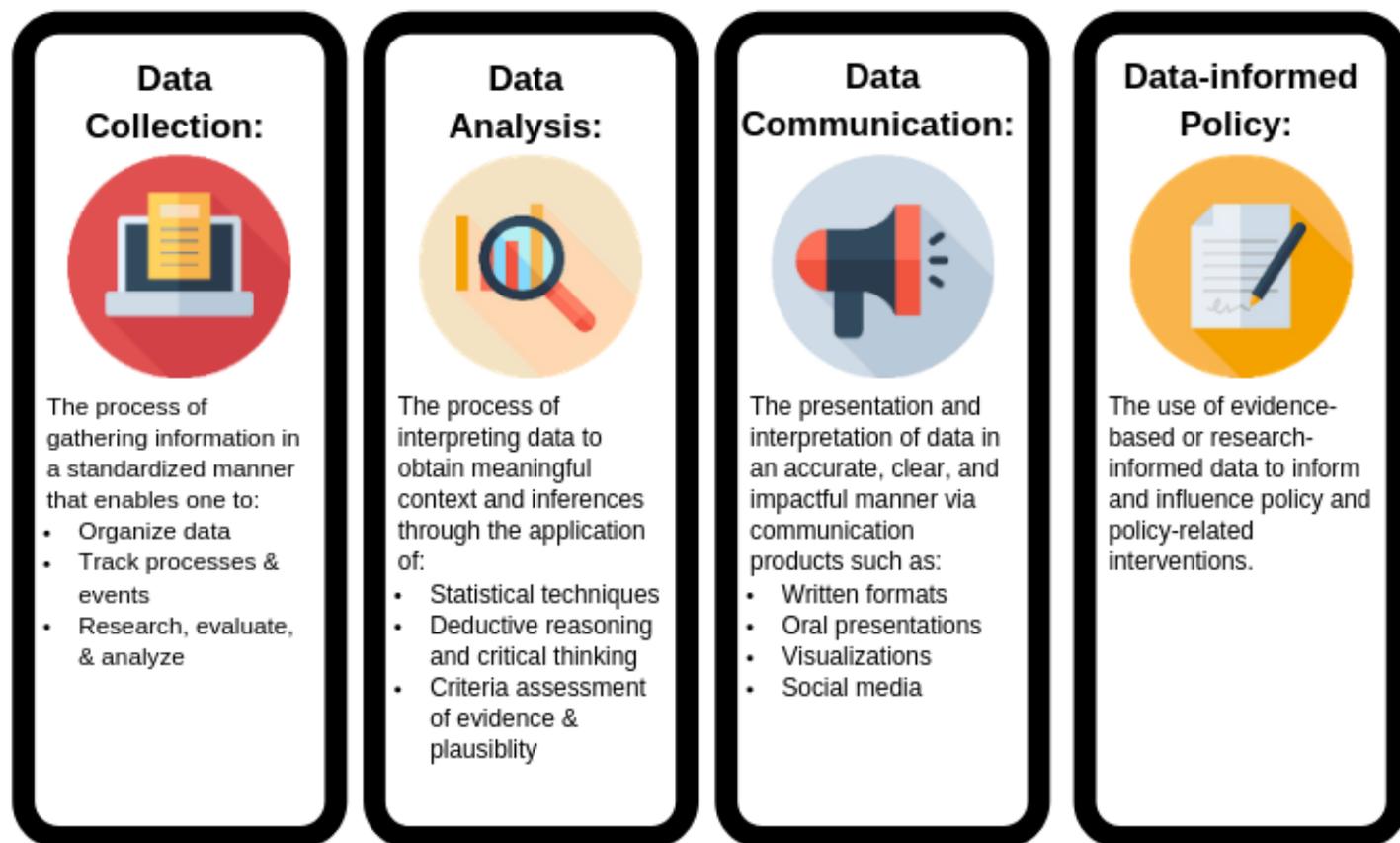


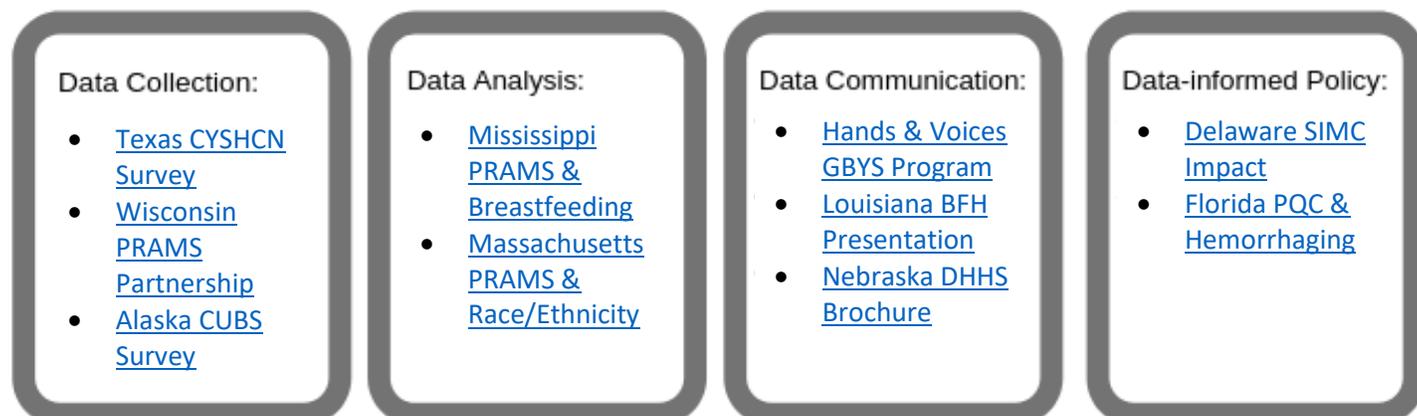
# DATA IN ACTION

Uses of data in maternal and child health to assess, achieve and communicate.

This guide contains examples from states health departments and non-profits on the active use of data. These examples were submitted and selected to represent ways to collect, communicate, and use data to achieve desired outcomes and influence policy. The guide is separated into four main sections:



## State & non-profit examples of data-in-action:





## Data Collection: Texas CYSHCN Survey

**Background:** In response to a need for additional, timely data to inform programs and policy, the Texas Maternal and Child Health Section created an annual [CYSHCN Outreach Survey](#). The CYSHCN Outreach Survey has helped the Texas Department of State Health Services (DSHS) identify gaps in parent/caregiver knowledge and has enabled the program to relay feedback from families to health care providers.

The Title V Maternal and Child Health (TVMCH) Section of the Texas DSHS prepares the Title V Five-Year Needs Assessment, which is conducted every five years to inform statewide Maternal and Child Health (MCH) programming. While analyzing the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN), TVMCH identified the need for additional data in specified areas. The program launched a state-specific Children and Youth with Special Health Care Needs (CYSHCN) Outreach Survey to obtain supplemental and relevant data to inform programmatic decisions.

**Methods:** In survey development, the TVMCH team worked with a partner organization to receive parental input on the survey content and layout. Terminology in the survey was tailored to the target audience. Employing clarifying statements increased respondents understanding of question content and improved data quality. The survey was made available in English and Spanish, and targeted outreach was conducted to ensure representation of Spanish-speaking CYSHCN population.

TVMCH distributed online and print copies of the survey to reach families across the geographically large state. Title V partners and stakeholders assisted in promoting the online survey. Annually, TVMCH printed and mailed over 2000 survey copies to children in the state CYSHCN Services Program. Families were given many months to complete and return the survey.

**Results & Discussion:** In 2015, survey data indicated that parents were not prepared for their child's transition to adulthood. Therefore, TVMCH partnered with Easter Seals of Greater Houston to develop a tool to better prepare families for transition. The survey data propelled the creation of programs for the transition from pediatric to adult health care for CYSHCN.

Information gathered from the Outreach Survey allowed TVMCH to drive CYSHCN programming with relevant and timely data. This yearly data collection permitted more credible statistics used to support important programs and policies. Challenges in implementing the annual Outreach Survey include staff time for data cleaning and analysis, and costs associated with printing, distributing, and promoting the survey.

