Understanding and Addressing the Drivers of Infant Mortality in Maine

January 2020

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QUALIDIGM

16 Association Drive
Manchester ME 04351

info@qualidigm.org
(800) 632-2008
www.qualidigm.org

Executive Summary

Introduction

Infant mortality, defined as the death of a child under the age of one, is a "sentinel measure of population health that reflects the underlying well-being of mothers and families, as well as the broader community, and social and economic environments".[1] In 1996, Maine had the lowest infant mortality rate (IMR) in the United States—4.4 deaths per 1,000 live births; 60 infants died that year. Over the next two decades, however, the IMR in Maine increased. In 2013, the IMR in Maine was 7.1 , which exceeded the U.S. rate of 6.0, and moved the state to a ranking of 43rd; 91 infants died in Maine before their first birthday in 2013. Although there has been some improvement in Maine's IMR since 2013, Maine can do better. Two states, Massachusetts and Washington, achieved infant mortality less than 4.0 in 2017, and New Hampshire's IMR was 4.2 in 2017.[2]

To understand the changes and identify the drivers of the changes in IMR in Maine over the past two decades, a group of partners representing the non-profit, health care, public health and state sectors designed and implemented the Maine Infant Mortality Project. The goals of this one-year project were to identify the drivers of infant mortality (IM) in the state using quantitative and qualitative data and develop recommendations to reduce IM that reflect the populations, cultures and environment of Maine. (A complete list of definitions and acronyms is included in Appendix A)

Methods

Mixed quantitative and qualitative methods were used to examine the changes and drivers of IM in Maine. Several sources of data were used. The two primary sources were the Maine CDC Vital Statistics birth and death files, and telephone interviews with a diverse group of 34 key informants. The key informants represented Maine state and city agencies, birth hospitals, private practices, community-based organizations, professional organizations, and news organizations. Their areas of experience and expertise included clinical areas (obstetrics, midwifery, pediatrics, neonatology, psychiatry, forensic medicine), home visiting (Public Health Nursing and Maine Families), diverse social and economic needs of vulnerable populations, child abuse and neglect, domestic violence, substance use, family planning, the emergency medical system, behavioral health, the criminal justice system, and Native American health and health care. Other sources included: the Maine CDC's Pregnancy Risk Assessment Monitoring System (PRAMS), the Maine Children's Alliance, Kids Count, Maine Medical Center and Northern Light Eastern Maine Medical Center NICUs, the Maine Office of the Medical Examiner, and safe sleep research conducted by Maine Medical Center and the Maine CDC. Ten telephone interviews were also held with a sample of key informants from other states to learn about successful IM strategies that they have implemented. Three in-person interviews were conducted with women who had recently delivered in order to hear about their experiences of pregnancy and birth.

The framework that we used for our research questions was a Social Ecological Model for Infant Mortality that we developed for this project. This framework includes multiple levels that contribute to an understanding of the dynamic inter-relationships between personal, community, institutional/organizational and social/political/environmental factors. We looked at the distribution of birth and infant deaths by maternal residence (county and rurality), risk factors associated with infant mortality, the causes of infant deaths, and the existing perinatal system of care in the state. The primary limitations of our study were that data were not available for all years of the study, small sample sizes in our stratifications of data, and the limitations of self-reported data that may be subject to error.

Findings and Discussion

Through this project, we documented changes in birth and infant deaths and identified the primary causes and drivers of IM in Maine. IM is complex and multi-factorial, and our research showed that there was no single primary cause or driver of the increases in IM in the state; however, many opportunities were identified to improve birth outcomes.

Consistent with other areas of the country, the number births in Maine over the last two decades have fallen, particularly among adolescents, but births to older (35+) women have increased. Infants deaths in Maine, however, have seen some increases over time. The highest IMR in the state over the past two decades was in 2013. This high rate is particularly concerning in the context of other states continuing to decrease their IMRs in recent years. One important consideration, however, is that in a small state like Maine, small numbers of births and decreases in them, in combination with small increases in infant deaths, more easily result in increases in the IMR, than in larger states with many more births.

Because Maine is a state where the majority of births occur to women living in rural areas and most of the birth hospitals, albeit small hospitals, are in rural areas/counties, rurality was an important area of study for our project. Although the IMR for women living in isolated rural areas was the highest compared to women living in other rural areas and metropolitan areas, it is again important to recognize the effects of changes when the numbers of births and deaths are small.

Most of the infant deaths in Maine and in the U.S. are due to causes related to being born too early. Infants born prematurely and/or low birth weight have the highest IMR. The earlier the pre-term infant is born, the higher the mortality. There are many known risk factors for prematurity such as a history of premature birth, multiple pregnancy, short pregnancy interval, tobacco use, other substance use, obesity, chronic conditions such as diabetes, maternal infections, and stress. Many of these risk factors are amenable to change through medical interventions, but also through behavioral interventions (for example smoking cessation programs) and social support.

The second and third major causes of infant deaths in Maine are congenital anomalies (birth defects) and SIDS/SUID (Sudden Infant Death Syndrome/Sudden Unexpected Infant Death), respectively. The causes of congenital anomalies are often genetic or unknown (the causes of 75% of congenital anomalies are unknown and therefore more difficult to address). However, many SIDS/SUID deaths are associated with unsafe sleep practices, and therefore may be amenable to interventions such as Maine Department of Health and Human Services/Maine CDC Safe Sleep

Campaign (safesleepforme.org) currently underway, enhanced education in clinical and other sites, and the Cribs for Kids program. Other causes of infant death—infections, injuries and other perinatal conditions and causes—were less stable over our period of study (due in part to small numbers), but also saw some increases.

In examining risk factors (drivers) of infant mortality, we identified several established factors associated with Maine infant deaths. These include: demographics (maternal age, maternal education, marital status, race/ethnicity), clinical considerations (multiple pregnancies, adequacy of prenatal care, obesity, mental health conditions), substance use (tobacco smoking, marijuana, alcohol, opioids and other substances), and other issues (domestic violence, unsafe sleep practices and social determinants of health).

Although demographics cannot be changed, the information about their relationships to IM may be used for targeted outreach, education and consideration in practice. For example, births to older women have been increasing at the same time that the IMR in this group has been increasing so this might be a group to target with additional information and/care such as referrals to high-risk obstetricians. Another example is marital status; we found higher IM among unmarried women compared with married women. The higher IMR among Black/African American, compared to White women and other groups, is also an important finding to consider. In the U.S., Black/African American women have consistently had 2–2.5 times higher IMR, compared to White women; and as Maine becomes more diverse, this may be an important measure to monitor.

We identified several risk factors related to clinical care and services. We found increased IM among multiple births, and among women with inadequate prenatal care, obesity, and depression. Other identified risk factors included: cigarette smoking, alcohol use, marijuana use, unsafe sleep practices, and domestic violence. Although quantitative data are not currently available linking social determinants of health to infant mortality, our key informant interviews identified issues such as poverty, unstable housing, hunger and transportation as important IM risk factors that need increased focus.

Results from this project allowed us to define the components of an ideal perinatal system of care for Maine. Examining the current system, we found fragmentation in the continuum of care, a lack of coordination across components, and barriers to services particularly in rural areas. Our findings reveal several opportunities for improvement. These include:

- Improved access to primary care for women before and between pregnancies,
- More perinatal screenings,
- Enhanced mechanisms in place to ensure risk-appropriate care,
- Improved access to mental health services,
- New models of care for women with substance use disorder,
- Strategies to ensure that all families that qualify for programs like Public Health Nursing, Maine Families and WIC enroll in these programs,
- New or enhanced strategies to address perinatal labor shortages and access to maternity services in areas where these services have closed such as rural areas,
- Increased access to specialists,

- Increased provider trainings,

- Increased family engagement and education,

- Stronger communication and collaboration between primary and specialty care providers who share patients, and

- Increased number of statewide and regional activities designed to improve the quality of care and outcomes for mothers and infants.

We also identified a number of assets and strengths to build upon, such as the statewide Perinatal Quality Improvement for Maine (PQC4ME) that includes birth hospitals across the state; the new Children's Cabinet that brings together all state agencies involved in child-related policy and initiatives; longstanding partnerships between the Maine Department of Health and Human Services, the Maine CDC and private sector physicians, hospitals and others; and providers of all types across the state who are deeply committed to ensuring that Maine pregnant women, infants and children experience the best possible outcomes.

Recommendations

We propose recommendations that are summarized below by the strategic areas outlined in the Ideal Comprehensive Perinatal System of Care for Maine framework developed through this project. The strategies include: 1) Infrastructure to Support the Strategies and Actions for the Ideal Comprehensive Perinatal System of Care for Maine; 2) Access to Services; 3) Workforce and Training; 4) Referrals, Coordination and Collaboration; 5) Family Engagement and Education; 6) Policies and Programs; and 7) Assessment, Monitoring and Evaluation. More information about the recommendations is provided in the full report.

Proposed Recommendations by Strategy

STRATEGY 1 **Infrastructure to Support the Strategies and Actions for the Ideal Comprehensive System of Perinatal Care in Maine**

1.1 **Establish and maintain a Work Group.**

1.2 **Determine a perinatal regionalization approach for the State of Maine to ensure access to risk-appropriate care for mothers and infants.**

1.3 **Align and coordinate the Work Group with the Maine CDC MCH Block Grant and the MFIMR (Maternal, Fetal, Infant, Mortality Review) panel to enhance the efforts across these entities and avoid duplication.**

1.4 **Align and coordinate the Work Group with the work of the PQC4ME to enhance the efforts across these entities.**

1.5 **Align and coordinate the Work Group with the work of the Maine Rural Transformation Team and similar high-level state initiatives to enhance the efforts across these entities.**

1.6 Incorporate into all strategies and actions considerations of cultural sensitivity and bias (structural and implicit), as appropriate.

STRATEGY 2 Access to Services

2.1 Design and implement a study to identify the areas of the state, particularly the rural areas, where gaps in services related to perinatal health exist.

2.2 Prioritize, design and implement new or enhanced models of care/services.

2.3 Identify and implement perinatal risk assessment and screening tools, and resources to address the results of the assessments and screenings.

STRATEGY 3 Workforce and Training

3.1 Design and implement strategies/models to fill the identified workforce shortages (clinical, mental health, substance use) across the state.

3.2 Design, implement and evaluate trainings for perinatal providers.

3.3 Design, implement and evaluate trainings for providers who see perinatal populations, but whose focus is not perinatal populations.

3.4 Design, implement and evaluate trainings or modules on perinatal topics for students.

STRATEGY 4 Referrals, Coordination and Collaboration

4.1 Establish written procedures and agreements for maternal and neonatal referrals and transports between community-based birth hospitals and providers, and Level III/V hospitals.

4.2 Establish and implement mechanisms for referrals to community-based programs and services such as Early Intervention (EI) at perinatal care sites (hospitals and practices).

4.3 Coordinate and collaborate (including the sharing of results) on perinatal activities such as PQC4ME QI (Quality Improvement) projects at the birth hospitals and birth centers.

STRATEGY 5 Family Engagement and Education

5.1 Conduct and assess provider trainings on family engagement and shared decision-making.

5.2 Create a comprehensive package of maternal/family education materials.

STRATEGY 6 Public Policies and Programs

6.1 Design and implement an analysis of eligibility (including opportunities for expanding eligibility), participation, services and costs for public programs that can optimize maternal and infant outcomes.

6.2	Examine payment strategies, provider performance incentives and quality improvement initiatives to improve birth outcomes and lower costs.
6.3	Implement and evaluate evidence-based public social media campaigns on select perinatal topics.
6.4	Ensure that eligible women and their families receive the services that promote optimal birth outcomes.
6.5	Design and implement a website of perinatal resources.

STRATEGY 7 Assessment, Monitoring, and Evaluation

7.1	Assess the effectiveness of new and enhanced models and activities using QI methods and data collection, and/or other appropriate evaluation methods.
7.2	Develop and distribute regular public heath reports or dashboards of maternal and infant outcomes.
7.3	Enhance the MFIMR panel reviews and reporting.
7.4	Improve Vital Statistics data, including accuracy, timeliness and reporting.

Summary

Through this project, we were able to describe the trends in births and IM in Maine over the period 2000–2017. We identified the primary causes, and many associated demographic, clinical and other risk factors. We explored the perceptions of a diverse group of experts from across the state about the risk factors they think are important, and how Maine's existing system of perinatal care is working and how it can be improved. Finally, we identified recommendations that address the findings of the report and if implemented, will improve Maine's IMR as well as birth outcomes overall.

While recognizing that the gaps and needs identified in this report are real and substantive, we clearly heard that many are committed to not only improving Maine's IMR but birth outcomes for all infants and families across the state. It is our hope that the findings and recommendations will help inform and guide the process of engagement and action.

Introduction

Infant mortality, defined as the death of a child under the age of one, is a "sentinel measure of population health that reflects the underlying well-being of mothers and families, as well as the broader community, and social and economic environments".[1] In 1996, Maine had the lowest infant mortality rate (IMR) in the United States—4.4 deaths per 1,000 live births; 60 infants died that year. Over the next two decades, however, the IMR in Maine increased. In 2013, the IMR in Maine was 7.1, which exceeded the U.S. rate of 6.0, and moved the state to a ranking of 43rd; 91 infants died in Maine before their first birthday in 2013. Although there has been some improvement in Maine's IMR since 2013, Maine can do better. Two states, Massachusetts and Washington, achieved infant mortality less than 4.0 in 2017, and New Hampshire's IMR was 4.2 in 2017.[2]

To understand the changes and identify the drivers of the changes in IMR in Maine over the past two decades, a group of partners representing the non-profit, health care, public health and state sectors designed and implemented the Maine Infant Mortality Project. The goals of this project were to identify the drivers of infant mortality (IM) in the state using quantitative and qualitative data and develop recommendations to reduce IM that reflect the populations, cultures and environment of Maine. (A complete list of definitions and acronyms is included in Appendix A)

The project was administered by Qualidigm (Maine Quality Counts merged with Qualidigm in January 2019) and jointly funded by the John T. Gorman Foundation, The Betterment Fund, The Bingham Program, the Maine Health Access Foundation and the Sam L. Cohen Foundation. The project also was guided by an Advisory Committee (Appendix C) and implemented through an Operations Team (Appendix L).

Overview of Maine

In the design of the Maine Infant Mortality Project, we identified characteristics of the state that we thought were important to consider in the specific data collected and analytic approaches taken. These included geography, populations, poverty levels and location of birth hospitals across the state.

