

# PRAMSGRAM

OKLAHOMA PREGNANCY RISK ASSESSMENT MONITORING SYSTEM VOL 16 NO 2 SUMMER 2012

## Birth Defects in Oklahoma

### Introduction:

Congenital anomalies or birth defects are structural defects that are present at birth.<sup>1</sup> Birth defects range from relatively minor to serious conditions requiring immediate medical intervention or lifelong care. Congenital anomalies affect 3% of babies born in the United States.<sup>2</sup> From 2004-2008, the cumulative prevalence of all birth defects in Oklahoma was 42.11 per 1,000 live births with a range of 45.53 per 1,000 live births in 2004 to 39.45 per 1,000 live births in 2008.

Birth defects are quite costly and result in numerous hospitalizations and increased infant mortality. In 2004, there were 139,000 hospitalizations associated with congenital anomalies in the United States with hospital costs totaling \$2.6 billion.<sup>3</sup> In Oklahoma, congenital anomalies accounted for 1,511 hospitalizations in 2008 (the latest data available) resulting in an average length of stay of 6 days and \$56,736 in average hospital charges per stay.<sup>4</sup> Nationally, birth defects accounted for 20.4% (5,819/28,527) of deaths among infants less than one year of age in 2006.<sup>5</sup> In Oklahoma from 2002-2006, birth defects were the second leading cause of death in infants (less than one year of age) and were responsible for 21.9% (450/2,055) of infant deaths.<sup>6</sup>

Risk factors for congenital anomalies include genetic, environmental, and maternal factors. Congenital anomalies have been linked to maternal exposure to tobacco, alcohol, illicit drugs, medications, and chemicals, as well as maternal health conditions such as illness, infections, and chronic health conditions like diabetes and obesity (body mass index (BMI)  $\geq$  30).<sup>6-7</sup> Since approximately 70% of birth defects have an unknown etiology, further exploration into the etiology of birth defects is necessary.<sup>8-9</sup>

The Oklahoma Birth Defects Registry § 63 Section 1-550.2 statute gives the Oklahoma State Department of Health (OSDH) the responsibility for operating

### In Oklahoma:

- Oklahoma Birth Defects Registry data indicate that 42.1 infants per 1,000 live births were born with a birth defect from 2004-2008.
- Singleton infants of 2004-2008 PRAMS respondents (n=759) were linked to records in the Oklahoma Birth Defects Registry.
- Eighty-eight percent of mothers of infants with birth defects were white.
- Almost 70% of mothers had prenatal care or delivery services paid for by Medicaid/SoonerCare.
- The most common birth defect in the linked dataset was an atrial septal defect impacting 23% of the 759 infants in the sample.

the birth defects registry and assuring confidentiality of the data collected. The Oklahoma Birth Defects Registry (OBDR) utilizes an active case ascertainment from delivery, pediatric, and tertiary care hospitals. Medical information related to the infant's birth defect is collected on over 470 conditions during the newborn period and up to three years after birth. The OBDR functions to protect and promote the health of Oklahomans through statewide surveillance and investigation, thereby identifying opportunities to prevent birth defects, optimize early detection of birth defects, and reduce infant mortality. The OBDR started in 1992 with active surveillance in eight Oklahoma County hospitals. In 1994, the OBDR was instituted statewide and active abstraction continues in all birthing hospitals. The OBDR contributes data to the Centers for Disease Control and Prevention (CDC), so that CDC can calculate national birth defects prevalence rates. Since 1997, the OBDR has promoted the use of folic acid to reduce the prevalence of neural tube defects and provides folic acid at no cost to women of reproductive age through county health departments.

A key goal of public health surveillance is to foster partnerships for effective dissemination of data for public health use, planning, and education through database linkage. Birth defects registries have been linked to hospital discharge, vital records, cancer registries, and Women, Infants, and Children (WIC) databases.<sup>10-15</sup> There has been no published description of a database linkage of birth defects registry data to the Pregnancy Risk Assessment Monitoring System (PRAMS), a population-based surveillance project that collects data on maternal attitudes and experiences before, during, and after pregnancy. This collaboration between Oklahoma PRAMS and OBDR is believed to be the first documented effort to link data between a surveillance system and a birth defects registry.

