

2015

Indiana Perinatal Quality Improvement Collaborative Annual Report



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Indiana Perinatal Quality Improvement Collaborative (IPQIC)

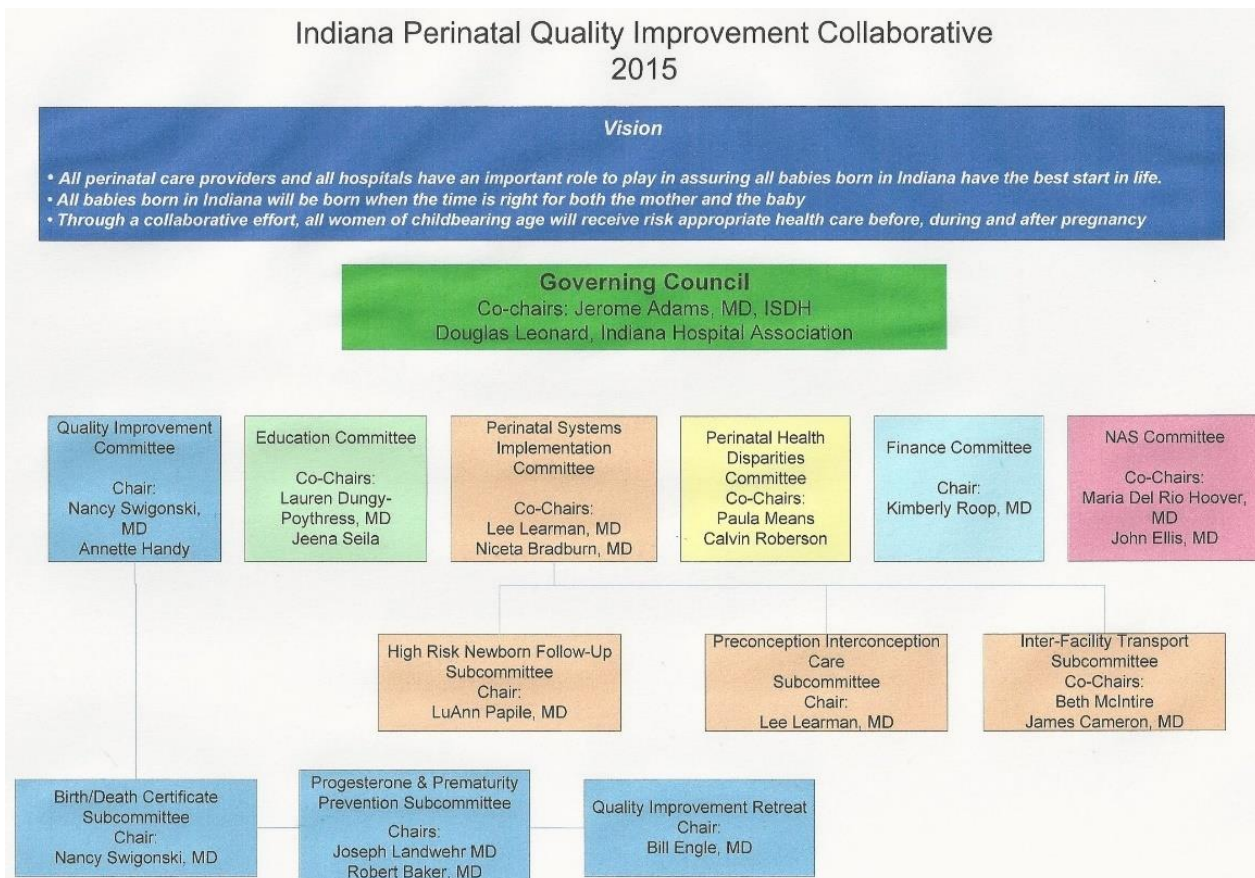
The death of a baby before his or her first birthday is called infant mortality. The infant mortality rate is an estimate of the number of infant deaths for every 1,000 live births. This rate is often used as an indicator to measure the health and well-being of a nation, because factors affecting the health of entire populations can also impact the mortality rate of infants.

-Centers for Disease Control and Prevention

Introduction

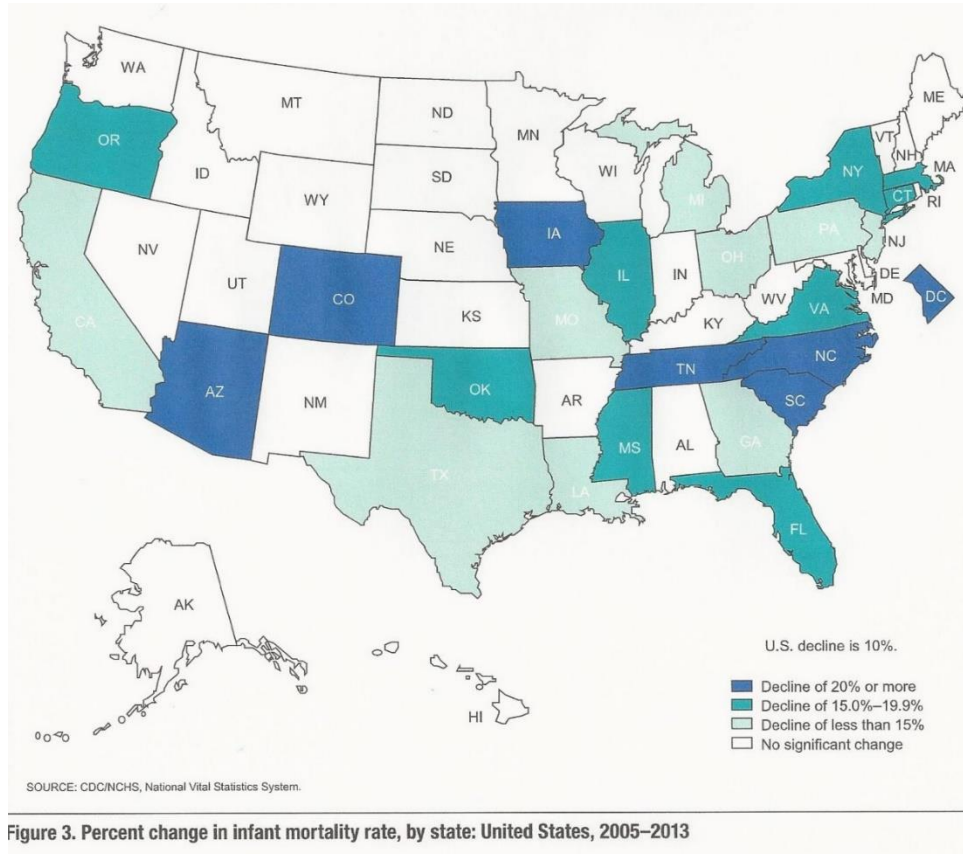
The vision of IPQIC is threefold:

- All perinatal care providers and all hospitals have an important role to play in assuring all babies born in Indiana have the best start in life.
- All babies in Indiana will be born when the time is right for both the mother and the baby.
- Through a collaborative effort, all women of childbearing age will receive risk



appropriate health care before, during and after pregnancy.

The following chart developed by the Centers for Disease Control and Prevention compares changes in infant mortality rates between 2005 and 2013.¹



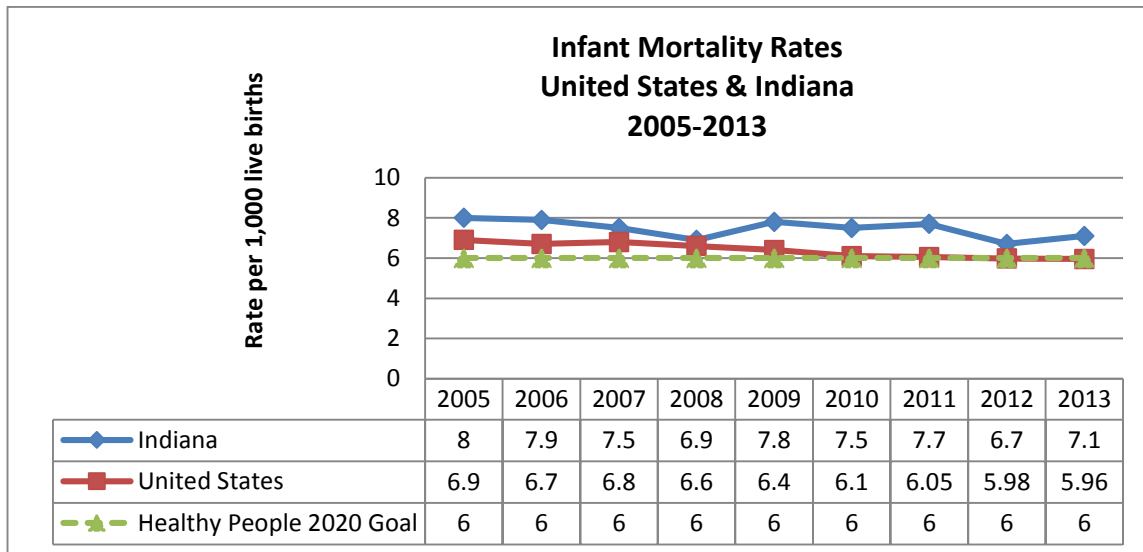
The report that follows will identify the 2015 activities of IPQIC's Governing Council and committees, the volunteers who have contributed their time and energy to move the agenda of mothers and babies forward, an overview of perinatal outcomes in 2013, work products that have been developed during 2015, and the activities that will become 2016 priorities.

¹ National Vital Statistics Reports, Vol. 64, No.9, August 6, 2015

Setting the Stage

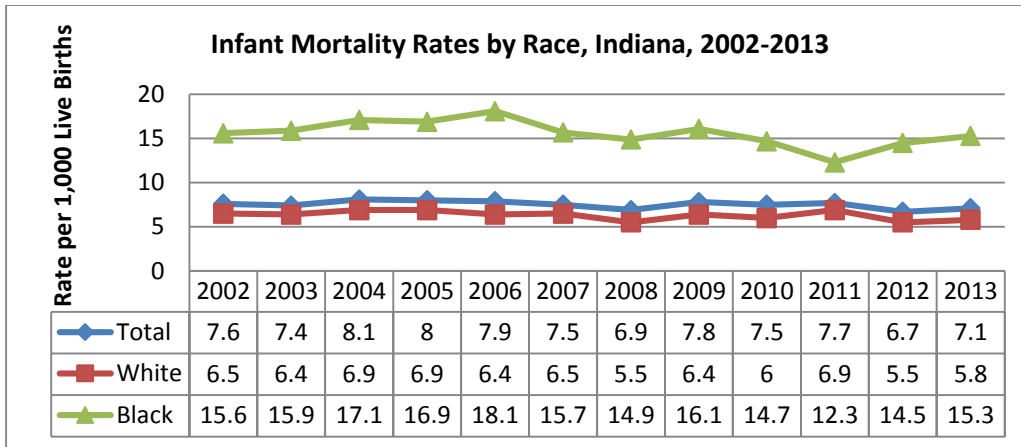
In order to fully understand the importance of the work that is occurring through the efforts of the dedicated volunteers involved in the IPQIC and the ISDH staff, it is important to have a complete understanding of the current status of infant mortality in the United States and Indiana.

The infant mortality rates in the United States have continued to fall and in 2013, for the fifth consecutive year, the rate continued to fall to 5.96 from 5.98, slightly below the Healthy People 2020 goal of 6.0. In 2013 the infant mortality rate in Indiana was 7.1 per 1,000 live births. Indiana remains at a higher rate than the United States' rate.



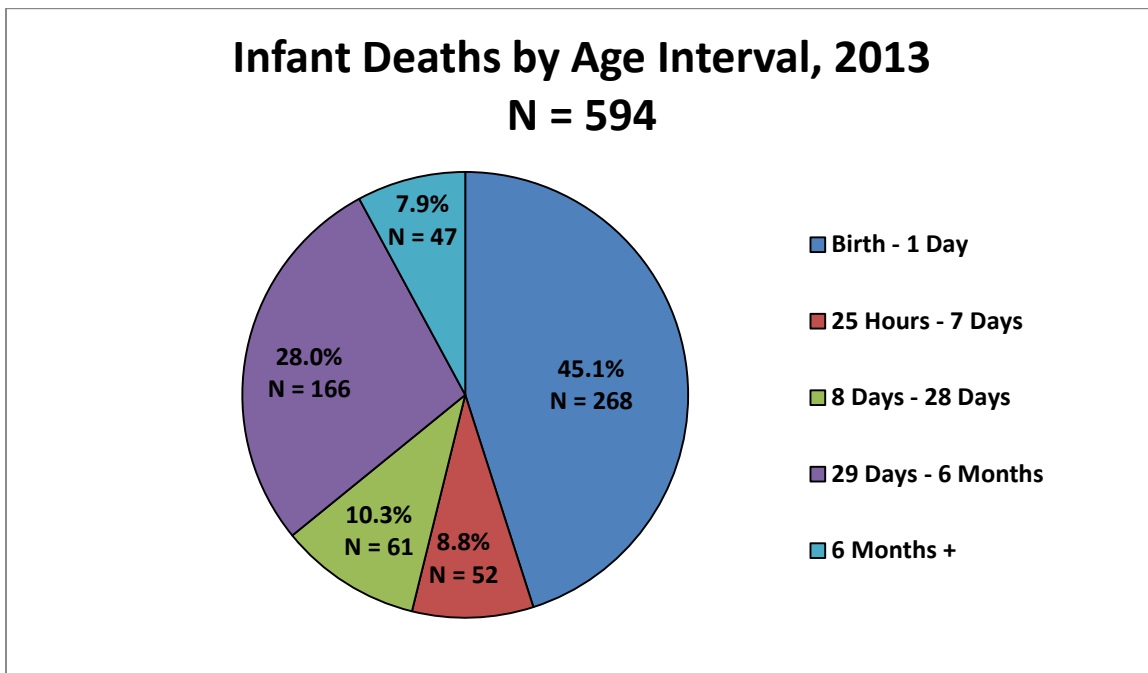
Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [Feb. 11, 2015]
 United States Original Source: Centers for Disease Control and Prevention National Center for Health Statistics
 Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team

Indiana had made progress in reducing its black infant mortality rate dropping from a high of 18.1 in 2006 to a low of 12.3 in 2011. In 2013 Indiana again saw an increase in the rate of black infant mortality from 14.5 in 2012 to 15.3 in 2013. The rate of white infant mortality increased as well from 5.5 in 2012 to 5.8 in 2013. The disparity between the white and black rates remains a significant issue for Indiana.



Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [April 13, 2015]
 Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team

The following chart represents the infant deaths in 2013 by age interval with the highest number of deaths occurring in the birth to one-day interval.

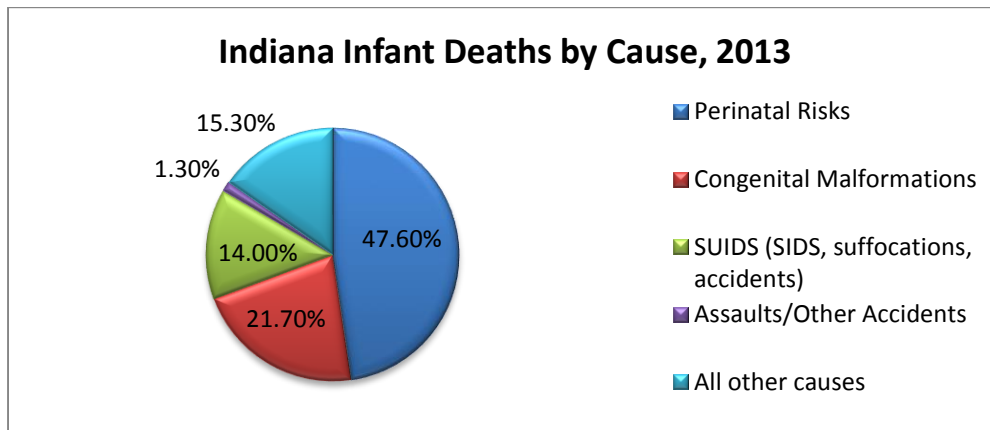


Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division (March 17, 2016)

In examining the cause of death, infant deaths are categorized by the following categories:

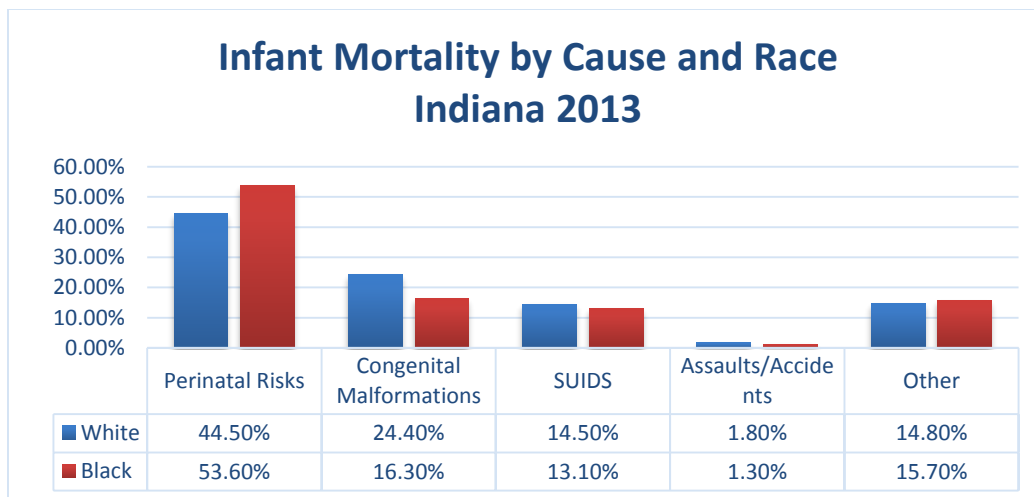
- *Perinatal Risks* = Certain conditions originating in the perinatal period (low birthweight, preterm, premature rupture of membranes, bacterial sepsis of newborn, etc.) Perinatal period = 22 completed weeks gestation to after birth;

- Congenital Malformations = A physical defect present in a baby at birth that can involve many different parts of the body (brain, heart, lungs, bones, etc). These can be genetic or result from exposure of the fetus to agents that cause developmental malformations, or be of unknown origin;
- SUID = Sudden Unexplained Infant Death;
- Assaults / Other Accidents = Homicide, accidental inhalation/ingestion, falls, MVA's, etc.; and
- All other causes = All deaths that do not meet the above four categories.



Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [April 13, 2015] Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team

In looking at the cause of death by race, there are notable differences especially in the categories of Perinatal Risks and Congenital Malformations.



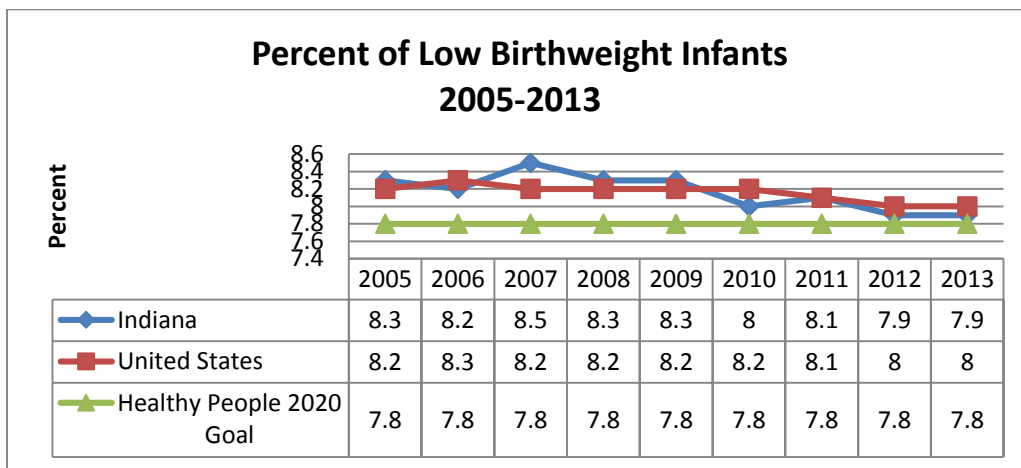
Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [April 13, 2015] Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team

BIRTH OUTCOME INDICATORS

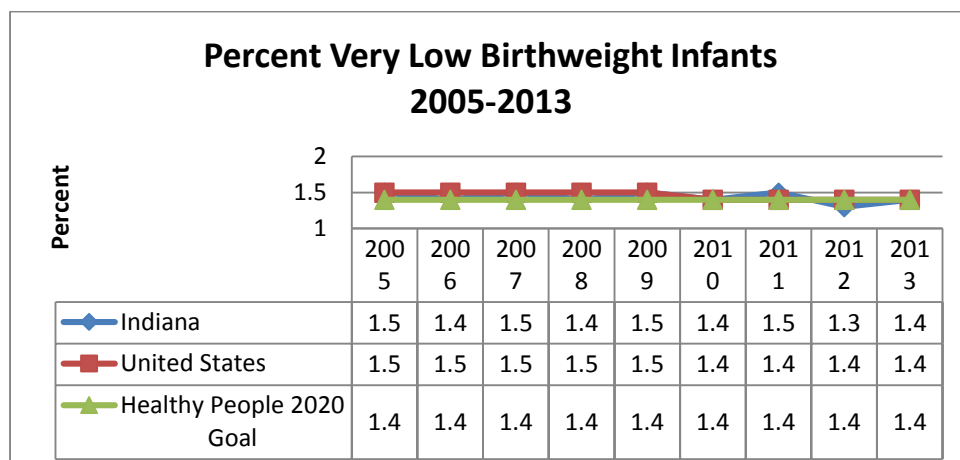
The following data track outcomes that are known to correlate with both infant mortality and morbidity (poor outcomes).

Low birthweight/Very low birthweight

When examining statistics for low birthweight (<2500 grams/5.5lbs.) and very low birthweight (<1500 grams/3.4 lbs), Indiana is more closely aligned with statistics for the United States. The most frequent cause of infant death is low birthweight/prematurity. Blacks have a higher percentage (12.9%) of low birthweight infants compared to whites (7.3%).

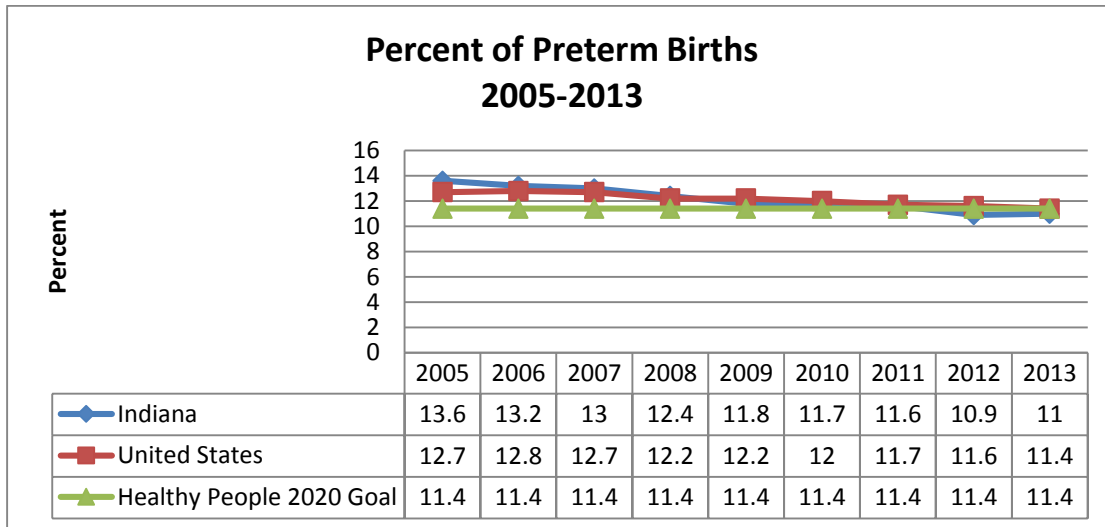


Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [February 20, 2015]
 United States Original: Centers for Disease Control and Prevention National Center for Health Statistics
 Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team



Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [February 20, 2015]
 United States Original: Centers for Disease Control and Prevention National Center for Health Statistics

Similar to low birthweight and very low birthweight, Indiana's statistics for preterm births are similar to those of the United States and close to the Healthy People 2020 goal. While the overall percentage is comparable, blacks have a higher percentage of preterm births (13.2%) than whites (9.2%).



Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [February 20, 2015]
United States Original: Centers for Disease Control and Prevention National Center for Health Statistics

"In 2012, preterm birth affected more than 450,000 babies—that's 1 of every 9 infants born in the United States. Preterm birth is the birth of an infant before 37 weeks of pregnancy. Preterm-related causes of death together accounted for 35% of all infant deaths in 2010, more than any other single cause. Preterm birth is also a leading cause of long-term neurological disabilities in children. Preterm births cost the U.S. health care system more than \$26 billion in 2005."²

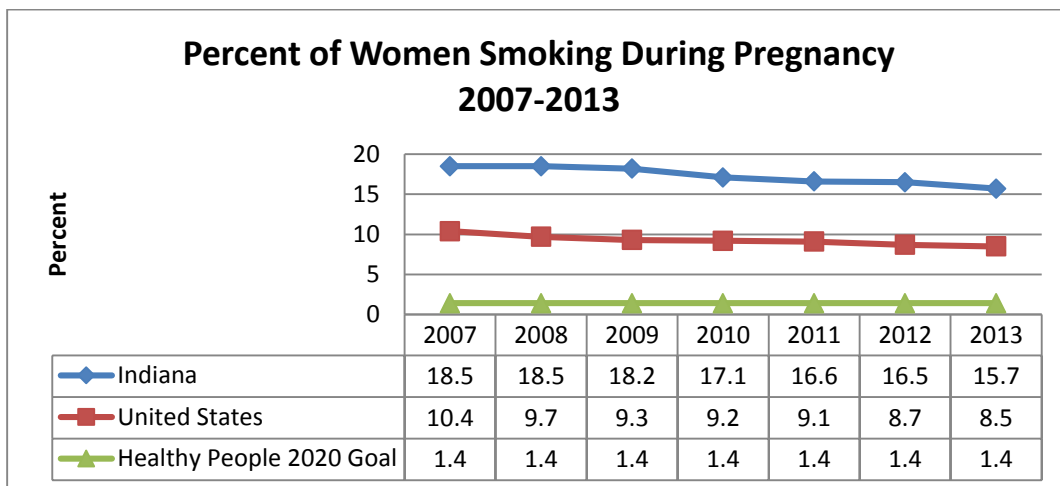
Smoking

The Healthy People 2020 goal for the percentage of women who smoke during pregnancy is 1.4%. In 2013, 15.7% of women in Indiana reported they smoked during pregnancy compared to 8.5% of pregnant women in the United States. In Indiana, smoking while pregnant is predominantly a white issue. The percentage of white women who smoked was 17.4% compared to black women at 11.8%.

² <http://www.cdc.gov/reproductivehealth/MaternalInfantHealth/PretermBirth.htm>

According to the Centers for Disease Control:

- Women who smoke during pregnancy are more likely than other women to have a miscarriage;
- Smoking can cause problems with the placenta;
- Smoking during pregnancy can cause a baby to be born prematurely or to have low birthweight—making it more likely the baby will be sick and have to stay in the hospital longer;
- Smoking during and after pregnancy is a risk factor for Sudden Infant Death Syndrome (SIDS); and
- Babies born to women who smoke are more likely to have certain birth defects, like a cleft lip or cleft palate.³



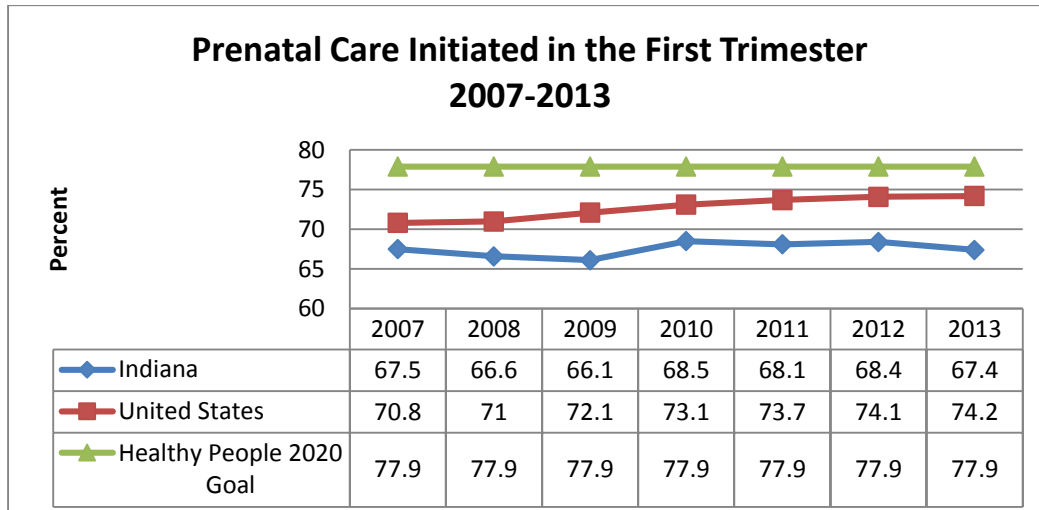
Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [February 20, 2015]
 United States Original: Centers for Disease Control and Prevention National Center for Health Statistics
 Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team

Prenatal Care

Another area where Indiana lags behind the rest of the country is women receiving prenatal care in the first trimester. The chart that follows documents the gap between Indiana and the rest of the country compared to the Healthy People 2020 goal. The

³ <http://www.cdc.gov/reproductivehealth/TobaccoUsePregnancy/index.htm>

disparity gap is significant here as well. Only 60% of black women received adequate prenatal care compared to white women (76.6%).



Early Prenatal Care = First Trimester

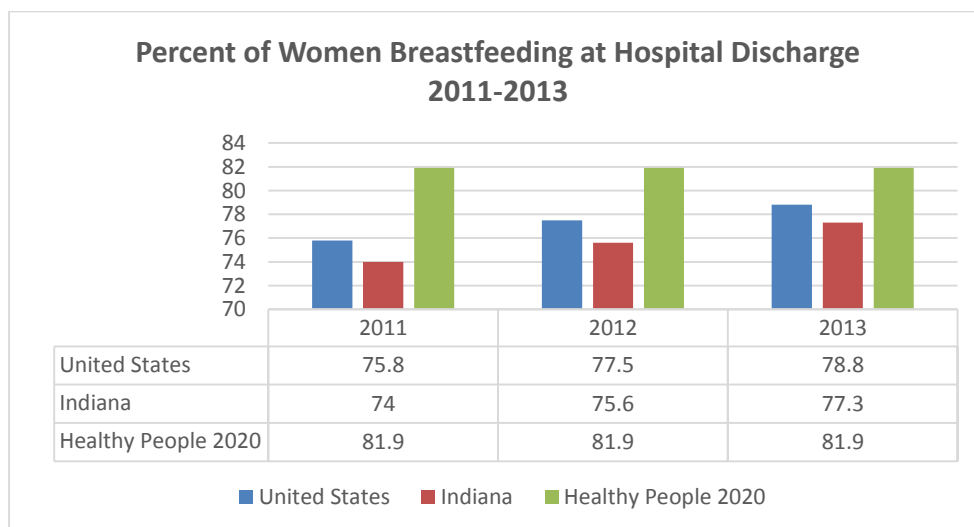
Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [February 20, 2015]

United States Original Source: Centers for Disease Control and Prevention National Center for Health Statistics

Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team

Breastfeeding

An additional outcome that has research to support its efficacy in promoting healthy infants is breastfeeding. Indiana falls below the Healthy People 2020 goal of 81.9% of all women breastfeeding at discharge. Seventy-eight percent of white women were breastfeeding at discharge compared to 64.1% of black women.

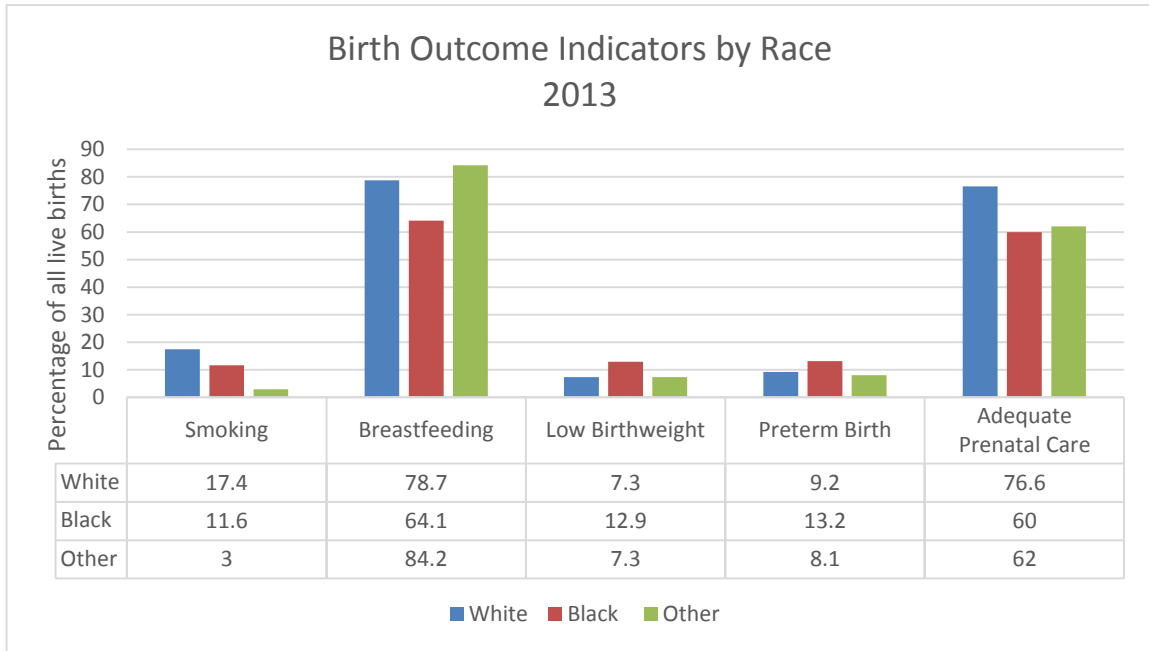


Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [April 13 2015]

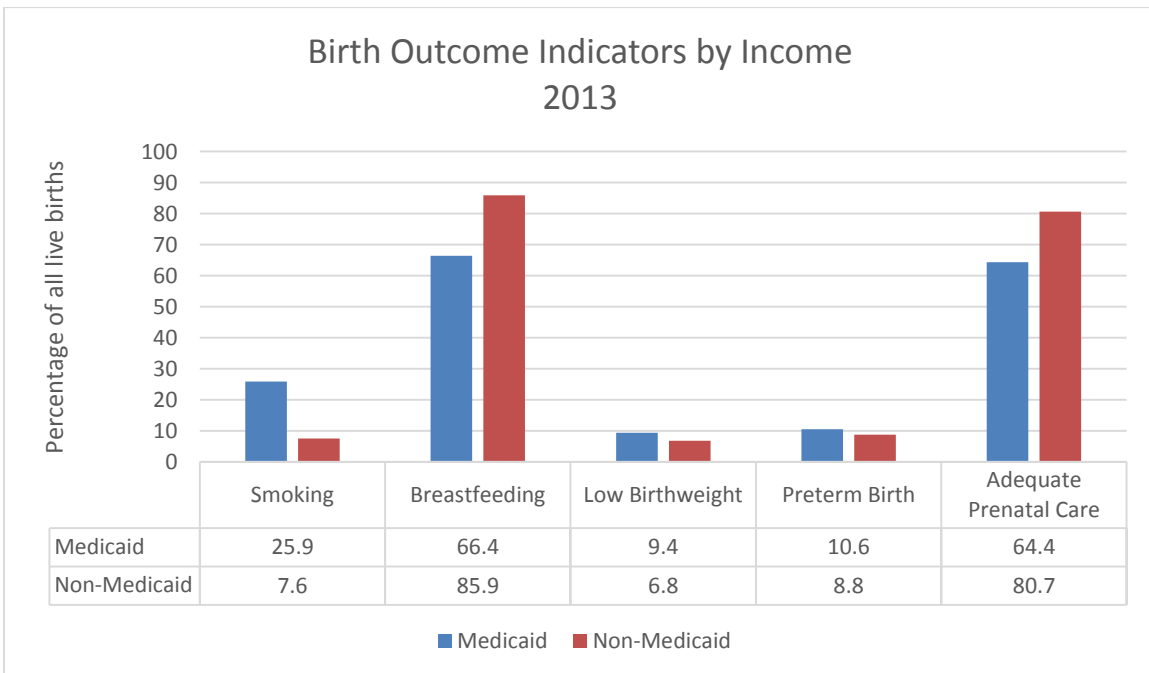
United States Original Source: Centers for Disease Control and Prevention National Center for Health Statistics

Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team

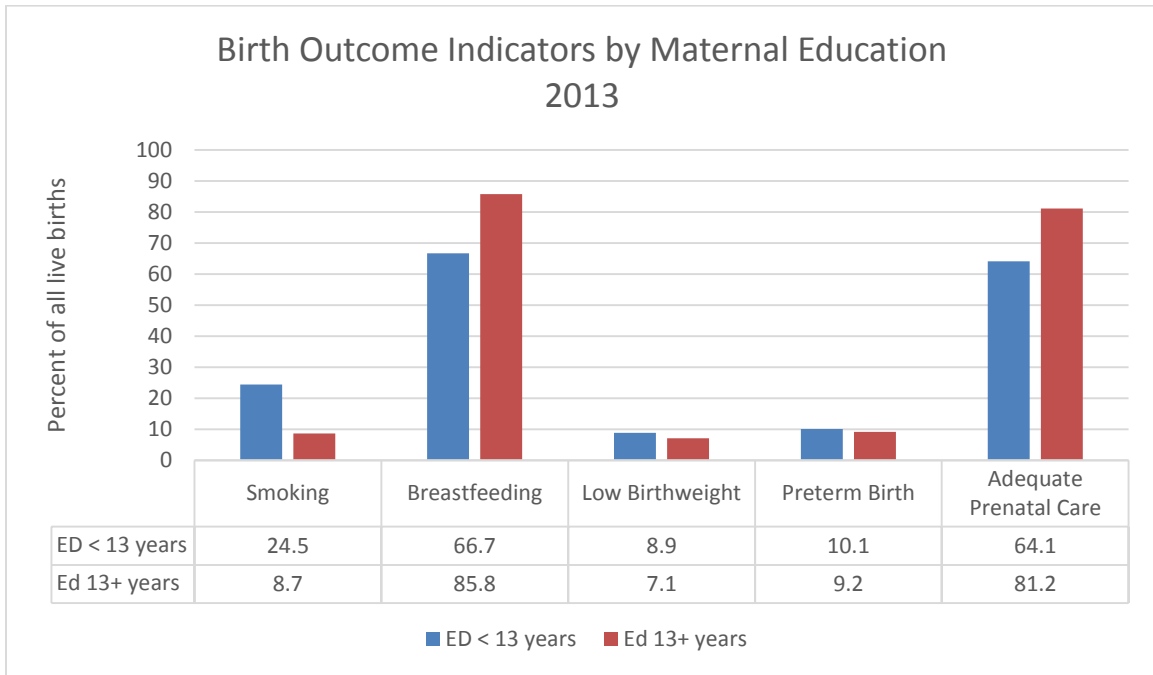
The following tables summarize birth outcomes by race, income, maternal education, maternal age, geography and employment status.



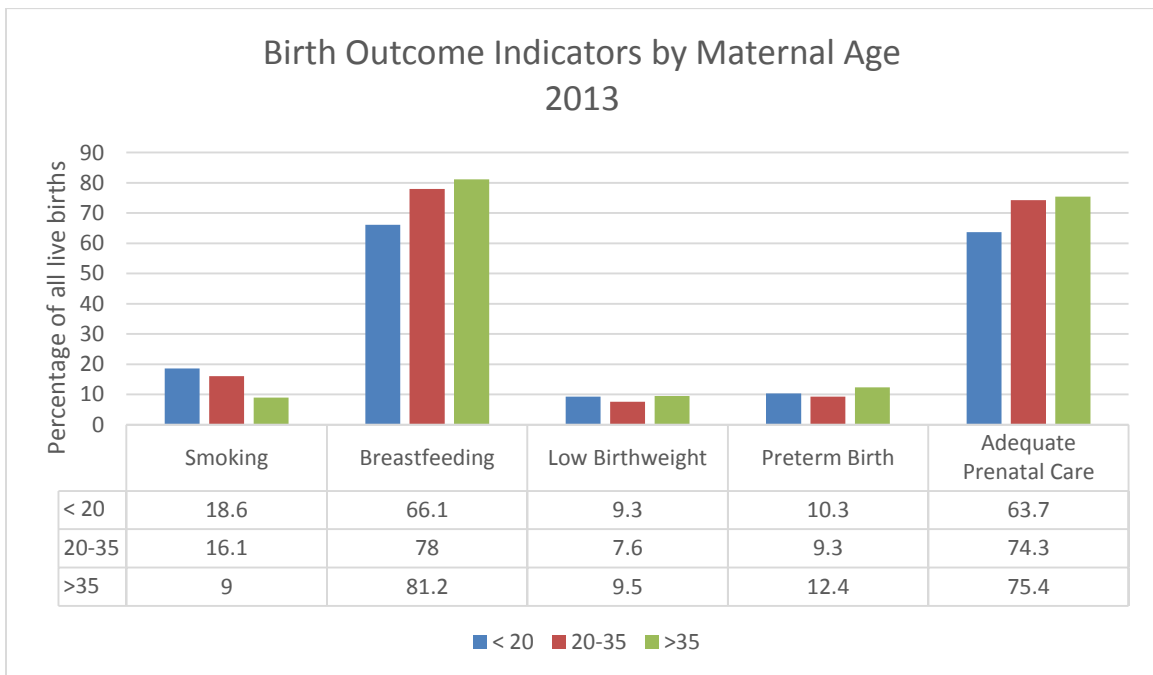
Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [April 13, 2015]
 Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team



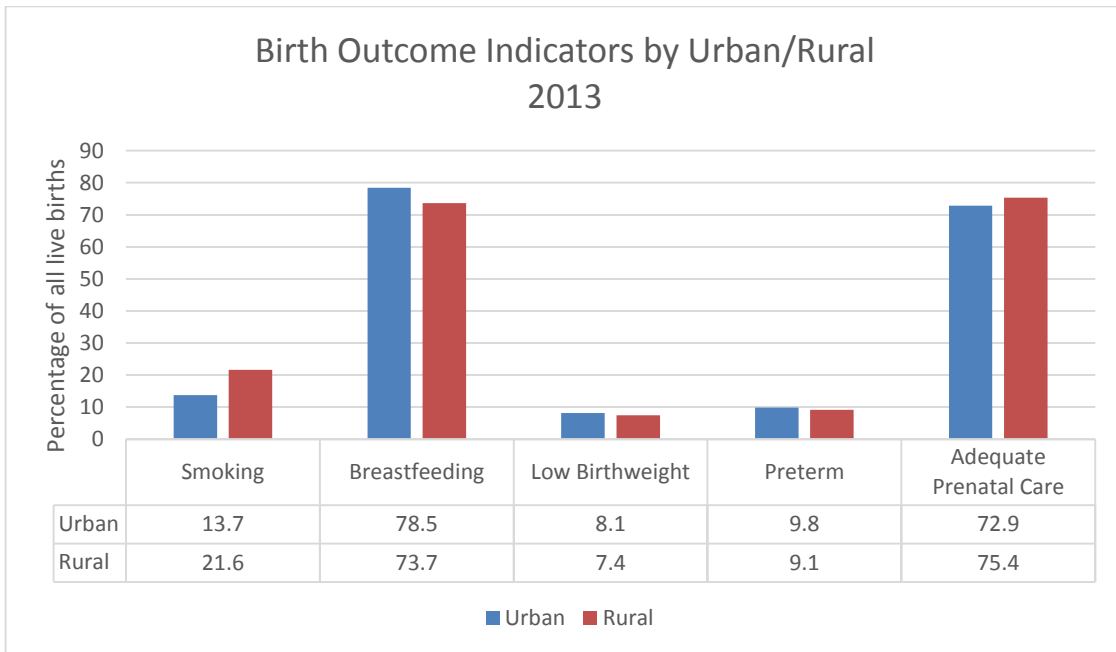
Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [April 13, 2015]
 Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team



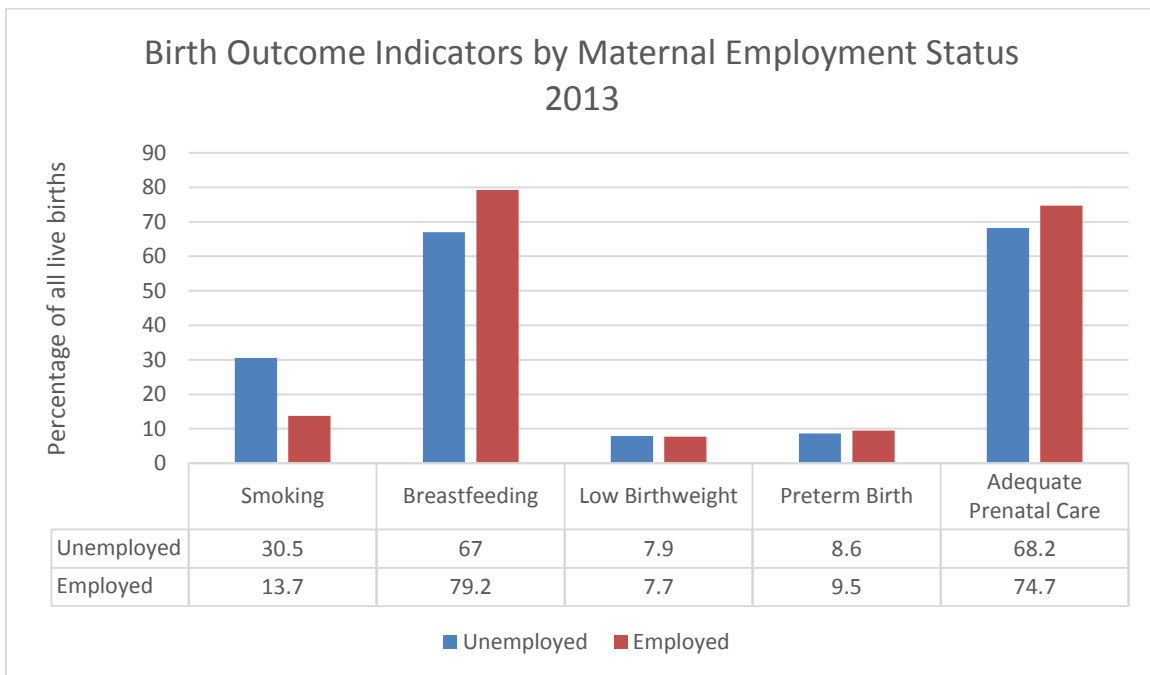
Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [April 13, 2015]
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 Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team



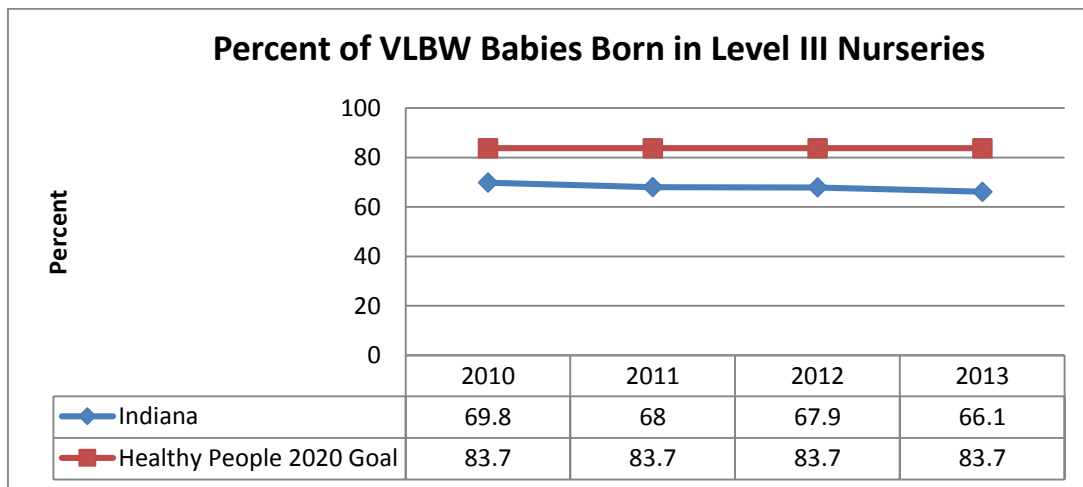
Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [April 13, 2015]
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Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [April 13, 2015]
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Published literature has stated that one factor in reducing infant mortality is for the highest risk babies to be born in hospitals with the appropriate level of support. "The most common modifiable factor associated with mortality was delivery at a Center without an appropriate level of support."⁴ The policy statement on Levels of Care developed by the American Academy of Pediatrics Committee on the Fetus and Newborn states "Facilities that provide hospital care for newborn infants should be classified on the basis of functional capabilities, and these facilities should be organized within a regionalized system of perinatal care."⁵

Indiana is developing regulations and a process for designating levels of care that are in compliance with the national recommendations. The chart below documents the percentage of Very Low Birth weight babies who were born in self-declared Level III nurseries. While it is unrealistic to think that 100% of VLBW babies would be born in Level III nurseries, Indiana is significantly below the Healthy People 2020 Goal of 83.7%.



Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division (February 24, 2016)
 United States Original Source: Centers for Disease Control and Prevention National Center for Health Statistics
 Indiana Original Source: Indiana State Department of Health, PHP, ERC, Data Analysis Team

⁴ Pediatrics Vol 135, number 1, January 2015

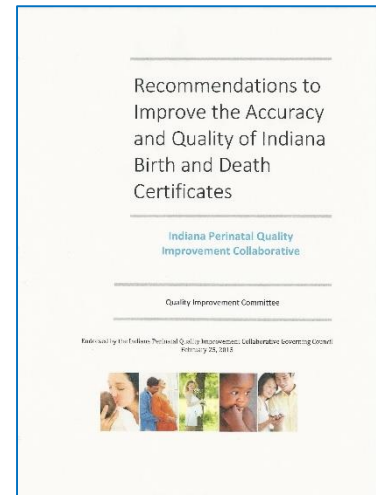
⁵ Pediatrics 2012;130:587–597

2015 Activities

In the third year of activity, the IPQIC Governing Council and its committees (Education, Finance, NAS, Health Disparities, System Development and Quality Improvement) committed significant resources to addressing the issues of infant mortality and morbidity. Building on the activities initiated in 2014, several major products were developed to support improving perinatal practice and infrastructure.

Birth/Death Certificate

The initial goal of the Birth and Death Certificate Subcommittee, chaired by Nancy Swigonski, MD and Erica Park, was to implement a quality improvement project to improve the timeliness and accuracy of the Indiana birth and death certificate. Although it quickly became apparent that implementation of a QI project was beyond the scope of current resources, moving forward with the first steps in such a project (i.e., gathering baseline data, process maps, and best practices) might lead to a greater understanding of the issues and allow the development of initial recommendations for improving the Indiana birth and death certificate processes. The goal of the subcommittee was to systematically gather data and to provide initial recommendations for the improvement of timeliness, completeness and accuracy of the data.



The committee focused their efforts on six components:

- 1) review of the literature;
- 2) review of Indiana's existing forms, data entry systems and web-based training modules;
- 3) one-on-one interview with a funeral home director and neonatologist who are experienced with the death certificate process;

- 4) interview and/or survey of those responsible for filling out the birth certificate at five of the major birthing hospitals in the state;
- 5) review of other state's best practices; and
- 6) review of state data including the Indiana 2013 Revised Natality Statistical Report from the CDC which includes number of births and deaths from birth certificate data, and Lag Analysis and Indicator Frequency data from the Data Committee.

Based on these components, the committee made the following recommendations to the IPQIC Governing Council:

1. Provide feedback:

- Distribute a list of variables that commonly have errors to hospital administration and all staff currently involved in the reporting process;
- Notify hospital administrative and clinical leadership about the deficiencies in vital records process;
- Design a website to publish performance reports to increase transparency; and
- Increase vital records staff to be able to provide more immediate feedback.

2. Provide training incentives:

- Recommend hospitals include completion of training modules in performance review;
- Provide regular trainings and newsletters for birth registration staff;
- Develop a post test and/or a Certificate of Completion for staff completing modules; and
- Pursue CEUs for nurses and CMEs for physicians for birth certificate training modules.

3. New systems improvements:

- Add definitions of fetal death and live birth on the electronic birth and death registration systems;
- Allow staff to receive email re: death certificate at the same time as the physician;
- Pre-load all physicians into the IDRS; and

- Update IDRS or implement a new system to include definitions, instructions and clear logical data entry fields.

4. Demonstrate and implement:

- Demonstrate to physicians how they should register in IDRS and how they can initiate the death record;
- Implement a QI project to increase registration and test initiation of death record;
- Encourage hospitals to have physicians register in the IDRS during hospital orientation when they are sitting and filling out other required paperwork and learning about the hospital and other systems;
- Work with hospitals that have highest volume of neonatal and postneonatal deaths to implement a system where staff (nurses and clerical staff) are authorized and trained to complete initial data entry that is then confirmed by the physician and submitted. Spread best practices through a learning community; and
- Test a process with hospitals to initiate the prenatal birth record.

The Governing Council unanimously adopted the report on February 25, 2015.

QI Retreat

In their paper “Addressing Infant Mortality in Indiana”, the Quality Improvement Committee recommended that IPQIC and ISDH sponsor a day-long retreat with state QI experts, infant mortality experts, data experts and current members from each of the IPQIC committees to:

- Leverage existing relationships with improvement partnerships to engage national consultant’s knowledge and experience to facilitate the retreat
- Prioritize and set time specific, measurable aims or goals;
- Define the contribution of each IPQIC subcommittee to achieving the priority goals;
- Delineate the organizational structure(s) necessary to support the implementation of QI processes to achieve priority goals;

- Determine resources including feasible funding necessary to implement priority improvement projects.
- Provide resources and funding to pilot the Comprehensive Perinatal Quality Collaborative priority project over the next 9-12 months.

Based on this recommendation and under the leadership of Dr. Nancy Swigonski and Dr. William Engle, a meeting was convened in February to provide an opportunity for hospitals, pediatricians, neonatologists, obstetricians, perinatologists, midwives, nurses, state health department staff, leaders in private, public, and academic health care settings with expertise in evidence-based obstetric and neonatal care and quality improvement to come together to define the infrastructure needed for an effective Perinatal Quality Collaborative in Indiana.

Approximately 100 individuals participated in the day-long retreat. Keynote speakers included:

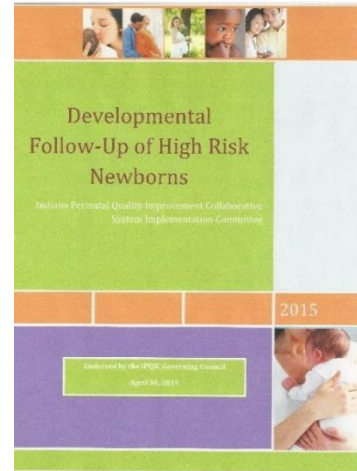
- Jay Iams, MD, Frederick P. Zuspan Professor & Endowed Chair Emeritus, Division of Maternal Fetal Medicine, Department of Obstetrics & Gynecology, The Ohio State University Wexner Medical Center and OB Lead for the Ohio Perinatal Quality Collaborative providing an ***Overview of Ohio Perinatal Quality Collaborative and Lessons Learned***
- Barbara Murphy, RN, MSN, Director, Perinatal Programs, Division of Neonatal and Developmental Medicine, Stanford University School of Medicine, Administrative Director, California Perinatal and Maternal Quality Care Collaborative addressing ***Operational Realities of a Perinatal Quality Collaborative***

Participants were also provided an overview of infant mortality in Indiana and current perinatal quality improvement efforts in Indiana. Participants made recommendations in the areas of financing, data systems, and administrative infrastructure. While no conclusions were reached immediately, work on this effort to establish a Quality Collaborative in Indiana continues through a strategic planning subgroup of the Quality Improvement Committee.

High-Risk Newborn Follow-up Report

One of the identified roles of Perinatal Centers is NICU Transition to Home and Follow-up. The High Risk Follow-up Subcommittee, chaired by LuAnn Papile, MD, was charged with the following activities:

- Review national guidelines, current practices from other states, relevant literature and identify promising/best practices for following high risk infants after discharge from NICU;
- Determine the cohort of high risk newborns that need to be followed;
- Recommend guidelines for follow-up methods based upon best practices; and
- Define indicators, benchmarks, and process measures to evaluate follow-up programs for high risk infants.



In trying to develop a set of statewide guidelines, the committee felt it was important to start with a group of infants that everyone can follow. While Perinatal Centers could add infants with other diagnoses to the cohort, the committee members were very conscious of the reality that financial support for follow-up programs is very limited and therefore were cautious in the identification of infants to be followed. The developmental follow-up screening program, at a minimum, must serve the following high risk infants:

- a. Infants less than 1001 grams;
- b. Infants less than 28 weeks;
- c. Triplets and Quadruplets regardless of gestational age;
- d. Infants who had major surgery;
- e. Infants who have end-stage renal failure;
- f. Infants diagnosed with Neonatal Abstinence Syndrome requiring medical treatment;

- g. Infants with documented bacterial or fungal sepsis;
- h. Infants with meningitis or osteomyelitis;
- i. Infants with pulmonary disorders including:
 - i. Chronic lung disease as indicated by oxygen dependency at 36 weeks corrected gestational age; (check with VON definition)
 - ii. Tracheostomy
 - iii. Congenital diaphragmatic hernia with or without ECMO;
 - iv. Inhaled nitric oxide therapy;
 - v. ECMO therapy;
 - vi. Chylothorax;
- j. Infants with Gastrointestinal disorders including:
 - i. NEC requiring surgical intervention and/or with associated bacterial sepsis;
 - ii. Isolated Bowel Perforation requiring surgical intervention
 - iii. Gastroschisis/Omphalocele/Malrotation
 - iv. Short Gut
 - v. Tracho-esophageal fistula;
- k. Infants with Neurologic disorders including:
 - i. Moderate/severe HIE with or without therapeutic hypothermia
 - ii. Grade 3 or 4 IVH with or without post hemorrhagic hydrocephalus
 - iii. PVL;
 - iv. Seizures documented with EEG and/or aEEG;
- l. Infants with cardiac disorders including:
 - i. PDA requiring surgical intervention; and
 - ii. Isolated congenital heart disease requiring surgical treatment in the neonatal period.

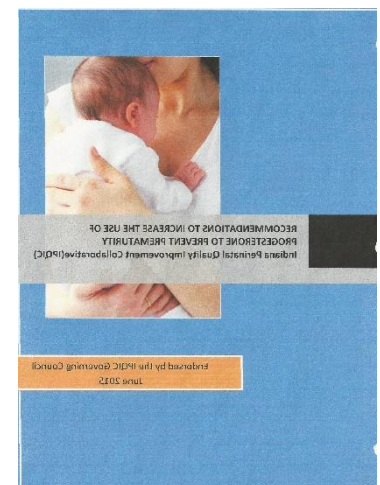
The screening tool recommended by the committee for use was the Ages and Stages Questionnaire (ASQ). The ASQ has been in use for over 15 years and is considered highly reliable and valid. ASQ is a series of questionnaires designed to screen the developmental performance of young children in the areas of communication, gross motor skills, fine

motor skills, problem-solving, personal-social skills and overall development. The committee recommended that the age appropriate ASQ questionnaire be administered at 4, 9, 12, 18 and 24 months, adjusted for prematurity. This is aligned with the national practice of ending these follow-along programs at 24 months adjusted age.

The Governing Council endorsed this report in April of 2015.

Use of Progesterone to Prevent Prematurity

The goal of the Progesterone to Prevent Prematurity (P3) committee was to ensure that 100% of eligible women receive progesterone to prevent a recurrent premature birth. Chaired by Robert Baker, MD and Joseph Landwehr, MD, the committee reviewed related literature, professional guidelines and efforts that other states have made regarding the use of progesterone. Based on their findings, the committee concluded Indiana must integrate the use of 17 hydroxyprogesterone (17P) to prevent recurrent spontaneous preterm birth into guidelines for preconception, interconception and early prenatal care. Prompting clinicians on the importance of and providing tools to assist with the identification of patients with a prior spontaneous preterm birth should be obtainable with minimal effort and cost. Disparity of care and clinician resistance should be evaluated and eliminated. With the plethora of available literature supporting the effectiveness and safety of weekly 17-P injections, clinician non-acceptance should not be tolerated. The use of 17-P in all eligible patients is the standard of care.



Their recommendations included:

- Identify ALL pregnant women with a prior preterm singleton birth delivered at less than 37 weeks gestation and not induced for a medical indication. There needs to be earlier and more consistent recognition of risk.
- Expedite the initiation of weekly 17P injections. Elimination of the barriers to access 17-P will be imperative to the success of the program.

- Develop a unified prior authorization process and unified distribution process.
- Use case management as an effective management strategy. This is currently available through Medicaid managed care entities.
- Use Birth Certificate data to monitor the use of 17P in eligible women annually.
- Quality measurement of the use of progesterone for eligible women should be done at the hospital level.
- Obstetric Perinatal Centers should include the appropriate use of progesterone to prevent recurrent spontaneous preterm birth (SPTB) as a training topic and a quality assurance measure to be used with hospitals in their systems.
- The IPQIC Education Committee should prepare materials for medical practitioners and consumers to promote the use of 17P to prevent recurrent SPTB.

The Governing Council endorsed the recommendations of the committee in June, 2015.

Health Disparities

Because of the significant disparity in perinatal outcomes for the black population, the decision was made to establish a Perinatal Health Disparities committee. Under the leadership of Paula Means and Calvin Roberson, the committee convened to look at disparities in racial groups, geography and other special populations. The committee established the following values to guide their work:

- Data used for the development of strategies, policies, and laws should consistently reflect a complete picture of the impact of infant mortality in Indiana, regardless of gender, ethnicity, race, geography, religious-spiritual affiliation, sexual orientation, or socio-economic status.
- Providers should always have the tools to be sensitive and responsive to the needs of every mother, caregiver, and baby in their care regardless of gender, ethnicity, race, geography, religious-spiritual affiliation, sexual orientation, or socio-economic status.
- Clients (mothers, caregivers, and babies) should without exception receive care during a pregnancy so that a healthy baby lives beyond the first year of life

regardless of gender, ethnicity, race, geography, religious-spiritual affiliation, sexual orientation, or socio-economic status.

The committee has reviewed current data elements collected through the birth certificate process. The provider subcommittee has examined local, state and national models for health professional training around disparities. The client focused subcommittee has examined the needs of pregnant women with mental health and substance use issues.

NAS Pilot Program

With the completion of the report to the General Assembly in 2014, the NAS Committee turned its efforts to an additional request in the Senate bill that the State Department of Health establish one (1) or more pilot programs with volunteer hospitals to implement appropriate and effective models for Neonatal Abstinence Syndrome identification, data collection, and reporting. The goal of the pilot is to establish the prevalence of NAS in Indiana and to test the processes used for potential expansion to all Indiana delivering hospitals. Four hospitals agreed to pilot the final recommendations of the Task Force. The hospitals are:

- Schneck Hospital (Seymour)
- Hendricks Regional Hospital (Danville)
- Columbus Regional Hospital (Columbus)
- Community East Hospital (Indianapolis)

The hospitals are testing the following components:

- A common definition of NAS;
- Comprehensive and uniform staff training in the use of the Finnegan Neonatal Abstinence Scoring Tool to determine the newborn's status;
- Universal screening of pregnant women at the first prenatal visit and when presenting for delivery;
- Screening of newborns whose mothers have had a positive screen or who have opted out of the screening protocol;

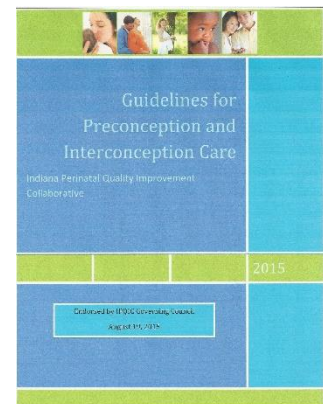
- Therapy protocol for providers for the treatment of pregnant women dealing with dependence/addiction;
- Educational materials for patients and providers developed jointly with the IPQIC Education Committee;
- Referrals for behavioral health supports; and
- Collection of a common set of data.

The pilots were operational on December 1, 2015.

Preconception and Interconception Care

The Preconception and Interconception Care subcommittee, chaired by Dr. Lee Learman, was charged with recommending:

- Guidelines for medical practitioners;
- Promising and best practices for providing preconception and interconception care; and
- Indicators, benchmarks, and outcome measures that could be used to evaluate preconception and interconception care in Indiana.



This subcommittee evaluated promising and best practices as well as guidelines and protocols for medical practitioners from many different states that have better infant mortality statistics to learn about and adopt better practices to improve infant mortality and morbidity in Indiana. In addition, members reviewed preconception and interconception indicators from federal and state resources to monitor if outcomes would improve.

Guidelines for Medical Practitioners

The subcommittee recommended creation of an ISDH-sponsored webpage through which clinicians can access web-based resources from other states. Some states (e.g., California) allow free access to their resources, while others (e.g., Wisconsin) charge a nominal cost. Because the out-of-state resources may include information on local health care programs, ISDH would also need to develop a list of Indiana-specific resources. The Guidelines

webpage should be maintained and periodically updated on a regular basis to assure it provides clinicians the most up-to-date resources and links.

The subcommittee also considered the value of creating new Indiana-specific resources to support clinicians' efforts in screening, diagnosis, treatment and patient education. In light of the expansive resources available from other states, the subcommittee felt this would create unnecessary duplication of effort and would create a delay in getting needed tools to preconception and interconception care providers.

Promising and best practices for providing preconception and interconception care

The subcommittee recommended several feasible, high impact initiatives:

- Improve community awareness through (a) media campaigns, and (b) outreach to provider organizations
- Pilot innovative models of care including (a) shared (group) medical visits similar to those which have been implemented for prenatal care, and (b) expansion of the Nurse-Family Partnership model.
- Expand access to care by (a) extended Medicaid postpartum benefits to enable interconception care visits and (b) streamlining presumptive eligibility to enable early prenatal care
- Expand access to post-partum long-acting reversible contraception (LARC) by developing tools for health care providers to facilitate billing and coding
- To increase use of LARC methods, barriers such as lack of health care provider knowledge or skills and low patient awareness should be addressed

Other practices to consider include expanded access to immunizations and mental health service, creation and tracking of a meaningful use measure of how often women's pregnancy plans are documented, and development of provider note templates in electronic health records including recommended elements of the preconception/interconception visit.

Currently, some patients must pay for negative pregnancy tests out of pocket, creating a barrier to early pregnancy identification. Facilitating provider reimbursement for pregnancy tests would promote early enrollment in prenatal care if the test is positive or a timely well woman visit during the preconception or interconception period if the test is negative.

The subcommittee recommends that ISDH develop an ongoing monitoring and surveillance system for women's health containing at a minimum:

- (1) Yearly summary of indicators by race and region that are available from Vital Records information including:
- (2) A 5-year study of BRFSS data on women of childbearing age (18-44 years old).
- (3) A mini-PRAMS survey in regions or geographic areas that are at high risk for poor perinatal outcomes.

LARC Reimbursement

In 2014 the Finance Committee identified that a significant barrier to providing post-partum LARC was related to facility reimbursement. In the Diagnosis Related Group (DRG) reimbursement system, which is widely used for inpatient payments, there is no additional reimbursement for the LARC as it is bundled into the facility payment for the admission. Given the cost of a device, it is seldom, if ever, used and the patient often leaves the hospital unprotected. This is a missed opportunity to provide reliable family planning while extending the inter-pregnancy interval and decreasing the risk of subsequent preterm birth. Although insertion may occur at a later post-partum visit, the likelihood of a new mother receiving this service falls dramatically if she leaves the hospital without it.

The initial reaction of the Office of Medicaid Policy and Planning focused on concern over reimbursement outside of the DRG process. However after thoughtful consideration and discussion OMPP announced in the provider bulletin released in April that effective June 1, 2015, OMPP would begin reimbursement for long-acting reversible contraception (LARC) devices implanted during an inpatient hospital or birthing center stay for a delivery.

Next Steps

In its second year, the Indiana Perinatal Quality Improvement Collaborative expanded to more than 200 volunteers working with ISDH staff to improve the health care infrastructure serving the pregnant women and infants of Indiana. While the IPQIC project recognized the critical issues related to social determinants and health disparities and their influence on perinatal outcomes, the primary focus in Year One was on infrastructure issues. In its second year, the Indiana Perinatal Quality Improvement Collaborative expanded to more than 200 volunteers working with ISDH staff to improve the health care infrastructure serving the pregnant women and infants of Indiana. In Year Three, the shift to move from a singular focus on infrastructure to broadening the work continued.

Indiana has a unique opportunity in 2016 and beyond to build on the work of those who have fought this good fight for many years. The System Implementation Committee is charged to develop recommendations for the implementation and monitoring of the Perinatal Center Structure. The Finance Committee is exploring the possibility of financing for Centering Pregnancy initiatives. The Quality Improvement Committee will address one of the leading causes of infant deaths: Sudden Unexplained Infant Death (SUID). The Education Committee is developing educational tools for medical practitioners and consumers in the areas of progesterone use, LARC use and Preconception and Interconception care. The NAS Committee has revised its name to Perinatal Substance Use and expanded its scope to include alcohol and tobacco with a focus on Fetal Alcohol Spectrum Disorder (FASD). Issues of disparity in outcomes will be infused into every committee and perinatal issue being addressed.

The generosity of IPQIC volunteers is amazing. With the commitment of their time and expertise, along with marshalling available resources and focusing on the identified outcomes, Indiana can look forward to improved perinatal outcomes and “making mothers and babies count in Indiana”.

Appendix A: IPQIC Membership

Governing Council Membership		
Jerome	Adams, MD*	ISDH Commissioner
Douglas	Leonard*	Indiana Hospital Association
Ann	Alley	ISDH - Office of Primary Care
Bob	Bowman	ISDH - Maternal and Child Health
Susan	Elsworth	Consumer, Central IN NOFAS
Mark	Gentry, MD	IN Chapter American College of Obstetrics and Gynecology
Paul	Halvorson	IU School of Public Health
Tanya	Hand	Consumer, At-Large
Kitty	Herndon	IN AWHONN
Julia	Tipton Hogan	Indiana Perinatal Network
Nancy	Jewell	Indiana Minority Health Coalition
Don	Kelso	Indiana Rural Health Association
Carolyn	Lytle, MD	IN Chapter American Academy of Pediatrics
James	McIntire	IN State Medical Association
Phil	Morphew	IN Primary Health Care Association
Joe	Moser	FSSA Office of Medicaid Policy and Planning
Risheet	Patel, MD	IN Academy of Family Physicians
Stephen	Robertson	IN Department of Insurance
Kimberly	Roop, MD	Anthem Medicaid
Jeena	Siela	March of Dimes
Nancy	Swigonski, MD	IN Academy of Pediatrics
	* Co-Chair	

System Development/Implementation Committee

Mary	Abernathy, MD	St. Vincent Hospital
Regina	Adair, MD	Community North Hospital
Kristin	Adams, Ph.D., CHES	Indiana Family Health Council
Farrah	Allen	St. Mary's Medical Center
Julie	Alvarez	Indiana University
Harold	Bivins, MD	St. Vincent Hospital
Mary	Blackburn, CNM,MSN	HealthNet Women's Services & Midwifery
Niceta	Bradburn, MD *	St. Vincent Hospital
Patti	Brahe	Parkview Hospital
Jeffrey	Brookes, MD	Parkview Hospital
Mindy	Brown	Lutheran Hospital
James	Cameron, MD	Northern IN Neonatal Associates
Michelle	Cherry, RN, MSN	Community Hospital Munster
Jennifer	Culler, RNC	Dupont Hospital
Sarah	Curry, MD	Community Hospital
Jenny	Davis	St. Mary's Hospital
Maria	Del Rio Hoover, MD	St. Mary's Neonatal Clinic
Lauren	Dungy-Poythress, MD	IU Health
Luis	Escobar, MD	St. Vincent Hospital
J Dennis	Fortenberry, MD	IU School of Medicine
Diane	Freel	South Bend Memorial Hospital
Birdie	Gunyon Meyer, RN, MA	IU Health
Heidi	Harmon, MD	Riley Hospital for Children
Elicia	Harris, MD	Women's Health Advantage
Meagan	Hostetter	Lutheran Hospital
Erica	Huddleston, MD	Community Health Network
Richard	Krueger, MD	Community Hospital, Munster

System Development/Implementation Committee

Lee A.	Learman, MD, PH.D. *	IU School of Medicine, Center for Women's Health
Janet	Leezer, MD	Northern IN Neonatal Associates
MaryBeth	Lodato, CNM	Deaconess Hospital
Elizabeth	McIntire, MSN, WHNP	St. Vincent
Teresa	Meece	Community Hospital Munster
Carla	Meyer, MS, BSN, RN	Community Hospital Munster
Stephen	Morse, DO	Lutheran Health Network
Michelle	Musgrave	St. Mary's Hospital
Lori	Norton	Parkview Hospital
Mary Jo	Paladino	IU Medical Home Project
Lu-Ann	Papile, MD	Indiana University
Krista	Peak	Lutheran Children's Hospital
Ron	Pyle, MD	The Women's Hospital
Christine	Riley, MD	St. Mary's Hospital
Carolyn	Runge	ISDH
Chris	Ryan	The Women's Hospital
Renata	Sawyer, MD	Memorial Hospital, South Bend
Frank	Schubert, MD*	IU Health
Jeena	Siela	March of Dimes
Michael	Trautman, MD	Indiana University
Thomas	Wheeler, MD	Ft. Wayne Perinatal Center
Robert	White, MD	Pediatrix Medical Group
Sharon	Worden	St. Vincent Women's Hospital
	* Co-Chair	

