Potential Data Sources for Generating Baseline Data

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## 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

	2008-2009	2009-2010	2010-2011
% births < 37 weeks EGA: women < 20 years of age	18.7%	18.9%	17.9%
% births < 37 weeks EGA: women 20-29	15.6%	14.3%	15.0%
% births < 37 weeks EGA: women 30-39	16.9%	17.3%	16.2%
% births < 37 weeks EGA: women ≥ 40	20.4%	19.2%	20.2%

## 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

	2010-2012: Before Intervention Began	2013-2014 Intervention Period	Difference between pre- intervention and intervention period
% Births < 37 weeks EGA, born to Medicaid beneficiaries, Center A	14.2%	9.6%	-4.6 percentage points
% Births < 37 weeks EGA, born to Medicaid beneficiaries, Center B	13.4%	11.3%	-2.1 percentage points

## 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

## U.S. Birth Certificate - 2003

#### **U.S. STANDARD CERTIFICATE OF LIVE BIRTH**

LOCAL FILE NO.		BIRTH NUMBER:	
CHILD	1. CHILD'S NAME (First, Middle, Last, Suffix)	2. TIME OF BIRTH 3. SEX 4. DATE OF BIRTH (Mo (24 hr)	o/Day/Yr)
	5. FACILITY NAME (If not institution, give street and number)	6. CITY, TOWN, OR LOCATION OF BIRTH 7. COUNTY OF BIRTH	
MOTHER	8a. MOTHER'S CURRENT LEGAL NAME (First, Middle, Last, Suffix)	8b. DATE OF BIRTH (Mo/Day/Yr)	
	8c. MOTHER'S NAME PRIOR TO FIRST MARRIAGE (First, Middle, Last, Suffix)	8d. BIRTHPLACE (State, Territory, or Foreign Country)	
	9a. RESIDENCE OF MOTHER-STATE 9b. COUNTY	9c. CITY, TOWN, OR LOCATION	
	9d. STREET AND NUMBER	9e. APT. NO. 9f. ZIP CODE 9g. INSID LIMI UYes	
FATHER	10a. FATHER'S CURRENT LEGAL NAME (First, Middle, Last, Suffix)	10b. DATE OF BIRTH (Mo/Day/Yr) 10c. BIRTHPLACE (State, Territory, or Foreign	Country)
CERTIFIER	11. CERTIFIER'S NAME:	_ 12. DATE CERTIFIED 13. DATE FILED BY REGISTRAF	2
OERTITIER	TITLE: DMD DO DHOSPITAL ADMIN, DCNM/CM DOTHER MIDWIFE	<i>1111</i>	-
	OTHER (Specify)	MM DD YYYY MM DD YYYY	
	INFORMATION FOR ADMINIS		
MOTHER	14. MOTHER'S MAILING ADDRESS: 9 Same as residence, or. State:	City, Town, or Location:	
	Street & Number:	Apartment No.: Zip Code	Ē
	15. MOTHER MARRIED? (At birth, conception, or any time between) IF NO, HAS PATERNITY ACKNOWLEDGEMENT BEEN SIGNED IN THE HOSPIT.	□ Yes □ No 16. SOCIAL SECURITY NUMBER REQUESTED 17. FACILITY AL? □ Yes □ No FOR CHILD? □ Yes □ No	Y ID. (NPI)
	18. MOTHER'S SOCIAL SECURITY NUMBER:	19. FATHER'S SOCIAL SECURITY NUMBER:	

