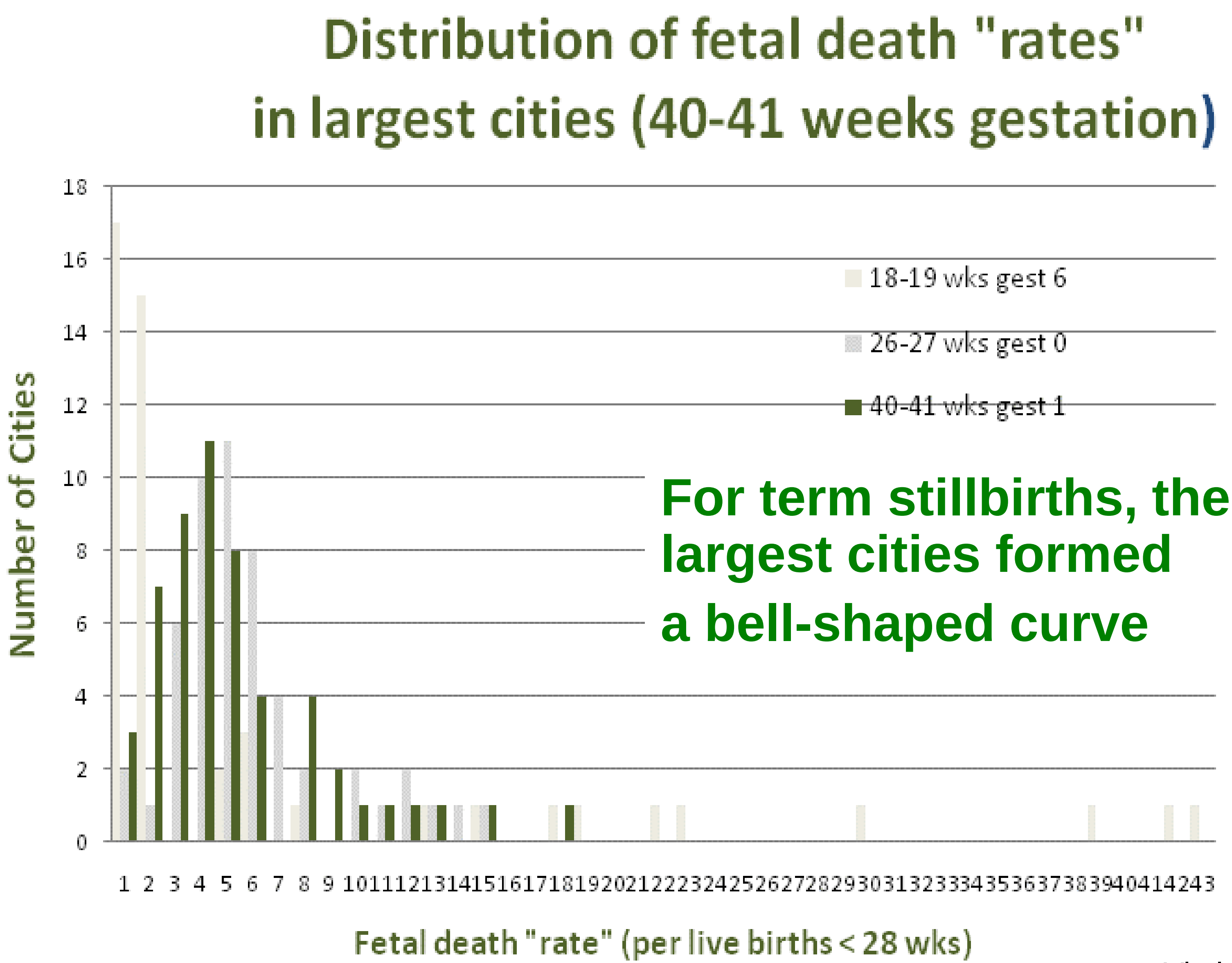
What does “data quality” mean?

- All cases (babies) are included
- All data items are in each baby’s record
- The data items were accurately known and correctly recorded