Quality Improvement Committee		
Robert	Baker, MD	MHS Indiana
Lisa	Barker	IN State Coroners Association
Georg'ann	Cattelona	Bloomington Area Birth Services
John	Ellis, MD	MHS Indiana
Bill	Engle, MD	Riley Hospital
Brennan	Fitzpatrick, MD	Women's Hospital
Kathleen	Frogge	ISDH- Vital Records
Deb	Givan, MD	IU Health
Lori	Grimm	Deaconess Hospital
Kendra	Ham	ISDH - MCH Epidemiology
Annette	Handy*	Indiana Hospital Association
Barb	Himes	First Candle
Cindy	Hoess, MD	Community Health Net
Kim	Hodges	IU Health Maternity
Dawn	Kackley, MSN, WHNP, RNC	Terre Haute Regional Hospital
Julie	Kathman	Bloomington Hospital
Joseph	Landwehr, MD	IU Health Ball Memorial
Gretchen	Martin	ISDH
Joanne	Martin, RN, DrPH	Goodwill of Central Indiana
Beth	McIntire, MSN, WHNP	St. Vincent Women's Hospital
Phil	Morphew	IN Primary Health Care Association
Erica Kimberly	Park	Children's Health Services Research
Maria	Reisenauer	Nurse Family Partnership
Ann	Reynolds	ISDH - Vital Records
Michelle	Sandoval	ISDH -
Daniel	Sunkel, MD	Women's Clinic

Quality Improvement Committee		
Nancy	Swigonski, MD *	Children's Health Services Research
Donald	Trainor, MD	Health Net
Kristi	Williams, Pharm.D., BCPS	Reid Hospital
Phil	Zahm	IN State Coroners Association
	* Co-Chair	

Perinatal Health Disparities		
Tatiana	Alvarez	DCS
Lynn	Baldwin	Goodwill Industries
Victoria	Ballard	Indianapolis Healthy Start
Yvonne	Beasley	Marion County Health Department
Lindsey	Bryant	NAMI
Laura	Chavez	ISDH
Lisa	Crane	Goodwill Industries
Kelly	Cunningham	ISDH
Kiahna	Davis	Alpha Kappa Alpha
Morella	Dominguez	Shalom Health Center
Susan	Elsworth	IN Title V Family Delegate
Toni	Elzy	DCS
Kelsey	Gurganus	ISDH-MCH
Kendra	Ham	ISDH-MCH
Felicia	Hanney	Indianapolis Healthy Start
Doris	Higgins	Covering Kids and Families
Jenni	Hill	IN Rural Health Association
Antoniette	Holt	ISDH
Hannah	King	MHIN
Keisha	Knight	IN Department of Corrections Wee One's Nursery

Perinatal Health Disparities		
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Joanne	Martin	Goodwill Industries – NFP
Gretchen	Martin	ISDH
Shaleea	Mason	Rae Synergistics
Paula	Means*	Tabernacle Presbyterian Church
Birdie	Meyer	IU Health
Barbara	Moser	NAMI
Millicent	Moye, MD	Aescalapien Society
Karl	Nichols	Phi Beta Sigma
Kimber	Nicolette	Multicultural Efforts to End Sexual Assault
Jessica	Nunez	Marion County Health Department
Sara	Pollard	NFP
Caitlin	Priest	Covering Kids and Families
Rise	Ratney	Northwest IN Healthy Start
Sarah	Renner	ISDH/WIC
Georgiana	Reynal	St. Vincent Hospital
Jennifer	Riley	Harrison County Early Start
Calvin	Roberson*	Indiana Minority Health Coalition
Sarah	Stelzner, MD	IU School of Medicine
Sue	Taylor	Memorial Hospital
Joy	Usigbe	Indianapolis Healthy Start
Renetta	Williams	Health Visions of Ft. Wayne
*co-chairs		

Education Committee		
Anita	Austin, RN,MS	Goodwill of Central Indiana
Barb	Beaulieu	Purdue University
Linda	Bundick	Promoting Smoke Free Pregnancy
Carol	Dinger	Lutheran Hospital
Lauren	Dungy-Poythress, MD *	Indiana University Health
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Laura	Green	Lutheran Hospital
Julie	Gries	DMHA
Ashley	Jones, RN, MS	Goodwill of Central Indiana
Joanne	Martin, RN, DrPH	Goodwill of Central Indiana
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Jenna	Siela*	March of Dimes
Laurie	Weinzapfel	MDWise
	* Co-chair	

Finance Committee		
Charles	Allen, MD	Action Health Center
Tiffany	Berry	Lutheran Health Network
Tina	Cady	The Women's Hospital
Carolyn	Carney-Doebbeling, MD	MDWise
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Penny	Dunning	Indiana Primary Health Care Assoc.
John	Ellis, MD	MHS Indiana
Bill	Engle, MD	Riley Hospital for Children
Spencer	Grover	Indiana Hospital Association
Richard	Hug	IU Northwest
Marissa	Kiefer	IU Health/Riley
Debra	Kirkpatrick, MD	IU Women's Healthcare
Joseph	Landwehr, MD	IU Health Ball Memorial
James	Lemons, MD	Riley Hospital for Children
Ed	Leichty, MD	Riley Hospital for Children
Diane	Lorant, MD	IU School of Medicine
Karen	Porter	Strategic Solutions
Ryan	Randall	Anthem Medicaid
Steve	Reynolds	St. Vincent
Kimberly	Roop, MD*	Anthem Blue Cross & Blue Shield
Ty	Sullivan, MD	MD Wise
Dana	Watters, MSN,RNC-OB	IU Bloomington
Barbara	Wilder	MD Wise
Ann	Zerr, MD*	OMPP
* Co-chairs		

Neonatal Abstinence Syndrome (NAS) Committee		
Jonell	Allen, DNP, MSN, CNS-BC, RNC-OB	Community Health Network
Ivy	Antonian, RN	Franciscan St Elizabeth East
Deb	Beynon	St Vincent Women & Children's
Jane	Bisbee	Department of Child Services
Sirrilla	Blackmon	DMHA
Mike	Brady	INSPECT
Victoria	Buchanan	ISDH
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Kathryn	Carboneau, MD	Anesthesiologist
Ellen	Clancy, RN	Staff Nurse, NICU
Teri	Conard	Marion Co Health Dept
Ted	Danielson, MD	ISDH
Mary	Degeneffe, MD	Pediatric Medical Group
Stan	DeKemper	ICAADA
Maria	Del Rio Hoover, MD**	St. Mary's Neonatal Clinic
Joan	Duwve, MD	ISDH / IU
John	Ellis, MD**	MHS Indiana
Susan	Elsworth	Central IN NOFAS
Nancy	Fitzgerald, MSN	
Donetta	Gee-Weiler, RN, BSN	Community Health Network
Mark	Gentry, MD	IN ACOG
Beth	Gephart, RN, BSN	Hendricks Regional Hospital
Dawn	Goodman-Martin, MA, LMHC, LCAC, NCC	Schneck Medical Center
Don	Granger, MD, MPH	St. Mary's Neonatal Clinic
Annette	Handy, RN CDE BSN	Indiana Hospital Association
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Leslie	Hulvershorn, MD	DMHA
Letitia	Jackson, MS, EdS, LMHC	Wellpoint
Chastity	Johnson	Schneck Medical Center

Neonatal Abstinence Syndrome (NAS) Committee		
Julie	Kathman, MSN, RN, CNS-BC, CPN	Bloomington Hospital
Julie	Keck, MD	Anthem
Kristen	Kelley	Attorney General's Office
Pam	Knight	DCS
Abigail	Kuzma	Attorney General's Office
Joseph	Landwehr, MD	IU Health Ball Memorial
Bethany	Littrell, LMHC, LCAC	St. Vincent Hospital
Art	Logsdon	ISDH
Joanne	Martin, RN DrPH	Goodwill of Central Indiana
Rainey	Martin, MSN, CNS,RNC-OB	Community Health Network
JoAnn	Matory, MD	Eskinazi Hospital - March of Dimes
Christina	McCaul	Community Health Network
Deborah	McCullough, MD	North Shore Community Health Center
Debra	McDaniel, MD	Southern Indiana Physicians
Ann	Morrow, MSN, RN	Columbus Regional Hospital
Cara	Nichols, RN	Schneck Medical Center
David	Orentlicher, MD JD	IU School of Medicine/School of Law
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Dheeraj	Raina, MD	Anthem
Anna	Schwartz, MD	IU Department of Pediatrics
Emily	Scott, MD	Methodist Hospital
Lisa	Scott, MSN, NNP-BC	Indiana University Health Physicians
Kimberly	Shimer, MD	The Women's Hospital
Jeena	Siela	March of Dimes
Kelly	Smith, RN	Anthem Medicaid Care Management
Laura	Sparkman, RNC-OB, BSN	Community Health Network
Anne Lise	Sullivan, RN, BSN, MA	Marion Co Public Health
Dan	Sunkel, MD	Franciscan St. Elizabeth East
Drew	Trobridge, MD	Interventional Spine/Pain Management
Brownsyne	Tucker-Edmonds, MD, MPH	IU School of Medicine

Neonatal Abstinence Syndrome (NAS) Committee

John	Wareham, MD	St Vincent Women & Children's
Aileen	Wehren	Porter Starke Services
Eric	Yancy, MD	MHS Indiana

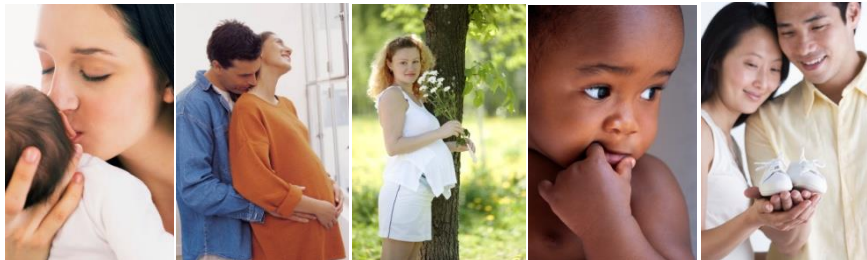
Appendix B: Birth/Death Certificate Report

Indiana Perinatal Quality Improvement Collaborative

Indiana Perinatal Quality Improvement Collaborative

Quality Improvement Committee

Endorsed by the Indiana Perinatal Quality Improvement Collaborative Governing Council
February 25, 2015



Subcommittee Participants

The following individuals were involved in the development of the recommendations:

Name	Agency	Role
Sue Beecher	Office Medicaid Policy & Planning	Policy Analyst
Kathleen Frogge	Indiana State Dept. of Health	Vital Records Staff
Lori Grimm, RN	The Women's Hospital Deaconess Health System	Manager, Quality and Patient Safety
Joanne Martin	Goodwill of Central Indiana	Nurse Family Partnership
Erica Park, Co-Chair	IU School of Medicine	2 nd year Medical Student
Anne Reynolds, MPH	Indiana State Dept of Health	Vital Records Epidemiologist
Michelle Sandoval	Indiana State Dept of Health / (CDC)	Epidemiologist
Nancy Swigonski, MD Co-Chair	IU School of Medicine	Children's Health Services Research



Overview

In March, 2013, the Indiana Perinatal Quality Improvement Collaborative (IPQIC) Data Committee was charged to support state and local efforts to improve perinatal outcomes in Indiana through the establishment of the Indiana Perinatal Data System. The Data Committee was also established to facilitate the accurate collection of data and analysis of data needs for the IPQIC. The Data Committee was to work with the Quality Improvement Committee to coordinate collection of population data and QI Project Data. The Data Committee and members of several other committees identified that the lag in receipt of birth and death certificate information at the ISDH handicapped the rapid analysis of infant birth and mortality data. In addition there were known to be problems with the quality of data reported and missing data on the birth and death certificates. Therefore, a new Birth and Death Certificate Subcommittee of the Quality Improvement Committee was formed.

Goal

The initial goal of the Birth and Death Certificate Subcommittee was to implement a quality improvement project to improve the timeliness and accuracy of the Indiana birth and death certificate. Although it quickly became apparent that implementation of a QI project was beyond the scope of current resources, moving forward with the first steps in such a project (i.e., gathering baseline data, process maps, and best practices) might lead to a greater understanding of the issues and allow the development of initial recommendations for improving the Indiana birth and death certificate processes. The goal of the subcommittee was to systematically gather data and to provide initial recommendations for the improvement of timeliness, completeness and accuracy of the data.

Data Sources and Methods

This report summarizes our findings from five data sources: 1) review of the literature; 2) review of Indiana's existing forms, data entry systems and web-based training modules; 3) one-on-one interview with a funeral home director and neonatologist who are experienced with the death certificate process; 4) interview and/or survey of those responsible for filling out the birth certificate at five of the major birthing hospitals in the state; 5) review of other state's best practices; and 6) review of state data including the Indiana 2013

Revised Natality Statistical Report from the CDC, which includes number of births and deaths from birth certificate data, and Lag Analysis and Indicator Frequency data from the Data Committee. We also developed process maps for better understanding of the birth and death certificate processes. Finally, the preliminary findings and recommendations were presented at the ISDH Labor of Love Infant Mortality Conference, where the session was attended by over 40 people who gave feedback regarding the findings and their experiences.

Findings

We briefly summarize the findings from each of our sources below.

Literature Review

Two recent reports highlight the challenges and strategies in obtaining quality data. The first report, called *More, Better, Faster, Strategies for Improving the Timeliness of Vital Statistics*, was published in 2013 (<http://www.naphsis.org>) by the National Association for Public Health Statistics and Information Systems (NAPHSIS). NAPHSIS represents the 57 vital records jurisdictions in the United States (US) responsible for collecting birth and death data. NAPHSIS partnered with the Anne E. Casey Foundation (AECF) to document challenges in vital statistics processes.

The NAPHSIS report identified several factors that slow the flow of data including financial capital, human capital, and political capital. The current fiscal climate has decreased monetary resources available for modernizing data systems and operations of state vital statistics departments. Staffing shortages and high turnover among data providers and vital records offices impact the timeliness of the data. The limited capacity of information technology personnel due to competing IT priorities within the state or health department delays the modernization of vital records systems and roll-out of electronic systems. In many states, vital records operations and infrastructure improvements are a low political priority compared to those competing needs with more vocal constituencies. Without strong leadership within the vital records offices to champion the importance of vital statistics within the state, these data are often taken for granted. Similarly, without a champion to educate external partners (e.g. hospital birth clerks, funeral home directors, and physicians) who are critical to the process, these partners do not realize the value of vital statistics and are thus not vested in efforts to enhance data quality and timeliness.

The report identified several short term strategies to improve timeliness and accuracy of data which centered on professional development to enhance performance of data providers and vital statistics leadership by:

- Enhancing communication about the importance of data and ways to prevent data errors

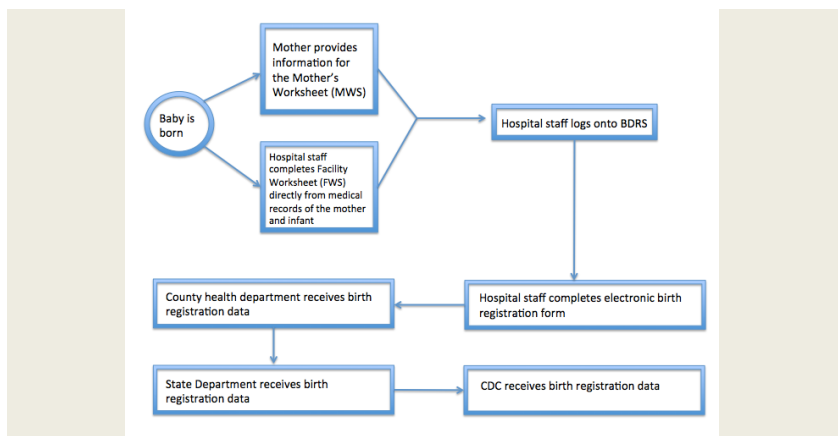
- Increasing opportunities for continuing education
- Training and mentoring to cultivate new leaders

NAPHSIS and the Centers for Disease Control and Prevention’s National Center for Health Statistics (NCHS) established a Birth Data Quality workgroup to address birth data quality issues. They conducted an online survey that was completed by 46 of the nation’s 57 jurisdictions (88%). This second report stated that most jurisdictions (82%) provided data collection worksheets using the same content as the U.S. standard worksheets developed by NCHS. About half (52%) of the jurisdictions provided data completeness reports to birth hospitals, and most (89%) of the jurisdictions provided feedback on logic checks. Audits were rarely utilized for ongoing data quality monitoring, and performance reports were rarely directed to upper-level hospital staff. Over half of jurisdictions reported being understaffed for birth certificate data quality activities. Direct feedback resulted in improvement in future hospital data quality. Recommendations based off this feedback were to support greater cooperation between birth registration and birth statistics staff, better adherence to standardized collection instruments, and increased and timelier evaluation of vital records for data quality. Specifically,

1. Data must be evaluated on an ongoing basis
 - Continuous, direct feedback provides the greatest improvement in future hospital data quality
 - Recommend quick response to poor data quality from birth facilities – weekly or monthly vs. quarterly or yearly
2. Effective communication of data quality is necessary
 - Concrete feedback
 - Increase awareness about the merit of data quality
 - Provide regular trainings and newsletters
 - Publish reports about performance to increase transparency
 - Connect with upper-level clinicians and hospital administrations

Process Mapping Using Data from Three Sources

1) Review of Indiana’s existing forms, data entry systems, and web-based training modules; 2) One-on-one interviews with a funeral home director and neonatologist who use the death certificate process; 3) Interview and/or survey of those responsible for filling out

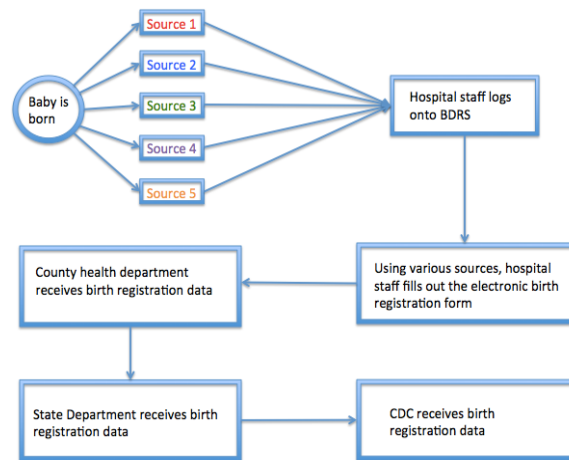


the birth certificate at five of the major birthing hospitals in the state.

Birth Certificate Process

The theoretical process for completing a birth certificate is depicted in the process map. A worksheet provided by ISDH / CDC assists clerks in filling out the birth certificate and contains 12 pages (attached). First the mother fills out the Mother’s Worksheet section (MWS) of the CDC-issued 12 page birth certificate form and the hospital staff fills out the Facility Worksheet section (FWS) of the form. Second, the hospital staff logs onto the Indiana Birth Registry System (IBRS), also known as Genesis. Third, hospital staff uses the completed worksheets to fill out the electronic birth registration form. Fourth, the local health department receives birth registration data and; fifth, the local health department forwards the data to ISDH. Finally, ISDH forwards the data to the CDC.

Our study focused on the early process of collecting and entering the data into the IBRS. The actual process is much more complex than the theoretical process. The individuals who collect the data and the sources used to identify the information vary by location. Data for the worksheets and /or IBRS may come from as many as five electronic and paper sources. As a result data, such as the number of prenatal visits, may be under-reported. This was especially apparent if the patient was transferred from another hospital during her pregnancy.



The largest hospitals may have as many as 300 births per month. Depending on the ease of finding the data, a birth certificate can take from 15 minutes to an hour and a half to complete. If there are no interruptions or other responsibilities, an experienced person can enter as many as 10-20 births into the IBRS daily.

Obstacles faced by the hospital staff include:

- Variation in who is collecting the data - for example, two different approaches were the clerk doing the actual interview and then inputting the data versus nurses (or other sources) collecting information and turning it over to the clerk for data input.
- Missing data - takes time to find sources of missing data and/or contact the mother for information.
- Variation in data sources (multiple online and/or paper) – sometimes data sources conflict and it is unclear which source has the correct information.
- Availability of external data – for example, prenatal care may have begun with a different hospital/health care professional and then transferred, but the birthing hospital may only have data available through their system.
- To simplify the process, hospitals have changed the 12 page worksheet. They may have divided the FWS into several forms. Some hospitals made changes to the questions and answer choices – for example, they used a non-standard response for “Mother’s Race”, leading to anomalies in the data.
- One part of the process that is not represented currently on the process map is the Paternity Affidavit. This was consistently named as a problematic area on the birth certificate survey and during the presentation discussion at the Labor of Love, Infant Mortality Conference. Workshop participants noted: “...the father’s information section- if he is not there or mother does not have information- the father information is not in the [prenatal] history. Sometimes fathers do not show up until the last minute for the paternity affidavit.” “The average for a [birth certificate that requires] paternity [affidavit] is 40-45 minutes [double the time] depending on how many correction or changes were needed.” “Often there is a problem with the father having a picture ID”.
- Data inaccuracies – one birth clerk was observed during the process and several inaccuracies were noted. First, if a field such as “Father’s Employment” is marked unknown, there is apparently an edit that will kick the birth certificate back to the hospital. One clerk put “unemployed” rather than unknown to avoid getting the kick back message since the mother had already gone home. Another common mistake is assuming the race of the mother, rather than asking.

Staff Roles and Training

Birth certificate clerks from the larger birth hospitals were generally hired to do other jobs, then moved into their role with birth certificates. Their training was primarily “on-the-job” along with the state training when the new IBRS was started several years ago. Some had used the state’s training modules, while others visited the website after our question was raised in regard to the modules, and stated they would use it in the future for new trainees. Generally, the birth certificate clerks have additional responsibilities such as processing

newborn screening, ordering supplies, stocking supplies, helping out on the floor when needed, and covering for OB clerks / receptionists.

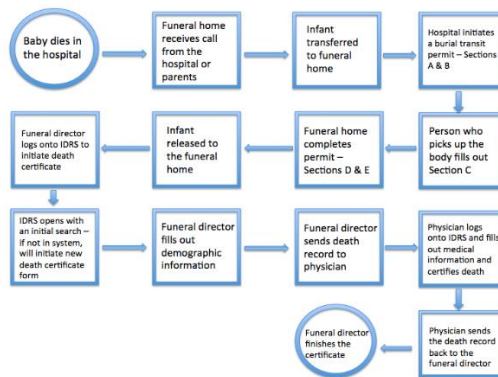
We reviewed the Vital Records Training Modules located at <http://in.gov/isdh/25584.htm>. The training consists of three modules which take approximately 30 minutes to complete:

- Module 1: Improving the Quality of Birth Certificate Data
- Module 2A: All Birth Worksheet Data Matters Part A
- Module 2B: All Birth Worksheet Data Matters Part B


The modules were easy to use. There was no certificate of completion or continuing education credits associated with the modules.

Death Certificate Process

There are several steps in entering the death certificate data.



1. Funeral home receives a call from the hospital or the parents
2. If parents decide to use their funeral services, infant will be transferred to the funeral home
3. Hospital initiates a burial transit permit by completing Sections A & B



PROVISIONAL NOTIFICATION OF DEATH - BURIAL TRANSIT PERMIT
 State Form 38220 (R2 / 9-06) / SDH 06-093-32
 _____ COUNTY HEALTH DEPARTMENT

387755

INSTRUCTION: Please type or print clearly.

A REPORT OF DEATH <small>(To be completed by facility where death occurred)</small>					
Name of deceased (First, middle, last)			Date of death (month, day, year)	Time of death (local) <input type="checkbox"/> AM <input type="checkbox"/> PM	
County of death	City of death	Age	Race	Sex <input type="checkbox"/> Male <input type="checkbox"/> Female	
Place of death (if not facility such as hospital, nursing home, etc. give street address)					
Name of Medical Certifier (official certifier of cause of death)				Telephone number ()	
Address of Medical Certifier (number and street, city, state, and ZIP code)					
B RELEASE <small>(To be completed by person having authority to release remains)</small>					
Authorization is hereby granted to release the remains of the above named to:					
Name of funeral home			City	State	
Signature of representative of facility releasing remains			Name of next of kin or legal representative authorizing release		

4. Person who picks up the body fills out Section C

C BURIAL - TRANSIT PERMIT (To be completed by funeral director or representative)		
I, representing _____ <i>name of funeral home</i> _____ <i>city</i> _____ <i>state</i> _____ <i>telephone number</i> _____ hereby accept the remains of the above named and agree to secure and file a complete certificate of death within the time limit established by law.		
Signature of funeral director or representative	Printed name of Indiana Licensed Funeral Director	Indiana Funeral Director License number
A certificate of death having been filed or a provisional notification of death received as required by law, permission is hereby given for transportation and disposition of the remains - except for cremation which requires a completed certificate of death.		
Signature of Health Officer	Local number	Date filed (month, day, year)

5. Funeral home completes the permit by filling out Sections D & E

Three copies of this permit are sent to:

1. Local health department
2. Crematory or cemetery
3. ISDH

D RESIDENCE (To be completed by funeral director)		
Last known county of residence	Last known address of deceased (number and street, city, state, and ZIP code)	
Address(es) two (2) years prior to death (if different)	(number and street, city, state, and ZIP code)	
	(number and street, city, state, and ZIP code)	
E DISPOSITION (To be signed by sexton of cemetery or representative of crematory)		
Name of cemetery / crematory	Date of disposition (month, day, year)	Date of cremation (month, day, year)
Place of disposition (City, county, state, and ZIP code)		
Method of disposition (check all that apply) <input type="checkbox"/> Burial <input type="checkbox"/> Cremation <input type="checkbox"/> Entombment <input type="checkbox"/> Inurnment <input type="checkbox"/> Removed from State <input type="checkbox"/> Donation <input type="checkbox"/> Scattering (location) _____		
Remains returned to :	Funeral Director	Family
Signature of sexton or crematory representative		Date (month, day, year)

DISTRIBUTION: White copy - Health Department copy to accompany the body to its disposition. Must be signed by the sexton of the cemetery or the representative of the crematory, and returned to health department in the county where the death occurred within two (2) days after burial or cremation. Copies may be made for faxing. Contact local health department for out-of-state shipment.
 Canary copy - Cemetery/Crematory copy for their records.
 Pink copy - To be mailed by the facility where the death occurred to the local health department within twenty four (24) hours following death. Copies of the white form may be made by the facility for its records and for faxing in lieu of mailing.

