Potential Data Sources for Generating Baseline Data

Julie C. Jacobson Vann, PhD, MS, RN
Senior Researcher
American Institutes for Research

Thomas L. Schlenker, MD, MPH
Director of Public Health
San Antonio Metropolitan Health District
Outline

- Introduction
- Purpose of collecting baseline data
  - Definition of baseline data
  - Intervention group
  - Type of baseline data
- Characteristics of baseline data
- Potential sources of baseline data
- Review of potential data sources
What is Baseline Data

- Collected before a program begins
- Expected outcome(s) of program
- Characteristics of people being served
- Example:
  - % of infants born to women served by the program in the past year who were born prior to 37 weeks gestation
Sample Baseline Data (Hypothetical):

Preterm Births for Medicaid Beneficiaries in Beachville County

<table>
<thead>
<tr>
<th></th>
<th>2008-2009</th>
<th>2009-2010</th>
<th>2010-2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>% births &lt; 37 weeks EGA:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>women &lt; 20 years of age</td>
<td>18.7%</td>
<td>18.9%</td>
<td>17.9%</td>
</tr>
<tr>
<td>% births &lt; 37 weeks EGA:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>women 20-29</td>
<td>15.6%</td>
<td>14.3%</td>
<td>15.0%</td>
</tr>
<tr>
<td>% births &lt; 37 weeks EGA:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>women 30-39</td>
<td>16.9%</td>
<td>17.3%</td>
<td>16.2%</td>
</tr>
<tr>
<td>% births &lt; 37 weeks EGA:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>women ≥ 40</td>
<td>20.4%</td>
<td>19.2%</td>
<td>20.2%</td>
</tr>
</tbody>
</table>
Purpose of Collecting Baseline Data

- Compare what happens before & after an intervention or program
- Assess effect of a program
- Foundation for showing performance improvement
- Needs assessment
Sample: Baseline and Post-Intervention Data (Hypothetical)

Preterm Births for Medicaid Beneficiaries in Organic County, Before & After ABC Program Implementation, in 2 Centers

<table>
<thead>
<tr>
<th></th>
<th>2010-2012: Before Intervention Began</th>
<th>2013-2014 Intervention Period</th>
<th>Difference between pre-intervention and intervention period</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Births &lt; 37 weeks EGA, born to Medicaid beneficiaries, Center A</td>
<td>14.2%</td>
<td>9.6%</td>
<td>-4.6 percentage points</td>
</tr>
<tr>
<td>% Births &lt; 37 weeks EGA, born to Medicaid beneficiaries, Center B</td>
<td>13.4%</td>
<td>11.3%</td>
<td>-2.1 percentage points</td>
</tr>
</tbody>
</table>
Intervention Group

- Group expected to be assigned to the program or receive the service
- Intention-to-treat: group expected to receive the service
Type of Baseline Data to Collect

- Appropriate for measuring changes as defined by the program objectives
- Outcome measures
- Sample characteristics
- Proxy measures
Identifying Data Sources

- Program data
- Alternative data sources
  - Public sources of data
  - Data requests
  - Partner with a local organization
Considerations for Selecting Baseline Data

- Obtain within timeline
- Accessible
  - Process to obtain
- Years of data available
- Data elements
- Specificity of data elements
Potential Sources of Data

- Birth Certificate
- Centers for Disease Control & Prevention
  - Natality Public Use File
- National Center for Health Statistics
- State Vital Records & Vital Statistics
- Local health department
  - Local WIC office
- Pregnancy Risk Assessment Monitoring System (PRAMS)
- Pregnancy Nutrition Surveillance System (PNSS)
- Local hospital
- State Medicaid program
- March of Dimes & PeriStats
### Mother's Information