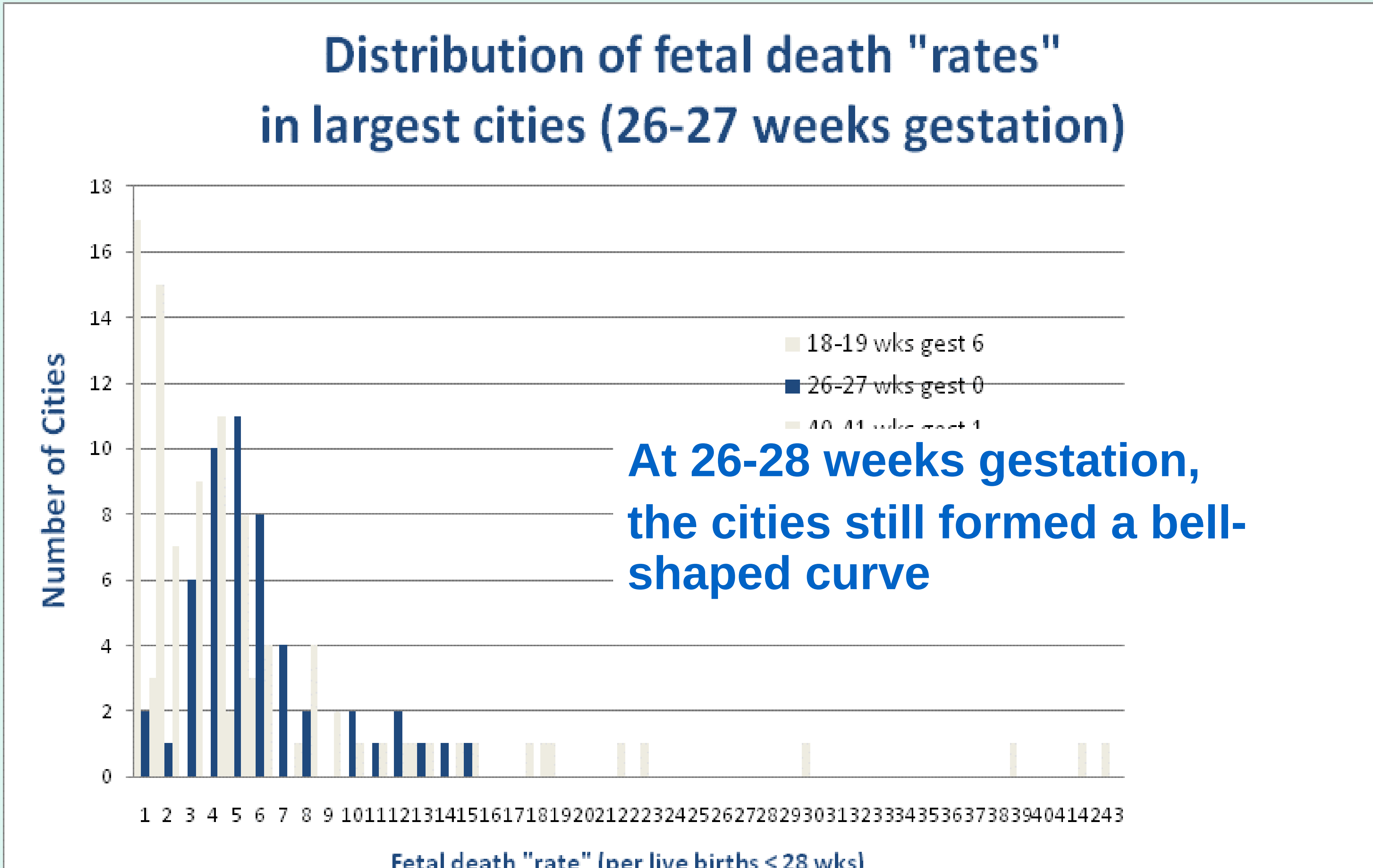
Missing information causes biased results

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
- City**M**at**CH** and the CDC examined the distribution of fetal mortality rates in cities across the country