6. Infant is released to the funeral home by the hospital. Release can be verbal or written, but varies by hospital.

7. Funeral director logs onto IDRS to initiate the death certificate – generally within 24-48 hours, but may be longer if waiting for the mother’s release from hospital

8. IDRS opens with an initial search

- If the name is already in the system, it will match the name to the search
- If a similar record is already in the system, it will prompt funeral director to check information, then either select existing record or create a new record
- If the name is not in the system, it will initiate a new death certificate form

9. Funeral director fills out demographic information with data collected from interview of the parents. Once the funeral director has gathered the information from the parents, the information is entered into the IDRS system. It takes about 10 minutes if the deceased was the product of a live birth (and therefore has much of the data already available), and about 20 minutes for a fetal death to be entered into the IDRS system.

10. Funeral director sends notification of a death record to the physician

- Physician must be registered in the system
- Physician will receive an email notifying him/her that a death certification is in queue
- Email includes decedent’s name, date and time of death, place of death

11. Physician logs onto IDRS and fills out medical information and certifies the death
12. Physician sends the death record back to the funeral director and the funeral director receives a similar email notification
13. Funeral director verifies demographic information and submits certificate

Fetal deaths are registered in a separate system with the key differences being that the fetal death report requires more parent demographic information (because no live birth certificate data are collected). Also, if the fetus is less than 20 weeks gestation, the funeral home does not report and the hospital disposes of the fetal remains. A recent law, however, allows parents to request a burial of fetal remains at less than 20 weeks gestation. There are reports that the release and disposition of the tissue to the funeral home is at least in some areas now forcing completion of a death certificate but lacking a live birth certificate. It is unclear at this time, how many parents will opt for this and how the data will be reconciled.

Several challenges and barriers exist with the death certificate process.

- Email from funeral directors to physicians may land in spam, leading to repeated contact attempts and loss of time
- Physicians not registered into the IDRS cause delays
- Wrong physician name on the transit record slows down the process
- Fetal death record takes a very long (interview and data entry take up to an hour) to complete
- Switch to electronic records and lack of training may be causing delays. Physicians used to have a stack of forms that they filled out after a death, including information for the death certificate; now the hospital's EHR processes are separate from the state electronic processes, so physicians do not immediately fill in the information, when data are likely to be most accurate and timely.
- Physicians are unaware that they have the option to initiate the death certificate themselves at the time of death
- Other hospital personnel can also start the death record (if they are registered with the system), and the physician would just need to sign in with their personal identification number (PIN) to verify the information; but this was unknown to hospital staff.
- Obtaining information on birth and death certificate data across state lines is a challenge

- The current reporting system from the hospital to the funeral home is a bit cumbersome, and requires many different approving channels, causing a lag in time and possible loss of valuable data.

Death Certificate Training and IDRS

Online training and training manuals are available on the Indiana government website: <https://myweb.in.gov/ISDH/IDRSThin/>. At first an old website was found more easily than a newer updated website. Indiana's training manual is 68 pages long and the CDC's training manual is 65 pages long. Although the information is technical and dry, there is a power point presentation and a "quick guide" that are user friendly. The IDRS itself is not totally intuitive in its navigation and there are no "help" buttons surrounding the fields. However, drop down boxes are available for many of the fields.

State Best Practices

Several states have begun to address concerns about their vital statistics timeliness, accuracy, and completeness. We outline below several examples currently being implemented by other states.

A. Ohio Hospital Data Quality Project

In April and May 2010, the Ohio Department of Health Office of Vital Statistics (ODH/VS) conducted sixteen site visits to maternity hospitals to assess gestational age calculations, number of prenatal visits, and data collection practices documented in the birth certificate. Each facility was asked to provide three pre-defined medical charts for review to compare to the information that had been entered into the Integrated Perinatal Health Information System (IPHIS.) They found problems similar to those that we have outlined above in the Indiana processes: data discrepancies, use of the mother's and facility worksheets, data quality and complexity of data collection. Seven of the sixteen facilities had at least one discrepancy (44% inaccuracy) between the medical record and the information entered into the IPHIS application due to human keying error or data collection. Approximately half of the sites did not use the provided Facility Worksheet, either creating their own worksheet or using a worksheet derived from their facility's Electronic Health Record (EHR). In this study, data quality and skill level of the staff members who were gathering the IPHIS application information seemed to be correlated. Facilities that used statistical or nursing staff, as opposed to medical records clerks, had more complete and accurate data. Two areas of incorrect data were noteworthy: the number of maternal prenatal visits and the gestational age of the newborn. Finally, as in Indiana, staff at surveyed facilities reported the need to access as many as five different databases, forms, and/or charts to obtain required IPHIS application information. Inter-system incompatibility issues of EHRs caused problems in accessing and using existing data.

In response to this challenge, Ohio’s Perinatal Quality Collaborative (OPQC) and the Ohio Department of Health Vital Statistics performed a study focusing on four phases of birth data registration.

Phase I: Completing the electronic health record

- Algorithms to flag incomplete charts
- Empowering nursing staff
- Increased teaching of hospital staff

Phase II: Process of EHR transmission by community OB

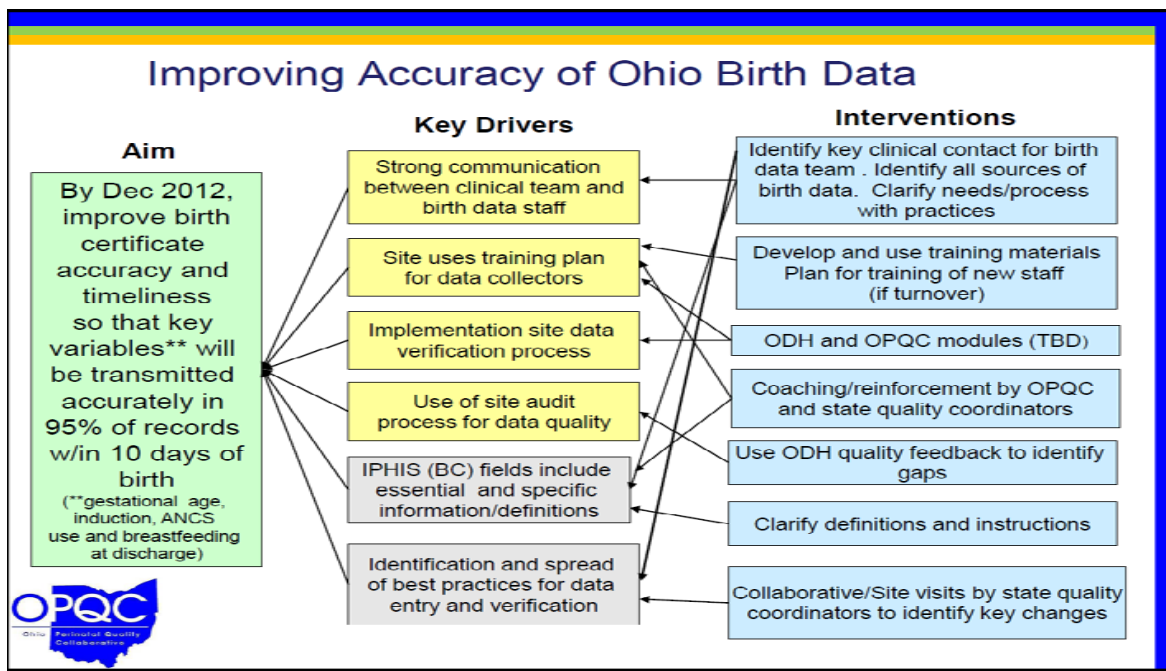
- New standardized H&P developed
- Nurses encouraged to contact OB providers if data was missing
- Emphasized safety benefits to hospital staff peer-to-peer

Phase III: Real Time Auditing

- Nursing supervisors began real time auditing for incomplete EHR
- Pregnancy card created for each pregnant woman

Phase IV: Real Time Auditing Continued and Expanded to High Risk Groups

The Drive Diagram for Improving the Accuracy of Ohio Birth Data is in the figure below.



B. Washington

In response to their vital statistics’ needs, the State of Washington has developed a Birth Data Quality Query System (BDQQ) webpage on their State Department of Health website ([https://fortress.wa.gov/doh/bdqq/\(S\(j3ff2t2eh0mvtcfncfclskf45\)\)/bdqq.aspx](https://fortress.wa.gov/doh/bdqq/(S(j3ff2t2eh0mvtcfncfclskf45))/bdqq.aspx)). The BDQQ is “a tool to help you improve your birth data quality”. It provides hospital profiles of “percent

unknown” for selected items on the birth certificate. The BDQQ aims these reports at the hospitals in order to encourage hospitals to maintain good quality birth data. There is a PDF link on this site to their guide, which explains the format of these reports and the birth certificate in layman’s terms.

There are four possible ways to look at the data for each birth facility using the BDQQ system:

1. “Average % Unknown” compared to facilities of similar birth volume

[Print Version](#)

Hospitals of Similar Birth Volume - Average % Unknown for 2011

Birth Facility	Average Percent Unknown	Total Births
Swedish Ballard	0.0	887
Othello Community	0.2	601
Providence Centralia	0.3	611
Grays Harbor Community	1.7	619
Capital Medical Center	1.9	661
Naval - Bremerton	2.1	796
Saint Mary Medical Center	2.2	568
Sunnyside Community	2.8	513
Valley Spokane	3.8	629
Highline Medical Center	4.5	969
Auburn Regional	6.3	877

2. “Percent Unknown” of certain birth data items compared to state

[Table Explanation](#) [Print Version](#)

Auburn Regional
Percent Unknown for 2011 compared to WA State

Birth Worksheet Items	Hospital	WA State
Mother's Education	3.5	0.9
Mother's Hispanic Origin	6.6	1.5
Mother's Race	10.0	2.0
Mother's Prepregnancy Weight	1.4	4.8
Mother's Weight at Delivery	0.2	3.5
Mother's Height in Feet	0.2	2.9
Smoking in 1st Trimester	0.1	0.5
Number of Other Pregnancy Outcomes	0.3	0.8
First Prenatal Visit Month	4.3	5.7
First Prenatal Visit Day	8.4	6.6
Number of Prenatal Visits	8.8	7.7
Month Last Normal Menses	24.6	11.4
Day Last Normal Menses	29.9	12.2
Risk Factors in this Pregnancy	1.1	0.6
Obstetric Procedures	0.6	0.4
Characteristics of Labor and Delivery	1.6	0.4
Congenital Anomalies of the Newborn	5.0	0.7
Total Births	877	86,989

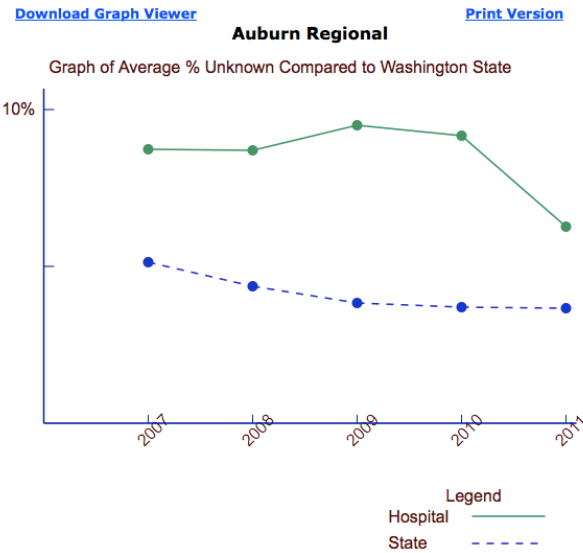
3. “Percent Unknown” of certain birth data items over time

[Table Explanation](#) [Print Version](#)

Auburn Regional
Percent Unknown Over Time

Birth Worksheet Items	2007	2008	2009	2010	2011
Mother's Education	3.9	1.7	1.2	3.6	3.5
Mother's Hispanic Origin	0.2	1.2	4.1	7.3	6.6
Mother's Race	0.2	1.0	3.6	8.4	10.0
Mother's Prepregnancy Weight	3.2	2.7	1.5	2.0	1.4
Mother's Weight at Delivery	2.3	1.9	0.7	0.2	0.2
Mother's Height in Feet	2.1	1.6	0.3	0.2	0.2
Smoking in 1st Trimester	0.0	0.4	0.0	0.0	0.1
Number of Other Pregnancy Outcomes	0.2	1.1	1.6	0.6	0.3
First Prenatal Visit Month	20.0	19.6	18.5	15.3	4.3
First Prenatal Visit Day	24.6	22.0	23.7	17.9	8.4
Number of Prenatal Visits	19.3	20.5	21.0	15.4	8.8
Month Last Normal Menses	34.5	36.1	38.5	37.6	24.6
Day Last Normal Menses	37.7	37.9	42.1	40.1	29.9
Risk Factors in this Pregnancy	0.0	0.0	0.7	0.9	1.1
Obstetric Procedures	0.0	0.0	0.7	0.7	0.6
Characteristics of Labor and Delivery	0.0	0.0	0.2	0.7	1.6
Congenital Anomalies of the Newborn	0.0	0.3	3.2	5.2	5.0
Total Births	1,077	1,094	970	940	877

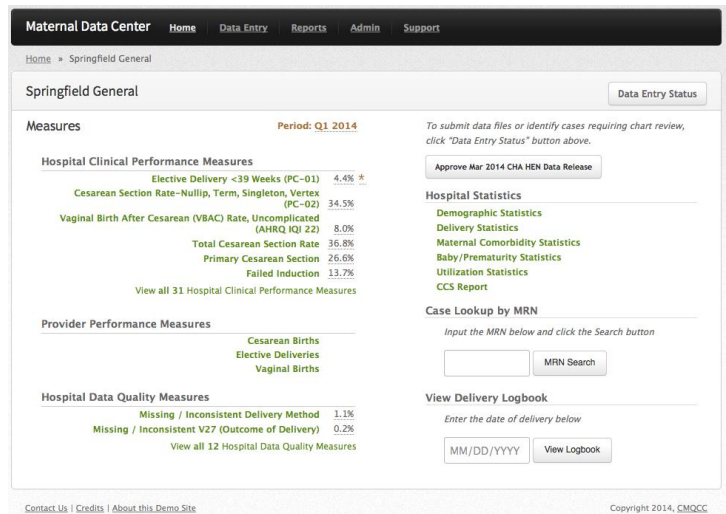
4. “Average % Unknown” compared to Washington state over time



Phyllis Reed, Epidemiology Supervisor from the Center for Health Statistics in Washington, was interviewed. She stated the project has benefited data providers and users by giving them better feedback and data users by giving them more complete birth data for their analyses. Improvements in data quality have been realized and this system has helped the Department of Health comply with data quality standards adopted by NCHS. The project was done within the existing Center for Health Statistics (CHS) budget and completed by full-time employees. Development and fielding costs were about \$20,651, and software licensing and training was around \$3,450. The system has been well received and supported by a variety of partners and stakeholders, including state health officers, hospital administrators, and perinatal groups.

C. California

California’s Maternal Quality Care Collaborative (CMQCC) developed a California Maternal Data Center (CMDC). The CMDC is a statewide data center that collects and reports timely maternity metrics (including data quality) in a way that is “low cost, low burden, and high value for hospitals”. The system is similar to Washington, but with much more detail. The CMDC is overseen by a multi-stakeholder Steering Committee composed of clinicians, hospitals, payers, purchasers, consumer organizations, and relevant state agencies. The demonstration site can be found at <https://demo.datacenter.cmqcc.org/hospitals/1>.



Data

Data from several sources were also analyzed for this report and are described below. These sources included Lag Analysis, Indicator Frequency, Hospitals Reporting Most Births and Deaths, and Physicians in the IDRS.

Lag Analysis - The Marion County Health Department Epidemiology Center ran a lag analysis that verified what was expected – there was a lag as long as a year in getting death certificates to the ISDH. Indiana law states that death certificates must be filed within five days; however, the state has no recourse against physicians, funeral homes, or parents not submitting death certificates. A repeat analysis was done comparing 2009 and 2011 data. The percentage of completeness improved in 2011 after the electronic reporting system was implemented. In 2009, 99% of infant death records were complete by 46 weeks; in 2011, 99% of infant death records were complete by 18 weeks.

Indicator Frequency – David Baize, former Director of ISDH Vital Records, provided data analysis showing the frequencies and percentages of the quality measures the data committee had selected as important. The percentages of unknown data for some important variables were very small (i.e. unknown race for infant births and infant deaths was only 0.3%, unknown entry into prenatal care was 1% for low birth weight infants). However, the Indiana 2013 Revised Natality Statistical Report from the CDC showed that one hospital with a large number of births had listed “other” as the mother’s race 35% of the time. Another hospital indicated 98% of the infants were breastfeeding. These examples demonstrate that some hospitals were likely making large mistakes.

Hospitals Reporting the Most Births and Deaths – In 2011 and 2012, 97.5% of all births in Indiana occurred in hospitals. Residents of Indiana reported 83,750 births in 2011 (ISDH, 2012). In 2011, five facilities accounted for approximately 48% of all neonatal deaths, and one facility accounted for about 33% of post-neonatal deaths. Indiana residents reported 83,250 births in 2012 (ISDH, 2013). In 2012, five facilities accounted for approximately 44% of all neonatal deaths, and one facility accounted for about 30% of post-neonatal deaths.

Birth and Death Certificate Data Recommendations:

“You can design and create, and build the most wonderful place [system] in the world. But it takes people to make the dream a reality.” Walt Disney

How do we make birth certificate and death certificate data accurate, timely, and complete? We need systematic implementation with “tests of change” in the hospitals to better understand “what works,” and to spread best practices. Broad suggestions are outlined below, but will not stand alone to improve data without behavior and systems changes in the birth hospitals. The suggestions below are divided into four broad categories. The workgroup then rated the suggestions in terms of feasibility and impact. The top two recommendations under each category were thought to have both impact and feasibility – the “low hanging fruit” so to speak. Some of the recommendations, although likely to have an impact, require a higher level of resources to accomplish; as such, they were listed lower within the categories. It is also recommended that we first focus on those hospitals with the highest number of infant deaths and births, to implement and test system changes using a QI framework, and then spread best practices and experiences.

1. Provide feedback

- Distribute a list of variables that commonly have errors to hospital administration and all staff currently involved in the reporting process
- Notify hospital administrative and clinical leadership about the deficiencies in vital records process
- Design a website to publish performance reports to increase transparency
- Increase vital records staff to be able to provide more immediate feedback

2. Provide training incentives

- Recommend hospitals to include completion of training modules in performance review
- Provide regular trainings and newsletters for birth registration staff
- Develop a post test and/or a Certificate of Completion for staff completing modules

- Pursue CEUs for nurses and CMEs for physicians for birth certificate training modules

3. New systems improvements

- Add definitions of fetal death and live birth on the electronic birth and death registration systems
- Allow staff to receive email re: death certificate at the same time as the physician
- Pre-load all physicians into the IDRS
- Update IDRS to include help and clear logical data entry fields

4. Demonstrate and implement

- Demonstrate to physicians how they should register in IDRS and how they can initiate the death record; implement a QI project to increase registration and test initiation of death record
- Encourage hospitals to have physicians register in the IDRS during hospital orientation when they are sitting and filling out other required paperwork and learning about the hospital and other systems
- Work with hospitals that have highest volume of neonatal and postneonatal deaths to implement a system where staff (nurses and clerical staff) are authorized and trained to complete initial data entry that is then confirmed by the physician and submitted. Spread best practices through a learning community.
- Test a process with hospitals to initiate the prenatal birth record

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Appendix C: High Risk Newborn Follow-up Report



Indiana Perinatal Quality Improvement Collaborative

2015

Endorsed by the IPQIC Governing Council

April 30, 2015



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High Risk Newborn Subcommittee	
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Overview

In *Coordinated Perinatal Systems of Care* endorsed by the Governing Council in May 2014, eight specific roles⁶ were identified for hospitals and their affiliate hospitals wishing to be identified as a Perinatal System. One of the identified roles was NICU Transition to Home and Follow-up. The High Risk Follow-up Subcommittee of the System Implementation Committee was charged with the following activities:

- Review national guidelines, current practices from other states, relevant literature and identify promising/best practices for following high risk infants after discharge from NICU;
- Determine the cohort of high risk newborns that need to be followed;
- Recommend guidelines for follow-up methods based upon best practices; and
- Define indicators, benchmarks, and process measures to evaluate follow-up programs for high risk infants

While each Perinatal System was charged with the responsibility for the following activities: Retinopathy of Prematurity (ROP) Screening; implementation of a developmental clinic for high risk newborns; and assistance in accessing pediatric subspecialty care as needed, the cohort of children to be followed, the periodicity of screening and the screening tool to be used had to be determined.

The committee members began their work with a review of the existing literature. The most cited and definitive document was *Follow-Up Care of High-Risk Infants* published by the American Academy of Pediatrics. The paper was developed as a result of a 2002 workshop sponsored by the National Institute of Child Health and Human Development, National Institute of Neurologic Disorders and Stroke, and the Centers for Disease Control and Prevention. The paper concluded that "There are currently no standardized guidelines for the provision of follow-up services for high-risk infants in tertiary care centers despite the requirement for follow-up clinic experience in the 97 approved neonatal fellowship training programs in the United States and the increasing number of centers participating in multicenter networks."⁷ The paper identified the need to

⁶ Perinatal Conferences, Training for Affiliate Hospitals, Quality Assurance, Support Services, Maternal-Fetal and Neonatal Transport, Post Partum and Interconception Care, NICU Transition and Follow-up, Interfacility Agreements

⁷ Pediatrics Vol 114 No. 5 November 2004

improve standardization, comparability and data collection within and among centers. There was general agreement that neurodevelopmental outcomes for the identified cohort of infants be systematically monitored. This paper addressed the benefits of neonatal follow-up, the population that should be followed, the periodicity of follow-up, tools to be used, finance issues and the role of the community physician. These components served as a road map for the activities of the subcommittee.

Cohort to be served

"Infants should receive follow-up assessments based on the severity of the perinatal problems, the interventions received in the NICU, the demographic risk factors of the infants' families, the outcome profile of the cohort in the individual NICU, and the NICU's resources. ... There is increased recognition of the potential disconnect between perinatal outcomes and long-term outcomes"⁸

The charge of the subcommittee was to identify the cohort of infants that Perinatal Centers would be responsible for engaging in the follow-up program. In trying to develop a set of statewide guidelines, it was important to start with a group of infants that everyone can follow. While Perinatal Centers could add infants with other diagnoses to the cohort, the committee members were very conscious of the reality that financial support for follow-up programs is very limited and therefore were cautious in the identification of infants to be followed. Since funding will remain an issue for follow-up programs, limiting numbers of children required to be followed through more restrictive gestational age and weight criteria will be more economically feasible. The goal was to address those infants with the highest risk of neurodevelopmental delay currently supported by the literature. There was general recognition that children with complex medical conditions would be receiving ongoing assessment and treatment from multiple specialists. The cohort of infants that the committee is recommending be followed is identified in Table 1.