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| Mother's Education (Check the box that best describes the highest      | 8th grade or less  
9th - 12th grade, no diploma  
High school graduate or GED completed  
Some college credit but no degree  
Associate degree (e.g., AA, AS)  
Bachelor's degree (e.g., BA, AB, BS)  
Master's degree (e.g., MA, MS, ME, Med, MSW, MBA)  
Doctorate (e.g., PhD, EdD) or Professional degree (e.g., MD, DDS, DVM, LLB, JD) |
| Mother of Hispanic Origin? (Check the box that best describes whether   |  
No, not Spanish/Hispanic/Latina  
Yes, Mexican, Mexican American, Chicana  
Yes, Puerto Rican  
Yes, Cuban  
Yes, other Spanish/Hispanic/Latina |
| the mother is Spanish/Hispanic/Latina)  
Check the “No” box if mother is not Spanish/Hispanic/Latina) |
| Mother's Race (Check one or more races to indicate what the mother     | White  
Black or African American  
American Indian or Alaska Native (Name of the enrolled or principal title)  
Asian Indian  
Chinese  
Filipino  
Japanese  
Korean  
Vietnamese  
Other Asian (Specify)  
Native Hawaiian  
Guamanian or Chamorro  
Samoan  
Other Pacific Islander (Specify)  
Other (Specify) |
| considers herself to be)                                               |                                                                       |

### Father's Information

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| Father's Education (Check the box that best describes the highest      | 8th grade or less  
9th - 12th grade, no diploma  
High school graduate or GED completed  
Some college credit but no degree  
Associate degree (e.g., AA, AS)  
Bachelor's degree (e.g., BA, AB, BS)  
Master's degree (e.g., MA, MS, ME, Med, MSW, MBA)  
Doctorate (e.g., PhD, EdD) or Professional degree (e.g., MD, DDS, DVM, LLB, JD) |
| Father of Hispanic Origin? (Check the box that best describes whether   |  
No, not Spanish/Hispanic/Latina  
Yes, Mexican, Mexican American, Chicano  
Yes, Puerto Rican  
Yes, Cuban  
Yes, other Spanish/Hispanic/Latina |
| the father is Spanish/Hispanic/Latina)  
Check the “No” box if father is not Spanish/Hispanic/Latina) |
| Father's Race (Check one or more races to indicate what the father     | White  
Black or African American  
American Indian or Alaska Native (Name of the enrolled or principal title)  
Asian Indian  
Chinese  
Filipino  
Japanese  
Korean  
Vietnamese  
Other Asian (Specify)  
Native Hawaiian  
Guamanian or Chamorro  
Samoan  
Other Pacific Islander (Specify)  
Other (Specify) |
| considers himself to be)                                               |                                                                       |

### Additional Information

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| Place Where Birth Occurred (Check one)                                  | Hospital  
Freestanding birthing center  
Home Birth: Planned to deliver at home?  
Yes  
No  
Clinic/Doctor's office  
Other (Specify) |
| Attendant's Name, Title, and NPI                                       | NAME:  
TITLE:  
MD  
DO  
CNM  
CM  
OTHER MIDDWIFE  
OTHER (Specify) |
| Mother Transferred for Maternal Medical or Fetal Indications for       | Yes  
No  
If Yes, enter name of facility mother transferred from: |
| Delivery?  
If Yes, indicate name of facility mother was transferred from: |