**Submitted by:** Rachel Jew, Texas Department of State Health Services in 2016



Click [here](#) to see the full write-up.



## Data Collection: Wisconsin PRAMS Partnership

**Background:** The Division of Public Health (DPH) of the Wisconsin Department of Health Services participates in the [Pregnancy Risk Assessment Monitoring System \(PRAMS\)](#). The University of Wisconsin Lifecourse Initiative for Healthy Families (LIHF) is a community-driven initiative aiming to develop and implement strategies to reduce disparities in infant mortality between blacks and whites. LIHF partnered with WI DPH to use PRAMS data to look at these disparities. The partnership allowed enhanced response rates from a population with a historically lower response rate on the PRAMS survey and utilized methods of enhanced oversampling and increased follow up to increase the response rate from black mothers.

**Methods:** Through the PRAMS/LIHF partnership, WI DPH conducted an enhanced oversample of non-Hispanic black mothers in four counties that had higher rates of infant deaths. For the enhanced oversample, DPH sent a survey to every black mother who gave birth within three of the four counties, and to one in six black mothers in the fourth county. Additional funding provided complete phone follow up for all mothers who did not respond to the mailed survey.

Also, LIHF formed a Communications and Public Awareness Workgroup to develop ideas for outreach methods to increase response rates for non-Hispanic black mothers. The workgroup changed the survey color and supplemental materials to purple to make the materials more noticeable. Each survey also included a \$5 cash incentive to increase response rates.

**Results & Discussion:** The PRAMS/LIHF partnership and the enhanced oversampling method increased the response rate for non-Hispanic black mothers and has shown substantial improvement over previous methods. The complete, intensive phone follow up further increased the response rates. Challenges in implementing the PRAMS oversample included lag time between data collection and data analysis and the cost of the enhancement.

The WI PRAMS black mothers oversample has been beneficial for both Wisconsin Title V programming and community partners. Now, WI DPH and LIHF can look at maternal and child health measures by race at a county-level for the counties that are oversampled, which is useful for evaluation for ongoing programming. Furthermore, the LIHF program office used data from the enhanced oversample to launch a series of data briefs that highlight priority areas within LIHF communities. The Title V program and partners now have access to a valuable dataset that enhances the ability to analyze MCH indicators by race and ethnicity in a way that is meaningful at both the state and local levels.

**Submitted by:** Angela M, Rohan, Wisconsin Department of Health in 2016

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## Data Collection: Alaska CUBS Survey

**Background:** The Maternal and Child Health (MCH) Epidemiology Unit of the Section of Women's, Children's, and Family Health at the Alaska Division of Public Health collects data through the [Alaska Pregnancy Risk Assessment Monitoring System \(PRAMS\)](#). PRAMS collects data on maternal attitudes and experiences before, during, and after pregnancy. Despite PRAMS' success, a gap in knowledge persisted about the well-being of young children in Alaska. The [Alaska Childhood Understanding Behaviors Survey \(CUBS\)](#) was developed in 2006 as a follow-up survey to PRAMS to gather additional information about the health and early childhood experiences of young children in Alaska.

The Alaska CUBS identifies issues faced by Alaska's young children in a timely manner. Its multiple forms of data access have led to partnerships across the state's health department to tackle and prevent issues pertaining to mothers and children that are not usually defined as Maternal and Child Health problems.

**Methods:** CUBS is conducted on an ongoing basis with funding from the federal Title V block grant. CUBS sends a three-year follow-up survey to mothers who completed the PRAMS survey and are still living in Alaska. CUBS is first mailed to the mother. If there is no response after two survey mailings, the team will follow up with a phone survey.

Prior to the sending out a CUBS pre-letter, extensive research is conducted to verify the mothers' current addresses. The team utilizes the Alaska's Permanent Fund Dividend Database to retrieve current addresses since it is updated annually. If an address is undeliverable, the team will refer to other state databases (i.e. Medicaid, WIC) for verification.

**Results & Discussion:** CUBS consistently collects high quality data about the health status and well-being of young children in Alaska. The annual response rate ranges 48% to 65%. Once the data is collected, the CUBS coordinator publishes topic-specific datasheets on the CUBS website and sends them to MCH stakeholders. The MCH Epidemiology Unit has published comprehensive data books focused on CUBS data. In addition, CUBS data is available on the Alaska Department of Health and Social Services' [Indicator-Based Information System \(AK-IBIS\)](#).