Located at the northeastern tip of the U.S., Maine is geographically the largest state in New England with an estimated population of 1.34 million. Maine is a sparsely populated state (the 41st most populous state in the U.S.), with the majority residing in rural towns and small cities. There are 16 counties in the state (Figure 1), and three metropolitan areas. The three metropolitan areas are in Portland-South Portland (Cumberland County), Lewiston-Auburn (Androscoggin County), and Bangor-Brewer (Penobscot County).[3]

In 2017, the median age of women in Maine was 46.0 years, and women of reproductive age (15–44 years old) comprised 17% of the population, compared to 20% nationally. About 95% of Maine residents are White, 2% are Black/African American, 1% are American Indian, and 1% are Asian.

About 2% of the population also has Hispanic ethnicity, and Maine has four federally recognized tribes living on reservations in northern and eastern Maine.[3]

Although Maine had an overall poverty rate of 11% in 2017, there are many areas in the state that exceeded this rate. Maine's northern counties had the highest percent of residents with household incomes below the federal poverty level (FPL) while Maine's southern counties had the lowest percent (in 2017, the FPL was set at an annual income of $24,600 for a household of four). The counties with the highest percent of poverty in 2017 were Piscataquis and Washington counties, and those with the lowest poverty rates were Cumberland and York counties.[4] The distribution of poverty by county in 2017 is found in Chart 1.
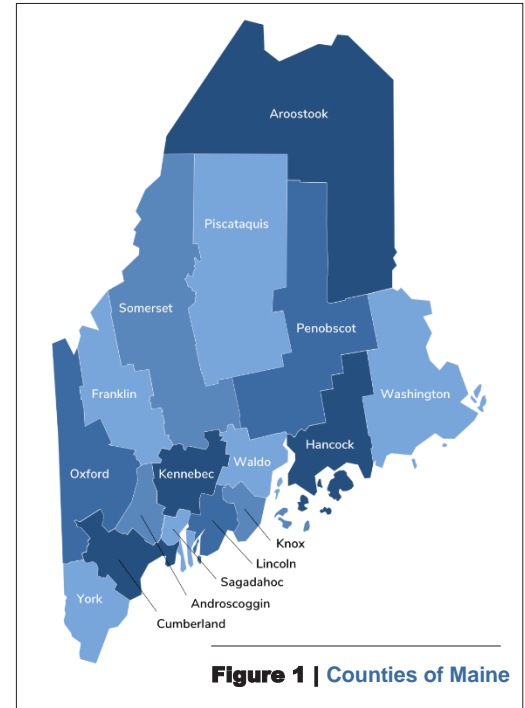
Figure 1 | Counties of Maine

Chart 1 | Percent of Maine Populations Living in Poverty by County: 2017
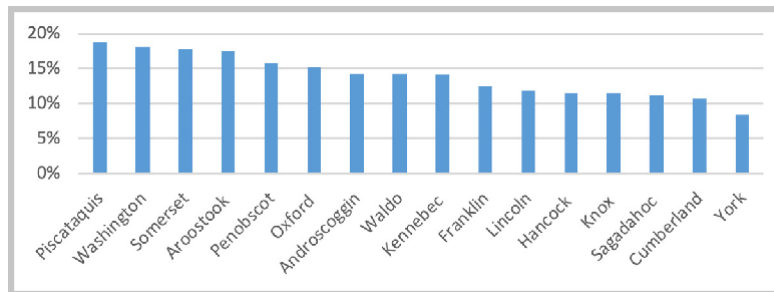
A cornerstone of Maine's Perinatal System of Care are the 26 birth hospitals located across the state (Figure 2 on the next page). Most of the hospitals are small community hospitals. Although the state does not currently have formal designations of levels of perinatal care, the state's two largest hospitals provide high risk care to mothers and infants. Maine Medical Center (MMC) is considered a Level IV hospital that provides the highest level of maternal and newborn care, and Northern Light Eastern Maine Medical Center (EMMC) provides what is considered Level III care to high risk mothers and infants. Both hospitals have Neonatal Intensive Care Units (NICUs) with a combined total of 86 NICU beds. Four Maternal Fetal Medicine physicians (high risk obstetricians) based at MMC provide coverage/consultation for high-risk women across the state. Two hospitals (Maine General Medical Center and Central Maine Medical Center) provide what may be considered intermediate level (Level II) care, and the other 22 hospitals provide community-based, basic (Level I) care. Maine birth hospitals recently completed the LOCATe (Levels of Care Assessment Tool) developed by the U.S. CDC. This tool was developed to provide standardized assessments that align with the 2015 ACOG/SMFM (American College of Obstetricians and Gynecologists/ Society of Maternal Fetal Medicine) and the 2012 AAP (American Academy of Pediatrics) guidance.[5] Descriptions of the levels of care are provided in Appendix A.

Maine Birthing Hospitals – 2018

Legend:
- • Birthing Hospitals (n=24)
- ★ Birthing Hospitals with Level III or IV Intensive Care (n=2)

Updated in December 2018

Figure 2 | Maine Birthing Hospitals

Access to the birth hospitals for delivery, however, varies by geographic location, and local access has been diminished over the last two decades. Since 1998, 7 delivery services have been closed; most were in rural areas. Closure occurred in Blue Hill (Hancock County), Boothbay Harbor (Lincoln County), Brunswick (Cumberland County), Calais (Washington County), Lincoln (Penobscot County), Millinocket (Penobscot County) and Sanford (York County).

Methods

Quantitative and qualitative methods were used to examine the changes and drivers of IM in Maine. Several sources of data were used. The two primary sources were the Maine CDC Vital Statistics birth and death files, and telepho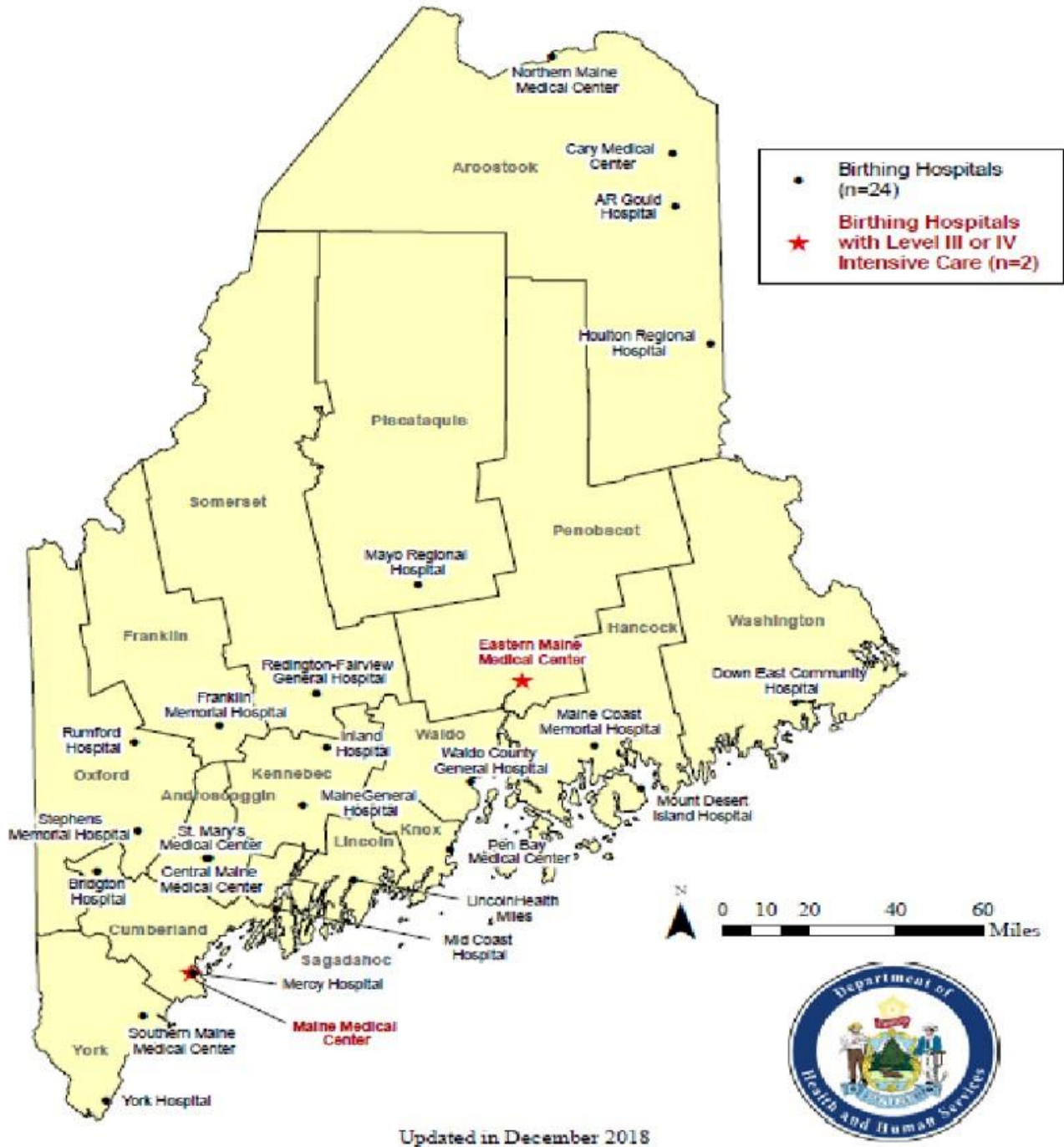ne interviews with a diverse group of 34 key informants. The key informants represented Maine state and city agencies, birth hospitals, private practices, community-based organizations, professional organizations, and news organizations. Their areas of experience and expertise included clinical areas (obstetrics, midwifery, pediatrics, neonatology, psychiatry, forensic medicine), home visiting (Public Health Nursing and Maine Families), diverse social and economic needs of vulnerable populations, child abuse and neglect, domestic violence, substance use, family planning, the emergency medical system, the criminal justice system, and Native American health and health care. A list of those interviewed is included in Appendix D.

Maine's Pregnancy Risk Assessment Monitoring System (PRAMS) survey was used to capture data on maternal experiences before, during and after pregnancy. PRAMS is a representative survey of new mothers in Maine that is administered on an annual basis by the Maine CDC.

Other sources included: the Maine Children's Alliance, Kids Count, Maine Medical Center and Northern Light Eastern Maine Medical Center NICUs, the Maine Office of the Medical Examiner, and safe sleep research conducted by Maine Medical Center and the Maine CDC. Ten telephone interviews were also held with a sample of key informants from other states to learn about successful IM strategies that they have implemented. Three in-person interviews were conducted with women who had recently delivered in order to hear about their experiences of pregnancy and birth.

Research Questions

The framework that we used for our research questions was a Social Ecological Model for Infant Mortality that we developed (Figure 3). This framework was adapted from the ecological model of McLeroy et al.[6] and includes multiple levels that contribute to an understanding of the dynamic inter-relationships between personal, community, institutional/organizational and social/political/environmental factors.

Figure 3. Social Ecological Model of Infant Mortality

Social, Political, & Environmental Level
- Federal and state public benefits programs
- Policies and laws governing payment and insurance coverage
- Federal and state funding opportunities

Institutional/Organizational
- Location of hospital(s), community health centers, private practices, and clinics
- Availability of trained health providers – OBs, pediatricians, PH nurses, mental health and substance use providers, primary care practitioners
- Domestic violence programs and case management services

Community Level
- Urban vs. rural setting
- Transportation
- Food security, including distance to grocery stores
- Housing - including access to safe and affordable housing, as well as housing discrimination
- Cultural and religious values

Household/Interpersonal
- Race/ethnicity
- Educational attainment
- Jobs/income/employment opportunities
- Family, friends, and social support

Our guiding quantitative research question was: how have IM and associated demographic, clinical and other risk factors, changed over the past two decades in Maine? Vital records data on Maine's births and infant deaths served as the primary source for these analyses Depending on the availability of the data, we conducted trend analyses over the years 2000–2017 or a subset of this time period, or compared subsets of years such as 2000–2004 and 2013–2017. A complete list of the questions for the quantitative analyses is included in Appendix E.

The guide used for the key informant interviews is included in Appendix F. Because of the diverse experiences and expertise of the key informants and the scope of the questions asked, a semi-structured interview guide was used expecting that some of the interviews would be focused on certain topics within the individuals' experience and expertise. In the interviews, we explored the interviewees' perceptions and understanding of the causes of IM in Maine, the perinatal system of care, and policies and programs that may impact infant mortality.

We also sought to address a variety of contextual questions in order to better understand the broad landscape of women's and children's health in the state. Data from Maine's PRAMS surveys, Maine KIDS Count, hospital records, and other sources were used. The research questions explored through these data sources are summarized in a table in Appendix G.

Data Limitations

There were limitations to the data we used. In 2003, the U.S. CDC's National Center for Health Statistics made significant revisions to the US standard certificate of live birth. Maine adopted these revisions and added several state-specific elements in August 2013. Due to these changes, not all birth certificate derived variables were available for the entire 2000–2017 study period. Additionally, Maine's overall small population and low annual counts of infant deaths necessitated

combining years and or grouping variable categories to improve stability and minimize the risk of indirect identification of individuals due to small cell size. Because of Maine's relatively low population, single year outcomes stratified by more than one demographic or risk factor, such as infant deaths in 2017 analyzed by race and cause of death, often result in small cell sizes.

The primary limitation of the PRAMS data, which are collected via a standardized data collection methodology developed by the U.S. CDC, is that the data are self-reported by new mothers and may be subject to potential sources of errors sometimes found in surveys of health and behavior. For example, women may not recall events that occurred before or in the early periods of their pregnancies, and they may also be hesitant to report behaviors seen as unhealthy.

Other supplementary data used are subject to several limitations. Many were collected for other reasons and over varying periods of time. Finally, the three patient interviews were not intended to represent all Maine women who delivered, but rather to highlight examples of the experiences of a small sample of pregnant women in Maine's perinatal system of care.

Findings

The findings are summarized in this section according to the following outline:

- Description of Maine Births and Infant Deaths
- Causes of Infant Deaths
- Infant Mortality Risk Factors
- Perinatal System of Care in Maine
- National and State Strategies to Reduce Infant Mortality

Unless otherwise noted, the source of the data presented is Maine CDC Vital Statistics birth and infant death files.

Highlights of the findings are in bold print.

Statewide and Regional Births and Infant Deaths

Trend in the Number of Births to Maine Residents: 2000-2017 (Chart 2)

- Over the 18–year period studied, there were 239,486 births to Maine residents, an average of 13,305 births per year.
- **From 2002 to 2006, there was a small steady increase in the number of annual births; and from 2006–2017, there was a steady decline in the number of births.**
- The lowest number of births during the study time period occurred in 2017 (12,290).