**REV: 11/2003**
<table>
<thead>
<tr>
<th>MOTHER</th>
<th>MEDICAL AND HEALTH INFORMATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>29a. DATE OF FIRST PRENATAL CARE VISIT</td>
<td>MM DD YYYY</td>
</tr>
<tr>
<td>29b. DATE OF LAST PRENATAL CARE VISIT</td>
<td>MM DD YYYY</td>
</tr>
<tr>
<td>30. TOTAL NUMBER OF PRENATAL VISITS FOR THIS PREGNANCY</td>
<td>[If none, enter “0”]</td>
</tr>
<tr>
<td>31. MOTHER’S HEIGHT</td>
<td>[feet/inches]</td>
</tr>
<tr>
<td>32. MOTHER’S PREPREGNANCY WEIGHT</td>
<td>[pounds]</td>
</tr>
<tr>
<td>33. MOTHER’S WEIGHT AT DELIVERY</td>
<td>[pounds]</td>
</tr>
<tr>
<td>34. DID MOTHER GET VITAMIN SUPPLEMENT DURING THIS PREGNANCY?</td>
<td>Yes ☐ No ☐</td>
</tr>
<tr>
<td>35. NUMBER OF PREVIOUS LIVE BIRTHS (Do not include this child)</td>
<td>Number ______</td>
</tr>
<tr>
<td>35a. Now Living</td>
<td>Number ______</td>
</tr>
<tr>
<td>35b. Now Dead</td>
<td>Number ______</td>
</tr>
<tr>
<td>36. NUMBER OF OTHER PREGNANCY OUTCOMES (spontaneous or induced losses or ectopic pregnancies)</td>
<td>Number ______</td>
</tr>
<tr>
<td>37. CIGARETTE SMOKING BEFORE AND DURING PREGNANCY</td>
<td>[for each time period, enter either the number of cigarettes or the number of packs of cigarettes smoked. If none, enter “0”]</td>
</tr>
<tr>
<td>Average number of cigarettes or packs of cigarettes smoked per day</td>
<td># of cigarettes OR packs</td>
</tr>
<tr>
<td>Three Months Before Pregnancy</td>
<td>______ OR ______</td>
</tr>
<tr>
<td>First Three Months of Pregnancy</td>
<td>______ OR ______</td>
</tr>
<tr>
<td>Second Three Months of Pregnancy</td>
<td>______ OR ______</td>
</tr>
<tr>
<td>Third Trimester of Pregnancy</td>
<td>______ OR ______</td>
</tr>
<tr>
<td>38. PRINCIPAL SOURCE OF PAYMENT FOR THIS DELIVERY</td>
<td>☐ Private Insurance</td>
</tr>
<tr>
<td>☐ Medicaid</td>
<td></td>
</tr>
<tr>
<td>☐ Self-pay</td>
<td></td>
</tr>
<tr>
<td>☐ Other (Specify)</td>
<td></td>
</tr>
<tr>
<td>39. DATE, LAST NORMAL MENSES Began</td>
<td>MM DD YYYY</td>
</tr>
<tr>
<td>40. MOTHER’S MEDICAL RECORD NUMBER</td>
<td></td>
</tr>
</tbody>
</table>

41. RISK FACTORS IN THIS PREGNANCY (Check all that apply) |
- Diabetes |
  - Prepregnancy (Diagnosis prior to this pregnancy) |
  - Gestational (Diagnosis in this pregnancy) |
- Hypertension |
  - Prepregnancy (Chronic) |
  - Gestational (Preeclampsia) |
  - Eclampsia |
- Previous preterm birth |
- Other previous poor pregnancy outcome (includes perinatal death, small-for-gestational age, intrauterine growth restriction) |
- Pregnancy resulted from infertility treatment: If yes, check all that apply: |
  - Fertility-enhancing drugs, Artificial insemination or Intratubal insemination |
  - Assisted reproductive technology (e.g., in vitro fertilization (IVF), gamete intrafallopian transfer (GIFT)) |
- Mother had a previous cesarean delivery: If yes, how many ________ |

42. INFECTIONS PRESENT AND/OR TREATED DURING THIS PREGNANCY (Check all that apply) |
- Gonorrhea |
- Syphilis |
- Chlamydia |
- Hepatitis B |
- Hepatitis C |
- None of the above |

43. OBSTETRIC PROCEDURES (Check all that apply) |
- Cesarean section |
- Tocolysis |
- External cephalic version: |
  - Successful |
  - Failed |
  - None of the above |

44. ONSET OF LABOR (Check all that apply) |
- Premature Rupture of the Membranes (prolonged, >12 hrs.) |
- Precipitous Labor (<3 hrs.) |
- Prolonged Labor (3-20 hrs.) |
- None of the above |

45. CHARACTERISTICS OF LABOR AND DELIVERY (Check all that apply) |
- Induction of labor |
- Augmentation of labor |
- Non-vaginal presentation |
- Steroids (glucocorticoids) for fetal lung maturation received by the mother prior to delivery |
- Antibiotics received by the mother during labor |
- Clinical chorioamnionitis diagnosed during labor or maternal temperature ≥38°C (100.4°F) |
- Moderate/severe meconium staining of the amniotic fluid |
- Fetal intolerance of labor such that one or more of the following actions was taken: Intravenous resuscitative measures; further fetal assessment, or operative delivery |
- Epidural or spinal anesthesia during labor |
- None of the above |