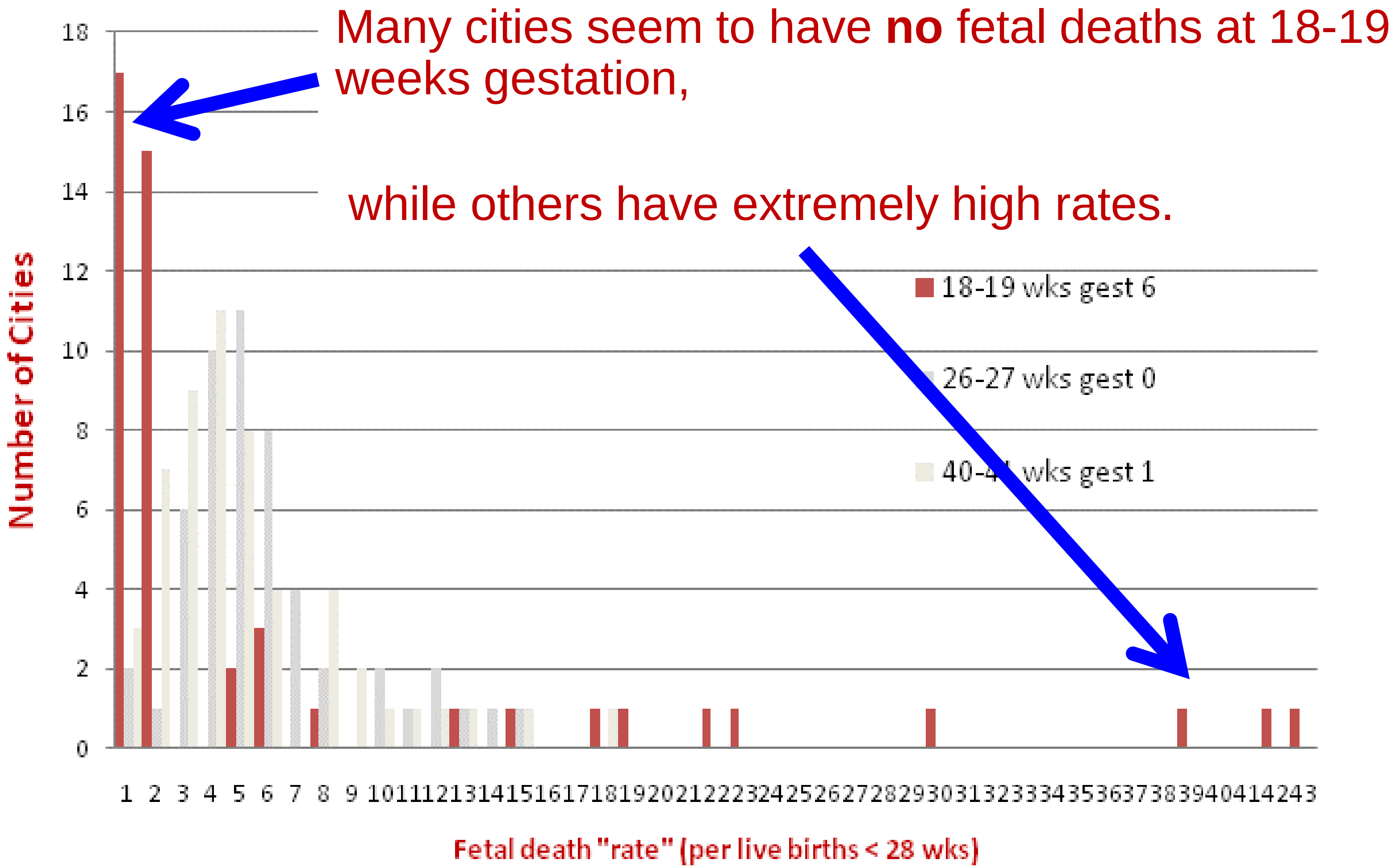


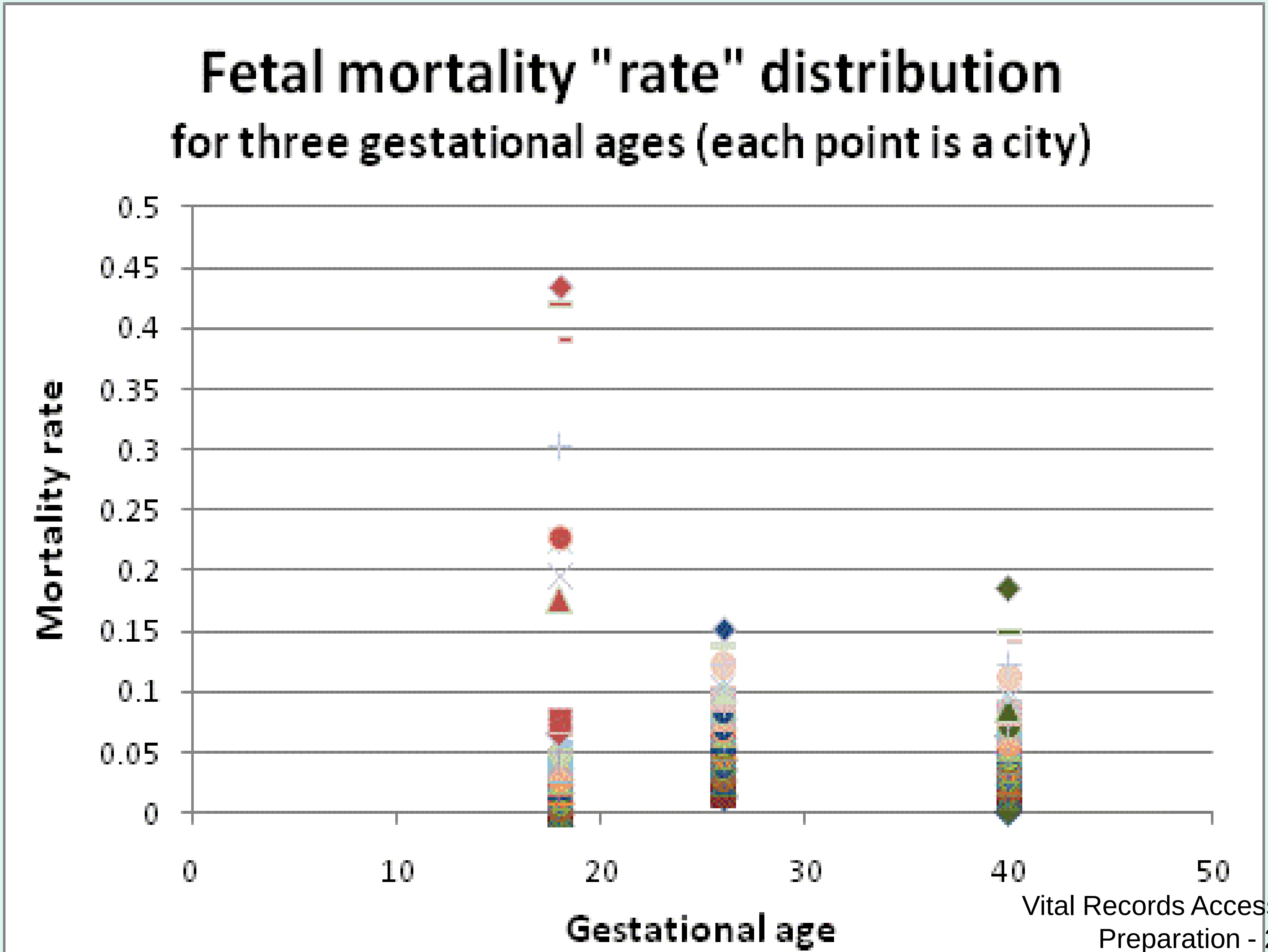
For term stillbirths, the 64 largest cities formed a bell-shaped curve