The Oklahoma PRAMS was linked to the OBDR to identify maternal risk factors associated with congenital anomalies in order to assist in program development for prevention strategies, enable policymakers to target awareness campaigns and public health education efforts as well as policies to reduce the prevalence of preventable birth defects. This article focuses on the linkage process between the PRAMS and OBDR, as well as the preliminary findings from the analysis of the linked data.

## Methods:

The data for this study came from linked records of the PRAMS survey and the OBDR. From 2004 to 2008, a total of 13,619 women were selected to participate in PRAMS and 9,829 (72.2%) of those women completed the PRAMS survey. The OBDR is a population-based surveillance system with active case ascertainment from delivery, pediatric, and tertiary care hospitals. Active case ascertainment involves staff investigating and

The Pregnancy Risk Assessment Monitoring System (PRAMS) is an ongoing, population-based study designed to collect information about maternal behaviors and experiences before, during and after pregnancy. On a monthly basis, PRAMS samples between 200 and 250 recent mothers from the Oklahoma live birth registry. Mothers are sent as many as three mail questionnaires seeking their participation, with follow-up phone interviews for non-respondents. A systematic stratified sampling design is used to yield sample sizes sufficient to generate population estimates for groups considered at risk for adverse pregnancy outcomes. Information included in the birth registry is used to develop analysis weights that adjust for probability of selection and non-response.

finding potential birth defects, allowing for the most complete assessment of birth defects among births and the highest quality of data. Medical information related to the infant's birth defect is collected during the newborn period and up to three years after birth. The OBDR collects diagnosis data based on ICD-9-CM codes and utilizes the CDC British Pediatric Association (BPA) coding system which offers more specificity. From 2004 to 2008, 11,272 de-duplicated records were available from the OBDR. The length of time birth defect surveillance was conducted differed between the 2004-2006 infant cohort and the 2007-2008 infant cohort, due to a change in OBDR policy from six years of follow-up to three, beginning with 2007 infants.

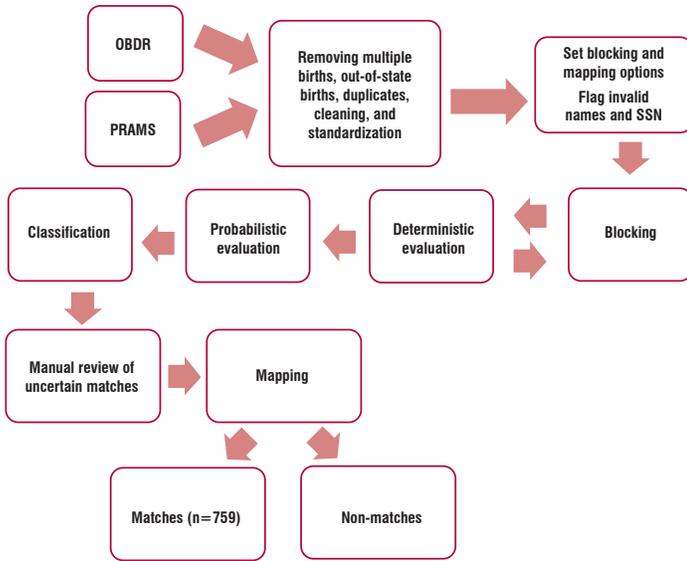
PRAMS data were linked to OBDR data for the same years using the software "The Link King." The Link King is a SAS-based, publicly available matching software, which uses both deterministic and probabilistic linking techniques. Both datasets were individually prepared by eliminating duplicates, standardizing identifying information, and creating new variables for important identifiers. The software allows manual review of all probable matches. More information about the linking process, variables, and methods used can be obtained from the Oklahoma PRAMS staff (PRAMS@health.ok.gov) or by visiting the website for this PRAMSGRAM.