46. METHOD OF DELIVERY |
- A. Was delivery done with forceps attempted but unsuccessful? |
  - Yes ☐ No ☐ |
- B. Was delivery done with vacuum extraction attempted but unsuccessful? |
  - Yes ☐ No ☐ |
- C. Fetal presentation at birth |
  - Cephalic |
  - Breech |
  - Other |
- D. Final route and method of delivery (Check one) |
  - Vaginal/Sponaneous |
  - Vaginal/Forceps |
  - Vaginal/Vacuum |
  - Cesarean |
  - If cesarean, was a trial of labor attempted? |
    - Yes ☐ No ☐ |

47. MATERNAL MORBIDITY (Check all that apply) (Complications associated with labor and delivery) |
- Maternal transfusion |
- Third or fourth degree perineal laceration |
- Ruptured uterus |
- Unplanned hysterectomy |
- Admission to intensive care unit |
- Unplanned operating room procedure following delivery |
- None of the above |
Centers for Disease Control & Prevention (CDC)

- www.cdc.gov

- Data and Statistics (FastStats)

- Natality Public Use File (after 2005 does not contain geographic detail)

- “B”, Birth Data, NCVS
National Center for Health Statistics

- Standard Forms (Live Births)
- Births Final Data for 2009
- Births Preliminary Data for 2010
- Related Links – State Health Departments
State Vital Records

- Wisconsin Births and Infant Deaths 2010
  January, 2012

- Birth and Fertility Rates
- Characteristics of Mother
- Characteristics of Pregnancy and Delivery
- Characteristics of Newborn
- Mortality
- *Statewide vs. Local and Regional
State Vital Records Analysis

- Special data request:
  - Report vs. electronic dataset for analysis
  - Current data
  - Time to obtain
  - Cost
Local Health Department

San Antonio Metropolitan Health District

- Report – Health Profile 2010
  - Maternal and Child Indicators: LBW (2), Prem
  - Averages and trends
- Data Requests: LBW & EGA to order
  - Medicaid only
  - Race/Ethnicity
  - Zip code and census tract
Local WIC Office

- Women Infants & Children (WIC) Program
- Supplemental foods, health care referrals, nutrition education
- Many based in local health departments
- Birth data for low income families
Pregnancy Risk Assessment Monitoring System (PRAMS)

- [http://www.cdc.gov/prams/](http://www.cdc.gov/prams/)
- CDC & state health department surveillance project
- PRAMS Analytic Research File
- Subset of data from birth certificate records
  - Demographic data
  - Survey data

- CPONDER: CDC’s PRAMS Online Data for Epidemiologic Research
  - [http://www.cdc.gov/prams/CPONDER.htm](http://www.cdc.gov/prams/CPONDER.htm)
  - PRAMS data: 2000 through 2008
Sample CPONDER Data Table:
Green State - 2007 Morbidity - Infant

The baby's weight, classified as low birth weight (LBW) if the weight was less than or equal to 2500 grams or normal birth weight (NBW) if the weight was greater than 2500 grams

<table>
<thead>
<tr>
<th></th>
<th>Low Birth Weight (LBW) &lt; 2,500 grams</th>
<th>Normal Birth Weight (NBW) 2,500+ grams</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>7.8%</td>
<td>92.2%</td>
</tr>
<tr>
<td>Confidence Interval (CI)</td>
<td>7.6 – 7.9%</td>
<td>92.1 – 92.4%</td>
</tr>
<tr>
<td>Sample size (n)</td>
<td>657</td>
<td>835</td>
</tr>
</tbody>
</table>
Pregnancy Nutrition Surveillance System (PNSS)

- Program-based public health surveillance system
- [http://aspe.hhs.gov/hsp/06/Catalog-Al-AN-NA/PNSS.htm](http://aspe.hhs.gov/hsp/06/Catalog-Al-AN-NA/PNSS.htm)
- Monitors risk factors associated with infant mortality & poor birth outcomes
- Low-income women in federally-funded programs
- Voluntary reporting of programs
PNSS (continued)

- Data:
  - Indicators of maternal health & behaviors

- Published tables
  - [http://www.cdc.gov/pednss/pnss_tables/index.htm](http://www.cdc.gov/pednss/pnss_tables/index.htm)