At 26-28 weeks gestation, the cities still formed a bell-shaped curve

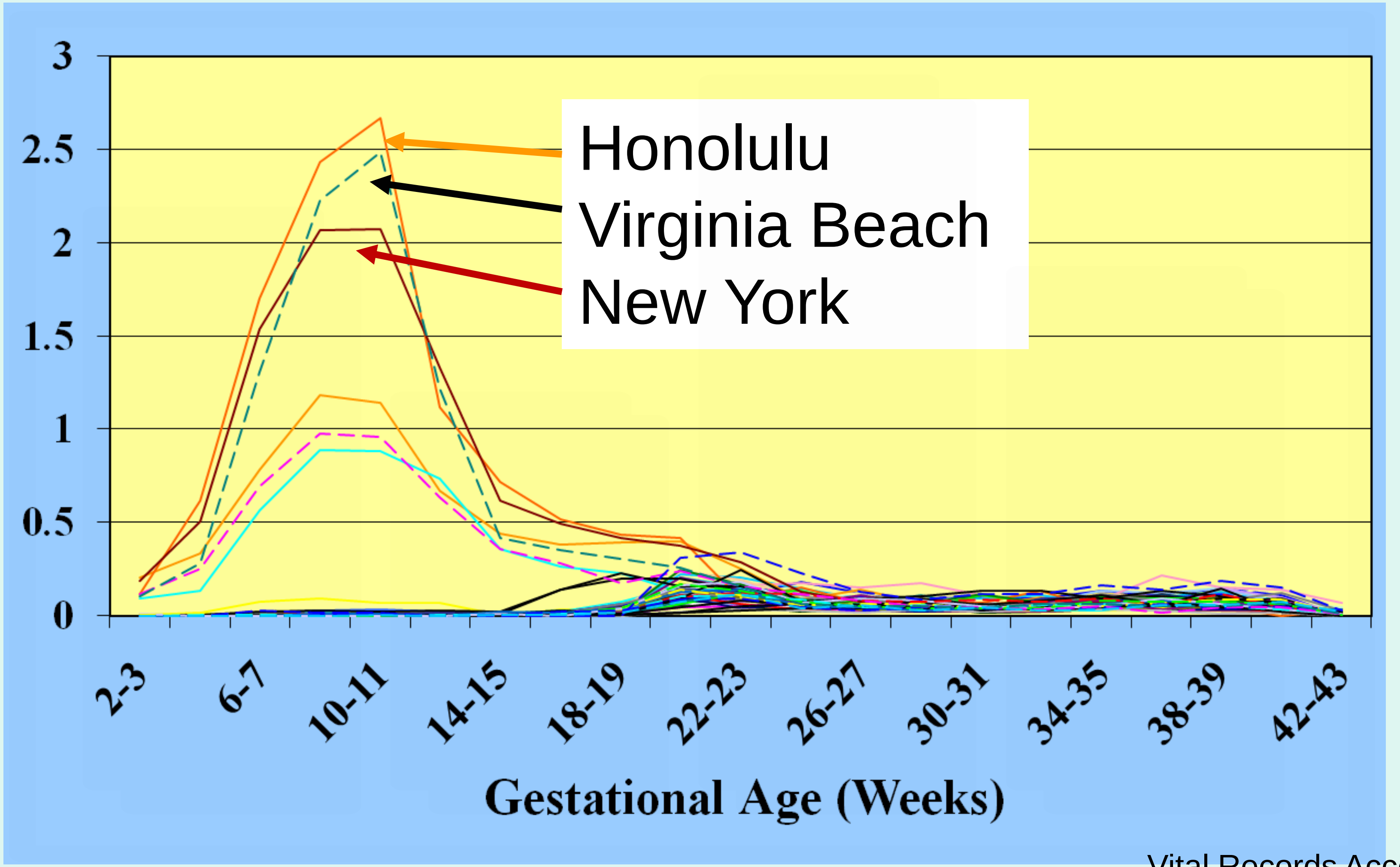
Distribution of fetal death "rates" in largest cities (18-19 weeks gestation)