Chart 2 | Number of Births to Maine Residents: 2000-2017 (in 1,000s)

Chart 2 | Number of Births to Maine Residents: 2000-2017 (in 1,000s)
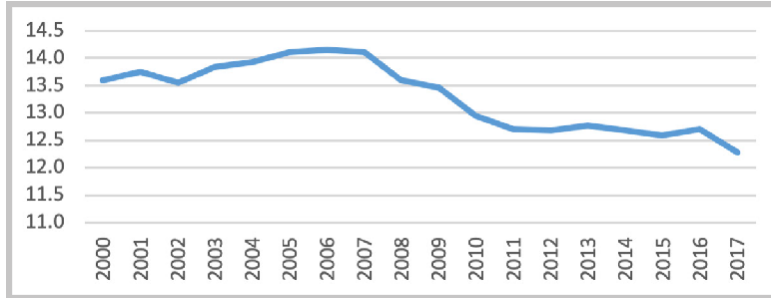
Trend in the Number of Infant Deaths to Maine Residents: 2000-2017 (Chart 3)

- There were 1,417 infant deaths, an average of about 80 per year, over the period 2000–2017.

- The lowest number of annual infant deaths was 66 in 2000, and highest number was 97 in 2005.

Chart 3 | Number of Infant Deaths in Maine: 2000-2017
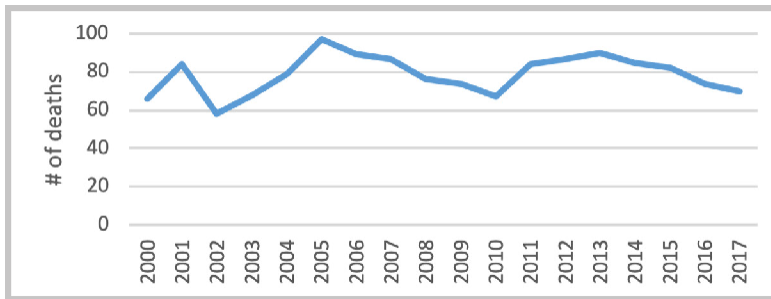
Trend in the Infant Mortality Rate in Maine: 2000-2017 (Chart 4)

- **The annual IMR (number of infant deaths per 1,000 live births) over 2000–2017 showed a cyclical pattern.**

- It was lowest in 2002 (4.3) and highest in 2013 (7.0); the 2013 IMR represented a 63% increase in IMR compared to 2002.

- Although the IMR steadily declined between 2013 and 2017 to 5.7 in 2017, the 2017 IMR was still 33% higher than it was in 2002.

Chart 4 | Maine Infant Mortality: 2000-2017
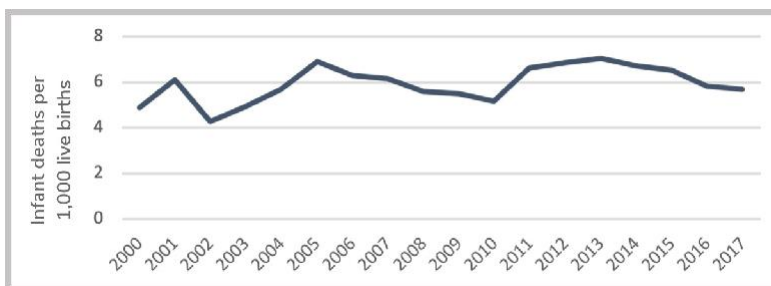
Distribution of Maine Births by Maternal Residence: 2013-2017 (Charts 5a, 5b)

We examined the distribution of births by both county and rurality of maternal residence for the periods 2003–2007, 2008–2012, and 2013–2017. The findings are depicted in Charts 5a and 5b for 2013–2017 (the distributions were similar for the earlier years).

- There was variability in the distribution of births across the 16 Maine counties.
- The 5 counties with the highest percent of births were: Cumberland, York, Penobscot, Androscoggin and Kennebec.
- The 5 counties with the lowest percent of births were: Piscataquis, Franklin, Lincoln, Washington and Sagadahoc.
- **More than one in five Maine births occurred to mothers living in Cumberland County, while only one in 100 births occurred to mothers living in Piscataquis County.**

Chart 5a | Distribution of Births (%) Across Maine Counties: 2013–2017
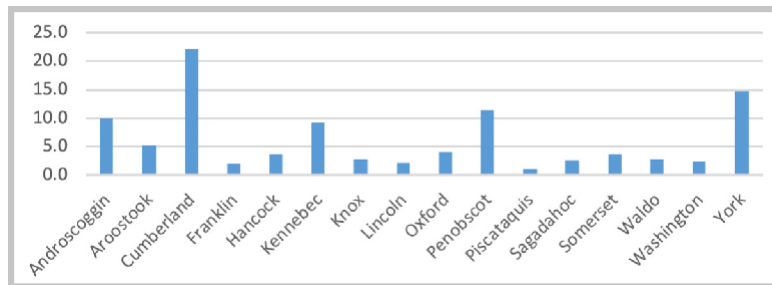
For the definition of rurality, we used: the Rural-Urban Community Area (RUCA) classification scheme (version 3.10)[7] with the RUCA 2010 Crosswalk to New England Rural Definition.[8] In this scheme, a community's rurality is determined using measures of population density, level of urbanization and commuting distance

Using this definition, we identified four levels of rurality (metro, large rural, small rural, isolated rural). Examples of communities in each of the four categories include:

- Metro: Portland, Lewiston, Biddeford
- Large rural: Augusta, Waterville, Sanford
- Small rural: Livermore Falls, Caribou, Presque Isle
- Isolated rural: Machias, Ft. Kent, St. Albans
- **About 65% of Maine births were to women living in rural areas with the majority of these women living in large rural areas.**

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Chart 5b | Distribution of Maine Births (%) by Rurality: 2013-2017
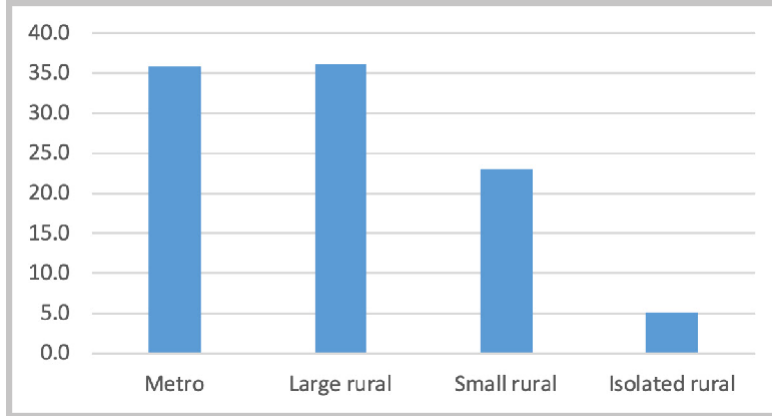
Infant Mortality Rate by Maternal Residence: 2003-2017 (Figure 4, Chart 6)

We examined the IMR by county and rurality and found the following:

- **In the period 2013–2017, the highest IMRs were found in the northern Maine counties (6.5 – 9.9), and the lower rates were found in the southern and western part of the state (4.7-6.2).**

- Except for isolated rural areas, the IMRs did not change much over the three periods examined.

- In 2013–2017, the IMR was highest in "isolated rural" areas of Maine, while in previous time periods the IMR in isolated rural areas were the lowest in the state. This change should be regarded with caution, however, as the IMR for the isolated rural category is the most un- stable due to very low absolute numbers of both births and infant deaths.

Figure 4 | Infant Mortality Rate by Maine Counties: 2013 – 2017

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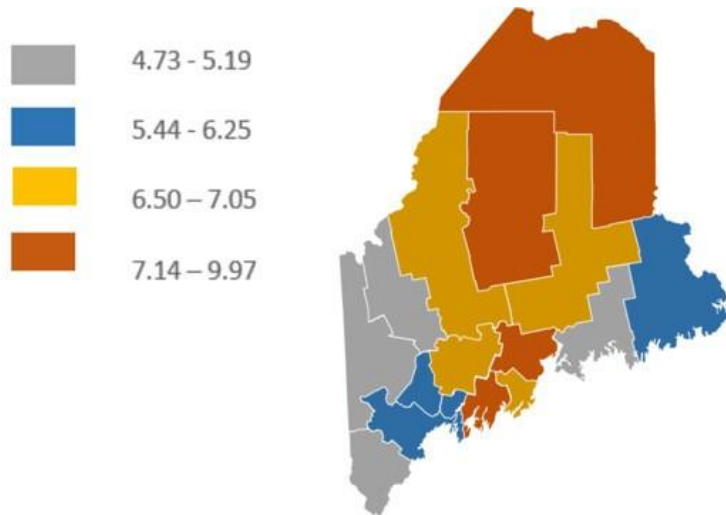
Chart 6 | Maine Infant Mortality Rate by Rurality: 2003-2017
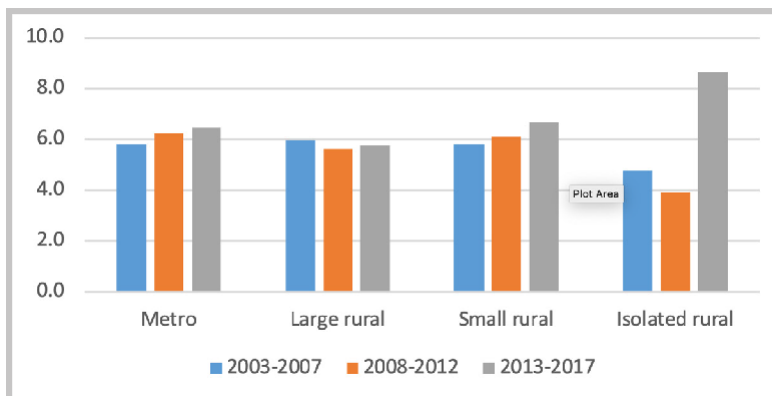
To further investigate the impact of rurality on Maine's IMR, the Kitagawa decomposition method was used to clarify the role of changes in Maine's birth distribution and changes in the location-specific survival of infants born at the beginning of the study period (2000–2004) versus the end of the study period (2013–2017). Due to small numbers of deaths in each period, a two-level (rural/urban) rurality variable was used. The results suggest:

- Shifts in the residential distribution of births between 2000–2004 and 2013–2017 played a very small role in the overall increase in IM between the two periods;

- **Both rural and urban infants experienced worse survival outcomes in the more recent 5-year period.**

- **The overall IM increase among rural infants between the two time periods was less in absolute terms (5.2 per 1,000 in 2000–2004 vs. 6.3 per 1,000 in 2013–2017) than among urban infants. However, because rural births declined in the later time period, those infants who were born in rural areas during 2013–2017 had even worse survival outcomes relative to their urban counterparts.**

Additional results and further details on the Kitagawa decomposition method are included in Appendix H.

Trends in the Place of Birth and Infant Death (Hospital or Home): 2000-2017

- 98–99% of births occurred in hospitals during the period 2000–2017.

- The percent of infants born at home doubled from 1% of births in 2000 to about 2% in 2017; the highest number of babies born at home was 264 in 2016 (the number was 244 in 2017).

- For 16 of the 18 years examined, 0-2 infants born at home died; however, this number increased to 3 in 2003, and spiked to 6 in 2013.

Trends in the Age of the Infant at Death: 2000-2017 (Chart 7)

- **Over the entire period of study, the IMR was highest during the early neonatal period (the first 6 days of life), followed by the post-neonatal period (days 28–364 of life), and then the late neonatal period (7-27 days of life). Newborns are most at risk during their first week of life.**

- **Among the deaths that occurred during the post-neonatal period, the IMR was highest in 2012 and 2013.** Also, the gap between post-neonatal deaths and late neonatal deaths increased between 2011-2015 but has since narrowed.

- In 2013, there were 6 deaths to infants that were born at home. Two of these deaths occurred in the neonatal period and four occurred in the post-neonatal period.
- **There do not appear to be rural/urban differences in the rates of deaths during the neonatal and post-neonatal period over time. The rate of neonatal deaths is higher in both rural and urban areas compared to post-neonatal deaths.**

Chart 7 | Age at Death for Maine Newborns: 2000-2017
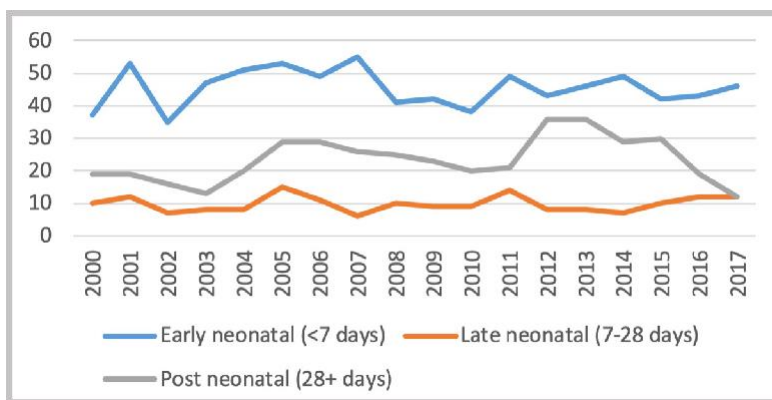
Infant Mortality Rate, Birth Weight and Gestational Age (Tables 1, 2)

We also examined both birth weight and gestational age, and found:

- **Newborns at the lowest birth weights and earliest gestational ages had the highest infant mortality.**
- Across the three periods (2003–2007, 2008–2012 and 2013–2017) the distribution of births by birthweight was generally consistent, with the exception of births classified as moderately low birthweight (1,500 grams–2,499 grams); births in this weight category increased by an average of 1% per year over the study period.
- Infants born at or below 1,499 grams had the poorest survival outcomes in all time periods. Among VLBW newborns, the IMR increased from 277 in 2003–2007 to 305 in 2008–2012, but then decreased in the latest period.
- Similarly, the IMR for MLBW babies increased in 2008–2012, but then decreased in 2013–2017 (Table 1).

Table 1 | Maine Infant Mortality Rate by Birth Weight: 2003-2017

Birth Weight	2003-2007	2008-2012	2013-2017
VLBW (<1500 grams)	276.7	304.7	280.4
MLBW (1500-2499 grams)	12.2	15.0	10.6
NBW (2500+ grams)	2.0	2.0	2.4

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- **The proportion of infants born preterm (less than 37 weeks gestation) has been increasing since a low of 8% in 2012. In 2017, 9% of Maine births were preterm. IMRs for infants born at 32 weeks or earlier were higher than the other two gestational age groups (Table 2).**

- **Maine's 2013–2017 IMR for the less than 32–week group was among the highest in the U.S. for that period.[9]**

Table 2 | Maine Infant Mortality Rate: 2003-2017

Gestational Age	2003-2007	2008-2012	2013-2017
Less than 32 weeks	247.9	260.3	243.6
32-36 weeks	8.9	8.7	8.8
37 weeks or more	2.0	2.2	2.5

To further investigate the impact of Maine's increasing number of preterm births on the state's IMR, gestational age–specific mortality rates during 2000–2004 and 2013–2017 were examined using the Kitagawa decomposition method. Results showed:

- **In 2013–2017, there were more infants born at less than 32 weeks and at 37–38 weeks compared to 2000-2004. These increased proportions of infants born at less than 32 weeks and those born between 37-38 weeks accounted for 15.1% and 14.1%, respectively, of the increase in mortality among infants at these gestational ages.**

- There was essentially no change in the distribution of infants born at full term, thus all of the increase in mortality of these infants in 2013–2017 was due to worse survival outcomes among full term infants in 2013–2017. Additional results and further details on the Kitagawa decomposition method are included in Appendix H.