The open avenues to access CUBS data have helped with numerous public health efforts in Alaska, such as obesity prevention and child immunization. Moreover, CUBS data has been used to advocate for funding for asthma prevention and inform a needs assessment examining school readiness among Alaska Native children in Anchorage.

**Submitted by:** Margaret Young, Alaska Division of Public Health in 2016



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## Data Analysis: Mississippi PRAMS & Breastfeeding

**Background:** In 2011, Mississippi's prevalence for breastfeeding initiation and breastfeeding continuation were significantly lower than Healthy People 2020's target. This prompted Mississippi Department of Health (MSDH) to analyze trends in breastfeeding using data from the Mississippi Pregnancy Risk Assessment Monitoring System. With funding support from AMCHP, the MS PRAMS team was encouraged to assess breastfeeding initiation, continuation, and exclusive breastfeeding, and to identify breastfeeding barriers or promoting factors.

**Methods:** MSDH analyzed PRAMS data from 2003-2011 ( $n=9,131$ ). The outcome variables included self-reported breastfeeding initiation. MSDH used a combination of descriptive statistics and chi-square tests to estimate the prevalence of breastfeeding. To identify factors associated with breastfeeding, MSDH used logistic regression. The team compared results based on array of factors, such as race, education attainment, and unintended/intended pregnancy. SAS 9.4 survey procedures were used to account for the complex sample design and unequal selection probabilities.

**Results & Discussion:** MSDH found that although the average percent of breastfeeding initiation among Mississippi women was consistent, there were large discrepancies within factors such as race, age, marital status, and educational attainment. For example, the breastfeeding initiation percentage was highest among white mothers, mothers 30 years and older, mothers with above a high school education, and married women.

A challenge of the project was calculation of breastfeeding continuation percentage since mothers are eligible to answer the survey as early as two months after birth and many of mothers turn in the survey before month three or six. To overcome this, MSDH calculated breastfeeding continuation with a timing for at least eight weeks. Another limitation of the study was that at the time, there were no questions on why the mother had discontinued breastfeeding. However, this was corrected in the phase seven version of the Mississippi PRAMS by including questions focused on breastfeeding discontinuation.

Results from this study have been shared throughout other MSDH programs such as Family Planning and Women, Infants, and Children (WIC). Furthermore, the analysis has been used to inform the Health & Resources Services Administration (HRSA) of the work being done to address National Performance 4: Breastfeeding in Mississippi for the state's Title V block grant application.

**Submitted by:** Mina Qobadi, Mississippi State Department of Health in 2016



Click [here](#) to see the full write-up.



## Data Analysis: Massachusetts PRAMS & Race/Ethnicity

**Background:** The Massachusetts State Department of Public Health found that non-Hispanic black and Hispanic mothers reported lower prevalence of supine sleep compared to non-Hispanic white mothers. This is important since it has been reported that placing infants on their back to sleep can reduce the incidence of sudden unexpected infant death.

Thus, the department conducted a study to analyze the frequency of supine sleep position by ethnic subgroups among MA mothers who self-identify as non-Hispanic black mothers and Hispanic mothers. The team used data from the [Massachusetts Pregnancy Risk Assessment Monitoring System \(PRAMS\)](#) from 2007-2012 (n=9,041). Massachusetts performed a disaggregation of racial and ethnic subpopulations beyond “non-Hispanic black” and “Hispanic”.

**Methods:** Data from PRAMS regarding the infant sleep position and maternal characteristics were analyzed. Mothers who identified as non-Hispanic black (n=1,718) [Cape Verdean, Haitian, Caribbean Islander, Ghanaian, Nigerian, Ugandan, Kenyan, Somalian, Ethiopian or other non-Hispanic black (mothers without further self-identification)] or Hispanic (n=1,940) [Puerto Rican, Dominican, Salvadoran, Guatemalan, Mexican, Honduran, Colombian, Cuban or other Hispanic] were included. The team used multivariate logistic regression to examine the adjusted relative risk of infant supine sleeping among the ethnic subcategories, while also controlling for maternal education, age, nativity, and marital status.