Fetal mortality "rate" distribution
for three gestational ages (each point is a city)
Mortality rate
0.5
0.45
0.4
0.35
0.3
0.25
0.2
0.15
0.1
0.05
0
0
10
20
30
40
50
Gestational age

Fetal Mortality Rate* Distribution across US Cities, by Gestational Age

(*fetal deaths per thousand live births <28weeks gestation)



Lessons

- The cities reporting low rates are the cities that were NOT reporting all deaths
- Some cities, hospitals, and physicians in states requiring reporting had suspiciously low rates
- We cannot reliably study disparities among the smallest babies when there is inconsistent reporting

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

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

Implausible data elements should not be used (treat as missing.)

- Check for very large or very small values, the so-called “outliers”
  - 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

Implausible birth weight and gestational age combinations are blacked out

birthwt	0-10	11-20 weeks	21-23 wks	24-27 wks	28-31 wks	32-35 wks	36-46 wks	47-up
0-500								
500-999								
1000-2000								
2000-2999								
3000-3999								
4000-7999								
8000-9999								

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

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;
```

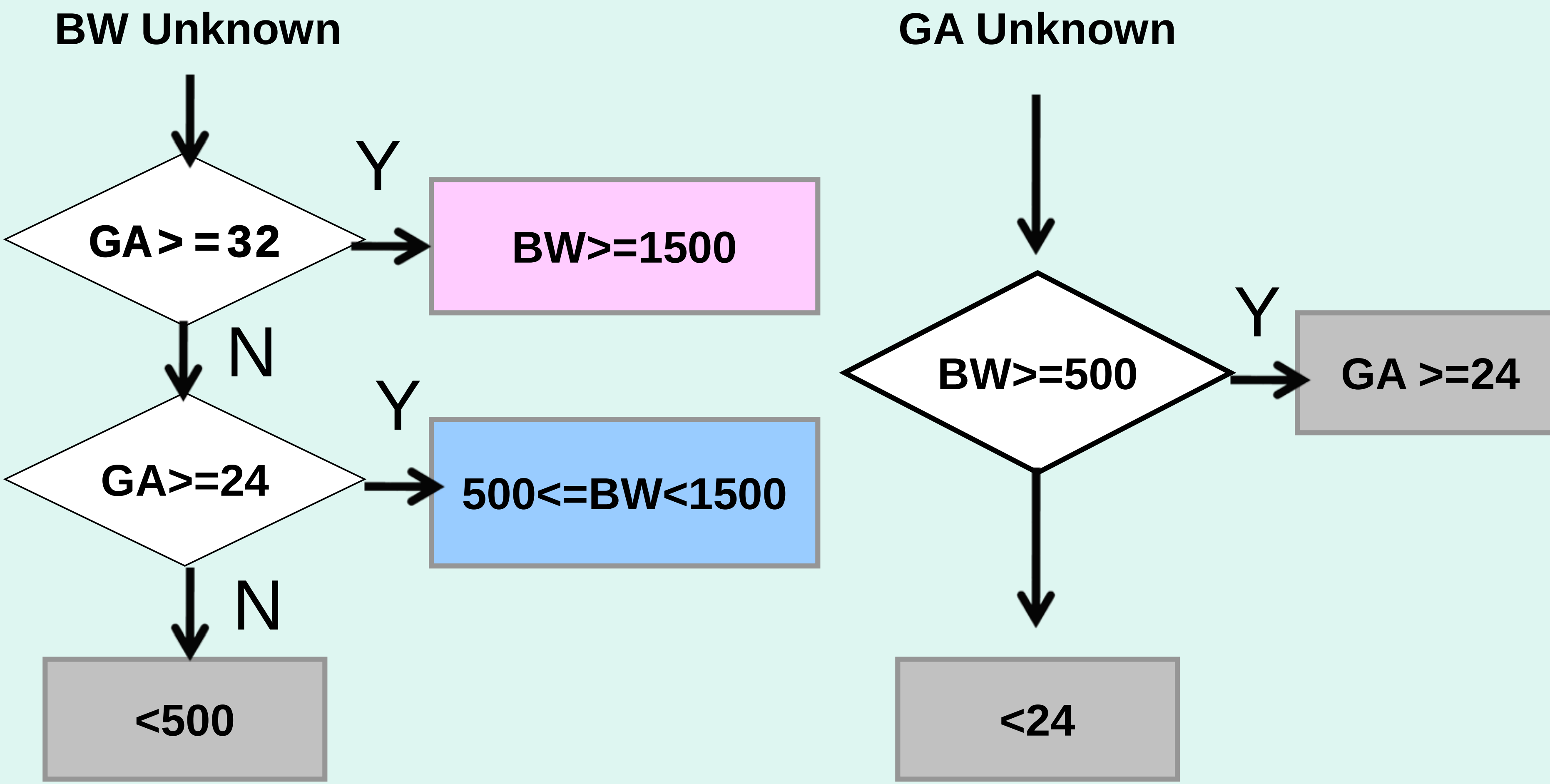
Procedures for Assessing Data Quality

- 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)

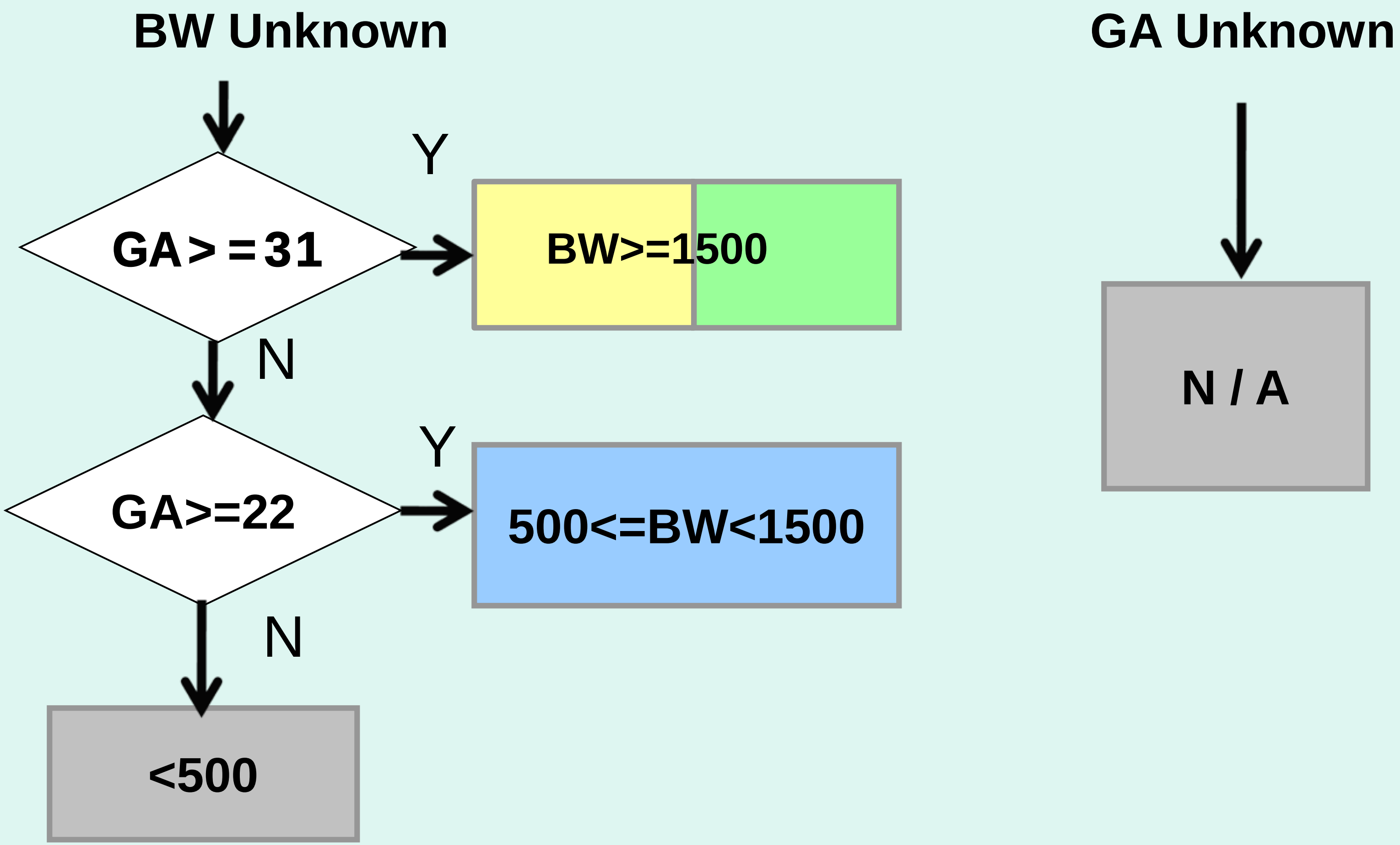