Excess Fetal and Infant Deaths by Risk Period

The perinatal periods of risk (PPOR) approach is a comprehensive, multidisciplinary approach frequently used to better understand the drivers of IM in a state or region. The first phase of PPOR includes calculating the rate of "excess" fetal and infant deaths and categorizing these deaths into four periods of risk based on age and weight at death. The rate of excess deaths is calculated by comparing a population with lower IM (a reference population) to those not included in the reference population.

Using birth, death and fetal death data from 2014–2017, and a reference population of white mothers aged 24-34 who had completed at least some college education, it was determined that Maine's overall excess mortality rate during this time period was 3.5 per 1,000. The findings showed that excess infant and fetal deaths were most likely to occur in the Maternal Care period (35%), followed closely by the Infant Health (32%) period, and the Maternal Health/Prematurity (25%) period (Figure 5). Additional details about Phase 1 of the PPOR approach are provided in Appendix I.

Figure 5 | PPOR Phase 1 Feto-Infant Mortality Map, Maine, 2014-2017
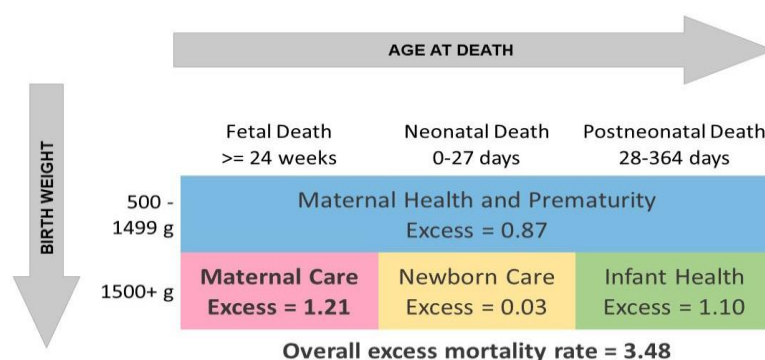
The PPOR findings suggest that Maine's prevention strategies should focus in three areas:

- **Reducing fetal mortality by focusing on ensuring adequate prenatal care and referring high risk pregnancies to specialty care.**

- **Reducing deaths among very low birth weight infants by improving preconception care, reducing high risk behaviors during pregnancy and ensuring appropriate perinatal care.**

- **Reducing post-neonatal mortality by reducing sleep-related deaths and preventing deaths due to child maltreatment, infection, and unintentional injury.**

Causes of Infant Mortality

Most infant deaths in Maine are due to causes related to being born too early. Preterm-related causes of IM were the leading cause of infant death in Maine during the study period. Congenital anomalies or birth defects were the second leading cause followed by SIDS/SUID. Other less frequent causes included infections, injuries, other perinatal conditions (not included in the pre-term related causes). The IMRs attributable to each cause fluctuated over the 2000–2017 study period. Highlights are noted below. Descriptions of the causes and examples also are included in Appendix A.

- **Between 2011 and 2014, which include the year (2013) in which Maine's IMR peaked at 7.0, the rate of deaths due to preterm related causes, congenital anomalies, and SIDS/SUID (Sudden Infant Death Syndrome/Sudden Unexplained Infant Death) all increased.**

- Preterm-related causes and congenital anomalies were the leading cause of IM during the neonatal period. In the post-neonatal period, the leading causes of IM were SIDS/SUID and congenital anomalies. Infections and injuries also contributed to post-neonatal infant mortality.

- **Among infants whose deliveries were covered by MaineCare, the top three causes of death were somewhat different than the causes among those with other payers. Preterm-related causes were the leading causes of death among infants whose delivery was covered by MaineCare; the second leading cause among these babies was SIDS/SUID.** In fact, the SIDS/SUID IMR for MaineCare births was 1.2 in 2014–2017, compared to 0.5 among births covered by other payers.

Chart 8 | Infant Mortality Rate of Three Leading Causes of Infant Deaths in Maine: 2000-2017
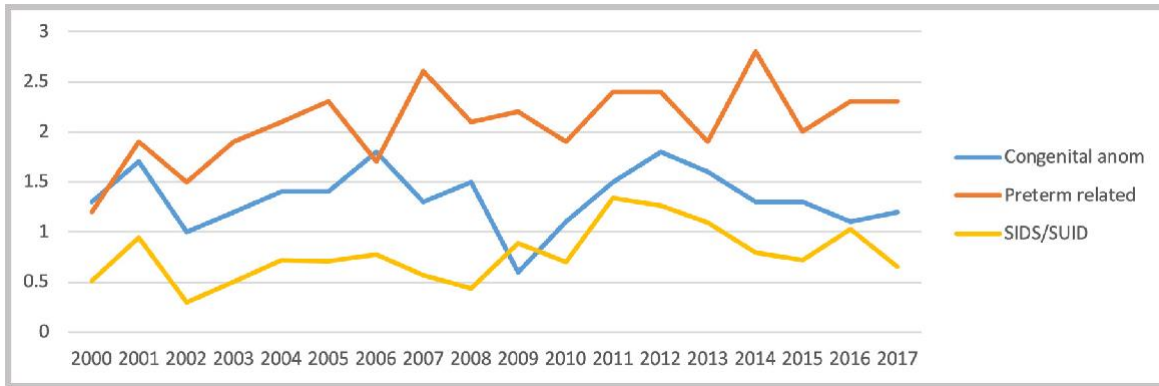
Chart 9 | Infant Mortality Rate of Other Causes of Infant Deaths in Maine: 2000-2017
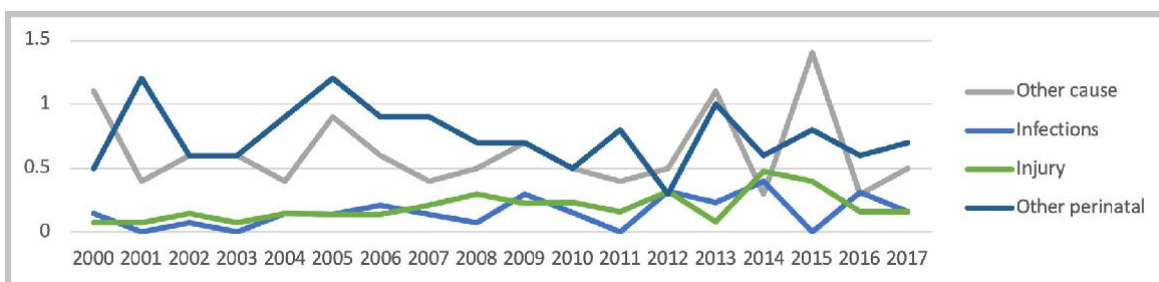
Infant Deaths by Risk Factors

Trends in Infant Mortality Rate (IMR) by Maternal Demographics - Age, Education, Marital Status, and Race/Ethnicity

Maternal Age: 2003-2017 (Chart 10)

We compared the IMRs in three age groups (women under 25, 25-34, and 35 or older), during three consecutive periods (2003–2007, 2008–2012 and 2013–2017) and found:

- **For each period studied, the IMR was lowest among women aged 25-34 years of age, followed by older women 35 and older, and women under 25.**

- **The number of births to Maine women under the age of 25 has declined over time, but births to older women have increased and the IMR in this group also increased in recent years.**

Chart 10 | Maine Infant Mortality Rate by Maternal Age: 2003-2017

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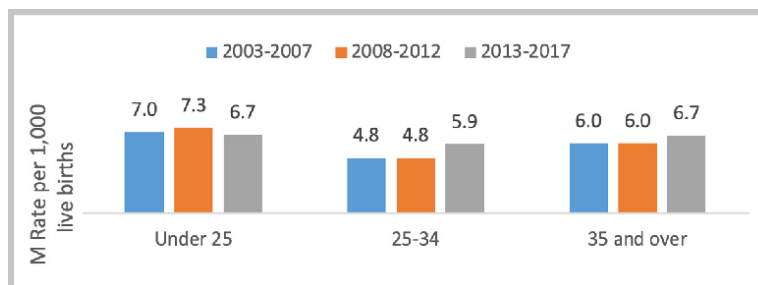
Maternal Educational Attainment: 2000-2017 (Chart 11)

Comparing women with less than a college education (high school diploma, GED or less education) with those with at least some college, we found:

- **The proportion of births to women with a high school diploma or less decreased over this period (from 47% in 2000 to 34% in 2017), but the IMR in this population was consistently higher than the IMR among women with some college education.**

- **In 2017, the IMR for those with a high school diploma or less was 8.6 compared to 4.0 for women with at least some college education.**

Chart 11 | Maine IMR by Maternal Education: 2003—2017
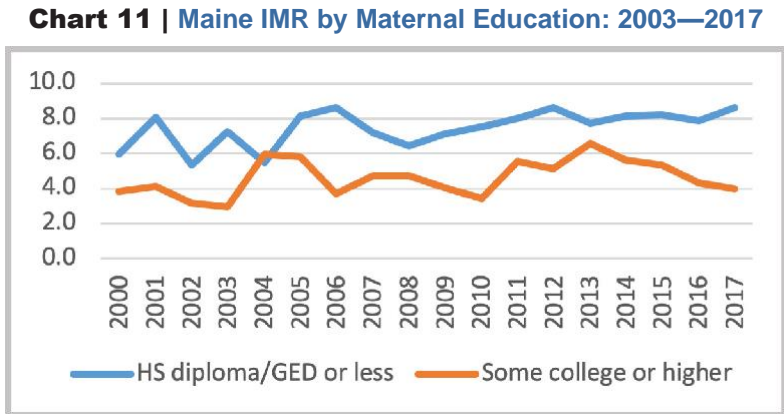
Marital Status: 2014-2017 (Chart 12)

- **Across all four years, the IMR was lower among infants whose mothers were married at the time of birth.**

- In 2017, the IMR among married women was 3.9, compared with 8.4 among unmarried women. The reason for this disparity is not clear, but it may be related to higher income and more available social support among women who are married.

Chart 12 | IMR by Maternal Marital Status and Year: 2014-2017
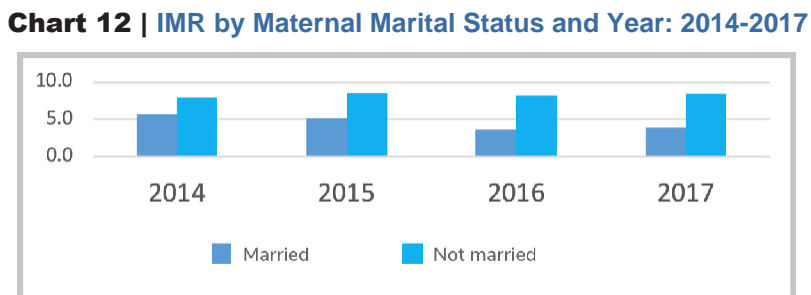
Race/Ethnicity: 2003 – 2017 (Charts 13 and 14)

We examined race and Hispanic ethnicity, and found differences in IMR across populations:

- **The IMR among Black/African American women in Maine was almost two times higher than the rate among White women between 2003-2007 (IMR of 11 vs. 6).**

- Since 2003-2007, the IMR among Black/African American Maine women has remained higher

than the IMR among White women, but the gap between Black/African American and White IMR has narrowed somewhat. The rate ratio for 2014–2017 is 1.4.

- The IMR among infants born to American Indian/Alaska Native mothers, Asian or Pacific Islander mothers, and mothers of other races fluctuated during the study period. Importantly, the absolute number of births and deaths among each group are too small to provide stable estimates, therefore evidence of change in the IMR among these groups over time should be interpreted with caution.

- For Hispanic women, the IMR for 2004-2007 was lower (4.2) than the rate for non-Hispanic women (5.9); however, since that time, the IMR among Hispanic women has exceeded the rates of non-Hispanic women.
  - o Because of the small number of births and deaths to Hispanic women in Maine (there are fewer than two deaths per year) these rates are subject to random variability.

Chart 13 | Maine Infant Mortality Rate by Race: 2003–2017
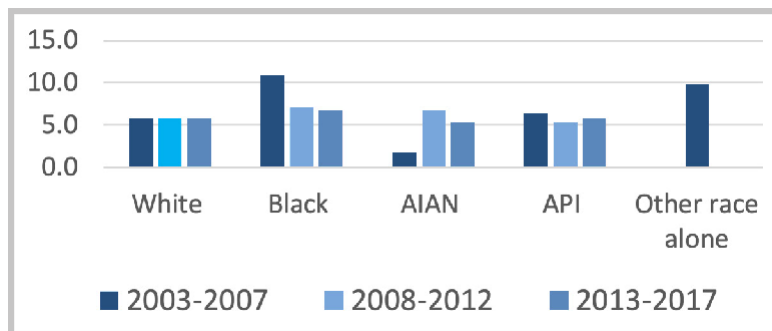
Chart 14 | Maine Infant Mortality Rate by Hispanic Ethnicity: 2003-2017
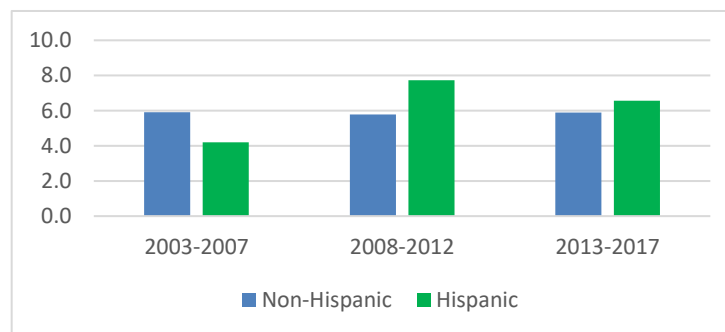
Clinical and Behavioral Risk Factors Related to Infant Mortality

We examined the following clinical and behavioral risk factors: multiple births, adequacy of prenatal care, substance use (tobacco, marijuana, alcohol, opioids and other substances), unsafe sleep practices, mental health conditions and domestic violence. Using several data sources to examine these risk factors (Vital Statistics, the key informant interviews and PRAMS), we found the following:

Multiple Pregnancies: 2003-2017 (Chart 15)

- Between 3%–4% of the annual births over the period 2000–2017 were multiples with little change over time; the annual average of multiple births was 435.