**Results & Discussion:** Overall, the study found significant differences in infant supine sleep position within the ethnic groups (i.e. 54.6% to 81.6% within non-Hispanic black mothers). The findings that there are differences among ethnic subcategories in safe sleep practices proves that important information is missing when these subcategories are grouped together. This showed that infant safe sleep educational programs may need to be tailored for specific maternal ethnic subgroups within Hispanic and non-Hispanic black communities for best infant health outcomes.

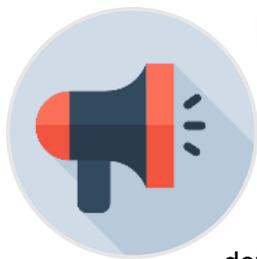
One of the challenges was the change in birth certificate coding of the ethnicity variable in 2011. Some of the finite subgrouping was not available early on, which caused a loss of power for some subgroups. This caused certain subgroups to be omitted or combined into the “Other” category. However, the team tried not to collapse the subgroups due to the significant cultural variations. Another limitation with using PRAMS data is selection bias since it only includes mothers reachable by mail or phone for survey administration.

Including a disaggregation step in analysis may help translate data to action by providing detailed information on how to more effectively tailor programs and materials in improving safe sleep practices and decreasing disparities in safe sleep.

Submitted by: Sarah Stone, Massachusetts State Department of Public Health in 2016

Click [here](#) to see the full write-up.





## Data Communication: Hands & Voices GBYS Program

**Background:** Hands & Voices is a non-profit, parent-driven organization committed to supporting families who are raising children who are deaf or hard of hearing (D/HH). Hand & Voices has used data to not only communicate the stories of many of its members but also, to finetune the development of many of its programs to the needs of the target population. The grant director often uses outside data sources (i.e. CDC, Census, peer-reviewed journals articles from the American Academy of Pediatrics) to communicate stories of families with D/HH children. Often, these family members have very compelling stories thus, when speaking to potential funders, data and statistics strengthen these narratives to show that their story is not a singular experience but rather part of a larger scale issue. Apart from these outside sources, Hands & Voices has utilized an internal source of data collection to communicate programmatic goals to each of their chapters.

**Methods:** [Guide By Your Side \(GBYS\)](#) is a parent-matching program that gives unbiased support to families with children who are D/HH by matching an experienced trained parent or D/HH adult, known as “guides”, to a newly diagnosed family.

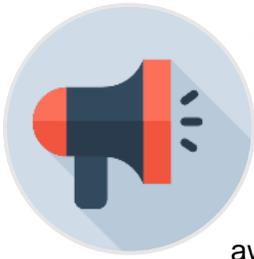
Each year, the program disseminates a health assessment questionnaire to the Chapter Board of Directors, who oversees the GBYS program. Once the questionnaires are completed, Hand & Voices’ compiles the responses into a format that helps each GBYS program develop goals based on the responses. For example, if the responses revealed that many people thought there was a lack of diversity of life experience among the guides, H&V would communicate back this information and recommend that the GBYS program incorporate “increased diversity within the guides” as one of their annual goals. Although each GBYS program has the authority to choose their own goals H&V follows up with each program annually to track their progress.

**Results & Discussion:** Overall, this method of data collection and communication has helped Hands & Voices to increase leadership within the organization and support the organization’s quality improvement process for its intended population. Moving forward, Hand & Voices needs assistance from other non-profit organizations to have both a firm understanding of where data is located and solid training on how to use data.



**Submitted by:** Molly Martze, Hands & Voices in 2016

Click [here](#) to see the full write-up.



## Data Communication: Louisiana BFH Presentation

**Background:** Louisiana's Title V program through the Office of Public Health (OPH) - Bureau of Family Health (BFH) created a communication product on the [maternal and child health \(MCH\) life course metric indicators](#). BFH crafted their presentation with the goal of raising awareness of the life course approach and introducing the [concentrated disadvantage \(CD\) indicator](#) within the Louisiana Department of Health (LDH) and among LDH partner organizations. BFH presented information to LDH, to make sure leaders were knowledgeable and prepared on concepts before outside audiences such as policymakers and funders.