- Download data:
  - North Carolina; California; West Virginia
PNSS -- Assessment

- Table format
- 1997-2010
- National level data
- Some state-level statistics
- Birth weight: very low, low, normal, high
## PNSS – Sample Data Table

### 2010 – Comparison of Infant Health Indicators


<table>
<thead>
<tr>
<th>Contributor</th>
<th>Birthweight % Low (rank)</th>
<th>Birthweight % High (rank)</th>
<th>Preterm % (rank)</th>
</tr>
</thead>
<tbody>
<tr>
<td>State 1</td>
<td>7.5% (16)</td>
<td>6.5% (12)</td>
<td>5.2% (1)</td>
</tr>
<tr>
<td>State 2</td>
<td>6.4% (5)</td>
<td>6.8% (15)</td>
<td>9.3% (11)</td>
</tr>
<tr>
<td>State 3</td>
<td>6.1% (3)</td>
<td>7.4% (20)</td>
<td>7.4% (3)</td>
</tr>
<tr>
<td>State 4</td>
<td>8.2% (23)</td>
<td>6.4% (10)</td>
<td>14.1% (31)</td>
</tr>
</tbody>
</table>
Local Hospital

- Infants born at the facility
- Recorded in different ways
  - Electronically, paper records
- Reports to Vital Records
  - Electronic or hard copy format
Local Hospital – Request Process

- Professional contacts
- Contact Research Office and/or Office of Medical Information Management

Be prepared:
  > Outline what you need
  > Data elements, timing, population of interest, research focus
  > Data availability
  > Identify request process
Local Hospital – Request Process -- Example

- Prepare & submit forms:
  - Purpose & data needs
  - List of names & credentials of persons who will access the data
  - Evidence of human subjects training
- Attend panel meeting
- Data availability: 4-6 weeks initially
  - On secured hospital-owned server
Local Hospital -- Assessment

- Format: electronic or hard copy
- Availability: few days to multiple weeks
- Data elements: depends on source
PeriData.Net – Example of Electronic System

- Wisconsin system
- Web-based perinatal database
- Electronic submission of birth information
- Hospital submit data
- Hospital own & control their own data
State Medicaid Program

- Medicaid Claims
- Medicaid Eligibility Files
- Special program:
  - Example: Prior authorization for palivizumab
- May use existing data sources
State Medicaid Program – Claims & Eligibility Files

 Medicaid Claims
   › ICD-9-CM Diagnostic Codes
     • Mother: 644.21: premature birth
     • Infant:
       • 765.1: prematurity
       • 765.0: extreme immaturity
     • Infant weight 5th sub-digits:
       • 1: < 500 grams
       • 9: ≥ 2,500 grams

 Medicaid Eligibility Files
   › Demographic data
March of Dimes -- PeriStats

- Online free resource
- March of Dimes Perinatal Data Center
- [http://www.marchofdimes.com/peristats/about.aspx](http://www.marchofdimes.com/peristats/about.aspx)
- Pie charts or tables
- Data availability: 2009 and earlier
  - Not preterm, moderately preterm, very preterm
  - Low birth weight: Not, moderately, very
  - Regional, state, some counties, some cities
March of Dimes – Peri-Stats:
Low birthweight by race/ethnicity: District of Columbia, 2007-2009 Average
Other Data Sources


Table 1:

- Pregnancy Risk Assessment Monitoring System (PRAMS)
- Pregnancy Nutrition Surveillance System (PNSS)
- Pediatric Nutrition Surveillance System (PedNSS)
- National Survey of Children’s Health (NSCH)
Pediatric Nutrition Surveillance system (PedNSS)

- Prevalence & trends of nutrition-related indicators
- Low-income children attending federally-funded MCH & nutrition programs
- State of New York
- Birth weight: < 2,500 grams; > 4,000 grams
- Data for children < 5 years: birth weight, breast feeding, TV viewing, smoking in household, etc.
National Survey of Children’s Health

- Sponsor: Child and Adolescent Health Measurement Initiative
- Data Resource Center
- Makes survey results available to the public
- Online queries of database
- 2003 or 2007
- Aggregate US level or states
- Child health
- Not birth weight or gestational age