- **Compared to singleton births, the IMR for the multiple births was consistently found to be 5-6 times higher.**

Chart 15 | Infant Mortality Rate for Singleton and Multiple Births: 2003-2017
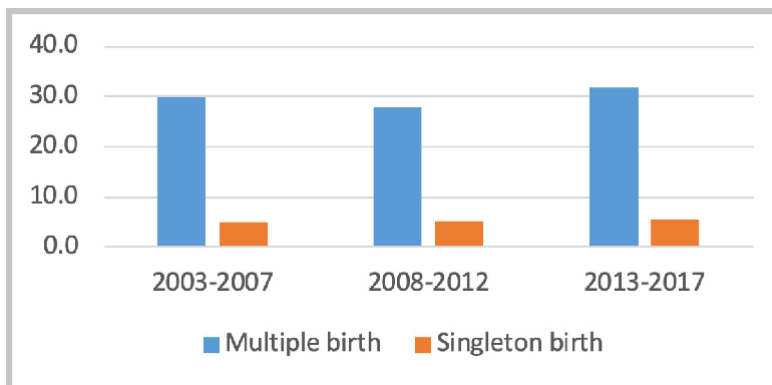
Adequacy of Prenatal Care: 2014-2017

Whether a woman has adequate prenatal care is measured by when she begins prenatal care (recommended to be within the first four months of pregnancy) and whether she has the recommended number of visits.[10] We examined adequacy of prenatal care for the years 2014—2017, and found:

- **At least 86% of pregnant women received adequate prenatal care; this percentage did not change over this four-year period.**

- **Even though less than 15% of Maine women did not receive adequate prenatal care, these women were more likely to have an infant die than the women who received adequate prenatal care.**

- **The IMR among women who did not receive adequate prenatal care was higher in each of the four years compared to the other women; in 2017, the IMR among these women was 9.1 compared to 5.2 among women who received adequate prenatal care.**

Obesity: 2014-2017 (Chart 16)

We reviewed 2014–2017 pre–pregnancy obesity rates and IMR by pre–pregnancy weight and found:

- **Among women who gave birth in Maine in 2014–2017, 29% were obese and 27% were over–weight before pregnancy.**

- **The IMR was highest for women who were obese (6.9), and lowest for women with normal weight (5.5).**

- **Compared to women with normal weight, the IMR for women who were obese was 25% higher.**

In addition to these data, clinicians and other key informants interviewed also reported an alarming increase in the number of pregnant women they care for who are obese.

Chart 16 | Maine Infant Mortality Rate by Pre-Pregnancy Weight, 2014-2017
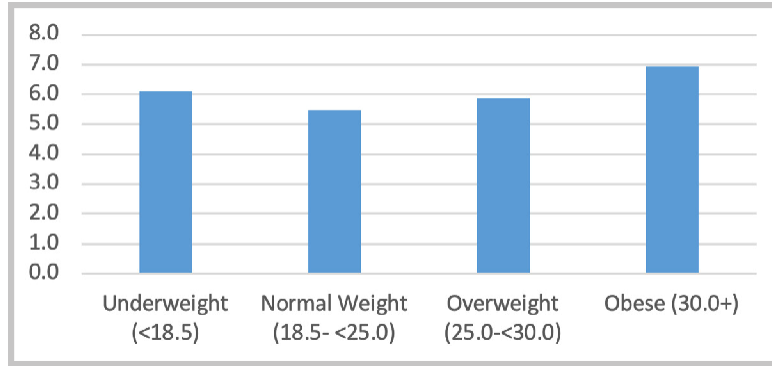
Mental Health: 2016-2017

Data on maternal mental health are not collected in Maine's birth or death certificates and were therefore not available for analysis in relation to IM. However, this important contextual factor was explored using data from the 2016–2017 Maine PRAMS survey and the key informant interviews. The PRAMS data showed:

- **About 16% of respondents for both years reported depression during pregnancy,**

- Postpartum depression symptoms were reported to be higher in 2017 (13%) than in 2016 (11%), although these findings were not statistically significant.

- **According to the interviewees who care for pregnant and post-partum women, anxiety and depression, including post-partum depression, are the most frequently encountered mental health conditions.** Key informants noted the contribution of these conditions to poor infant and maternal outcomes.

Tobacco Use: 2014-2017

We examined smoking rates in the last three months of pregnancy during the period 2014– 2017, and found:

- According to data collected in Maine's birth registry, **the percentage of Maine mothers who smoked during the last three months of pregnancy decreased from 14% in 2014 to 11% in 2017, however, Maine continues to have one of the highest rates of smoking during pregnancy in the nation.**

- **For the period 2014–2017, the IMR was 82% higher among pregnant women who smoked during the last three months of pregnancy compared to those who did not smoke, 10.0 vs. 5.5.**

Maine's PRAMS survey also includes questions about maternal tobacco use. Data from the 2016 survey showed a 14% smoking rate during pregnancy (somewhat higher than the 12% above), with the highest rates among women 20-24 (26%) and the lowest among those 35 or older. Tobacco smoking during pregnancy also was identified as a major concern in the key informant interviews.

Marijuana Use: 2017

PRAMS data on marijuana use during pregnancy and after birth showed:

- **11% of pregnant women used marijuana during pregnancy in 2017.**
- **In 2017, 14% of mothers used marijuana in the post-partum period.**

Key informants also raised significant concerns about increases in its use, and its potential effects on the fetus. Recent legalization in Maine that allows the use of medicinal and recreational marijuana was specifically cited as a contributory factor in increased use during pregnancy, as well as decreased tobacco smoking during pregnancy. Data were not available to assess the relationship between IM and marijuana use.

Alcohol Use: 2008-2017 (Chart 17)

We were unable to assess the relationship between IM and maternal alcohol consumption, but we were able to examine data on alcohol use during the last three months of pregnancy from Maine's PRAMS survey, and the key informant interviews. **PRAMS data showed variability in the percent of women who drank alcohol in the last trimester of pregnancy over this ten-year period with a rate of 10% in 2017.**

Chart 17 | % of Women Who Used Alcohol During the Last 3 Months of Pregnancy: 2008-2017
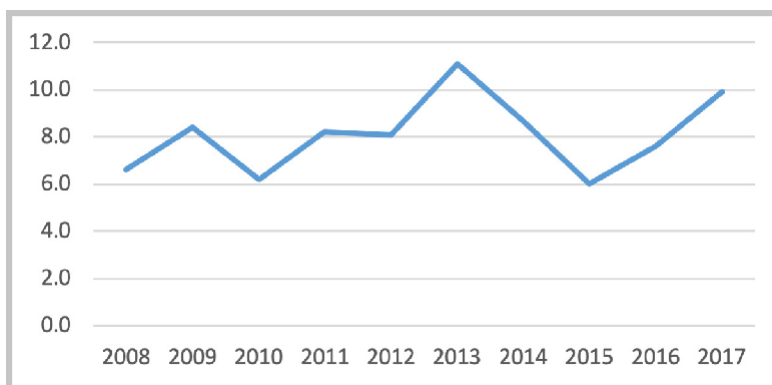
Many of the key informants believe alcohol use during pregnancy is a major problem, and expressed concerns that the focus on opioids in recent years has taken away from a needed focus on alcohol use in pregnancy not only for effects on the fetus, but also as a potential contributing factor related to unsafe sleep practices. Unlike most of the other risk factors for IM, alcohol use during pregnancy is more commonly reported among women with more education and higher incomes.

Opioids and Other Substances

We were not able to obtain quantitative data on women's use of opioids during pregnancy, but we obtained data on substance-exposed infants reported to the Maine Office of Child and Family Services. These reports showed a **steady increase in the numbers of reports of drug-exposed newborns and percent of births with reported drug-exposed infants from 2012 to 2016. The trend shifted in 2017 with decreased numbers in that year as well as 2018.** In 2016, there were 1,024 reports of drug–exposed newborns, who represented 8% of the births, but in 2018, these had dropped slightly to 7% (904 births).[11]

Key informants in clinical practice and from community-based organizations reported both caring for and knowing about many pregnant women with substance abuse disorders, including opioids. Many of these women were receiving methadone or suboxone. Providers noted more acceptance of these women in clinical settings which they expect to contribute to better outcomes. **Two concerns were raised about women with substance abuse disorders: these disorders may contribute to increased unsafe sleep practices, and the stress of new parenthood may contribute to relapse in the post-partum period.**

Domestic Violence: 2016-2017

Analyses of 2016–2017 PRAMS data showed:

- In 2016 and 2017 respectively, 3% and 2% of women reported domestic violence by a current or former partner during pregnancy[12]; however, it is widely suspected that domestic violence during pregnancy and more generally is widely unreported.

Across the board, the key informants said that they think domestic violence is a significant issue in Maine, that it is hard to identify, highly underreported, and a contributing factor in IM. Although there are domestic violence services across the state, two of the biggest challenges are getting women who are in domestic violence situations to disclose and seek help, and the variability in the screening approaches. **Although screenings are regularly done in health care settings including hospitals, one expert interviewed recommended the screening processes can be improved to better identify those in these situations.** For example, the specific questions asked, when they are asked, and where and by whom they are asked are important considerations. More training of health care providers was recommended.

Unsafe Sleep Practices

Unsafe sleep practices were raised as significant contributors to IM in data reviewed from the PRAMS survey, data from the Medical Examiner's Office and the hospital and MMC research, and in the interviews. The practices cited included: co-sleeping, prone or side sleeping, unapproved sleeping surfaces such as couches, and other items in the sleeping area such as blankets and bumpers.

Based on Maine 2017 PRAMS data:

- **89% of Maine infants are placed to sleep on their backs.**
- **28% are usually put to sleep alone on an approved sleep surface.**
- **49% are put to sleep without soft bedding (including blankets, quilts, pillow, or toys).**

Often infant deaths that are initially characterized as SIDS or SUIDS are later determined to result from unsafe sleep practices. Two studies were conducted by researchers at Maine Medical Center and the Maine CDC in 2001–2006 and 2009–2010 to understand deaths that may have been related to unsafe sleep.[13] In the first study, 54 deaths whose causes were **SIDS, SUID or unknown were examined.** The results of the analyses showed:

- Most of the deaths occurred at home (89%); other sites were: day care settings (6%), and hospitals, shelters and strollers (about 2% each).

- **Most of the deaths (94%) were related to unsafe sleep practices:**
  - 67% involved improper sleep surfaces.
  - Improper items were in the sleep area for 67% of cases.
  - 61% of the infants were in the non-supine position.
  - Bed-sharing was involved in 56% of the deaths.

In the second study that examined 23 2009–2010 **sleep–related deaths,** the following was found:

- **52% were related to bed-sharing.**
- **70% had exposure to tobacco smoke.**
- **For 39%, there were drugs and/or alcohol in the home.**

A review of infant deaths referred to the Medical Examiner's Office during the period 2013 − 2017, also found several deaths associated with unsafe sleep practices:

- **Of 30 deaths found to be immediately caused by asphyxia or postural asphyxia:**
  - **70% involved co–sleeping/bed–sharing**
  - **10% involved blankets or other furnishings**
  - **17% were related to sleeping facedown, falling off the bed and other unspecified sleeping condition**

Additionally, there were several other deaths (13) whose manner of death was considered natural or undetermined that may have been related to unsafe sleep practices.

In addition to the data above, those interviewed raised several concerns about unsafe sleeping practices among Maine families:

- **Many families co-sleep with their newborns because of cultural norms, and/or the tradition of co-sleeping in their families making these practices hard to change.**
- **Sometimes co-sleeping occurs in order to calm infants who are "high criers."**
- **Several cited poverty as a factor in unsafe sleep practices.** For example, some families who live in poverty cannot afford to adequately heat their homes so they co-sleep with their infants or cover them in multiple blankets to keep them warm.
- **Some families do not have cribs for their infants**, and even those families who receive cribs from the Maine Cribs for Kids program, do not always use them because they cannot fit them in their small living spaces.
- **Many are concerned that women with substance abuse issues (alcohol or other substances) who co-sleep with their infants may be especially at high risk for rolling onto the infants and smothering them. Relapse during the post-partum may contribute to this problem.**
- **Although safe sleep practices are discussed with families in the hospital post-delivery and families are usually given written materials and/or shown videos, the concern was raised by many that this may not be the best time to raise this topic** because families may be overwhelmed by the birth and all the information they are receiving before discharge. The hospital stay is also short.

In addition to the concerns the key informants raised about unsafe sleep practices, they also made several recommendations to reduce these practices:

- **Information about safe sleep should be provided during several touchpoints** (during prenatal visits, in the hospital after delivery and at the post-partum visit) by multiple providers.

- **The home visiting programs (Public Health Nursing and Maine Families) should have protocols in place before and after birth to provide safe sleep education and materials and connect women with Cribs for Kids, if needed.**

- **Although many key informants were aware of the new Maine DHHS safe sleep campaign and were very positive about the initiative, several recommended that multiple strategies are needed, including ongoing education in hospitals and practices to tackle this problem in a sustainable way.**

Social Determinants of Health

Examining the impact of social determinants of health on specific health conditions and outcomes has received increasing focus in the U.S. over the past several years. In the interviews, we asked the key informants how significant a role they thought that the following specific social determinants has played in the IM increases in Maine—poverty/ low-income, homelessness/unstable housing, hunger/food insecurity, unemployment/ underemployment, low education level, and lack of transportation and health insurance. Across the board, the interviewees said that they think that these issues play an important role. More specifically:

- **Poverty is an overarching issue that affects other social determinants such as housing, hunger/food insecurity and access to food.**

- According to data from the 2016 PRAMS survey, **13% of new mothers reported eating less than they should have and using emergency food resources such as food pantries in the 12 months prior to delivery**. Food insecurity was highest among younger women.

- There are especially **high rates of poverty in rural Maine communities**, particularly those areas where mills have closed, and unemployment has risen.

- **Limited transportation options in rural areas affect access to healthcare and other services and contribute to social isolation.**

- **Many key informants talked about the importance of public programs such as MaineCare (Medicaid), WIC, SNAP and TANF that help to mitigate the effects of poverty, and expressed concerns that reductions in these programs over the last decade have negatively affected some of the poorest Mainers (these programs are described more fully in the Public Policies and Programs section).**

Perinatal System of Care in Maine

The findings in this section are presented using the Components of an Ideal System of Perinatal System of Care framework developed as part of this project (Figure 6 on the following page). The data collected are presented by the components included in the framework: Access to Services; Workforce and Training; Referrals, Coordination and Collaboration; Family Engagement and Education; and Public Policies and Programs. In this section, we also include indicators of perinatal regionalization. Perinatal regionalization is a system-based approach to improve maternal and neonatal outcomes.