**Methods:** BFH introduced the life course framework using definitions without jargon and visualizations. A clear explanation of the lifecourse perspective allowed the presenter to use that framework to discuss further topics. To communicate the importance of understanding concentrated disadvantage, BFH used a combination of a life course framework, storytelling, targeted audience messaging, and continuous review and revisions to their presentation based on audience and partner feedback. The presentation discussed indicator data by telling stories of infants that incorporated data on the comparative risk of life long MCH health outcomes and how the risks differed based on where infants live. The presentation also included quotes from women living in areas of high concentrated disadvantage about their economic and family health struggles.

BFH sought constructive feedback from several groups in the course of developing the communications product including audiences internal and external to LDH. The presentation was given over 20 times to community groups, public health colleagues, BFH contractors, city council members, and university students. The slides and script were reviewed regularly ensuring current and effective content based on audience feedback.

**Results & Discussion:** BFH gained insights about the effectiveness of the presentation. For example, internal LDH test audiences found polarizing wording which prompted wording edits to avoid potential negative reactions. BFH planned to create shorter versions of the presentation to reach larger audiences. A success from this work came when material from this presentation helped BFH secure a grant to include social determinants of health and concentrated disadvantage data in communication materials for conversations about community, economics, and health with large employers in Louisiana.

Through the life course approach and concentrate disadvantage metrics, BFH hopes to shift to an approach that does not blame individuals for their health circumstances and focuses on addressing social determinants of health inequity (e.g. housing, childcare availability, transportation, neighborhood development, etc.).

**Submitted by:** Rebecca Majdoch, Louisiana Department of Health in 2016



Click [here](#) to see the full write-up.



## Data Communication: Nebraska DHHS Brochure

**Background:** Nebraska Department of Health and Human Services (NEHHS) designed the “Building a Healthy Community” as a resource for conversations about how neighborhood can impact the health of its residents and how community partnerships can address [concentrated disadvantage \(CD\)](#) in their community. The brochure focused on concentrated disadvantage as it captures the synergistic effects of economic and social factors that cluster geographically. To understand how concentrated disadvantage was related to an individual’s health, NEHHS explored CD’s relationship with the teen birth rate.

**Methods:** NEHHS assigned each teen birth that occurred from 2009-2013 a CD score based on where the mother lived when she gave birth and then calculated the teen birth rate in each of the four quartiles. With that data, NEHHS developed a four-page, consumer-oriented brochure and an interactive PDF counterpart.

The “Building a Healthy Community” brochure was given final approval in July 2016. Prior to final approval NEHHS was able to pilot its use within the state and revise the brochure after receiving feedback from four target organizations that serve communities impacted by high concentrated disadvantage. After the “Building a Healthy Community” brochure was finalized, NEHHS posted it on their website and mailed it to local health departments, health centers, and community action agencies in Nebraska. Included was a cover letter introducing them to the brochure, explaining its development, and encouraging review of the brochure and use of it within communities. To increase the utility of the brochure for communities, NEHHS included a fillable insert so communities could suggest local partners to approach for collaboration.

**Results & Discussion:** NEHHS has received positive feedback about the brochure. One local health department requested and received larger maps of their service area and said the maps are useful in presentations with local businesses and program staff. The local health department director said, “It is a GREAT tool when talking with business partners and community leaders who often do not SEE poverty in their area!”

A main challenge in the development of the “Building a Healthy Community” brochure was how to communicate information about concentrated disadvantage without losing interest or understanding. NEHHS overcame this with the use of graphics that supported and built upon the text of the brochure.

Submitted by: Jessica Seberger, Nebraska Department of Health and Human Services in 2016



Click [here](#) to see the full write-up.



## Data-informed Policy: Delaware State Infant Mortality Collaborative Impacts

**Background:** [The State Infant Mortality Collaborative \(SIMC\)](#) was established in 2002 in response to an increase in the infant mortality rate (IMR) and persistent racial and ethnic disparities in infant mortality rates.