Table 1: Cohort of High Risk Infants to be Followed		
<u>General:</u>	<u>Pulmonary</u>	<u>Gastro-intestinal</u>
<ul style="list-style-type: none"> • Less than 1001 grams • Less than 28 weeks gestational age • Triplets & Quadruplets 	<ul style="list-style-type: none"> • O2 Dependency at 36 weeks Corrected 	<ul style="list-style-type: none"> • NEC requiring surgical intervention and/or with associated bacterial SEPSIS • Isolated Bowel Perforation requiring

⁸ Ibid

Table 1: Cohort of High Risk Infants to be Followed

<p>(irrespective of gestational age)</p> <ul style="list-style-type: none"> • Major Surgery (other than those listed below) • End-Stage Renal Failure • Neonatal Abstinence Syndrome Requiring Medical Therapy • Documented Bacterial or Fungal Sepsis • Meningitis/Osteomyelitis 	<p>Gestational Age</p> <ul style="list-style-type: none"> • Tracheostomy • Congenital Diaphragmatic Hernia w/ or w/o ECMO • Inhaled Nitric Oxide Therapy • ECMO Therapy • Chylothorax 	<p>surgical intervention</p> <ul style="list-style-type: none"> • Gastroschisis/Omphalocele/Malrotation • Short gut • Tracho-esophageal fistula <p><u>Neurologic</u></p> <ul style="list-style-type: none"> • Moderate/Severe HIE w/ or w/o Therapeutic Hypothermia • Grade 3 or 4 IVH w/ or w/o Post hemorrhagic Hydrocephalus • PVL • Seizures Documented with EEG and/or aEEG <p><u>Cardiac</u></p> <ul style="list-style-type: none"> • PDA requiring surgical intervention • Isolated Congenital Heart Disease
--	--	--

Screening Tool and Periodicity

As cited in Pediatrics, it is not realistic to expect all NICUs to support a comprehensive follow-up program because of limited resources, both personnel and finances. In addition, the subcommittee was committed to a process that would involve the family and their child's medical home.

Screening Tool

The recommended tool is the Ages and Stages Questionnaire (ASQ). The ASQ is an easy to administer questionnaire that can be completed by the family or could be administered by the medical home during routine visits. The ASQ has been in use for over 15 years and is considered highly reliable and valid. ASQ is a series of questionnaires designed to screen the developmental performance of young children in the areas of communication, gross motor skills, fine motor skills, problem-solving, personal-social skills and overall development. The age appropriate scale is completed by the parent or caregiver. Each questionnaire looks at the strengths and challenges of the child and educates parents about their child's developmental milestones. The questionnaires

take approximately 10-20 minutes to complete and are available in English, French, Korean and Spanish. The questionnaires can be administered in an online format or by paper and pencil. There is no minimum degree or license requirement to administer the scale.⁹ Additional information about the ASQ is included in the Appendices.

Medical Home

The Regional Perinatal Center should foster a relationship with the Primary Care Physician of each infant. An agreement with the medical home should be established upon discharge of the infant from the NICU regarding the administration and reporting of the ASQ results. Should the medical home be unable to participate in the administration of the ASQ the perinatal center should facilitate the completion of the questionnaire. Results should be shared between the center and the PCP with any recommended interventions done at a local level.

Periodicity

The committee has recommended that the age appropriate ASQ questionnaire be administered at 4, 9, 12, 18 and 24 months, adjusted for prematurity. This is aligned with the national practice of ending these follow-along programs at 24 months adjusted age.

Next Steps

The committee has two remaining issues to address:

- 1) *Define indicators, benchmarks and outcome measures to evaluate newborn follow-up programs for high-risk infants.*

The development Data elements that would be required to evaluate the effectiveness of the follow-up programs in terms of participation and linkage to community resources will need to be defined.

- 2) *Recommend guidelines for referral to appropriate community resources.*

⁹ <http://www.cebc4cw.org/assessment-tool/ages-and-stages-questionnaire/>

Community resources will vary across the state and linkages to other family organizations will need to be included. The connection to community resources outside of traditional medicine (such as housing, education, social support), is an opportunity for innovation and new partnerships in the community. One concept that has shown promise is linking families to home visiting programs that are specifically tailored to their needs and are connected to local resources. Nurse-Family Partnership is an evidence-based home visiting program that follows a first-time, high-risk mom from less than 28-weeks' gestation through the target child's second birthday. Other home visiting programs and early start programs have great potential to change the outcome trajectory upward. Federal programs such as Early Head Start and Part C early intervention programs also may provide resources but varying eligibility criteria and resources may limit access to the services.

Appendix A: ASQ Screening Toolkit

Appendix B: Sample ASQ Questionnaire

Appendix D: Use of Progesterone to Prevent Prematurity



Indiana Perinatal Quality Improvement Collaborative



Endorsed by the IPQIC Governing Council
June 2015

Recommendations to Increase the Use of Progesterone to Prevent Prematurity

Aim

The aim of the Progesterone to Prevent Prematurity (P3) subcommittee is to ensure 100% of eligible women receive progesterone to prevent a recurrent premature birth.

Subcommittee Participants

The following individuals were involved in the development of the recommendations:

Name	Agency	Role
Robert Baker, MD-CoChair	Managed Health Services	Vice President for Medical Affairs
Brennan Fitzpatrick, MD	The Women's Hospital	Director, High Risk Obstetric Services
Lori Grimm, RN	The Women's Hospital Deaconess Health System	Manager, Quality and Patient Safety
Kendra Ham	Indiana State Dept of Health	MCH Epidemiologist
Dawn Kackley	Terre Haute Regional Hospital	Clinical Coordinator, Women & Children's Services
Joseph Landwehr, MD-CoChair	IU Health Ball Memorial	Perinatologist
Minjoo Morlan, MSW	IN March of Dimes	Associate Director, Program Services
Daniel Sunkel, MD	Women's Clinic	Obstetrician-Gynecologist
Erin Walsh	Family and Social Services Administration	Office of Medicaid Policy and Planning
Kristi Williams, PharmD	Union Hospital	Director of Maternal and Child Services

Overview

Preterm birth is the leading cause for infant morbidity and mortality in Indiana and in the United States. Premature delivery affects 11.4% of the births in the US. Preterm births account for 50% of the pregnancy cost as estimated by Medicaid data, largely coming from the costs associated with neonatal admissions.(MHPA) In Indiana, according to data from 2011-2013, 8.7-9.0% of all preterm births were a second preterm birth. If progesterone could prevent 30-40% of all the recurrent preterm births, 220 preterm births in 2011, 209

preterm births in 2012 and 215 preterm births in 2013 could have been eliminated (644 preterm births over 3 years). Among Indiana mothers who had a history of a previous preterm birth, 29-33% gave birth to a second preterm birth (ISDH, MCH). (ISDH, MCH) March of Dimes has estimated each preterm birth on the average cost \$54,000 per NICU admission. This would lead to a potential savings of \$11.9 million in 2011 and \$11.2 million in 2012. This does not take into account the long term costs and the emotional toll that is placed on the families and society of infant deaths and of surviving premature infants with ongoing physical and developmental problems.

Since only 8-10% of the preterm births in Indiana were recurrent preterm births, this does not address the other 7600 preterm deliveries in 2011 or the other 7300 preterm deliveries in 2012. In order to make a significant impact on preventing a preterm delivery, therefore, a screening strategy for identifying asymptomatic women at risk for preterm delivery must be devised. *Iams et al* and *Hassan et al* have described universal cervical length screening protocols and treatment options. These studies and protocols estimate a 30% reduction in preterm birth in these otherwise asymptomatic women which could eliminate 450-500 premature births in Indiana yearly. This translates into huge savings both monetarily and in the prevented morbidity and mortality of these newborns.

As the subcommittee was evaluating the most effective strategy to tackle the daunting task to reduce the number of premature births in Indiana, it became very evident that the strategy should take place in phases. The resources are not readily available to approach all issues simultaneously; therefore, we divided the long term strategy into two major phases:

Phase 1 – Identify women with a prior preterm birth and place them on 17 alpha-hydroxyprogesterone caproate (17-P) injections per well published protocols. To facilitate this strategy, the barriers that are facing the patients and the medical practitioners need to be identified and minimized. The goal of the committee is to develop a strategy that will facilitate the ease of access to 17P for all parties. Phase 1 will be the area for the recommendations presented in this document.

Phase 2 – Develop a screening protocol that identifies the women who are highest risk for a preterm delivery, both low and high risk groups. The current screening protocols recommend universal cervical length screening, which poses a challenge from both an access standpoint and cost/benefit analysis. Women who meet the short cervical length criteria would then be placed on vaginal progesterone if they have not had a previous preterm birth. These recommendations will be addressed at a later date as Phase 2.

New Professional Society Practice Guidelines

Below is a summary of recent practice guidelines from the American Congress of Obstetricians and Gynecologists (ACOG). (American College of Obstetrics and Gynecology)

Progesterone strongly recommended:

- 17-P for singleton pregnancies with a prior spontaneous preterm singleton birth, regardless of cervical length. Preterm birth is defined as less than 36 6/7 weeks.

Progesterone not recommended:

- Singleton without a prior spontaneous preterm singleton birth with an unknown or normal cervical length
- Multiple gestations regardless of cervical length
- Symptomatic pregnancies (preterm labor or preterm premature rupture of membranes), regardless of cervical length

Barriers to the Use of 17P

The subcommittee discussed barriers to the use of 17P and observed they fit in the following categories:

Payment:

- Multiple prior authorization mechanisms dependent on the member's Medicaid or commercial insurance;
- Home based injection providers not familiar to the medical practitioner, e.g., use of Alere Home Health Services;
- Practitioner not directly reimbursed for the service and has additional paperwork; and
- Office visits for injection require the medication to be stocked and consume office space and time.

Administrative:

- Additional paperwork;
- Different policies and processes by the various health plans, Medicaid and commercial, specifically regarding coverage of brand-name Makena or compounded 17-P; and
- Insurer requirement for prior approval can be very onerous; it is unclear why prior approval is needed since this is the only recognized intervention and it is unlikely it is being used by patients for whom it is not indicated.

Practitioner:

- May not be convinced that 17-P or intravaginal progesterone is effective;

- Aware, but no sense of urgency;
- Women may present for care outside of recommended timeframes;
- May not be aware of 16-24 week entry or continuation to 36+ weeks; and
- Confusion over use of Makena vs. compounded 17-p.

Patient:

- Requires home injections or self-administered injections;
- Late entry into prenatal care;
- Lost to follow-up, not clear if restarting progesterone is helpful;
- Not aware that treatment is available –does not demand treatment;
- May not self-identify as having given a previous preterm birth if new to the practice; and
- Transportation to practitioner’s office or clinic.

Examples from Other States of 17-P Interventions

The subcommittee reviewed what some other states have done to increase the use of 17-P to reduce their preterm delivery rates and thus reduce their perinatal morbidity and mortality rates. The following states have developed programs utilizing different strategies.

Louisiana

The state developed a program to help the clinicians with the ordering process. In order to reduce the often time-consuming and cumbersome use of pre-authorization forms and the referral process, Louisiana developed a website called the 17P Louisiana Resource Center Website, www.17pla.org. From this website the ordering process, billing process and referral process are easily accessible. Information about the preterm birth initiative and outcomes are presented.

North Carolina

North Carolina took a different approach and put 17-P therapy within a broader program called the Pregnancy Medical Home Program. The goal of this program was to improve access and the quality of prenatal care to all pregnant women. All pregnant women are screened for their preterm delivery risks and then appropriate therapy is initiated through the program. Their website can be accessed through the following link:

<http://www.communitycarenc.com/population-management/pregnancy-home/>.

Ohio

The Ohio Perinatal Quality Collaborative (OPQC) has developed a statewide progesterone quality improvement project and has streamlined the access to services. Their website is

<https://www.opqc.net/projects/progesterone>. Their strategy involves enrolling physicians and clinics into their project provider network. These locations are then listed on the website as providers of 17-P and the patients would obtain therapy through these approved centers. All offices and clinics are encouraged to enroll in their program and become an “approved” center. The centers in return are charged with helping the OPQC obtain accurate records and outcome data. The approved Centers then collect data on their enrollment of patients to receive progesterone therapy and have an easy on-line form they can fill out to report the barriers they encounter in trying to obtain or administer the progesterone to the patients.

South Carolina

South Carolina has the South Carolina Birth Outcome Initiative. Their website is <https://www.scdhhs.gov/organizations/boi>. From this website providers will access the Universal 17-P authorization form. It is part of their Progesterone Outreach Program; one of the major objectives of the Birth Outcomes Initiative is to make access to 17-P “hassle free.”

Expanding the Progesterone Strategy

A recent Issue Brief from Medicaid Health Plans of America (MHPA) Center for Best Practices (available at http://www.mhpa.org/Education_Resources/MHPA_Center_for_Best_Practices/MHPA_Best_Practices_Compedia/) (Medicaid Health Plans of America) summarized action steps for Medicaid health plans wanting to accelerate evidence-based use of progesterone to prevent preterm birth. These steps may be helpful in Indiana:

Improve early identification of pregnant mothers

One of the biggest challenges to improvement of all Perinatal outcomes is early entry in to prenatal care. Access to early prenatal care will ensure early identification of patients at risk for a preterm birth through both history and cervical length screening strategies. Submission of a timely Notification of Pregnancy (NOP) would identify the patients at risk and would allow assignment of a case manager to coordinate the appropriate services for the patient. Initiating 17-P therapy prior to 20 weeks improves its efficacy. Ideal initiation of therapy begins weekly at 16 weeks of gestation.

Ensuring adequate obstetric history

Reminding providers to identify the patients at risk for preterm delivery and to initiate therapy at the appropriate gestational age is crucial for the success of the program.

Referral to high risk case management in a timely manner can ensure the patients have access to the appropriate treatment.

Improve use of 17-P

Under utilization of 17-P is still the major concern. 17-P is covered by all major insurers, the difficulty arises in the manner in which the progesterone is obtained and administered. Some companies cover home therapy which is both convenient for the patient and ensures compliance as well. Minimizing the barriers to the referral process is crucial to the program's success.

Improve patient adherence to therapy

Patient compliance always presents a challenge for clinicians. Convenience helps ensure compliance in many circumstances. Home therapy is ideal for many reasons but some of the major benefits include patient convenience, patient satisfaction and patient compliance.

Evaluate Cost-Benefit Analysis

Identifying and treating patients for preterm birth has been shown to be cost-effective in many studies. (Jennifer I. Bailit) The use of 17-OHP has been associated with a potential \$2 billion opportunity. (Joanne Armstrong) When evaluating costs MHPA recommends the following issues should be considered:

- Cost of covered screening modalities
- Projected utilization of screening over time
- Expected numbers of high risk patients identified and treated
- Potential reductions in preterm birth rates
- Estimated reductions in maternal and newborn medical services, especially NICU admissions
- Estimated reduction in long-term medical and other costs on the basis of fewer modalities

Quality Improvement Strategies

The focus of efforts to improve practices to prevent preterm birth may include:

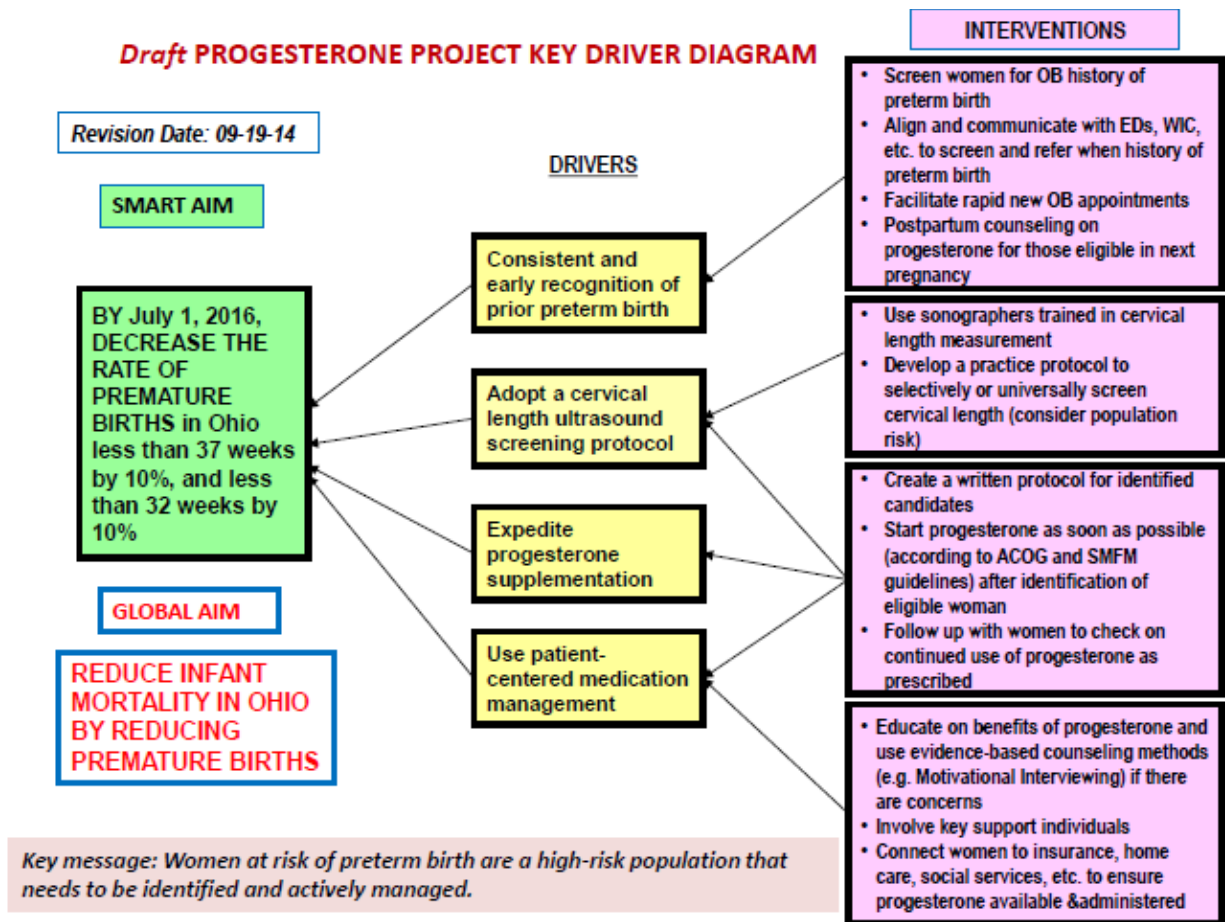
- Improve the Risk Screening and utilization of progesterone therapy into our prenatal care programs
- Improve the consistency in the physician screening process

- Address the formulary gaps in the available forms of progesterone, an example would be Makena versus compounded 17-P
- Engage ALL pregnant women into early prenatal care and screening programs
- Secure executive buy-in
- Use project managers and a cross-functional team
- Develop clinical algorithms
- Review and update policies, processes and provider information
- Establish metrics to track, uptake and evaluate impact on outcomes and costs
- Alert clinicians and build momentum for change
- Empower patients
- Maximize case management utilization and effectiveness
- Promote greater awareness of evidence based recommendations

Recommendations

The subcommittee believes there should be an initial phase and the aim of that phase should be to ensure 100% of eligible women receive progesterone to prevent a recurrent premature birth. Ideally this phase should be conducted in primary obstetric providers' offices as a quality improvement project. When a Perinatal Learning Collaborative with a rapid response data system is developed in Indiana, increasing the use of progesterone to prevent prematurity, as was instituted in Ohio, would be an ideal Quality Improvement Project.

The Figure below shows how the Ohio Perinatal Quality Collaborative approached increasing the use of Progesterone to prevent prematurity. The key driver diagram can be found at <https://opqc.net/projects/progesterone%20joining>



In the interim, the subcommittee recommends developing tools to assist obstetric providers and pregnant women in receiving 17OH progesterone as needed.

- The first step is to identify ALL pregnant women with a prior preterm singleton birth delivered at less than 37 weeks gestation and not induced for a medical indication. There needs to be earlier and more consistent recognition of risk. Potential interventions include:
 - Use a prompting system (such as a checklist) at the first OB visit to screen for history of spontaneous preterm birth (SPTB)
 - Use systems that allow for fast-track of the first prenatal visit for women with a history of SPTB
 - Provide early dating ultrasounds routinely to pregnant women
- Once these patients are identified the next step is to expedite the initiation of weekly 17-P injections. Elimination of the barriers to access 17-P will be imperative to the success of the program.
 - The subcommittee recommends the development of a unified prior authorization process among all Indiana health insurers similar to the one Medicaid uses now.

- In addition there should be a unified process for 17P distribution.
- The development of a unified prior authorization process and unified distribution process will require continued work by the members of this subcommittee and representatives of commercial health insurance providers. The use of the OPQC provider survey on [Barriers To Efficient Administration of Progesterone to Prevent Preterm Birth \(Injectable 17-OHPC and Vaginal Products\)](#) may be helpful to bring the group together. This survey is available at <https://opqc.net/projects/progesterone%20data%20collection%20forms>
- Case management is an effective management strategy and is available through current Medicaid Managed Care Entities. Use of the member's managed care plan, if applicable, can smooth the path to authorization approval. All MCEs strongly promote use of 17-P. Use may be simplified by the use of the grid similar to that attached in Appendix A. Cooperation from commercial health insurance companies will be necessary for complete information on the grid.
- The subcommittee recommends in the long term using Birth Certificate data to monitor the use of 17P in eligible women annually. However, this would require some changes in the way data is collected:
 - There must be accurate information on the birth certificate about a previous preterm birth.
 - The section of medical procedures during pregnancy would need to be revised to specifically include use of 17P
- The subcommittee recommends that quality measurement of the use of 17P for eligible women be done at the hospital level.
 - The metric would be the percentage of eligible women who receive 17P to prevent a recurrent SPTB.
 - The gestational age at initiation of therapy should also be recorded.
 - An outcome measure would be the average gestational age of babies of eligible mothers who received 17P and those eligible who did not receive 17P.
 - These metrics could be used as for measurement of the effectiveness of a quality program at the hospital level.
 - The metrics could also be used as a quality indicator for physician re-credentialing decisions.
 - The measures could also be used to demonstrate meaningful use of electronic health records.
- As Indiana develops Coordinated Perinatal Systems of Care, the subcommittee recommends that Obstetric Perinatal Centers include the appropriate use of 17P to prevent recurrent SPTB as a training topic and a quality assurance measure to be used with hospitals in their systems.

- The subcommittee recommends that the IPQIC Education Committee prepare materials for medical practitioners and consumers to promote the use of 17P to prevent recurrent SPTB.
 - Patient Education materials are available (e.g., <http://www.marchofdimes.org/pregnancy/progesterone-treatment-to-prevent-preterm-birth.aspx>) and should be widely distributed especially to women who have had one preterm birth.
 - Medical practitioner materials including an Inpatient Prematurity Form, Outpatient Progesterone Candidate Form, Outpatient Data Collection Form, Outpatient Enrollment Log Sample, and an Outpatient Monthly Site Profile Sample are available on the OPQC Progesterone Project site at <https://opqc.net/projects/progesterone%20data%20collection%20forms>
 - Use of 17P to prevent recurrent spontaneous preterm birth should be integrated with all preconception, interconception, and early prenatal care educational materials and tools.

Conclusion

Indiana must integrate the use of 17 P to prevent recurrent spontaneous preterm birth into guidelines for preconception, interconception and early prenatal care. Prompting clinicians on the importance of and providing tools to assist with the identification of patients with a prior spontaneous preterm birth should be obtainable with minimal effort and cost. Disparity of care and clinician resistance should be evaluated and eliminated. With the plethora of available literature supporting the effectiveness and safety of weekly 17-P injections, clinician non-acceptance should not be tolerated. The use of 17-P in all eligible patients is the standard of care.

Enrollment in treatment and acquisition of 17-P may prove more challenging but should also be an obtainable goal. Universal coverage by all insurance plans in Indiana, whether private or public, should be expected. Elimination of barriers to access 17P will require further work of IPQIC, Indiana Medicaid and Indiana commercial insurance providers. Monitoring the use of progesterone to prevent premature births with the use of vital records will require changes to the Indiana birth certificate. In the interim and for quality improvement purposes, the subcommittee recommends that hospitals use metrics to increase the use of progesterone among eligible women in their obstetrics programs. In addition, the measurement of the appropriate use of progesterone to prevent preterm births should be used by the developing Indiana Obstetric Perinatal Centers as training topics and quality assurance measures. Educational materials for consumers and tools for medical practitioners are available and this subcommittee requests the help of the IPQIC Education Committee in deciding on effective materials and promoting their dissemination.

