

Using Experience from Birth Defects Surveillance to Rapidly Monitor Neonatal Abstinence Syndrome



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Overview

How Pennsylvania, as a state with no Birth Defects Surveillance prior to 2016, used Zika Birth Defects Surveillance resources and lessons learned to rapidly respond to an emerging threat – Neonatal Abstinence Syndrome.



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Birth Defects Surveillance Prior to CDC Funding

- **August 2016:** Zika-related birth defects funding awarded
 - * Prior to this funding (2015): Six states had no birth defects surveillance program – approximately 7% of national live births


States Without Birth Defects Surveillance	2015 Live Births
Pennsylvania	141,047
Alabama	59,657
Idaho	22,827
Montana	12,583
South Dakota	12,336
Wyoming	7,765



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Pennsylvania Challenges for Birth Defects Surveillance



- **Legal challenges: No specific legislative authority**
- **Birth certificates: Limited source**
- **Hospital discharge data (outsourced): Provides de-identified data**
 - Problematic for following transferred infants
 - No history of state surveillance exists to evaluate validity of coding if case verification is not performed



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Zika Birth Defects Surveillance Process

- **Legal authority gained in 2016**
 - After review, outcomes like possible birth defects from a reportable infectious disease were reportable
- **Surveillance method: Passive + Active**
 - **PASSIVE:**
 1. Contact birthing facilities (ICD-10 discharge codes)
 2. Process facility-provided case lists to remove non-cases
 3. Send final case list for review to facility
 - **ACTIVE:**
 4. Review medical records for case verification and abstraction
 5. Record data in REDCap Cloud electronic database

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Birth Defects Surveillance — Initial Activities Timeline

Progress after CDC Zika Birth Defect Surveillance funding began August 2016:

April 2017

New team of three people in place

➔


September 2017

Received first facility-provided list of potential cases for review

➔

October 2017

Uploaded first abstracted cases to CDC portal



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Three Months Later...

Jan. 10, 2018: 90-day emergency declaration for the opioid epidemic

- NAS reportable – rapid case ascertainment



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Neonatal Abstinence Syndrome

Neonatal Abstinence Syndrome (NAS):
Newborn withdrawal from prenatal substance exposure

Signs and Symptoms

- Tremors
- Irritability
- Increased muscle tone
- Poor feeding
- Gastrointestinal tract dysfunction
- Hyperactive deep tendon reflexes
- Seizures
- High-pitched crying



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Neonatal Abstinence Syndrome (NAS) in Pennsylvania

NAS in Pennsylvania leading up to state of emergency:

Hospital inpatient data report from PHC4:

- More than 1000 percent increase in newborn stays
- More than \$14 million in estimated costs for NAS-related stays in 2017



• 2017 estimated costs based on 2013 average Medicaid payments
• Pennsylvania Health Care Cost Containment Council, (PHC4) (2018, March). Hospitalizations for Newborns with Neonatal Abstinence Syndrome.



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Leveraging Knowledge Gained from ZBDS

BIRTH DEFECTS SURVEILLANCE	NAS REPORTING
Birth Records Data	Birth Records Data
REDCap Cloud Database	REDCap Cloud Database

- **Birth Records Data:** Apply ZBDS knowledge of infant's medical record
- **REDCap Cloud Database:** Leverage extensive validation performed during ZBDS setup

DATA PREPAREDNESS



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Creating a Case Report Form

Background

- Perform literature review
- Identify variables for collection
- Consider target users, data available at time of entry



Time spent

- Create defined response sets
 - Visually shortened with skip-patterns and dropdowns
 - Balance between:
 1. Robust clinical data
 2. One page template

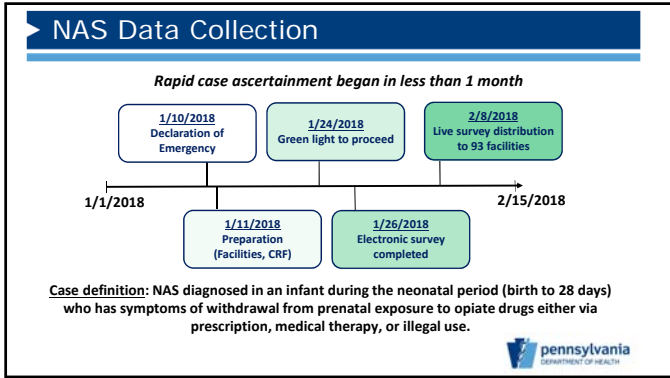


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Case Report Form



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NAS Data Collection

Day 0: NAS becomes reportable

Day 2: 18 cases from 6 facilities

2 years: **3,725 cases**
86 (91%) facilities

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NAS Data Summary - Demographics