10 T H E R		<ul> <li>MATION FOR MEDICAL AND HEALTH PURPOSES ONLY</li> <li>21. MOTHER OF HISPANIC ORIGIN? (Check the box that best describes whether the mother is Spanish/Hispanic/Latina. Check the "No" box if mother is not Spanish/Hispanic/Latina)</li> <li>No, not Spanish/Hispanic/Latina</li> <li>Yes, Mexican, Mexican American, Chicana</li> <li>Yes, Puerto Rican</li> <li>Yes, Cuban</li> <li>Yes, other Spanish/Hispanic/Latina</li> <li>(Specify)</li> </ul>	22. MOTHER'S RACE (Check one or more races to indicate what the mother considers herself to be)         White         Black or African American         American Indian or Alaska Native (Name of the enrolled or principal tribe)         Asian Indian         Chinese         Filipino         Japanese         Korean         Vietnamese         Other Asian (Specify)         Native Hawaiian         Guamanian or Chamorro         Samoan         Other Pacific Islander (Specify)         Other (Specify)
Mother's Medical Record No.	<ul> <li>23. FATHER'S EDUCATION (Check the box that best describes the highest degree or level of school completed at the time of delivery)</li> <li>8th grade or less</li> <li>9th - 12th grade, no diploma</li> <li>High school graduate or GED completed</li> <li>Some college credit but no degree</li> <li>Associate degree (e.g., AA, AS)</li> <li>Bachelor's degree (e.g., MA, MS, MEng, MEd, MSW, MBA)</li> <li>Doctorate (e.g., PhD, EdD) or Professional degree (e.g., MD, DDS, DVM, LLB, JD)</li> </ul>	<ul> <li>24. FATHER OF HISPANIC ORIGIN? (Check the box that best describes whether the father is Spanish/Hispanic/Latino. Check the "No" box if father is not Spanish/Hispanic/Latino</li> <li>No, not Spanish/Hispanic/Latino</li> <li>Yes, Mexican, Mexican American, Chicano</li> <li>Yes, Puerto Rican</li> <li>Yes, Cuban</li> <li>Yes, other Spanish/Hispanic/Latino</li> <li>(Specify)</li> </ul>	25. FATHER'S RACE (Check one or more races to indicate what the father considers himself to be)         □       White         □       Black or African American         □       American Indian or Alaska Native (Name of the enrolled or principal tribe)         □       Asian Indian         □       Chinese         □       Filipino         □       Japanese         □       Korean         □       Vietnamese         □       Other Asian (Specify)         □       Native Hawaiian         □       Guamanian or Chamomo         □       Samoan         □       Other Pacific Islander (Specify)         □       Other (Specify)
on - Rittan 1906	26. PLACE WHERE BIRTH OCCURRED (Check Hospital Freestanding birthing center Home Birth: Planned to deliver at home? 9 Yes Clinic/Doctor's office Other (Specify)	NAME:NPI:	28. MOTHER TRANSFERRED FOR MATERNAL MEDICAL OR FETAL INDICATIONS FOR DELIVERY? □ Yes □ No IF YES, ENTER NAME OF FACILITY MOTHER TRANSFERRED FROM:

MOTHER	<i>T</i>		RE VISIT No Prenatal Care	29b. DATE O	F LAST F	PRENATAL CARE VISIT	30. TOTAL NUN		L VISITS FOR THIS PREGNANCY (If none, enter A0".)
	MM DD	YYYY							
	(feet/inches)(; 35. NUMBER OF PREVIOUS 36. NUMBER OF O LIVE BIRTHS (Do not include PREGNANCY this child) (spontaneous			OUTCOMES For each time period, enter either the number of ci or induced number of packs of cigarettes smoked. IF NONE, pic pregnancies)			DURING THIS PREGNANCY?   Ves  No		
			36. NUMBER OF O PREGNANCY ( (spontaneous o losses or ectopi			cigarettes or the PAYMENT FOR THIS IE, ENTER A0". DELIVERY			
	35a. Now Living Number	35b. Now Dead Number Done	36a. Other Outcom Number Done	es	Three First T Secor	e number of cigarettes or Months Before Pregnanc hree Months of Pregnanc d Three Months of Pregna Trimester of Pregnancy	# of cigarettes y cy		Private Insurance     Medicaid     Self-pay     Other     (Specify)
	35c. DATE OF LA	ST I IVE BIRTH	36b. DATE OF LAS	TOTHER	10071000000	TRINESSER OF Pregnancy	SES BEGAN		EDICAL RECORD NUMBER
	second second second	YYY YYY	PREGNANCY		WARKER MORENO		1225	TO, MOTHER OW	
MEDICAL AND HEALTH INFORMATION	Diabetes  Prepregnar  Gestational  Hypertension  Prepregnar  Gestational  Eclampsia  Previous preter  Other previous pernatal death growth restricte  Pregnancy res check all that a  Fertility-eni Intrauterin. Assisted re fertilizetion transfer (G  Mother had a p If yes, how I  None of the ab  42. INFECTIONS	all that apply) ancy (Diagnosis prior (Diagnosis in thi (Diagnosis in thi ancy (Chronic) (PIH, preeclampsia m birth poor pregnancy out , small-for-gestation and birth) uited from infertility apply: hancing drugs, Artifi e insemination productive echnolo (IVF), gamete intrafi (ITF)) previous cesarean d many present AND/OI S PRESENT AND/OI S PREGNANCY (C	to this pregnancy) s pregnancy) a) come (Includes al age/intrauterine treatment-If yes, cial insemination or gy (e.g., in vitro allopian elivery	Cervical Cervical Cervical Constraints Co	cerclage phalic ver isful the above OF LABO A Rupture is Labor ( Labor ( Labor ( Labor ( Check of labor terceived ioricamnin tempera heavy me erance of actions w s, further r spinal a	R (Check all that apply) of the Membranes (protor <3 hrs.) 120 hrs.) S OF LABOR AND DELIN all that apply)	nged, ∃12 hrs.) /ERY ation pr por of milotic fluid rice of the itative	unsuccessful? Yes Hest Selivery with but unsuccess Yes C. Fetal presentat Cephalic Breech Other D. Final route and Vaginal/Sp Vaginal/For Vaginal/For Vaginal/Ya Cesarean If cesarean Yes No 47. MATERNAL (Complections delivery) Maternal tra Third or four Ruptured utt Unplanned to Admission tt	ith forceps attempted but No th vacuum extraction attempted ful? No ion at birth method of delivery (Check one) ontaneous rceps cuum was a trial of labor attempted? MORBIDITY (Check all that apply) is associated with labor and nsfusion th degree perineal laceration erus hysterectomy intensive care unit operating room procedure livery