Figure 6. Components of an Ideal Comprehensive Perinatal System of Care in Maine

Goals: *1) Achieve healthy pregnancies & the best possible maternal & birth outcomes <u>in all areas of the state</u>, and <u>across all populations</u>.2) Ensure all mothers and infants receive the right care in the right place at the right time through perinatal regionalization efforts.*
Target populations: *Low-, medium- and high-risk women of reproductive age; prenatal, intrapartum & post-partum women; & infants up to the age of one. Includes vulnerable populations at risk due to clinical, psychological, social, & economic factors.*
Place of birth: *Birth hospitals, birth centers, home.*

Access to Services	Workforce & Training	Referrals, Coordination & Collaboration	Family Engagement & Education	Public Policies & Programs
Local pre- & post-pregnancy well-woman care including: primary care screenings, chronic disease management & reproductive life planning.	**Adequate supply of providers** - OBs, midwives, FMs, PEDs, nurses, SWs & other MH providers.	Maternal & neonatal **referrals & transports mechanisms** in place, as needed, to hospitals w/ **higher level of care.**	Referrals & care/services provided involve **shared decision-making between families & providers.**	**Public policies support payment mechanisms** (e.g., MaineCare) to cover **needed perinatal services.**
All recommended screenings completed & addressed including: clinical/genetics & social/behavioral screens (e.g., substance use, mental health, oral health, domestic violence, social determinants of health).	**Availability of medical specialists:** perinatal ultrasound, genetics/ counseling, MFM & neonatology to all areas of the state.	**Mechanisms for referral & F/U** to **community-based services, including Early Intervention,** in place.	Providers who care for perinatal populations provide **families with information and education on priority topics** (e.g., smoking, safe sleep).	**Policies and procedures in place to ensure that eligible perinatal populations participate in public programs/services that promote good birth outcomes** (e.g., Maine Families, PH Nursing, MaineCare, EI, WIC, SNAP, TANF).
Prenatal, intra-partum, post-partum & pediatric care, including all level of risk & trauma-informed care across the different care settings.	**Perinatal providers trained** in all screening & referral activities, and current topics (e.g., trauma-informed care, shared decision-making, telehealth).	**Team-based care; inter-provider communications & collaboration** re: shared patients (w/ patients' consent).	Families across the cultural spectrum are invited to participate in program development and evaluation as **family advisors** in practices.	**Federal, state and other perinatal funding opportunities** (e.g., CDC, CMS, HRSA) monitored & pursued to enhance availability of services.
Mental health (MH) services.	**Interdisciplinary perinatal trainings for SU, MH, DV providers** caring for these populations.	**Statewide & local efforts** established to **collaborate and coordinate perinatal activities** (e.g., QI projects through PQC4ME).		
Substance use (SU) services, including nicotine.				
Domestic violence (DV) services.				
Other public and private community-based services such as case management (e.g., PH Nursing, WIC, Maine Families), including services for CYSHCN.	**Training for all providers** caring for diverse families on cultural competency & structural & implicit bias (e.g., race).			
Telehealth, including care & referrals, as needed.				

Assessment, Monitoring & Evaluation – Includes: 1) **quality assurance processes** to review adverse perinatal outcomes to ID & address causes; 2) **review panels** for maternal, fetal & infant deaths (Maine CDC) & child deaths and serious injury (OCFS), 3) statewide & regional key **perinatal outcome data identified, reported & distributed.**

Effective perinatal systems of care often include perinatal regionalization strategies.[14]

The primary source of data for this section was the key informant interviews, but the following data sources were also used: birth and death certificates, MMC and EMMC NICUs, PRAMS surveys, Maine Children's Alliance and Kids Count.

Access to Services

Aspects of access to services explored with the key informants included: women's health, perinatal health, screenings in clinical practice, access to community-based services (such as mental health and domestic violence) and telehealth. Available data from the PRAMS survey also are included. The findings showed:

- **The key informants were generally not sure if women are receiving primary care and reproductive life planning before or between pregnancies, but they recognized its importance particularly for women with chronic health conditions. Many cited the 2019 expansion of MaineCare as a strategy to improve this access.**

- 2017 PRAMS data showed that 74% of new mothers reported having a health care visit during the 12–months before pregnancy, but the nature of the visit is unknown.

- **Access to perinatal (prenatal, intra-partum, post-partum and pediatric) care can be challenging particularly in rural areas.** More specifically:

  o **The closures of delivery services have occurred primarily in rural areas where populations are already at risk for IM because of other factors.** Over the past two decades, Labor and Delivery units closed in 6 counties (Cumberland, Hancock, Lincoln, Penobscot, Washington and York), and 7 cities/towns (Blue Hill, Boothbay Harbor, Brunswick, Calais, Lincoln, Millinocket and Sanford).

  o **For some women, the closures have limited access to local hospitals for Labor and De- livery, as well as prenatal and post-partum care (OBs, midwives, FM, nurses and social workers).**

  o Many women also must wait for, or travel long distances to, specialty obstetrical care.

  o **Local pediatric shortages were also reported for general pediatricians, as well specialists (neonatologists)**. Currently, the neonatologists are in the two NICU's in Portland and Bangor. To fill the shortages, some of the rural communities use locums, who do not provide continuity of care.

  o **Shortages in mental health providers with perinatal expertise were reported all over the state.**

- **There is wide variability in prenatal and postpartum screening for both clinical/genetics and social/behavior issues, and adequate services to address positive screens are not always available.**

  o **The key informants reported that depression screening is generally done using evidence-based tools such as the Edinburgh Postnatal Depression or the PHQ-2 tools.** How- ever, among those interviewed, there was consensus that there are not enough mental health services available across the state. As noted above, there is a particular shortage of providers with perinatal expertise.

- In 2016, about 88% of PRAMS respondents said that that they were asked if they felt down or depressed by their providers during pregnancy; however, more young women (under 20) were asked this question (98%) than women 35 or older (82%). Most (94%) of new mothers in Maine reported that they were asked about depression during their post-partum visits; fewer older women were asked about depression (89%) than women younger than 20 years old (100%).

  - **Screening for tobacco use is generally done. However, the only treatment referral source known by those interviewed is the state-funded Tobacco Helpline.**

  - Ninety-eight percent of PRAMS respondents also reported that they were asked by a health provider during prenatal visits whether they smoked tobacco during pregnancy. Providers were less likely to ask women if they were smoking during their post-partum check-ups (72%), and they were most likely to ask younger women than older women.

  - **The key informants generally thought that screening for other substances such as opioids is done but when and how often is not known. For example, some thought it is probably done once in the prenatal period. Suggestions were made to do multiple screenings during and after the pregnancy, particularly in the post-partum period when there is an increase in relapse. The interviewees reported that they think substance use services are generally available, but they do not know how often referrals are made for those women with positive screens.**

  - **In 2016, 98% of Maine PRAMS respondents reported they were asked by a health care worker about their alcohol use during pregnancy.**

  - **Domestic violence screening is generally done, particularly in hospitals, but many of the key informants identified the need for training on how to do these screens; services are generally available in most areas of the state, except for the mid-coast area.**

  - Sixty-six percent of pregnant women reported that their providers screened for domes- tic violence in 2016 (PRAMS). The screen was most often done with women 20–24 (71%), least often done with older women 35 and older (56%). During the post-partum visit, the percentage of women who were screened for domestic violence was similar to the percent- age screened during pregnancy (66%–67%); and, again, younger women reported being screened more frequently (82% for those under 25, and 56% of those 35 or older).

- **Screening for social determinants of health are generally <u>not</u> done, but there is interest in doing these screens among clinicians and other service providers. However, what services are available to address the identified needs is unknown.**

- Two services that were mentioned as particularly important to ensuring optimal birth out- comes were the **Public Health Nursing and Maine Families home visiting programs**. These are described more fully in the Changes in Public Policy and Program section.

- Many of the key informants said that they are interested in developing telehealth programs across the state as a strategy to improve access to perinatal health.

Workforce and Training

The following **workforce and training priorities** were identified by key informants.

- **More local primary care and specialty perinatal providers in rural areas, especially areas that have lost their maternity services.**

- **More training for perinatal providers in screening and referrals for services, and on special topics** such as trauma-informed care.

- **Trainings for primary care and other providers who do not offer perinatal care per se but see infants and women of reproductive age.**

- **More cultural sensitivity and bias training for providers** who care for diverse populations. This includes topics related to race/ethnicity, including Native Americans; poverty; and rurality.

Referrals, Coordination and Collaborations

Three areas of need were identified:

- **Stronger team-based care** to coordinate services and outcomes across primary care, specialty care and other providers who share patients.

- **Strengthening maternal and neonatal transfers/ transports to the Level III/Level IV hospitals.**

- **More local and statewide collaborations on perinatal programs** and activities to improve the quality of care.

Family Engagement and Education

Observations were made that there is a need to strengthen family and provider engagement and shared decision-making. Work also is needed to expand and educational materials that are provided to families comprehensive, and easily available to all families across Maine, and reflect cultural and language considerations.

Public Policies and Programs

To identify changes in public policies and programs that may have affected IM in Maine, we asked the key informants for their perceptions about public policies and programs changes, and examined available enrollment data in three public programs: WIC (Women, Infant and Children),

> # Patient Profile
>
> Ms. S lives in rural western Maine. She recently delivered a healthy full term baby (her first) at her local community hospital. While her overall prenatal care experience was positive, she had to miss several days of work in order to travel to a tertiary care center more than an hour away for tests that were not available at her local hospital. Ms. S had an unplanned C-section and felt the hospital (and her doctors) did a good job helping her make an informed, shared decision to go forward with the C-section.
>
> After the birth of her baby she had difficulty connecting with the home health nurse due to confusing information about who was supposed to make the contact and was only able to make the connection after she felt she no longer needed a home visit.

SNAP (Supplemental Nutrition Assistance Program), and TANF (Temporary Assistance for Low-Income Families). These programs are important in addressing hunger/food insecurity and other social determinants of health in Maine. Enrollment data for WIC, SNAP and TANF were compared for 2013 and 2017[15] and all three programs saw declines in infant enrollment between these two years.

WIC is the special supplemental nutrition program that provides grants to states for supplemental foods, health care referrals, breastfeeding support and counseling, and nutrition education for low-income pregnant, postpartum and breastfeeding women, and infants and children up to age five who are found to be at nutritional risk. **WIC data showed an overall 9% decrease in the percent of infants under one year of age enrolled across the state between 2013 and 2017. Fourteen of Maine's 16 counties had decreases in enrollment ranging from 1% to 25%.** The counties that were hardest hit (with at least 10% decreases) were Washington (25%) Piscataquis (19%), Waldo (17%), Oxford (14%), Aroostook (14%), Somerset (13%), and Kennebec (11%) counties. Only two counties— Sagadahoc (5%) Franklin (1%) – had enrollment increases. In 2018, the Mills administration increased the amount of the WIC benefits by 22% and increased the amount of the program's housing allowance.

Formerly known as Food Stamps, SNAP provides food-purchasing assistance to low-income individuals and families living in the U.S. In Maine in 2014, work requirements for SNAP for childless adults were reinstated, and limits were put in place on the numbers of months of allowed coverage for able-bodied adults (SNAP benefits were restricted to three months in a three-year period). Although these changes did not directly affect the SNAP enrollment of pregnant women, they could have affected the pregnancy since poor nutrition status prior to pregnancy can adversely affect a pregnancy. **SNAP data showed an overall 9% decrease in the percent of infants under the age of one enrolled in SNAP between 2013 and 2017. Every county had a decrease in these enrollments, and the average decrease was 10%.** The counties with the highest decreases (10% or higher) were: Waldo (16%), Piscataquis (15%), Kennebec (14%), Franklin (13%), Know (13%), Washington (12%), Oxford (11%), and Sagadahoc (10%).

TANF (Temporary Assistance for Low-Income Families) provides temporary cash assistance to low

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Patient Profile

Ms. B and her family came to Maine seeking asylum. Initially, she and her family lived in a shelter but they now have an apartment. Ms. B had a challenging pregnancy and postpartum period. She experienced gestational diabetes and lost one of the twins she was carrying. After discharge, both she and her newborn were readmitted with complications. Speaking through an interpreter, she reported receiving excellent care from the all her providers, but especially from the hospital labor and delivery team and her home visiting nurse.

Ms. B, her new baby and other children received a number of services including: WIC, SNAP, TANF, Public Health Nursing, Early Head Start and Cribs for Kids. She also received help finding a part-time job. Her only negative experience was with TANF staff, whom she felt treated her disrespectfully. Overall, she was very grateful for all the help her family received and looks forward to the time when she doesn't need these resources and can give back to others who need them.

income families as they move toward self-sufficiency. A woman is eligible for TANF beginning in the seventh month of pregnancy. **In Maine, there was a dramatic one-year decrease from 23,922 children under 18 with TANF in December 2011 to 15,293 in December 2012** that resulted from a new 60-month lifetime limit and stricter policies related to meetings with TANF caseworkers. **Looking only at infants under one, we found an overall 3% drop in the percent of infants on TANF between 2013 and 2017.** One county—Somerset saw no decrease, but the others saw between 1% and 5%. The counties with the highest drop (5%) were Penobscot, Oxford and Knox.

One of the challenges in enrollment in these programs is the effect of rule changes. Families may not realize that rule changes do not apply to them so may not apply or complete their applications. The changes in the enrollment for all three programs are depicted by county in the maps in Appendix J.

Key informants raised concerns about what they saw as families' decreased access to WIC, SNAP and TANF, but changes to the state's Public Health Nursing Program was the change about which they were most concerned. These changes resulted from significant cuts in staffing and changes in eligibility. **However, beginning in 2019, the cuts began to be restored, and in July 2019, the eligibility was expanded to include all pregnant women and infants up to the age of one, regardless of insurance.**

Many of the key informants talked about the value of public health nurses, particularly in rural communities where families are often isolated and without transportation. According to interviewees, not only do the nurses provide clinical assessment and information, but they also provide education on a range of topics such as safe sleep and can connect women with needed referrals to community-based services. Many of those interviewed knew that the Maine CDC is currently in the process of recruiting nurses to build the program back up and were very supportive of these efforts. Some interviewees also talked about the importance of the federally-funded Maine Families home visiting program. This model, which is staffed by family visitors, provides education and support in the home, and referrals to community-based organizations across Maine. Maine Families often works in tandem with the public health nurses. The Maine Families program in Washington County was specifically named as a home visiting best practice.