All records related to multiple births were excluded from linking since the PRAMS sampling methods randomly select only one infant from a multiple birth to review, therefore equal representation could not be guaranteed once the two datasets were linked if multiple births were not excluded. Once linked, data were de-identified to ensure confidentiality.

Overall, 8% (n=759) of all the singleton infants included in the PRAMS data matched to a record in the birth defects data. This rate remained steady between 2004 and 2008. A schematic of the linkage process is given in Figure 1.

Prevalence rates and 95% confidence interval (C.I.) estimates were calculated and the potential risk factors were identified using the Cochran-Mantel-Haenszel Chi-Square ( $\chi^2$ ) Test. All analysis in this study was done using the statistical software SUDAAN. Variables were considered significant at  $p < 0.05$ .

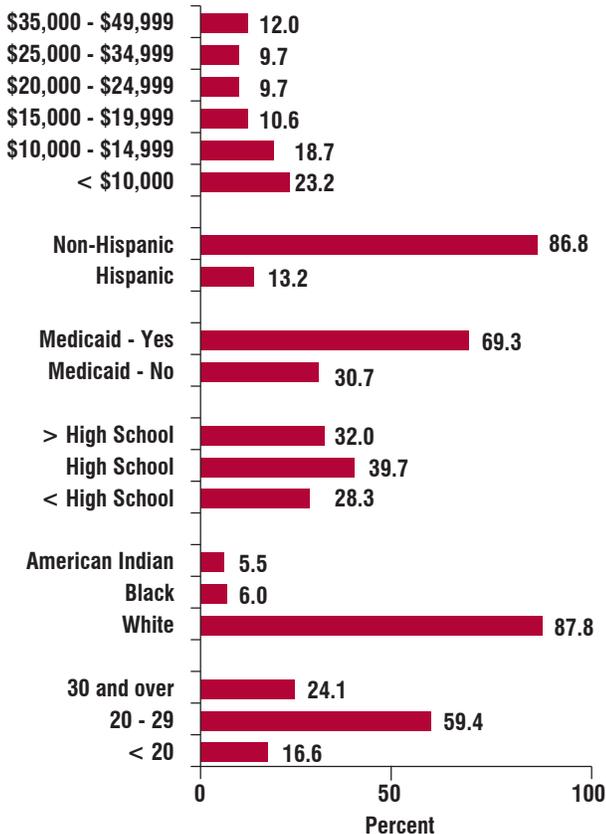
**Figure 1. PRAMS and OBDR linkage process**



**Results:**

Linked PRAMS and OBDR data show that mothers of singleton infants born with a birth defect were predominantly white (87.8%), non-Hispanic (86.8%) and in the age group 20-29 years (59.4%, Figure 2).

**Figure 2. Selected characteristics of Oklahoma mothers of singleton infants born with a birth defect, PRAMS 2004-2008**



Sixty-eight percent of these mothers had a high school education or less.

Almost one in four infants with birth defects lived in households with annual incomes of \$10,000 or less (23.2%). Altogether, 41.9% reported annual household incomes of \$15,000 or less. Because so few infants with birth defects lived in households with annual incomes of \$50,000 or more, the data were suppressed due to inadequate cell size. Directly related to annual income, Medicaid/SoonerCare paid for prenatal care or delivery services for 69.3% of the mothers with infants diagnosed with birth defects in this study.

A review of maternal behaviors and health history found several significant associations among mothers of infants with birth defects (Table 1). Forty-five percent of mothers were primiparous, compared to 54.8% who were multiparous. According to Oklahoma Vital Records data from 2004-2008, 38.9% of all births in Oklahoma were to primiparous women compared to the 61.1% born to multiparous women.