Imputing missing data elements

- 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

Imputation Algorithm for Fetal Deaths



Imputation Algorithm for Live Births



How do we measure gestational age?

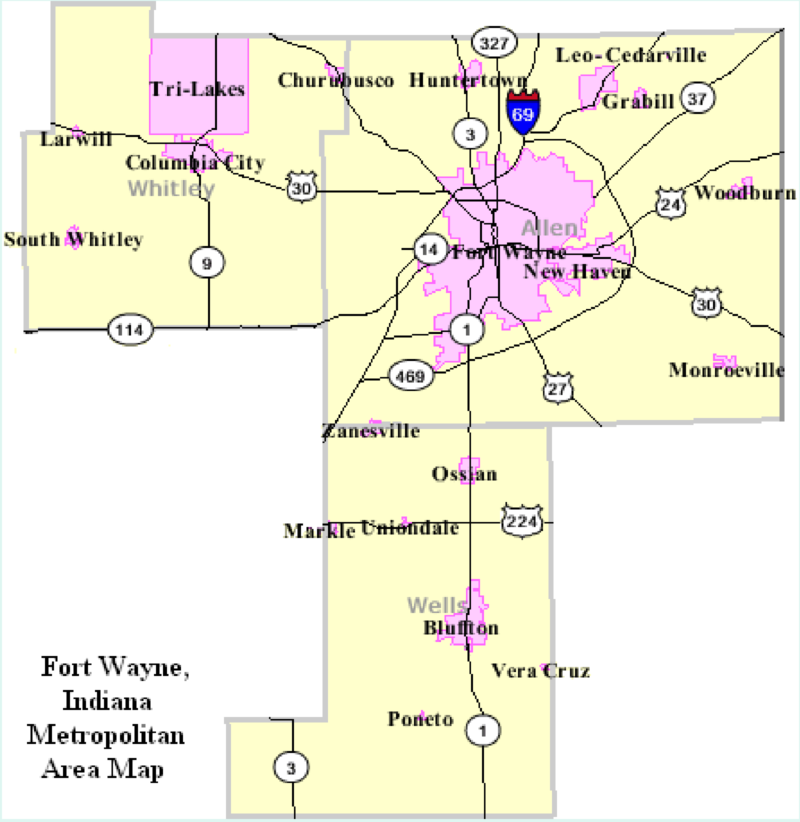
- Physician estimate of gestational age takes into account LMP, ultrasound, physical exams
- Last menstrual period estimate of gestational age requires error checking

use whichever is best

- Imputing gestational age from birth weight (and vice versa) is reasonable

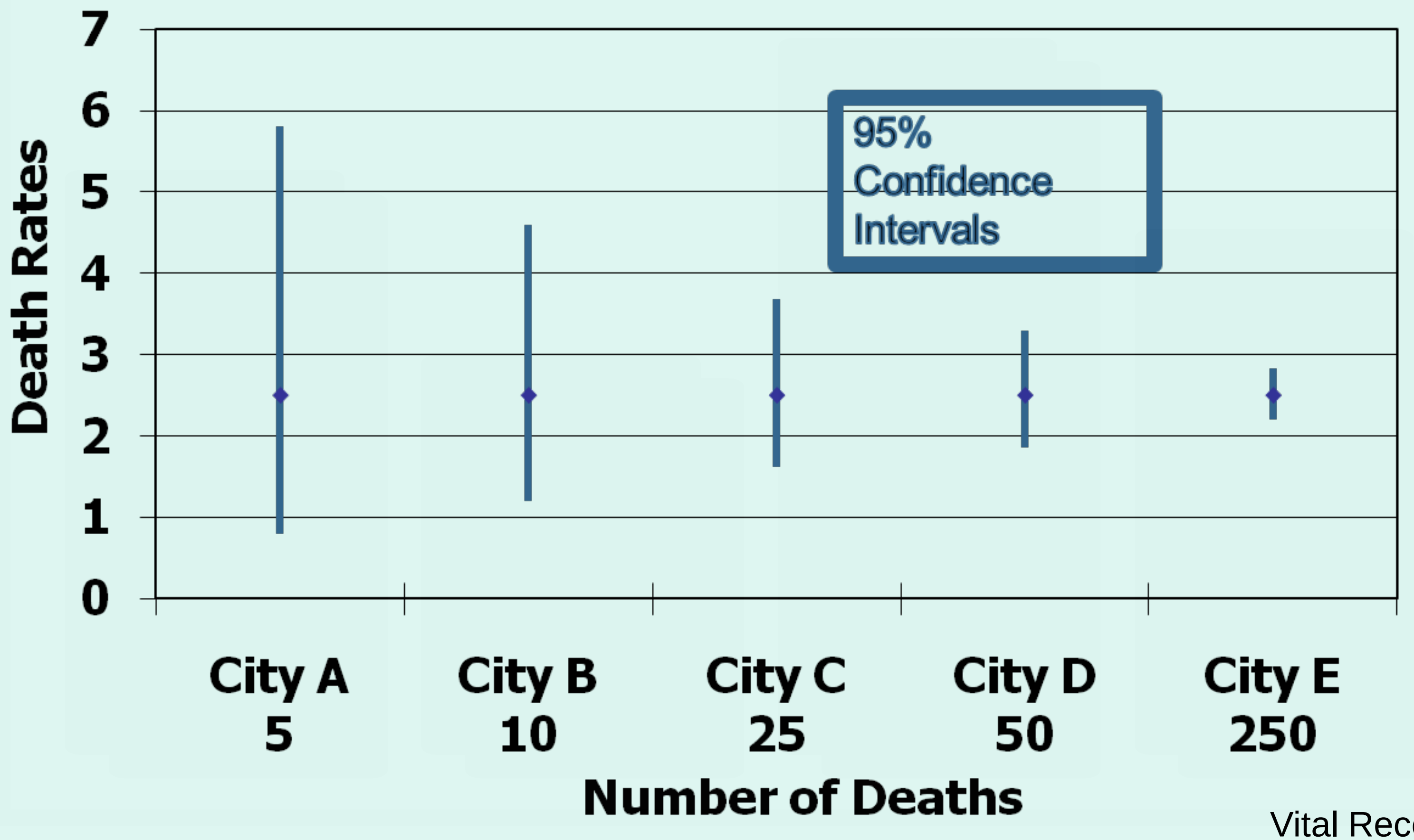
After processing, how many deaths?

- Does your study sample have at least 60 fetal and infant deaths that meet PPOR criteria?
- If necessary, re-define the study population (geo-political boundaries, racial/ethnic group, timeframe)



Why 60 deaths minimum?

Rates based on a small number of events fluctuate AT RANDOM, even when there is no real underlying change in conditions (they are "unstable")



Why 60 deaths minimum?

This recommendation is based on a PPOR analysis of US cities with at least 250,000 or more population which showed that most US cities with 60 feto-infant deaths would generally have no fewer than 10 feto-infant deaths in any one risk period.

If the expected number of deaths is 10

- the 95% confidence interval is about 5 to 16 (+/- 50%)

Online Poisson Confidence Interval Calculators

http://statpages.org/confint.html
http://anesi.com/poisson.htm

Minimum Number of Deaths