Another issue that was also raised by many key informants was problems with the CradleME referral system which provides referral mechanisms to maternal and infant services for providers. The primary issue cited was the lack of communication and follow-up about referrals made; these issues are currently being addressed by the Maine CDC.

The other significant public policy that consistently came up in the interviews was **access to MaineCare**. Payer data from the Maine birth certificate (Table 3) showed a small drop in the percent of births for which MaineCare was the primary payer in 2014–2017, but it is not clear what caused these decreases. It is also important to note that MaineCare coverage is self-reported by the parents on the birth certificate worksheet and is not confirmed with MaineCare. **Additionally, as previously noted, the prior state administration had decided not to expand MaineCare through the Affordable Care Act, but the current administration expanded MaineCare coverage in 2019. Many were concerned that the health status of women was negatively impacted by lack of insurance.** As a result, many women may be entering pregnancy with poor health status. An example is a woman with hypertension, diabetes and/or obesity who may have a high-risk pregnancy that may have

been avoided or mitigated with pre-pregnancy management of conditions like these. Additionally, primary care before or between pregnancies presents an opportunity for reproductive life planning. Unplanned pregnancies are a risk factor for IM.

Table 3 | Distribution of Births by Payer: 2013-2017 (Unknown Payer Not Included)

Year	MaineCare		Private		Other		Self-Pay		Total
	#	%	#	%	#	%	#	%	
2014	5,552	44%	6,273	50%	324	3%	447	4%	12,597
2015	5,237	42%	6,460	52%	314	3%	489	4%	12,501
2016	5,011	40%	6,869	54%	269	2%	486	4%	12,636
2017	4,817	39%	6,705	55%	252	2%	476	4%	12,251
Total	20,617	41%	26,307	53%	1,159	2%	1,898	4%	49,982

Perinatal Regionalization

Two indicators of perinatal regionalization were examined: location of VLBW births by level of care, and hospital transfers. The percent of VLBW newborns who are born in Level III/IV facilities is a well-established measure of perinatal regionalization. VLBW Infants born at these hospitals have consistently been found to have better outcomes than those born at other hospitals. Our analyses showed:

- **Annually, about 80% of VLBW infants are born in Level III/IV facilities.**
- **There have not been substantial changes in the percent of VLBW infants born in Level III/IV facilities over the period 2000–2017.**
- **VLBW infants whose mothers live in urban settings are more likely to be born in a Level III/IV facility compared to infants whose mothers reside in rural areas.**
- **Those living in more rural areas are the least likely to be born in a Level III/IV if they are low birthweight.**
- The percent of VLBW infants born in Level III/IV facilities has decreased among mothers living in rural areas. It has slightly increased for those living in more urban areas.
- **The percentage of VLBW babies born in Level III/IV facilities in 2000–2017 varied by maternal county of residence.** Births to Androscoggin women represented 10% of all VLBW births but accounted for 23% of VLBW births that did not occur in a Level III/IV facility. Similarly, births to Kennebec women represented 9% of all VLBW births but accounted for 15% of VLBW births that did not occur in a Level III/IV facility. In contrast, births to Cumberland women represented 22% of all VLBW births but accounted for only 5% of VLBW births that did not occur in a Level III/IV facility.

Although it is preferable to have women with high risk pregnancies deliver in the Level III/IV hospitals, this is not always possible for several reasons. A pregnancy may not be identified as high risk until the women presents in labor at the hospital. Women with high-risk pregnancies may not be receiving adequate prenatal care or testing to identify their high-risk status. Women in rural

areas or those far from the Level III/IV hospitals may not be able to get to the Level III/IV hospital for high-risk care. **For situations like these, there must be effective transport systems in place to safely get the mother and/or infant to the Level III/IV hospital as soon as possible.**

Maine has air and ground transport available, although most of the transports are for the newborns post-birth. Arranging transports for both pregnant women and infants can be challenging due to the availability of EMS services. The background and training of those providing transport varies, and some communities rely on volunteer services. Arranging transports for women is especially challenging because they often need to happen very quickly while the women are in labor. Costs may also be a factor. These are areas that need additional exploration and more data to understand the system strengths and gaps. Interviewees suggested that there needs to be more maternal transports before delivery, if this can be safely done.

Data collected internally by EMMC and MMC were used to assess transport patterns. The data showed:

- In the period 2016–2017, there were 575 transfers to MMC (368) and EMMC (207).
- About 66% of the transfers were for term infants, 8% were early preterm infants born before 32 weeks gestation, and 25% were preterm infants born between 32-36 weeks gestation.
- The MMC transfers generally come from southern Maine and the EMMC transfers are from northern Maine, although there is overlap mostly in the central part of the state.
- Infants are also sometimes transferred to Boston hospitals (Boston Children's Hospital and Mass. General Hospitals) by MMC (7–10/year) and EMMC (about 4/year).

National and State Strategies to Reduce Infant Mortality

This information, which is summarized in Appendix B, provides a brief overview of notable examples of evidence–based/informed and best practice approaches to addressing IM that have been implemented by professional organizations, hospitals and health systems, state governments and others. Some include coordinated strategies to reduce the risk of maternal mortality. These examples were selected to illustrate the broad range of effective actions that should be assessed for potential replication in Maine in addition to those already underway (such as the Maine Department of Health and Human Services' Safe Sleep campaign and PQC4ME, a collaboration between Maine birth hospitals).

Discussion of Findings

Through this project, we were able to document the changes in birth and infant deaths in Maine and in areas of the state and identify the primary causes and drivers of IM in the Maine. IM is complex and multi-factorial, and our research showed that there was no single primary cause or driver of the increases in IM in the state; however, many opportunities were identified to improve birth outcomes.

Consistent with other areas of the country, Maine's birth rate has declined over the past two decades. This downward trend has been particularly marked among adolescent mothers. The birth rate among older mothers (35+), however, has steadily increased during the same time period. The trends in infant deaths have been more unstable. **Maine's IMR peaked in 2013**. This high rate is particularly concerning in the context of the consistent progress in reducing IM made by other states in recent years. One important consideration, however, is that in a small state like Maine, small numbers of births and decreases in them, in combination with small increases in infant deaths, can more easily results in increases in the IMR, than in larger states with many more births.

Additionally, although there has been some annual variability in IMR and rankings among other states in New England over the past two decades, the other three Northern New England states have consistently had lower IMR and rankings than Maine. In both 2013 and 2017, Massachusetts had the lowest IMR in the country; Vermont ranked 3rd in 2013, and 12th in 2017; and New Hampshire ranked 18th in 2013, and 4th in 2017.[9] Vermont and New Hampshire, in particular, are most like Maine, and have maintained lower IMRs.

Chart 19 | IMR in Northern New England States: 2013 and 2017
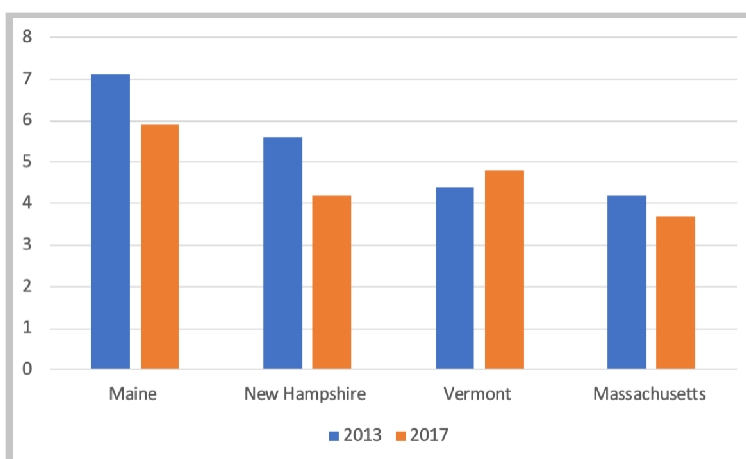
Because Maine is a state where the majority of births occur to women living in rural areas and most of the birth hospitals, albeit small hospitals, are in rural areas/counties, rurality was an

important area of study for our project. Although the IMR for women living in isolated rural areas was the highest compared to women living in other rural areas and metropolitan areas, it is again important to recognize the effects of changes when the numbers of births and deaths are small.

One area of concern that we identified was a spike in the number of deaths among home births in 2013. Although the number of home births in Maine is small, they increased over the period of study (doubled from 2000 to 2017). The number of deaths among home births was small over the period of study (0-2/year), but this number spiked to 6 in 2013; however, the reasons for this spike are not well understood at this time. A review of these deaths by the state's MFIMR (Maternal, Fetal, Infant Mortality Review) panel may help to understand the causes of these 2013 infant deaths. Additionally, the Maine Certified Professional Midwives licensing law went into effect on January 1, 2020, and part of the law requires outcome data for home births. This will provide some new opportunities to maintain ongoing review of home births and deaths.

Most of the infant deaths in Maine and in the U.S. are due to causes related to being born too early. This is reflected in the highest IM in the infants with the early gestational ages and related low birth weight. Additionally, the earlier the pre-term infant is born, the higher the mortality. **Although the specific causes of preterm birth have not been identified, there are a number of known risk factors such as a history of premature birth, a multiple pregnancy, a short inter-pregnancy interval, tobacco smoking, other substance use, chronic conditions such as diabetes, maternal infections and stress. Many of these risk factors are amenable to change through medical interventions, but also through behavioral interventions (for example smoking cessation programs) and social support.**

For the other major causes of infant deaths—SIDS/SUID and congenital anomalies (birth defects), there are different drivers. The causes of congenital anomalies are often genetic or unknown (the causes of 75% of congenital anomalies are unknown) and therefore more difficult to address. On the other hand, **some SIDS/SUID deaths have been found to be associated with unsafe sleep practices, and therefore may be amenable to interventions such as the state Safe Sleep Campaign currently underway, enhanced education in clinical and other sites, and cribs through the Cribs for Kids program.** The other causes of infant death—infections, injuries and other perinatal conditions and causes—were less stable over our period of study (due in part to small numbers), but also saw some increases.

In examining risk factors (drivers) of infant mortality, we identified through quantitative data several key factors associated with Maine infant deaths. These included:
- **Demographics (maternal age, maternal education, marital status, race/ethnicity).**
- **Clinical considerations (multiple pregnancies, adequacy of prenatal care and obesity).**
- **Behavioral issues (tobacco smoking and unsafe sleep practices).**

But in addition, through the key informant interviews, we identified other areas thought to be connected to IM including substance use (marijuana, alcohol, opioids and other substances), domestic violence and social determinants of health, but we could not verify the relationships to IM with data.

Although demographics cannot be changed, the information about their relationships to IM may be used for targeted outreach, education and consideration in practice. For example, the

number of births to older women has been increasing at the same time that the IMR in this group has been increasing so this might be a group to engage and target with tailored interventions. Another example is marital status. Although the reasons for the higher IM among unmarried women compared with married women are not clear, screening for social determinants of health and available social support may be important to identify areas where referrals for help could be provided.

The higher IMR among Black/African American, compared to White women and other groups, is also an important finding to consider. In the U.S., Black/African American women have consistently had 2–2.5 higher IMR, compared to White women; and as Maine becomes more diverse, this may be an important measure to monitor. This racial disparity continues to be an important area of study in the U.S. Additionally, among Hispanic women, there have been increases in IMR over the past 10 years, exceeding the IMR for non-Hispanic women, although the numbers are small so the results should be interpreted with caution. One of the challenges in Maine is identifying disparities in access and outcomes in the tribal communities because there are little data available and the numbers are small.

We identified several risk factors related to clinical care and services. The increased rates of IM for multiple births raises a couple of issues. First, it would important to determine whether the multiple pregnancies involve twins or higher order multiples such as triplets and quadruplets, although the number of higher order multiples is so small it would be difficult to assess changes over time. **Higher order multiples are at greater risk for infant death than twins. Also, given the increased risk for multiples, the mother may need assessment and care by high-risk obstetricians, and referral to Level III/IV hospitals for delivery.**

Regarding adequacy of prenatal care, even though more than 85% of Maine women received adequate prenatal care in 2014–2017, it would be important to identify those women not receiving adequate prenatal care and address the reasons for not accessing this care. There are many factors that can influence whether a woman is able to access timely and comprehensive prenatal care. These can include: problems with transportation, lack of health insurance, distance to a prenatal care provider, fear of stigma due to mental illness or substance abuse, and fear of being reported to child protection services due to substance use.

Obesity during pregnancy is another risk factor for IM that has been increasing in Maine and the U.S. over the last three decades. One approach to address this issue is for women to receive care and counseling about obesity and reproductive life planning in primary care prior to pregnancy so women are healthy when they enter pregnancy. The 2019 MaineCare expansion may help more women access primary care before and between pregnancies.

Depression and anxiety during pregnancy and in the post-partum period are also thought to be contributors to poor birth outcomes and are experienced by at least 10% of Maine women. The key informants identified the lack of mental health providers generally and those with perinatal expertise specifically as a major challenge.

We identified several areas to address related to substance use. **Maine has among the highest rates of smoking during pregnancy in the U.S., and although there has been some improvement in these rates, more than 10% of pregnant Maine women reported smoking during pregnancy**

in 2017. It is important to reduce smoking during pregnancy because it is a known risk factor for preterm birth, a leading cause of infant mortality. **One of the challenges in addressing smoking in Maine is a lack of resources for smoking prevention and interventions to quit smoking.** Our project only identified one tobacco resource (the state-funded Tobacco Helpline), and this resource does not provide any targeted interventions for pregnant women.

The rates of alcohol use during pregnancy were found to be similar to the smoking rates, but concerns were raised that focus on this topic has diminished as the focus on opioids has increased. Marijuana use during pregnancy has also recently emerged as an important relatively new concern. Interviewees identified recent increases in its use during pregnancy, and concerns about its effects on the pregnancy. Regarding opioids and other substances, we found recent decreases in reported substance-exposed babies, and perceptions that many women who were receiving methadone or suboxone were receiving prenatal care, but concerns were raised about unsafe sleep practices and/or relapse after the birth.

In looking at the other three risk factors we examined—unsafe sleep practices, domestic violence, and social determinants of health, we received feedback that all were related to IM, but much of these data (except safe sleep) were qualitative. We reviewed data that quantified deaths (many initially labeled SIDS/SUID) related to unsafe sleep practices and heard concerns about these deaths resulting from substance use and poverty. Domestic violence was thought to be a significant, but underreported, problem across the state with a need for further training on identifying domestic violence in health and social service settings. Although we had no concrete data on social determinants of health such as poverty, housing, transportation, food insecurity, all key informants perceived these factors as major contributors to IM, especially in rural areas. Poverty is a well-established risk factor for poor birth outcomes.