**Table 1. Health behaviors and characteristics of Oklahoma mothers of singleton infants born with a birth defect, Oklahoma PRAMS-OBDR linked data, 2004-2008**

Maternal Characteristic	(%)	95% C.I. (Confidence Interval)
<b>PREVIOUS LIVE BIRTH</b>		
NONE	45.2	37.9 - 52.7
1 OR MORE	54.8	47.3 - 62.1
<b>MULTIVITAMIN/FOLIC ACID USE PRIOR TO PREGNANCY</b>		
NONE TAKEN	66.4	59.2 - 73.0
1-3 TIMES/WEEK	5.8	3.4 - 9.7
4-6 TIMES/WEEK	4.0	1.9 - 8.3
EVERY DAY	23.7	18.1 - 30.5
<b>SMOKING 3 MONTHS PRIOR TO PREGNANCY</b>		
NO	59.4	51.7 - 66.6
YES	40.6	33.4 - 48.3
<b>SMOKING LAST 3 MONTHS OF PREGNANCY</b>		
NO	74.6	67.3 - 80.8
YES	25.3	19.2 - 32.7
<b>ALCOHOL USE 3 MONTHS PRIOR TO PREGNANCY</b>		
NO	46.7	39.3 - 54.3
YES	53.2	45.7 - 60.7
<b>ALCOHOL USE LAST 3 MONTHS OF PREGNANCY</b>		
NO	96.6	92.7 - 98.5
YES	3.4	1.5 - 7.3
<b>BODY MASS INDEX (BMI)</b>		
Underweight (< 18.5)	15.0	10.3 - 21.4
Normal (18.5-24.9)	49.8	42.4 - 57.2
Overweight (25.0-29.9)	16.6	11.9 - 22.8
Obese (30.0+)	18.6	13.5 - 25.1

Thirty-three percent of mothers with an infant diagnosed with a birth defect took any multivitamins weekly in the month prior to getting pregnant. Forty-one percent of the linked mothers smoked during the three months prior to pregnancy; over half used alcohol in the three months prior to pregnancy. Almost 65% of the mothers in the linked group were classified as normal or underweight, with a pre-pregnancy BMI of less than 25. Nineteen percent were obese prior to pregnancy.

A review of the most common birth defect categories from the PRAMS-OBDR linked data set found that congenital anomalies of the heart and circulatory system were the most prevalent birth defects, at 42% (Table 2). The second most common category was the musculoskeletal defects (29%). Many of the infants in the linked data set had a diagnosis from more than one birth defect category and, within categories, more than one birth defect. The three most commonly diagnosed birth defects among the infants in the linked dataset were atrial septal defect (23%), ventricular septal defect (15%), and obstructive defects of renal pelvis and ureter (11%; data not shown).

<b>Table 2. Unweighted relative frequencies of the most common birth defect categories, Oklahoma PRAMS-OBDR linked data, 2004-2008</b>	
<b>Category of birth defect</b>	<b>Percent</b>
Congenital anomalies of the heart and circulatory system	42%
Congenital anomalies of the musculoskeletal system	29%
Congenital anomalies of the genital and urinary system	21%
Congenital anomalies of the nervous system	13%
Congenital anomalies of the upper alimentary canal/digestive system	12%
Chromosomal anomalies	8%
Cleft palate and cleft lip	5%
Congenital anomalies of the respiratory system	4%
Other diseases of gastrointestinal system	3%
Congenital anomalies of the eye	3%
Congenital anomalies of the ear, face, and neck	3%
Other and unspecified congenital anomalies	2%
Infectious conditions occurring in the perinatal period	2%

## Discussion:

By linking PRAMS and OBDR data, a more detailed history of the maternal experience before, during, and after pregnancy can be explored. From the linked data in Oklahoma, even with sample size limitations, some important factors emerged.