Universal cervical screening is a long term goal of this committee but implementation strategies will be deferred to Phase 2. It is the hope of the committee that the screening protocol devised by *Jay Iams et al* may someday be universally implemented. (See algorithm attached in Appendix B)

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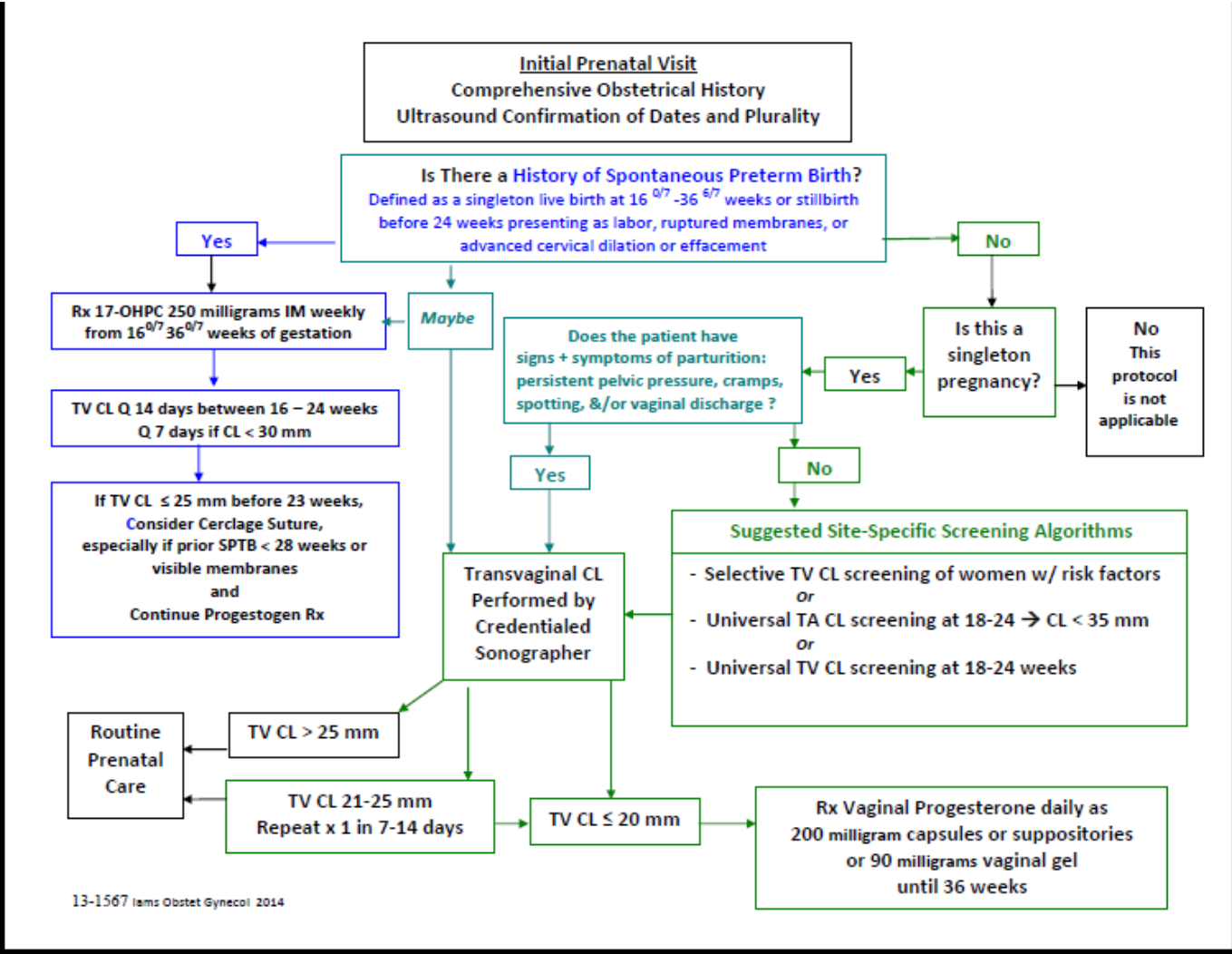
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Appendix A
Managed Care Grid

17-P Authorization

Plan	UM Process	UM Contact Info
State of Indiana	Yes	Phone: 855-577-6317 (Catamaran) Email: PDL@fssa.in.gov Website: https://inm.providerportal.catamaranrx.com/providerportal/faces/PreLogin.jsp
MHS	Yes	Phone: 877-647-4848 Fax: 866-912-4245 Website: http://www.mhsindiana.com/for-providers/provider-forms/
Anthem	Yes	Phone: 866-408-7187 Fax: 800-601-4829 Website: http://www.anthem.com/wps/portal/ahpprovider?content_path=provider/in/f3/s4/t1/pw_ad089349.htm&state=in&root_level=2&label=Pharmacy%20Information
MDWise	Yes	Phone: 855-491-0633 Fax: 855-811-9324 Website: http://www.mdwise.org/for-providers/forms/prior-authorization/
Commercial Sample: Aetna	Yes	Phone: 866-503-0857 Fax: 866-267-3277 Website: https://www.aetna.com/health-care-professionals/precertification.html

Appendix B
Iams Algorithm



Appendix E: NAS Pilot Overview



NEONATAL ABSTINENCE SYNDROME PILOT PROCESS

Neonatal Abstinence Syndrome (NAS) is a drug withdrawal syndrome that presents in newborns after birth when transfer of harmful substances from the mother to the fetus abruptly stops at the time of delivery. NAS most frequently is a result of opioid use in the mother but may also occur as a result of exposure to benzodiazepines and alcohol. Fetal exposure most frequently occurs for one of three reasons:

- The pregnant woman is dependent/addicted to opioids, either prescribed or illicit;
- The pregnant woman requires treatment with prescription opioids for another disease process; or
- The pregnant woman is receiving prescribed opiate replacement therapy.

The incidence of NAS has increased significantly over the last fifteen years. In 2000, the rate per 1,000 births was 1.2. In 2009, the rate was 3.39 per 1,000 births. Maternal opiate use has increased even more dramatically. In 2000, the rate was 1.19 per 1000 births per year and in 2009 the rate was 5.63 per 1,000 births per year. The cost of care for infants diagnosed with NAS has also increased from \$190 million in 2000 to \$720 million in 2009.¹⁰

In a report released by the Centers for Disease Control and Prevention (CDC),¹¹ prescribers wrote 82.5 Opioid Pain Reliever (OPR) prescriptions and 37.6 benzodiazepine prescriptions per 100 persons in the United States in 2012. The range nationally for OPR was a high of 142.9 per 100 persons for Alabama and a low of 57.0 per 100 persons for California. The range for benzodiazepine prescriptions was a high of 41.5 per 100 persons for Delaware and a low of 34.2 per 100 persons for Illinois. Only eight states had a higher prescribing rate for opioid pain relievers than Indiana's rate of 109.1 per 100 persons and 16 states had a higher prescribing rate for benzodiazepine than Indiana's rate of 42.9 per 100 persons.

In 2014, the 118th Indiana General Assembly passed Senate Bill 408 which added Section 244.8 to Indiana Code 16-18-2 stating:

¹⁰ Patrick S, Schumacher R, Benneyworth B, *et al.* "Neonatal abstinence syndrome and associated health care expenditures: United States, 2000-2009." *JAMA*. 2012. 307(18):1934-40.

¹¹ http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6326a2.htm?s_cid=mm6326a2

"Neonatal abstinence syndrome" and "NAS", for purposes of IC 16-19-16, refer to the various adverse effects that occur in a newborn infant who was exposed to addictive illegal or prescription drugs while in the mother's womb.

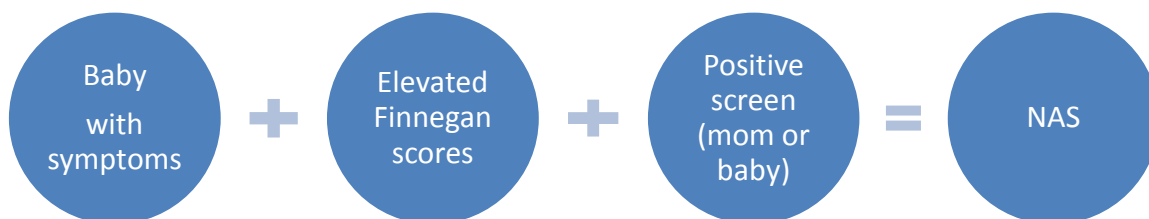
The legislation added IC 16-19-16 which required that the State Department of Health establish a task force that included, at a minimum, representatives from the Indiana Hospital Association, the Indiana Perinatal Network, the Indiana State Medical Association, the Indiana Chapter of the American Academy of Pediatrics, the Indiana Section of the American Congress of Obstetricians and Gynecologists, and the Indiana Chapter of the March of Dimes. The task force was charged with five deliverables:

- (1) The appropriate standard clinical definition of "Neonatal Abstinence Syndrome";*
- (2) The development of a uniform process of identifying Neonatal Abstinence Syndrome;*
- (3) The estimated time and resources needed to educate hospital personnel in implementing an appropriate and uniform process for identifying Neonatal Abstinence Syndrome;*
- (4) The identification and review of appropriate data reporting options available for the reporting of Neonatal Abstinence Syndrome data to the state department, including recommendations for reporting of Neonatal Abstinence Syndrome using existing data reporting options or new data reporting options; and*
- (5) The identification of whether payment methodologies for identifying Neonatal Abstinence Syndrome and the reporting of Neonatal Abstinence Syndrome data are currently available or needed.*

The Task Force was convened in May 2014 with approximately 50 members who met monthly to accomplish the deliverables. The committee reviewed national guidelines, relevant literature and practices related to NAS developed by other states in order to fully inform the decision-making process. After completion of the review process and substantive discussion of the issues related to NAS, the Task Force recommended

that the diagnosis of NAS should be applied to babies who meet the following criteria:

- Symptomatic;
- Have two or three consecutive Modified Finnegan scores equal to or greater than a total of 24; and
- Have one of the following:
 - A positive toxicology test, or
 - A maternal history with a positive verbal screen or toxicology test.



Additional recommendations¹² included an identification process for the pregnant woman and her newborn along with a discussion of screening tools, an educational agenda for hospital and other medical personnel, and data elements that need to be collected to document the prevalence of this diagnosis.

The task force completed their report to the General Assembly in October 2014. While the work described above was completed, the Senate bill had also requested that the State Department of Health establish one (1) or more pilot programs with volunteer hospitals to implement appropriate and effective models for Neonatal Abstinence Syndrome identification, data collection, and reporting. The goal of the pilot is to establish the prevalence of NAS in Indiana and to test the processes used for expansion to all delivering hospitals. Four hospitals agreed to pilot the final recommendations of the Task Force. The hospitals are:

- Schneck Hospital (Seymour)
- Hendricks Regional Hospital (Danville)
- Columbus Regional Hospital (Columbus)
- Community East Hospital (Indianapolis)

The hospitals will be testing the following components:

- A common definition of NAS;
- Comprehensive and uniform staff training in the use of the Finnegan Neonatal Abstinence Scoring Tool to determine the newborn's status;
- Universal screening of pregnant women at the first prenatal visit and when presenting for delivery;
- Screening of newborns whose mothers have had a positive screen or who have opted out of the screening protocol;
- Therapy protocol for providers for the treatment of pregnant women dealing with dependence/addiction
- Educational materials for patients and providers
- Referrals for behavioral health supports; and
- Collection of a common set of data.

With the submission of the report to the General Assembly, the Task Force was re-established as a committee under the umbrella of the Indiana Perinatal Quality Improvement Collaborative (IPQIC) to continue to address the issues related to NAS. Five deliverables were identified for the committee:

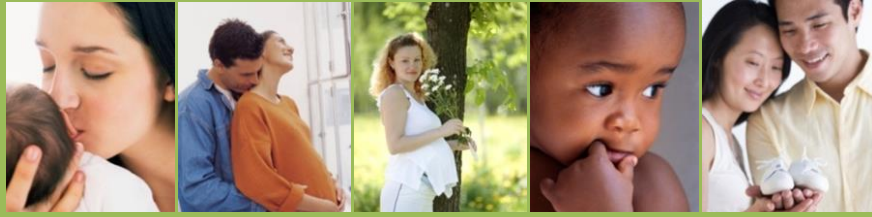
- *Provide support to ISDH for implementation of the pilot process.*
- *Develop recommendations to ISDH regarding the drug screening panel and its cost to be used in the NAS identification process.*
- *Develop a therapy protocol for the treatment of pregnant women who are dealing with addiction.*
- *Develop recommendations for screening tools to be used with pregnant women.*

¹² Appendix H

- *Collaborate with the IPQIC Education Committee in the development of materials for both medical caregivers and consumers.*

All deliverables were met in 2015 including the development of educational materials (in both English and Spanish) for both consumers and health care providers.

Appendix F: Preconception and Interconception Care



Indiana Perinatal Quality Improvement Collaborative

2015

Endorsed by IPQIC Governing Council

August 19, 2015



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I. Executive Summary

In light of the role maternal health plays in fetal and infant mortality the IPQIC Systems Implementation Committee formed a subcommittee to make recommendations regarding the care of women before and between pregnancies. The subcommittee was charged to recommend guidelines for medical practitioners, identify promising and best practices for providing preconception and interconception care, and suggest indicators, benchmarks and outcome measures for program evaluation. The subcommittee's process was to look first at models and resources developed in other states and then to identify Indiana programs and resources that could be applied successful to improve preconception and interconception care.

Guidelines for care and web-based resources to assist practitioners have been developed in several other states in collaboration with March of Dimes, ACOG and federally funded initiatives. The subcommittee consolidated these resources into a proposed list of guidelines for care and also identified the best resources from other states that could be adapted for use in Indiana.

- The subcommittee recommends creation of an ISDH-sponsored webpage through which clinicians can access web-based resources from other states. Some states (e.g., California) allow free access to their resources, while others (e.g., Wisconsin) charge a nominal cost. Because the out-of-state resources may include information on local health care programs, ISDH would also need to develop a list of Indiana-specific resources. The Guidelines webpage should be maintained and periodically updated on a regular basis to assure it provides clinicians the most up-to-date resources and links.

Promising programs from other states have been highlighted in national summaries promoting preconception and interconception care. After reviewing a range of programs the subcommittee identified three which were scrutinized in detail. Unfortunately these programs were not readily applicable to Indiana due to limitations in their scope, impact, or sustainability. The subcommittee then turned its attention to Indiana programs that could be expanded or adapted to support improvements in preconception and interconception care. These were prioritized using a web-based survey and group discussion, yielding several recommendations felt to be high in both impact and feasibility:

- Improve community awareness through (a) media campaigns, and (b) outreach to provider organizations
- Pilot innovative models of care including (a) shared (group) medical visits similar to those which have been implemented for prenatal care, and (b) expansion of the Nurse-Family Partnership model

- Expand access to care by (a) extending Medicaid postpartum benefits to enable interconception care visits, and (b) streamlining presumptive eligibility to enable early prenatal care
- Expand access to post-partum long-acting reversible contraception (LARC) by developing tools for health care providers (clinicians, hospitals) to facilitate reimbursement
- To increase use of LARC methods, barriers such as lack of health care provider knowledge or skills and low patient awareness should be addressed.

Other practices to consider include expanded access to mental health services and immunizations, creation of a meaningful use measure of how often women's pregnancy plans are documented, facilitating provider reimbursement for pregnancy tests even if they are negative, and development of electronic health record provider note templates including recommended elements of the preconception/interconception visit.

Indicators and benchmarks for preconception and interconception care are vital for understanding the state's baseline performance and gauging the impact of initiatives to improve care. The subcommittee tried to coordinate its recommendations with the state's ongoing efforts to monitor chronic diseases such as smoking, obesity, diabetes, and hypertension which are also risk factors for poor pregnancy outcomes. Additional indicators more specific to preconception and interconception care include the mean number of months between pregnancies, the proportion of women with any interval care between pregnancies the proportion screened for mood disorders, and the proportion of women with a prior preterm birth or pregnancy loss with early entry into care for the next pregnancy. Some of the recommended indicators are already assessed as part of the Title V MCH National Performance Measures or ISDH MCH quality indicators and most can be measured using PRAMS, BRFSS or vital records databases.

II. Importance of Preconception & Interconception Care

Indiana continues to rank among the states with the highest infant mortality. The exact etiology of this status is not entirely clear. However, a Perinatal Periods of Risk (PPOR) analysis was completed in 2015 using data from 2011. The PPOR analysis concluded that excess deaths occurred in two primary periods of risks: Maternal Health/Prematurity and Infant Health. Therefore, prevention efforts to reduce fetal and infant mortality as well as infant morbidity across Indiana would best be geared towards evidence-based strategies to reduce the number of very low birth weight births and sudden unexpected infant deaths.

Maternal health includes preconception health and health behaviors among women of childbearing age. According to the 2014 Women's Health Report Card, which relies upon

national data from the CDC, Kaiser Family Foundation and March of Dimes, Indiana ranks 43rd: 37th in health coverage for women, 44th in access to care for women, and 38th for health outcomes in women. Poor maternal health in Indiana is likely to contribute to Indiana's excess rates of preterm birth and infant mortality.

The Indiana Perinatal Quality Improvement Collaborative (IPQIC) was formed by the Indiana State Department of Health and tasked with researching and identifying ways to reduce infant mortality and morbidity in Indiana. IPQIC formed several subcommittees to create best practices that can help combat the high rate of infant mortality in Indiana. Recognizing that improving the health of women before, during, and after conception is vital to improving perinatal outcomes IPQIC initiated the Prenatal and Interconception Care Subcommittee of the Systems Implementation Committee.

According to a 2005 ACOG Committee Opinion, "because reproductive capacity spans almost four decades, for most women, optimizing women's health before and between pregnancies is an ongoing process that requires access to and the full participation of all segments of the health care system." Although some adverse outcomes of pregnancy cannot be prevented, optimizing a woman's health before pregnancy and between pregnancies can eliminate or reduce the risk. (ACOG, 2005) For example, adequate glucose control in a woman with diabetes before conception and during pregnancy can decrease maternal morbidity, spontaneous abortion, fetal malformation, fetal macrosomia, intrauterine fetal death and neonatal morbidity. (ACOG, Practice Bulletin #60)

Preconception care should be an essential part of primary and preventive care, rather than an isolated visit. Whereas a prepregnancy planning visit in the months before conception has been recommended, improving preconception health will require changes in the process of care, including the types of screening and risk-reduction interventions offered to women of childbearing age. *Guidelines for Perinatal Care*, jointly issued by AAP and ACOG, has recommended that all health encounters during a woman's reproductive years, particularly those that are a part of preconception care, should include counseling on appropriate medical care and behavior to optimize pregnancy outcomes (American Academy of Pediatrics). Several national organizations have recommended the routine delivery of preconception care. For example, the March of Dimes has recommended that the key physician/primary care provider and the obstetrician/gynecologist take advantage of every health encounter to provide preconception care and risk reduction before and between conceptions, the time when health encounters can improve health status (March of Dimes).

III. Subcommittee Charge, Membership and Process

The Preconception and Interconception Care subcommittee was charged with recommending:

- Guidelines for medical practitioners
- Promising and best practices for providing preconception and interconception Care
- Indicators, benchmarks, and outcome measures that could be used to evaluate preconception and interconception care in Indiana

Work of the Subcommittee

This subcommittee evaluated promising and best practices as well as guidelines and protocols for medical practitioners from many different states that have better infant mortality statistics to learn about and adopt better practices to improve infant mortality and morbidity in Indiana. In addition members reviewed preconception and interconception indicators from federal and state resources to monitor if outcomes would improve.

The Preconception & Interconception Care subcommittee began by defining preconception care using the definition supplied by the CDC/ATSDR Preconception Care Workgroup in 2006. The Select Panel defined preconception care as “a set of interventions that aim to identify and modify biomedical, behavioral, and social risks to a woman’s health or pregnancy outcome through prevention and management.” Members began researching what other states had used or done to combat infant mortality including clinical practice guidelines, intervention pilots, policy statements and programmatic indicators and benchmarks. One theme repeatedly emerged from states with the lowest infant mortality rates “simply start pregnancies with healthier mothers!” Thus the subcommittee wanted to include a broad life course view which includes primary and preventive health care as well as chronic disease management in the preconception and interconception period. The vision developed that in order to have healthier infants there must be healthier mothers in Indiana! This care needs to start prior to any planned or unplanned pregnancy. The subcommittee aim was to identify proven methods that would guide the care for reproductive aged women prior to pregnancy. These guidelines need to include patients with specific risk factors for preterm birth including diabetes, hypertension, obesity, smoking, heavy alcohol use, substance abuse, and depression.

The subcommittee began its task by researching and identifying catalogued evidence-based interventions that can be delivered before a woman becomes pregnant or early in her

pregnancy to improve her health and pregnancy outcomes. Members agreed with the Institute of Medicine and the CDC that preconception care be a component of the clinical preventive services delivered to women during well-woman visits. The following recommendations have been developed from extensive research and collaborative meetings in order to improve the health of mothers in Indiana during the preconception and interconception period.

Subcommittee Participants

The following individuals were involved in the development of the recommendations:

Name	Agency	Role
Mary Abernathy, MD	St. Vincent Hospital	Maternal Fetal Medicine
Kristin Adams, PhD	Indiana Family Health Council	Executive Director
Ann Alley	Indiana State Dept. of Health	Director, Office of Primary Care
Mary Alexander	Indianapolis Healthy Start	Project Manager
Mary Blackburn CNM MSN	HealthNet	Manager, Women's Services and Midwifery
Jeffrey Brookes MD	Parkview Hospital	Family Practice
Mindy Brown	Lutheran Hospital	Nurse Director
Sarah Curry MD	Community Physician Network	Family Medicine
Jenny Davis	St. Mary's Hospital	Labor & Delivery
Dennis Fortenberry MD	Indiana University School of Medicine	Adolescent Health
Birdie Gunyon Meyer RN MA	IU Health	Coordinator, Perinatal Mood Disorders
Kendra Ham, MPH	Indiana State Dept. of Health	Epidemiologist
Erica Huddleston MD	Community Health Network	Family Medicine
Mary Beth Lodato CNM MSN RN	Deaconess Hospital	Residency Program
Lee Learman MD PhD, Chair	Indiana University School of Medicine	Chair, Department of Obstetrics & Gynecology
Carla Meyer MSN RN	Community Hospital Munster	Director, Patient Care Services
Minjoo Morlan MSW	March of Dimes	Associate Director (former)
Carolyn Runge	Indiana State Dept. of Health	Maternal Child Health
Renata Sawyer MD	Beacon Health System	Maternal Fetal Medicine
Gayla Winston	Indiana Family Health Council	Executive Director (retired)

IV. Guidelines for Medical Practitioners

The subcommittee reviewed clinical tools developed for pre/interconception care in Wisconsin, Colorado, California and North Carolina to inform recommendations for Indiana. We found the most useful care planning guide at the Wisconsin Association for Perinatal Care website:

http://store.perinatalweb.org/index.php?route=product/category&path=62_66.

For the purpose of this document we define a pre/interconception care visit as any primary and preventive care visit of a woman of childbearing age, unless she plans no additional children and is using a long-acting method of contraception.

The following should be addressed at each visit and prioritized subsequently based on need for improvement:

- Daily use of a multivitamin with 400mcg of folic acid
- Level of physical activity
- Weight and BMI
- Daily nutrient and water consumption
- Tobacco smoking, exposure to second-hand smoke
- Use of illicit drugs and/or alcohol
- Presence of any acute or chronic health problems
- Identification of barriers to regular mental, dental and overall health care
- Safety of living and working environments
- Social connection or isolation
- Stress, anxiety and depression
- Intimate partner violence
- Desire to become pregnant now

For patients desiring pregnancy now, additional care should include including the following list, with referral, consultation or co-management as appropriate.

- Medical history
- Review of medications and determination of risk in pregnancy
- Family history, including genetic conditions
- Offer screening for varicella, rubella, HIV, syphilis, Hepatitis B, hemoglobinopathies
- Review previous pregnancy outcomes
- Discuss interventions to prevent recurrence of adverse outcomes in next pregnancy
- Optimize status of diabetes, hypertension, obesity and other medical conditions present
- Discuss importance of healthy child spacing

- Discuss partner involvement

For patients not desiring pregnancy now, discuss:

- Current birth control method and safe sex practices
- Importance of pregnancy planning and healthy child spacing
- Immunization status
- Pre-pregnancy visit when pregnancy is desired
- Resources to help with pregnancy planning

Screening checklists are important but not sufficient. Additional resources (toolkits, care algorithms) are needed to determine next steps for patients who screen positive for risk factors. We found a robust set of resources developed by California' Preconception Health Council in collaboration with California ACOG District and the March of Dimes:

http://www.everywomancalifornia.org/content_display.cfm?categoriesID=120&contentID=359

Every Woman California's resources include care algorithms for clinicians as well as downloadable English and Spanish-language handouts for the following conditions:

Anemia

Immunizations

Thyroid Disorder

Chronic Hypertension

Migraines

Seizure

Thrombocytopenia

Overweight and Obesity

Gestational Diabetes

Preeclampsia

Prior Cesarean Section

Premature Birth

Postpartum Depression

Domestic Violence Screening

Substance Abuse

Tobacco Use

Alcohol Use

HIV

Hepatitis

Syphilis

Gonorrhea & Chlamydia

The handouts from Every Woman California can be found here:

http://www.everywomancalifornia.org/content_display.cfm?categoriesID=120&contentID=359

Additional handouts are available on these topics:

Pregnancy and Nutrition

<http://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000584.htm>

Folic Acid Supplementation (English and Spanish-language)

www.cdph.ca.gov, www.cdc.gov/ncbddd/folicacid/freematerials.html

Weight Gain in Pregnancy

http://www.womenfirst.net/pdf/GD/Weight_Gain_Pregnancy.pdf

Exercise and Pregnancy

<http://cdn2.hubspot.net/hub/38254/file-13956817-pdf/docs/exercpregnancy.pdf>

Birth Spacing

<http://Dethrives.com/wp-content/uploads/2013/Birth-SpacingHandout.docx>

Contraception

<http://healthteamworks-media.precis5.com/6f2268bd1d3d3ebaabb04d665d099425>

www.healthteamworks.org: Search Birth Control for English and Spanish-language handouts

V. Promising/Emerging Practices

Pilot Programs in Other States

Promising pilot programs implemented in other states have been highlighted in national summaries promoting preconception and interconception care. After reviewing a range of programs for their potential adaptability the subcommittee identified three which were scrutinized in detail. Unfortunately these programs were not readily applicable to Indiana due to limitations in their scope, impact, or sustainability. They are summarized here briefly.