The goal of the SIMC was to assist state public health agencies in investigating their increasing, persistent, or high infant mortality rates. Each state in the SIMC worked alongside national experts to develop tools and resources compiled into the [State Infant Mortality \(SIM\) Toolkit](#). From their participation in SIMC and the SIM toolkit, Delaware state identified gaps in data and developed new hospital policies.

**Methods:** Starting with data reporting, the state team determined if inconsistencies within data reporting significantly contributed to the state's IMR prior to analyzing other causes. If this was the case, then the state would take the necessary action to correct the inconsistency

Beginning with data from 1990's, Delaware's SIMC team found inconsistent data reporting on the infant mortality rate. By examining quality, completeness, and timeliness of the hospital records, the Delaware SIMC team could clarify definitions and reporting requirements for fetal death, which improved communication among the hospital staff. Further issues identified through participation in the SIMC, such as the misclassification of infant and fetal deaths, revealed that the state's live-born infant count was higher than what was previously reported between 1993-2002.

**Results & Discussion:** Revised hospital protocol included flagging records with missing or unknown birth weight and records of infants weighing less than 750g for follow up to confirm live birth at the time of reporting. Delaware's participation in SIMC contributed to continued efforts to improve quality of infant death reporting and change hospital protocol. The Delaware Division of Public Health also started reporting death data to the public online through statistical micro-reports. Public health partners have used these data for their own reports and analyses to support both new programs and policy development. By deciphering between misclassifications and new causes of infant mortality, the SIM Toolkit stands as a resource other states can use to analyze IMR trends.

**Submitted by:** [Caroline Stampfel](#), Association of Maternal and Child Health Programs in 2016



Click [here](#) to see the full write-up.



## Data-informed Policy: Florida PQC on Hemorrhaging

**Introduction:** The Obstetric Hemorrhage Initiative by Florida Perinatal Quality Collaborative (FPQC) has helped combat Florida's pregnancy-associated mortality. Florida's Pregnancy Associated Mortality Review (PAMR) committee revealed hemorrhage was one of the top three causes of maternal deaths in Florida between 2005-2009 accounting for 15% of deaths. To address this issue, the Florida Department of Health contracted with FPQC to assemble a collaborative called the Maternal Mortality Prevention Initiative. The collaborative identified hemorrhage as the state's most preventable and highest priority mortality issue. The workgroup enacted a multihospital collaborative of 35 hospitals to implement process changes regarding hemorrhages.

**Methods:** Each hospital implemented the recommended changes for 18 months and institutionalized them for six months. FPQC enacted a series of actions to help each hospital implement the recommended changes. FPQC provided each pilot hospital with a range of resources such as technical assistance from an advisory team, an implementation guide, and a hemorrhage management toolkit. To monitor the outcomes of the initiative, the FPQC staff quantified blood loss for vaginal deliveries by recommending the hospital measure blood loss using visual percent saturation, by weight, and by collection in graduated containers. All measurements were added to the patient's OB Hemorrhage Chart. To gain an estimate of the hospitals' progress, each hospital was asked to audit 30 charts per month. The hospital would then send FPQC monthly aggregate reports for data collection and subsequent analysis.

**Results & Discussion:** At the end of 18 months, FPQC found significant changes in hemorrhage admission protocol among the 35 pilot hospitals. The chart audit indicated that initiative-wide, approximately 79% of women were assessed for risk of hemorrhage upon admission, up from 14% of women at baseline. In addition, the percent of vaginal deliveries in which blood loss was quantified increased from 4% to approximately 62% for all reporting hospitals. By the end of the initiative, each participating hospital educated 100% of their clinical staff on training and active management of the third stage of labor and 71% of their obstetricians/midwives on obstetric hemorrhage.

Overall, FPQC has been influential in encouraging hospitals to change practice to improve health outcomes for mothers and infants. By allowing each hospital to have access to their own baseline data, hospitals were more receptive to implement changes to their systems. FPQC hopes to inspire other hospitals to make an actionable change. Thus, toolkits, webinars, and other resources are available on the collaborative's [website](#).

**Submitted by:** William Sappenfield, Florida Perinatal Quality Collaborative in 2016



Click [here](#) to see the full write-up.