The first was that multivitamin use prior to pregnancy was not at optimal levels; two-thirds of mothers in the linked dataset did not take any multivitamins before they became pregnant. Among all Oklahoma mothers the rate is much different, as 36.1% of new mothers did not take any multivitamins before conception (Oklahoma PRAMS data, unpublished). Folic acid consumption prior to conception has been proven in multiple studies to prevent a multitude of birth defects, including neural tube defects, some types of cardiac defects, and cleft lip and palate.<sup>16</sup> Folic acid may also prevent some birth defects in women with preexisting diabetes.<sup>17</sup>

Another factor identified from the linked dataset was the level of alcohol consumption prior to pregnancy; more than half of the mothers in the linked dataset had consumed alcohol in the three months prior to conception. Alcohol has been implicated in a number of adverse effects on pregnancy and on the fetus. Alcohol passes through the placenta and is broken down by the fetus much more slowly than in an adult.<sup>18</sup> No measurable amount is considered safe.

Preconception health is key to the prevention of certain birth defects and in enhancing the health of women prior to pregnancy. As almost 50% of live births in Oklahoma are the result of unplanned pregnancies, being in optimal health is the best way to ensure the best outcome for the baby. Encouraging healthy behaviors like folic acid consumption, proper nutrition, physical activity, and reproductive life planning furthers health across the life course for both parent and child.

On a public health level, linked data sources are vital in developing strategies and targeted interventions for the state’s infant mortality reduction initiative “Preparing for a Lifetime, It’s Everyone’s Responsibility” and the Oklahoma Children’s Health Plan: Keeping Kids Healthy, part of the Oklahoma Health Improvement Plan (OHIP). State-level data of this type are necessary to understand this magnitude of the public health issue in Oklahoma and to demonstrate the effectiveness of prevention strategies.

More analysis work on this dataset will occur to review how these rates compare to both the birth defects cohort and the overall birth cohort of the infants in the linked dataset. As additional years of data become available, more linking and review will be performed.

In order to obtain more in-depth analysis on certain

types of birth defects data, more state registry and state PRAMS projects data would be necessary. Currently, 12 states in the United States participate in both the CDC-funded Birth Defects Registry and PRAMS. Although some states are passive (meaning case reports are submitted to the surveillance program by outside entities) and others are active like Oklahoma, meaningful information could be mined from a multi-state linked data set to obtain a more complete picture of the mother and infants health and behaviors before, during, and after pregnancy, including medical diagnoses and hospitalization information.

Limitations for this dataset include sample size. Only 759 infants were linked and because of the oversampling done by PRAMS (for very low, low, and high birth weight infants) they are not representative of the entire birth defects population in Oklahoma. PRAMS data are based on maternal self-report and not medical records, and are therefore subject to recall and social desirability bias. However, the enhanced information obtained will provide insight into key issues important to birth defects prevention and surveillance in the state. Another potential limitation to this data set is the difference in birth defects surveillance follow-up between the 2004-2006 and 2007-2008 infants (from six years to three). More review of the data is needed to determine the extent of the impact.

## Recommendations:

1. Renew statewide activities and campaigns targeting preconception use of multivitamins by all females of reproductive age, particularly those planning a pregnancy in the next one to two years.
2. Support community and state efforts to reinforce abstinence from alcohol while trying to get pregnant as well as during pregnancy.
3. Advocate for a Medicaid state plan amendment for an interconception health waiver to support the provision of necessary care (to include nutrition counseling) during the postpartum period and beyond.
4. Encourage providers to use the American Congress of Obstetrics and Gynecology (ACOG) guidelines for preconception health care visits to ensure women are receiving quality preconception health care.
5. Educate health care providers to view every

interaction with a female or male of reproductive age as an opportunity for preconception health counseling.

6. Perform nutritional assessments for all underweight or obese females seen in a health care setting and link to appropriate nutrition services.
7. Advocate for other states to create their own PRAMS-BDR datasets and review potential for a multi-state collaboration to examine specific behaviors and conditions in detail on a regional or national level.
8. Conduct more detailed analysis of the Oklahoma linked data to better identify risk factors and outcomes related to birth defects in this state.

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Supplemental information on the data linking process and data preparation can be found online with the web version of this *PRAMSGRAM*.