- *At least 60 fetal and infant deaths* that meet PPOR criteria, *for each population* being studied (minimum of 10 per cell)
- May combine up to 5 years (no more, due to changes in medical practice and public health systems)
- Phase 2 analyses require even more deaths.

What if your numbers are too small to create stable rates (<20? <10?)

1. Combine more years of data
   ASSUME ALL YEARS ARE ALIKE

2. Combine groups of people (e.g. all race/ethnicities instead of only black)
   ASSUME ALL GROUPS ARE ALIKE

3. Combine geographical areas (e.g. county instead of city, three neighboring counties)
   ASSUME ALL GEO AREAS ARE ALIKE

4. Use state data (also allows use of state datasets such as PRAMS)
   ASSUME YOUR CITY IS LIKE THE STATE

Each of these requires an assumption

PPOR Phase 2 work-arounds for small numbers

1. Green Box Infant Health period: do not use 5-6 categories for cause of death analysis. Instead, collapse all categories with small numbers into one category (other). Many cities end up with SUID/Other.
2. Blue Box Maternal Health/Prematurity Period: We have proposed alternate birth weight stratification limits for Kitagawa that combine strata with the smallest numbers:

0-499
500-699
700-899
900-1,199
1,200-1,499
1,500-1,999
2,000-2,499
2,500+

(note that only rows 2 and 3 are used in estimating the reasons for excess mortality in the MH/P period of risk)

If you don't think any of those assumptions is valid,