## U.S. Birth Certificate - 2003

		NEWBORN INFORMATION	2 2	
IEWBORN	48. NEWBORN MEDICAL RECORD NUMBER	54. ABNORMAL CONDITIONS OF THE NEWBORN (Check all that apply)	55. CONGENITAL ANOMALIES OF THE NEWBORN (Check all that apply)	
	49. BIRTHWEIGHT (grams preferred, specify unit) 9 grams 9 lb/oz 50. OBSTETRIC ESTIMATE OF GESTATION:	<ul> <li>Assisted ventilation required immediately following delivery</li> <li>Assisted ventilation required for more than six hours</li> </ul>	Anencephaly     Meningomyelocele/Spina bifida     Cyanotic congenital heart disease     Congenital diaphragmatic hernia     Omphalocele     Gastroschisis     Limb reduction defect (excluding congenital	
e cal Record	(completed weeks) 51. APGAR SCORE: Score at 5 minutes: If 5 minute score is less than 6, Score at 10 minutes:	<ul> <li>NICU admission</li> <li>Newborn given surfactant replacement therapy</li> <li>Antibiotics received by the newborn for suspected neonatal sepsis</li> </ul>	amputation and dwarfing syndromes)  Cleft Lip with or without Cleft Palate  Cleft Palate alone  Down Syndrome  Karyotype confirmed  Karyotype pending  Karyotype confirmed  Karyotype confirmed  Karyotype pending  Karyotype pending	
	52. PLURALITY - Single, Twin, Triplet, etc. (Specify) 53. IF NOT SINGLE BIRTH - Born First, Second, Third, etc. (Specify)	<ul> <li>Seizure or serious neurologic dysfunction</li> <li>Significant birth injury (skeletal fracture(s), peripheral nerve injury, and/or soft tissue/solid organ hemorrhage which requires intervention)</li> <li>None of the above</li> </ul>		
Mother's	56, WAS INFANT TRANSFERRED WITHIN 24 HOU IF YES, NAME OF FACILITY INFANT TRANSFE TO:	RS OF DELIVERY? 9 Yes 9 No 57. IS INFANT LIVING A RRED I Yes I No Infant 1	T TIME OF REPORT? transferred, status unknown PREASTFED AT DISCHARGE? Yes D No	

Centers for Disease Control & Prevention (CDC)

• <u>www.cdc.gov</u>

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
- > Report Births Change 2009-2010 Bexar Co.
  - 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/
- 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
  - <u>http://www.cdc.gov/prams/CPONDER.htm</u>
  - > 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

	Low Birth Weight (LBW) < 2,500 grams	Normal Birth Weight (NBW) 2,500+ grams
Percent	7.8%	92.2%
Confidence Interval (CI)	7.6 – 7.9%	92.1 – 92.4%
Sample size (n)	657	835

## Pregnancy Nutrition Surveillance System (PNSS)

- Program-based public health surveillance system
- 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
  - > <u>http://www.cdc.gov/pednss/pnss\_tables/ind</u> <u>ex.htm</u>
- 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 http://www.cdc.gov/pednss/pnss\_tables/pdf/national\_table8.pdf

Contributor	Birthweight % Low (rank)	Birthweight % High (rank)	Preterm % (rank)
State 1	7.5% (16)	6.5% (12)	5.2% (1)
State 2	6.4% (5)	6.8% (15)	9.3% (11)
State 3	6.1% (3)	7.4% (20)	7.4% (3)
State 4	8.2% (23)	6.4% (10)	14.1% (31)

## 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 5<sup>th</sup> 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/a bout.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

- Kasehagen, L. (2011). Underutilized MCH Data Sources. City Lights, 19(2), retrieved from <u>http://webmedia.unmc.edu/Community/CityMat</u> <u>ch/CityLights/CityLights201105.pdf</u>
  - > <u>Table 1:</u>
    - Pregnancy Risk Assessment Monitoring System (PRAMS)
    - <u>Pregnancy Nutrition Surveillance System (PNSS)</u>
    - Pediatric Nutrition Surveillance System (PedNSS)
    - National Survey of Children's Health (NSCH)

## Pediatric Nutrition Surveillance system (PedNSS)

- http://www.health.ny.gov/statistics/prevention/pednss/index.htm
- Prevalence & trends of nutrition-related indicators
- Low-income children attending federallyfunded MCH & nutrition programs
- State of New York
- $\odot$  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