Internatal Care Program (ICP) (Phoenix 2007-2010)

<http://www.amchp.org/programsandtopics/BestPractices/InnovationStation/ISDocs/ICP.pdf>

The ICP program served underserved/uninsured women of child bearing age who previously experienced an adverse birth outcome such as a pregnancy loss or preterm birth. The goals of the program were to Improve the health of women prior to pregnancy or before pregnancy is recognized and to improve their birth outcomes. Program components included initial and ongoing education, coordination of services both prenatal and postnatal, and ongoing health promotion prior to a subsequent pregnancy. There was

no explicit attention to optimizing long-term health or chronic disease management. ICP was only available in the metropolitan area and focused heavily on the Spanish speaking population.

Applicability to Indiana was limited by the urban focus of the program and by its reliance on multilingual and multicultural providers which are currently lacking in Indiana. Sustainability was also uncertain.

Baby Blossoms Collaborative (Omaha 2005-2008)

<http://www.amchp.org/programsandtopics/BestPractices/InnovationStation/ISDocs/Baby-Blossoms-Preconception-Health.pdf>

The Baby Blossoms Collaborative (BBC) Preconception Health Program-Now and Beyond was developed to examine root causes of neonatal deaths and enhance existing health efforts. The BBC's overall goal was to improve the health of women and infants by eliminating disparities and reducing fetal/infant mortality in the Douglas County, Nebraska. The program trained professionals to implement the Now and Beyond Toolkit which educated women about the importance of a healthy lifestyle and the value of pregnancy planning. Participants set goals and were followed at 1,3, 6 and 9 month intervals. The BBC program did not focus on primary health or chronic disease management.

To use BBC in Indiana would require county-specific strategies and would be difficult to scale up to improve statewide outcomes. Variation in local resources would be challenge. The BBC program is not currently funded or operational.

Power Your Life Preconception Campaign (Utah 2010-11)

<http://www.amchp.org/programsandtopics/BestPractices/InnovationStation/ISDocs/Power-Your-Life.pdf>

This statewide social marketing campaign targeted young, minority, and low-income women. Messaging focused on nutrition and exercise; vitamins and folic acid supplementation; knowledge of family history; keeping up to date on vaccinations; avoidance of tobacco, alcohol, and other substances; and prevention of sexually transmitted infections. Very little attention was given to chronic disease management and or obstetrical risk factors that have poor pregnancy outcomes. Evaluation demonstrated improved folic acid use and improved knowledge in target populations.

Social marketing builds on substantial formative work with target populations so that interventions reflect local language, customs, and topics. This limits usefulness of this program for unmodified implementation in Indiana. Substantial adaptations would be needed, although the existing program could be used as a template. The campaign would require full localization, with adaptation of all materials to local uses.

Promising Indiana Initiatives

The subcommittee explored initiatives and opportunities available in Indiana which could be adapted to improve preconception and interconception care and outcomes. The opportunities listed below were subsequently prioritized to identify those with the potential for highest impact and sustainability.

- Improve community awareness
 - Media campaigns
 - Provider organizations
- Pilot innovative models of care
 - Shared (group) medical visits
 - Nurse-Family Partnership model
- Expand access to care
 - General healthcare: extending Medicaid postpartum benefits to enable interconception care visits, streamlining presumptive eligibility to enable early prenatal care
 - Specific services: immunizations, mental health services, postpartum long-acting reversible contraception
- Improve electronic health records
 - Meaningful use measure tracking how often reproductive-age women's pregnancy plans are documented
 - Provider note templates including recommend elements of the preconception / interconception visit

Improve Community Awareness

Raising awareness of preconception in the community can be done in partnership with ISDH initiatives (e.g. decreasing obesity and smoking) through interventions such as public service announcements, bus advertisements and other social media campaigns. Baby and Me-Tobacco Free is a smoking cessation program for pregnant and postpartum women currently promoted by ISDH. This program is a novel individual-level treatment approach designed to improve smoking cessation effectiveness because it includes evidence based components, provides continuity and counseling long-term, appeals to low income women and is feasible in real world settings. A 2009 evaluation study showed the prenatal quit rate to be 60% while postpartum quit rate varied by model from 34 to 62% at six months. (Gadomski et al)

Raising awareness in the medical community can be done by defining every primary care visit for reproductive age women as a potential preconception care visit. Integration of preconception components into primary care can better serve women across their lifespan

and at various levels of risk. Primary care integrates various health promotion, prevention, and acute care services and also can include screening for and ongoing management of chronic conditions in a primary care setting. Elements of preconception care can be integrated into every primary care visit. This can be accomplished through professional organizations as well as incentivizing providers by insurers to make preconception counseling a quality indicator. Medical Practitioners can use the tools described in the preceding section on Clinical Guidelines for Medical Practitioners. (ACOG) (Lu)

Pilot Innovative Models of Care

Currently, there is great awareness that obesity and smoking are strongly correlated to negative health outcomes and pregnancy complications. Less clear is how to help women, especially of lower economic resources with evidence based programs to can lead to behavioral change. Some promising models involve group care facilitated by health care providers where group support and problem solving can lead to positive change.

<https://innovations.ahrq.gov/profiles/group-visits-focused-prenatal-care-and-parenting-improve-birth-outcomes-and-provider>

Shared (group) Appointments. A shared medical appointment, also known as a group visit, occurs when multiple patients are seen as a group for follow-up care or management of chronic conditions. These visits provide a secure but interactive setting in which patients have improved access to their physicians, the benefit of counseling with additional members of a health care team (for example a behaviorist, nutritionist, or health educator), and can share experiences and advice with one another. The American Academy of Family Physicians (AAFP) believes that group visits are a proven, effective method for enhancing a patient's self-care of chronic conditions, increasing patient satisfaction, and improving outcomes. (<http://www.aafp.org/about/policies/all/shared-medical.html>)

A critical review of research articles that were published between 1998 and 2009 and involved participants of individual and group prenatal care was conducted. Among the 17 research studies that met inclusion criteria for this critical review, five examined gestational age and birth weight with researchers reporting longer gestations and higher birth weights in infants born to mothers participating in group prenatal care, especially in the preterm birth population. Current evidence demonstrates that nurse educators and leaders should promote group prenatal care as a potential method of improving perinatal outcomes within the pregnant population. (Thielen)

The Centering Healthcare Institute offers two group care models, one for pregnant woman (known as CenteringPregnancy®) and one for new mothers and babies (known as CenteringParenting®), that integrate health care, interactive learning, and community

building into a unified program. Groups meet in 9 or 10 2-hour sessions in which participants receive health assessments, learn care skills, participate in facilitated discussions, and develop a support network. A study of CenteringPregnancy® found that group care participants received better prenatal care, had fewer preterm births, were more likely to initiate breastfeeding, and had better prenatal knowledge than those receiving usual care. Sites using the model also report an enhanced capacity to serve nonpregnant patients, as the group sessions free up resources previously used to provide one-on-one care. **Another randomized control trial found that the program reduced sexually transmitted infections, which are associated with increased risk of preterm delivery. Sites using the model also report an enhanced capacity to serve nonpregnant patients and to meet payer documentation requirements.** (<https://innovations.ahrq.gov/profiles/group-visits-focused-prenatal-care-and-parenting-improve-birth-outcomes-and-provider>)

Nurse-Family Partnership (NFP) Model. The NFP follows first time mothers in the first or second trimester through birth and for the first 5 years of life. This program has had improved smoking quit rates, improved breastfeeding rates, improved childhood immunizations, improved educational attainment of mothers and increased income and benefits. Expanding coverage of this evidence based program to vulnerable populations would improve the health of families in the state. Healthy Families outcomes demonstrate reduced child maltreatment, increased healthy child development, encouraged school readiness, promoted family self-sufficiency and demonstrated positive parenting skills. For detailed findings on the three randomized, controlled trials of the Nurse-Family Partnership model, please refer to: <http://www.nursefamilypartnership.org/proven-results/published-research>

Expand Access to Care

Streamline Presumptive Eligibility. Indiana is fortunate to have a presumptive eligibility (PE) process for pregnant women. This committee encourages the state to work on a streamlined application process where the application process only needs to be completed once and a primary care provider can be easily selected based on the woman's choice or convenient location. Currently, the PE process is separate from the Medicaid application and financial screeners or the woman herself must complete two applications for insurance.

Increase length of Medicaid coverage after delivery. For women who have qualified for Medicaid during their pregnancy, often insurance coverage has ended at 6-8 weeks after the birth of the baby. The committee recommends providing ongoing woman care for the first year following birth of child, especially if overweight or obese, and has any co-morbid conditions. In this important first year, providers can work with women on reducing risk

factors by encouraging weight loss, healthy eating, exercise and effective birth control methods.

Long Acting Reversible Contraception (LARC). The IPQIC Finance Committee strongly recommended providing Long-Acting Reversible Contraception to all women who desire it. Providing LARCs while in the immediate postpartum period is cost effective and convenient for patients. (<http://www.choiceproject.wustl.edu/>) Effective June 1, 2015, the Indiana Health Coverage Programs (IHCP) will allow separate reimbursement for long-acting reversible contraception devices implanted during an inpatient hospital or birthing center stay for a delivery. (IHCP, IHCP Banner Page, BR201517, April 28, 2015)

Observational studies suggest no effect on breastfeeding initiation or continuation or on infant growth and development. LARC can be used by nulliparous women and adolescents. (ACOG Practice Bulletin #121, July 2011) To increase use of LARC methods, barriers such as lack of health care provider knowledge or skills and low patient awareness should be addressed.

Immunizations. Immunizations are essential to good health. Indiana could improve the health of all citizens by expanding the provision of vaccinations to all women of reproductive age. Tdap can help prevent life threatening pertussis in the new born. Providing free or low cost Tdap to all pregnant women at \$42 per dose is far less expensive than a NICU hospitalization for a sick child and avoids additional stress and burden on parents.

Mental Health Services. Women who are depressed can have impaired parenting and self-care. Decreasing barriers to mental health support through home counseling programs or expanded services in underserved communities can improve mother-child bonding and the home environment. Often patients in need of behavioral health are on waiting lists for 3-4 months. Quicker access is provided by some psychiatric providers who accept cash only which is beyond the means of many of our patients. One innovative model is through expanding state health care coverage through Federally Qualified Health Centers in each community. More information and examples can be found at: www.mdwise.org/MediaLibraries/MDwise/Files/For%20Providers/Announcements/2011/provider-Nov2011IntegratedCareSlides.pdf

Improve Electronic Health Records (EHRs)

Financial incentives to follow best practices are becoming more common and more rigorous, as exemplified in the CMS “meaningful use” program which was developed to assure EHRs are used to improve quality, safety, efficiency, and equity in health care. The State of Indiana could establish a meaningful use measure such as, was the patient asked if

pregnancy is desired and when? This response can be measured and then financial rewards can be issued to those practices meeting established benchmarks.

Most electronic health records include provider note templates tailored to different specialties and visit times. To facilitate implementation of the preconception and interconception care guidelines, ISHD could work with the major health systems and EHR vendors to create provide templates listing the recommended visit components.

Additional EHR capabilities include provider reminders triggered by specific orders, test results, or patient characteristics. For example, if a patient presents for a nurse visit for a pregnancy test, the EHR could issue a reminder regarding the need to start a multivitamin with folic acid and to arrange follow-up for a preconception or interconception care visit.

VI. Indicators and benchmarks for monitoring and evaluation

Subcommittee members discussed what measures would help Indiana know if it is improving. They considered the following important:

- Chronic disease management
- Smoking status among reproductive age women
- Obesity
- Diabetes - HgbA1C – level of control, post partum screen of gestational diabetic
- Hypertension
- Identification of screening for mood disorders
- Birth spacing
- Outcomes of a prior pregnancy
- Well woman visit – any visit to any provider between postpartum visit and next pregnancy
- Prior preterm – early entry into prenatal care for subsequent pregnancy

The Indiana Title V Maternal Child Health (ISDH,MCH) program has performance measures it is responsible for. Each state has to choose 8 National Performance Measures (NPMs) for FY 16.

In regard to Women's/Maternal Health, Indiana chose Low-risk Cesarean Deliveries (Definition: % cesarean among term, singleton, vertex, first births.) In addition, they will examine Breastfeeding using the definition of percentage of infants ever breastfed. The ISDH MCH program will also be monitoring the Percentage of Women who Smoke during Pregnancy and % children in households where someone smokes.

In addition to NPMs, the ISDH MCH Program chose to look at Prenatal Care for a state performance measure with the objective to increase early and adequate prenatal care. The metric will be the percentage of pregnant women that receive prenatal care in the first trimester. As a metric for preconception/interconception care, the ISDH MCH program will

follow Unplanned Pregnancy using the definition the percentage of women aged 14-44 who had an unintended pregnancy.

Committee members reviewed resources including:

Recommendations to Improve Preconception Health and Health Care --- United States: A Report of the CDC/ATSDR Preconception Care Work Group and the Select Panel on Preconception Care. It can be retrieved at:
<http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5506a1.htm>

The 2006 national recommendations to improve preconception health included monitoring improvements in preconception health by maximizing public health surveillance Core State Preconception Health Indicators — Pregnancy Risk Assessment Monitoring System and Behavioral Risk Factor Surveillance System, 2009. This reference is available at:http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6303a1.htm?s_cid=ss6303a1_e

Action Plan for the National Initiative on Preconception Health and Healthcare, 2012-14. This reference contains a section on surveillance and research and can be retrieved at:
<http://www.cdc.gov/preconception/documents/actionplannationalinitiativepchhc2012-2014.pdf>

Providing Quality Family Planning Services: Recommendations of CDC and the U.S. Office of Population. This report contains a section on Quality Improvement and how to determine which measure are important which was very helpful. It can be reviewed at:http://www.cdc.gov/mmwr/preview/mmwrhtml/rr6304a1.htm?s_cid=rr6304a1_w

The main sources for preconception and interconception indicators appear to be: The Pregnancy Risk Assessment Monitoring System (PRAMS) which is an ongoing state- and population-based surveillance system designed to monitor selected self-reported maternal behaviors, conditions, and experiences that occur shortly before, during, and after pregnancy among women who deliver live-born infants; and

The Behavioral Risk Factor Surveillance System (BRFSS) which is an ongoing state-based telephone survey of noninstitutionalized adults aged ≥ 18 years in the United States that collects state-level data on health-related risk behaviors, chronic conditions, and preventive health services. For pre and interconception health, researchers look at data from nonpregnant women of reproductive age (aged 18–44 years).

The Indiana Birth Certificate and Vital Records information is also a source of data.

Considering available data resources, committee members reviewed suggested indicators focusing on importance of the topic (e.g., does it address a priority aspect of health care, and is there opportunity for improvement?); what is the level of evidence for the measure (e.g., that a change in the measure is likely to represent a true change in health outcomes?); does the measure produce consistent (reliable) and credible (valid) results about the quality of care?; are the results meaningful and understandable and useful for informing quality improvement; and is the measure feasible (i.e., can it be implemented without undue burden)? (CDC, Providing Quality Family Planning Services).

Results of evaluating each measure are documented in Appendix A.

Items most immediately available to monitor women's health in Indiana would be any variables from the birth certificate. However, there are data elements that are stronger than others as far as birth certificate data. The strongest at this time appear to be birth spacing/ interpregnancy interval, prenatal care (early and adequate), and history of a previous preterm birth.

Smoking and body mass index are self-reported on the birth certificate so are not as accurate as the previous indicators. However they are important and could also be obtained for the general population of women of childbearing age on the BRFSS. Obtaining data from the BRFSS would require a special study looking at several years data for women of childbearing age. This could be a good project for an MPH Epidemiology graduate student. Obtaining data from PRAMS would require the ISDH to obtain a cooperative agreement with CDC and start the PRAMS program statewide. Or another possibility is to use priority questions that have been validated for the PRAMS program and implement surveys in selected hospitals or geographic areas of the state for limited time periods. This approach is usually called a "mini-PRAMS."

VII. Subcommittee Recommendations

Guidelines for Medical Practitioners

The subcommittee recommends creation of an ISDH-sponsored webpage through which clinicians can access web-based resources from other states. Some states (e.g., California) allow free access to their resources, while others (e.g., Wisconsin) charge a nominal cost. Because the out-of-state resources may include information on local health care programs, ISDH would also need to develop a list of Indiana-specific resources. The Guidelines webpage should be maintained and periodically updated on a regular basis to assure it provides clinicians the most up-to-date resources and links.

The subcommittee also considered the value of creating new Indiana-specific resources to support clinicians' efforts in screening, diagnosis, treatment and patient education. In light of the expansive resources available from other states, we felt this would unnecessary duplication of the effort and would create a delay in getting needed to tools to preconception and interconception care providers.

Promising and best practices for providing preconception and interconception care

The subcommittee recommends several feasible, high impact initiatives:

- Improve community awareness through (a) media campaigns, and (b) outreach to provider organizations
- Pilot innovative models of care including (a) shared (group) medical visits similar to those which have been implemented for prenatal care, and (b) expansion of the Nurse-Family Partnership model.
- Expand access to care by (a) extended Medicaid postpartum benefits to enable interconception care visits and (b) streamlining presumptive eligibility to enable early prenatal care
- Expand access to post-partum long-acting reversible contraception (LARC) by developing tools for health care providers to facilitate billing and coding
- To increase use of LARC methods, barriers such as lack of health care provider knowledge or skills and low patient awareness should be addressed

Other practices to consider include expanded access to immunizations and mental health service, creation and tracking of a meaningful use measure of how often women's pregnancy plans are documented, and development of provider note templates in electronic health records including recommended elements of the preconception/interconception visit.

Currently, some patients must pay for negative pregnancy tests out of pocket, creating a barrier to early pregnancy identification. Facilitating provider reimbursement for pregnancy tests would promote early enrollment in prenatal care if the test is positive or a timely well woman visit during the preconception or interconception period if the test is negative.

Indicators, benchmarks, and outcome measures that could be used to evaluate preconception and interconception care in Indiana

The subcommittee recommends that ISDH develop an ongoing monitoring and surveillance system for women's health containing at a minimum:

(1) Yearly summary of indicators by race and region that are available from Vital Records information including:

- Birth spacing - defined as the length of interval between pregnancies (<18 month interval, >18 month interval))
- Month of gestation entered prenatal care
- Incidence of previous preterm birth
- Incidence Smoking before and during pregnancy
- BMI before pregnancy indicating percentage overweight and percentage obese
- Hypertension before and during pregnancy
- Diabetes before and during pregnancy

(2) A 5 year study of BRFSS data on women of childbearing age (18-44 years old) that would look at the following indicators:

- Current smoking
- Incidence of overweight and obesity
- Incidence of diabetes
- Incidence of hypertension
- Percentage of women receiving a well woman visit – any visit to any provider between post partum and next pregnancy
- Percentage of women with current health-care coverage defined as having some type of health-care coverage at the time of the BRFSS survey, including health insurance, prepaid plans, or government plans.
- Percentage of women receiving a routine checkup during the preceding year

(3) A mini-PRAMS survey in regions or geographic areas that are at high risk for poor perinatal outcomes. Women’s health indicators that could be determined with a “mini-PRAMS” include:

- Smoking before pregnancy
- Percentage overweight and obese
- Percentage of prepregnancy hypertension
- Percentage of postpartum depressive symptoms
- Percentage with an unintended pregnancy
- Percentage who received preconception counseling

VIII. Conclusion

Improving the health of women before and between pregnancies will pay dividends in improved maternal-neonatal-child outcomes and have a multigenerational impact. A comprehensive strategy to optimize preconception and interconception care includes implementation of practice guidelines as well as improved access to care after pregnancy, immunizations, mental health services and long-acting reversible contraception. Piloting expansions in successful care models in Indiana (such as group care visits and the Nurse-

Family Partnership) may have a greater impact on women's health behaviors than traditional care models. Indiana's baseline performance and improvements in preconception and interconception can be monitored using a variety of available data sources.

We appreciate this opportunity to provide guidance to IPQIC regarding an important strategy for reducing infant mortality in Indiana. Improvements in preconception and interconception care quality and access will benefit women and families throughout their reproductive years and beyond. We realize that much work will be needed to put our recommendations into motion. Several members of the subcommittee have expressed an interest in continuing to guide IPQIC and ISDH as these initiatives are considered further and ultimately implemented.

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Appendix A
Evaluation of Indicators for
Preconception and Interconception Care

Evaluation of Indicators for Preconception and Interconception Care

The indicators recommended by the subcommittee and used by other entities evaluating and monitoring women's health care were researched for feasibility and lack of undue burden in Indiana. Results are summarized below.

Chronic disease management does not appear to be available on BRFSS or PRAMS

Current smoking is defined in BRFSS as smoking ≥ 100 cigarettes in a lifetime and currently smoking cigarettes every day or some days at the time of the interview.

Therefore, smoking status among reproductive age women can be determined.

- **Smoking before pregnancy** is defined in PRAMS as smoking ≥ 100 cigarettes in the preceding 2 years and smoking any number of cigarettes, including less than one cigarette, on an average day during the 3 months before pregnancy.
- **Smoking before and during pregnancy** is also available via Vital Records

Overweight body mass index (BMI) can be obtained on BRFSS and PRAMS and is calculated as weight (kg)/height [m²]. Overweight (but not obese) was defined as having a BMI of 25.0–29.9 kg/m² Obesity (BRFSS)

- **Being obese** can also be determined by BRFSS and PRAMS and is defined as having a BMI of ≥ 30.0 .
- **Prepregnancy weight and height** are asked on the Indiana Birth Certificate

Diabetes- The incidence of Diabetes can be determined on the BRFSS. Women with diabetes are those who reported ever being told by a health-care provider that they had diabetes, not including gestational diabetes.

- The Indiana Birth Certificate asks about prepregnancy and gestational diabetes.
- Level of control does not seem to be available in the usual resources.

Hypertension- The incidence of hypertension can be determined on the BRFSS. Women with hypertension were those who reported ever being told by a health-care provider that they had hypertension, not including hypertension during pregnancy.

- **Hypertension during the 3 Months before pregnancy** can be found on PRAMS. Women with pre-pregnancy hypertension are those who reported having high blood pressure during the 3 months before their most recent pregnancy.
- On the Indiana Birth Certificate there are questions for pre-pregnancy and gestational hypertension as well as eclampsia

Birth spacing- defined as the length of interval between pregnancies (<18 month interval, >18 month interval by race, region) can be determined using Vital Records.

Previous preterm birth among multiparous women is defined in PRAMS as a live birth (before the respondent's most recent live birth) having been delivered >3 weeks before the due date; women whose most recent live birth was their first birth were excluded.

- **Prior preterm** is also identified on the BRFSS
- **Prior preterm** can be obtained from Vital Records

Well woman visit – any visit to any provider between post-partum and next pregnancy (BRFSS)

- **Current health-care coverage** was defined as having some type of health-care coverage at the time of the BRFSS survey, including health insurance, prepaid plans, or government plans.
- **Routine checkup during the preceding year** in the BRFSS is defined as having visited a doctor for a routine checkup within the preceding year.
- **Receiving preconception counseling** was defined in PRAMS as talking with a doctor, nurse, or other health-care worker about five or more of 11 possible lifestyle behaviors and prevention strategies before the pregnancy of her most recent live-born infant.

Unintended pregnancy is a question on PRAMS defined as a pregnancy among women who, just before their most recent pregnancy, wanted to be pregnant later or did not want to be pregnant then or at any time in the future.

Postpartum Depressive Symptoms can be determined on PRAMS. Experiencing postpartum depressive symptoms was defined as feeling down, depressed, or sad; hopeless; or slowed down by a substantial degree since the infant's birth. Whether a medical practitioner inquired about Postpartum Depressive Symptoms is not asked.

Early prenatal care enrollment can be determined by Vital Records.

**Appendix G: Long Acting Reversible Contraception (LARC)
Reimbursement**