- You can assume your own opinion is correct (or your stakeholders' opinions)

- You can use several of those methods and see how the estimates vary, or do a more formal sensitivity analysis

- Or you can use a synthetic estimate, which means you partly believe in the state data, but adjust ***based on known differences between your population and theirs.***

Example: State of MIND

- State of MIND has a 44.84% rate of unintended pregnancy based on PRAMS statewide data.

- The 12% of mothers who are teens have a 95% rate.
- The older mothers have a 38% rate of unintended.

	Number of mothers	**Number of unintended**	**% with unintended pregnancy**
Teens	12,000	11,400	95%
Adults	88,000	33,440	38%
Total	100,000	44,840	44.84%

You happen to know there is an important population difference between YOUNGCOUNTY and STATE OF MIND.

YOUNGCOUNTY has more teen births.

So you would expect YOUNGCOUNTY to have a higher unintended rate than STATE OF MIND.

In synthetic estimation

- We assume the unintended rates for teens and older mothers are the same in YOUNGCOUNTY as in STATE OF MIND (95% and 38% respectively), i.e. use the STATE OF MIND unintended rates.
- We use the actual YOUNGCOUNTY numbers of mothers

YOUNGCOUNTY	State % with unintended pregnancy	YOUNG COUNTY Number of mothers	Estimated Number of YOUNGCOUNTY unintended
Teens	95%	3,000	2,850
Adults	38%	7,000	2,660
Total		10,000	5,510

YOUNGCOUNTY Estimate is

55.1 % unintended

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/