		NAS (2018-2019)			PA 2018 live births	
		Total Responses	n	%	n ¹	%
Total NAS Cases (Jan. 10, 2018 – Dec. 31, 2019)		3725	3725	(100%)		
Maternal						
Race	Identified as White	3453	3148	91	95,066	70
Prenatal Care	Any known prenatal care	3362	3068	91	129,069	98
Payment Source	Principle source = Medicaid	3626	3043	84	45,572	35
Infant						
Birth Weight	Less than 2500 grams at birth	3674	684	19	11,261	8
Gestational Age	Less than 37 weeks	3673	613	17	12,896	10
Level of Care	Received care in a NICU	3725	1828	49		
Symptoms	3 or more NAS symptoms	3725	3439	92		

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NAS Data Summary - Laboratory Testing

	n	%	
Total Number of NAS Cases Reported	3725	100	
Laboratory Evidence of Exposure in Infant (Missing=102)	3623	(100%)	
Test Results	Tested positive	2384	66
	Tested negative	492	14
	Pending	371	10
	Not Tested	376	10
Among Total Number of Infants Testing Positive		2384 (100%)	
Type of Opioid Detected	Some form of opioids	2010	84
	Medications used to treat substance use (methadone, buprenorphine)	1642	69
	Oxycodone, fentanyl, other opiates or synthetic opioids	509	21

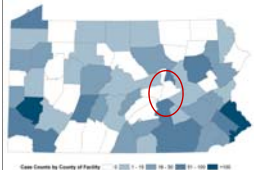


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2018 NAS Annual Report


Total NAS Case Count 2018 = 2,140

Case Counts by **County of Facility**
Range: 0-482 in Allegheny



Case Counts by **County of Residence**
Range: 0-263 in Philadelphia



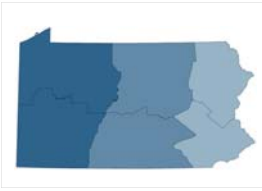



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2018 NAS Annual Report

NAS Incidence Rates per 1,000 Births By Region of Facility and County

Region	# Facilities	Rates by Facility County	Rates by Resident County
NW	13	27.0	28.0
SW	17	27.0	26.0
NC	8	14.3	14.3
SC	15	15.5	15.4
NE	11	12.0	12.7
SE	31	10.7	10.4






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2018 NAS Annual Report

NAS Incidence Rates per 1,000 Births By Region of Facility and County

Region	# Facilities	Rates by Facility County	95% Confidence Interval	Rates by Resident County	95% Confidence Interval
NW	13	27.0	(23.7-30.8)	28.0	(24.8-31.7)
SW	17	27.0	(25.2-29.1)	26.0	(24.1-28.0)
NC	8	14.3	(12.7-18.5)	14.3	(11.7-17.6)
SC	15	15.5	(13.8-17.4)	15.4	(13.7-17.3)
NE	11	12.0	(10.4-13.8)	12.7	(11.0-14.6)
SE	31	10.7	(9.9-11.6)	10.4	(9.6-11.3)






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2018 NAS Annual Report

NAS Incidence Rates per 1,000 Live Births (Pennsylvania 2018)


Region	Rate Range
Region of Facility	10.7 – 27.0
Region of Residence	10.4 – 28.0
County	
County of Residence	0.0 – 111.1
State vs National	Rate
Pennsylvania (2018)	16
United States (2014)	8





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Additional Efforts

- Provided personalized data reports to facilities
- Heavily involved in creating new national case definition (CSTE)
 - State adoption of CSTE case definition
- Produced 2018 NAS Annual Report
- Secured NAS grant funding
- CDC Epi-Aid project: Case verification and ascertainment; reporter barriers to diagnosis and reporting








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Additional Efforts (continued)


- Transitioned data collection to Bureau of Family Health, Department of Health
- Collaborating with Philadelphia Department of Public Health
- Working to make NAS reportable
- Contributing to the Multi-Disciplinary Workgroup on Infants Born Substance Exposed (MDWISE)
- Working with local NAS focus groups



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Challenges and Successes

Challenges	Successes
No Nationally Standardized Case Definition	Built Upon Capacity (ZBDS)
Little Time for Reporter Education	Maintained State Momentum
Limited Resources for Ongoing Facility Outreach	Provided Precedent, Expanded Opportunities




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