For the data about the Perinatal System of Care we collected and analyzed—primarily through the key informant interviews, we identified areas of strength and opportunities to build an Ideal Comprehensive Perinatal System of Care in Maine. We support using the Components of an Ideal Comprehensive Perinatal System of Care in Maine (Figure 6) as a framework to guide the planning, implementation and evaluation of the system.

For the **Access to Services** components, we identified the following opportunities: **a need to more fully understand women's access to primary care (including chronic disease management) and reproductive life planning**; a need for **more perinatal screenings**; **mechanisms in place to ensure risk appropriate care**, including trauma informed care, for all who need this care; more mental health (particularly perinatal) services; **new perinatal models for women with substance use disorder**; **strategies to ensure that all families that qualify for programs like Public Health Nursing, Maine Families and WIC**; and **services for CYSHCN are enrolled or receiving these services; and more telehealth**. Regarding screening, it is most frequently done for depression (although different tools are used), smoking, alcohol and domestic violence. **Screenings are less frequently done for social determinants of health, but this is a new area, and there is considerable interest in screening for these factors.** There also are tools available for this screening, but since this is a new area, there is not yet standardization of screening tools.

We identified five areas of recommendations for the **Workforce and Training** component. These include:

- **New or enhanced strategies to address perinatal labor shortages and access to maternity services in areas where these services have closed (such a rural areas).**
- **Increased accessed to specialists.**
- **Increased trainings in screenings and referrals.**
- **Increased trainings in topics such as domestic violence, substance use, cultural competence and bias.**

Cultural and bias training is especially important in communities with newly arrived immigrants, refugees, asylees, and Native American populations. These training should be available to all provider and staff who work with perinatal populations.

New referral, coordination and collaboration activities includes **stronger maternal and neonatal transport mechanisms** in place for care at the highest level of care, as appropriate; **enhanced mechanisms for referral to community-based services** such as Early Intervention; **team-based care and stronger communication and collaboration among providers** who share patients; and **more statewide and regional activities to coordinate and collaborate on shared perinatal activities** such as quality improvement.

To strengthen family engagement and education, we identified the need for **more shared decision-making between providers and families**, the provision of **comprehensive and consistent patient education by perinatal providers**; and inclusion of **family advisors** in practices to provide the family perspective on practice activities. Family advisors are typically paid advisors who bring the family perspective and expertise into practices to inform and enhance the practice activities.

For the public policies and programs, there was a decrease in the births covered by MaineCare, and an increase in births paid for by private payers over the four years for which data were available (2014–2017), but the reasons and implications are not clear. For example, were fewer women eligible for MaineCare, or did women eligible for the coverage not access this program and if so, for what reasons? As noted above, MaineCare coverage in the state was expanded in 2019.

It also is difficult to interpret the decreases in the enrollments in the other programs—WIC, SNAP and TANF. How did changes in eligibility or eligible families' knowledge about rule changes affect enrollment? More research is needed to answer this question, but mechanisms should be in place to reduce barriers and ensure that all eligible families receive these benefits.

Another critical and ongoing activity is to monitor and respond to funding opportunities to enhance services for the perinatal populations, and build and sustain the Maine System of Perinatal Care. These opportunities can come from Federal, state and private sector sources, such as the Health Resources and Services Administration (HRSA), the U.S. CDC, the Maine DHHS, hospitals and health systems and private foundations.

Many states, national organizations, and regional organizations have undertaken initiatives to reduce IM and improve birth outcomes. Notable examples of these may be found in Appendix B. **There are particular opportunities to learn about successful IM policies and programs**

implemented in other New England states that have lower IMRs than Maine. The Northern New England Perinatal Quality Improvement Network (NNEPQIN) provides an excellent forum for sharing best practices and evidence-based research and is but one example of how Maine can learn from others in the region.

Recommendations

In this section, we propose recommendations, provide the rationales for the recommendations, and offer examples of implementation steps. The recommendations are presented by the strategic areas outlined in the Ideal Comprehensive Perinatal System of Care for Maine framework developed through this project. The strategic areas include: 1) Infrastructure to Support the Strategies and Actions for the Ideal Comprehensive Perinatal System of Care for Maine; 2) Access to Services; 3) Workforce and Training; 4) Referrals, Coordination and Collaboration; 5) Family Engagement and Education; 6) Policies and Programs; and 7) Assessment, Monitoring and Evaluation.

The recommendations are based on the following key principles:

- Evidence-based practices, tools, and resources are used, if available; and if not available, the practices, tools and resources used are tested.
- The actions selected are coordinated and non-duplicative across the strategic areas as well as other related initiatives in the state.
- The actions are informed by the knowledge and experiences of national and state organizations, and parent and family advisors.
- The goals/outcomes, timelines and resources needed for the actions are explicitly identified at the outset of all initiatives.

Some of the recommendations are broad and general; others are very specific. Some may be accomplished in the short-term; others may require multiple years to fully accomplish.

Strategy 1: Infrastructure to Support the Strategies and Actions for the Ideal Comprehensive System of Perinatal Care in Maine

A critical first step in addressing the findings of this project and the recommendations is to convene a statewide Work Group under the auspices of the MDHHS Commissioner, in collaboration with the Children's Cabinet and other state agencies. Members of the Work Group should include public and private sector leaders and key stakeholders (large and small hospitals, primary and specialty care clinicians, and others who are involved in caring for or providing services to women of reproductive age). Women and family members must be represented as well. While all recommendations in this report are subject to review and consideration by multiple stakeholders, the Work Group is one in particular that requires initial outreach to key leaders in the Maine DHHS, other public sector officials, and the private sector to seek and secure their support and buy-in.

RATIONALE A successful initiative of this size and scope must have an infrastructure and process in place to define, support and prioritize the work; leaders who can provide a vision, influence and the ability to identify and/or allocate resources; stakeholders with expertise and experience who can assist in the design and implementation of the actions; and clear goals, timelines and

resources. We recommend that the Work Group use the Components of an Ideal Comprehensive Perinatal System of Care in Maine framework to guide the planning, implementation and evaluation of the work.

Strategy 2: Access to Services

These services include the full-range of services/programs/resources needed by the perinatal populations in Maine at every level of risk and need. The services include: screening, inpatient and outpatient (general and specialty) medical care, community-based social and support services and education. They cover women's health, obstetrics, pediatrics, mental health and substance use. To ensure access, no barriers should be in place.

RATIONALE Access to the full range of services needed are critical to ensuring the best possible maternal and newborn outcomes in Maine. The project identified many opportunities to improve access to all types of screenings and other services for women and infants. Currently, screenings are inconsistently performed across topic areas, with different tools being used for the same screening. With the closures of several maternity units in rural areas, access to local maternity care has become increasingly challenging for many families living in these communities.

Strategy 3: Workforce and Training

This strategy addresses two aspects of the workforce that provides care to perinatal populations across the state. The first issue addresses the shortages in the workforce, particularly in rural areas of the state; the second addresses training across all providers and staff who care for these populations.

RATIONALE Access to the right care at the right time in the right place can only happen if there are available workforces to provide the care. Primary care, general and high-risk maternity care, and pediatric care must be available to families. With the closures of obstetrical services in rural communities over the past several years, some women have been limited in their access to local hospitals for Labor and Delivery, as well as prenatal and post-partum providers (obstetricians, midwives, Family Medicine providers, nurses and social workers). It also has been reported that women must wait for, or travel long distances to, specialty obstetrical care. Four Maternal Fetal Medicine physicians based in Portland provide coverage/consultation for high-risk women across Maine. Shortages also have been found among general pediatricians, as well as specialists (neonatologists). Currently, neonatologists are in the two NICU's at Maine Medical Center in Portland and Northern Light Eastern Maine Medical Center in Bangor. To fill shortages, some of the rural communities use locums, which do not provide continuity of care. Nursing shortages, specifically in-home visiting, also have been reported. Shortages in mental health providers generally, but also those with perinatal expertise specifically, have been noted. Additionally, for providers who see pregnant women and infants, the project identified several areas of training needs: risk assessments, screenings and resources, telehealth, cultural competency, bias, and current topics such as trauma-informed care and shared decision-making.

Strategy 4: Referrals, Coordination and Collaboration

This strategy includes mechanisms to ensure that: 1) women and infants undergo risk assessments to identify their needs, 2) women and infants are referred to facilities and community-based services that meet their needs; 3) there are communications and collaborations between and among providers sharing patients (with the patients' consent); and 4) perinatal activities are coordinated across the continuum of care.

RATIONALE Referral mechanisms between hospitals and community services must be in place to ensure that the needed services can be accessed, and barriers are eliminated. The sharing of patient information across caregivers facilitates coordinated care, and the coordination of perinatal activities such as Quality Improvement (QI) activities in hospitals will strengthen the projects and their results through shared learning.

Strategy 5: Family Engagement and Education

This strategy covers patient/family/provider engagement, and education provided to patients/families by providers and their staff. Family Engagement involves goal setting, care plan development, and shared decision-making, and often includes Family Advisors in practices. The provision of comprehensive educational materials to patients/families during perinatal visits and hospital stays is a critical part of these interactions. The recent trend to establish patient and family advisory groups to provide meaningful input is an important step that that should be encouraged and supported by hospitals and provider organizations.

RATIONALE Family engagement is a key component of family-centered care, and shared decision-making can only occur if families are engaged and informed. The project found that educational materials are not being consistently provided, in terms of content as well as timing, and are often hard to access.

Strategy 6: Public Policies and Programs

This strategy includes: data analyses to determine potential changes to public policies and programs (including services reimbursed and providers who can receive reimbursement), and the implementation of changes to improve maternal and newborn outcomes. An important component of this strategy is collaboration with national, state and local professional organizations and advocacy groups.

RATIONALE Sound, evidence-based policies and programs are needed to influence the equitable allocation of resources and to enhance and sustain the impact of other actions. Maine has the potential to build on renewed commitment of the legislative and executive branches of State government through entities like MaineCare and the Maine CDC. These should be in collaboration with commercial payers, professional organizations and advocacy groups such as the American College of Obstetricians and Gynecologists (ACOG), the American Academy of Pediatrics (AAP)-Maine, the Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN), Maine Children's Alliance, Maine Public Health Association, the March of Dimes, and others.

Strategy #7: Assessment, Monitoring and Evaluation

This strategy includes: data collection and analyses to assess the effectiveness of new and enhanced models and activities, the development and dissemination of regular public health reports of maternal and infant outcomes, additional reviews of fetal and infant deaths, and improvements in the public data collected on births and infant deaths in Maine.

RATIONALE Assessment, monitoring and evaluation are key health care and public health functions that assure accountability. It is especially important to conduct these activities for new initiatives to determine if they are effective or need to be changed.

Table 4 | Recommendations and Examples of Action Steps by Strategy

RECOMMENDATIONS	EXAMPLES OF SPECIFIC IMPLEMENTATION STEPS
Strategy 1 Infrastructure to Support the Strategies and Actions for the Ideal Comprehensive System of Perinatal Care in Maine	
1.1 Establish and maintain a Work Group.	• Determine who leads and facilitates the Work Group, resources needed (e.g., staffing). • Identify members and expectations. • Gain endorsement for Ideal Perinatal System of Care conceptual framework and establish goals and measures/outcomes of success. • Convene the Work Group and sub-groups, and establish a meeting schedule. • Develop and implement dissemination plan for tracking activities and reporting progress (e.g., annual reports or dashboards).
1.2 Determine a perinatal regionalization approach for the State of Maine to ensure access to risk-appropriate care for mothers and infants.	• Complete the process to officially designate the levels of perinatal care (LOC) at all Maine birth hospitals – already underway using the CDC LOCATe tool; other approaches such as guidance or regulations could also be considered in the future. • Strengthen the maternal and newborn referral and transport systems from community hospitals to hospitals with higher LOC. • Develop and implement a communications plan for providers and the public re: LOC available at each birth hospital. • Identify and implement other perinatal strategies such as satellite ambulatory Maternal and Child Health (MCH) services and telehealth consultations in rural communities.
1.3 Align and coordinate the Work Group with the Maine CDC MCH Block Grant and the MFIMR (Maternal, Fetal, Infant, Mortality Review) panel to enhance the efforts across these entities and avoid duplication.	• Include the Work Group leadership or designee(s) in the MCH Block Grant needs assessment and application, and MFIMR panel. • Include the Block Grant and MFIMR leadership or designee(s) on the Work Group for sharing information and joint planning.

RECOMMENDATIONS	EXAMPLES OF SPECIFIC IMPLEMENTATION STEPS
1.4 Align and coordinate the Work Group with the work of the PQC4ME to enhance the work across these entities.	• Include the Work Group leadership or designee(s) in the PQC4ME (Perinatal Quality Collaborative for Maine). • Include the PQC4ME leadership or designee(s) on the Work Group for sharing information and joint planning.
1.5 Align and coordinate the Work Group with the work of the Maine Rural Transformation Team and similar high-level state initiatives to enhance efforts across these entities.	• Include the Work Group leadership or designee(s) in the Rural Transformation Project. • Include the Rural Transformation leadership or designee(s) on the Work Group for sharing information and joint planning.
1.6 Incorporate into all strategies and actions considerations of cultural sensitivity and bias (structural and implicit), as appropriate.	
Strategy 2 Access to Services	

2.1 Design and implement a study to identify the areas of the state, particularly the rural areas, where gaps in services related to perinatal health exist.	• Use the results of this project to inform the study design.
	• Determine the study methodology, and identify the study topics such as:
	  o Women's health, reproductive life planning and contraception
	  o Primary and specialty inpatient and outpatient midwifery, obstetrical, pediatric, mental health and substance use services
	  o Other community-based services such as domestic violence and case management
	  o Cost of pregnancy-related care under MaineCare and private payers, and in rural and urban areas

RECOMMENDATIONS	EXAMPLES OF SPECIFIC IMPLEMENTATION STEPS

2.2 Prioritize, design and implement new or enhanced models of care/ services.	• Identify existing evidence-based models that can be replicated in Maine; test new models, as needed.
	• Select the topics/models to be implemented and evaluate:
	  o Increased access to LARC (Long-acting Reversible Contraception) and other contraceptives through: a) provider training, and b) collaborations with Maine Family Planning and Planned Parenthood of Northern New England (could include co-locating Family Planning/Substance Use service models).
	  o Tobacco/nicotine treatment (including vaping) programs for pregnant women, and adolescents/women of reproductive age before and between pregnancies.
	  o Additional community-based prenatal and reproductive health care services such as the Centering Pregnancy Group Care Model in areas where there are gaps.
	  o Outreach to other New England states, and organizations such as NNEPQIN (Northern New England Perinatal Quality Improvement Network) to identify and assess/adapt successful policies and programs.
	  o New and/or enhanced perinatal care coordination models.
	  o HRSA/ACOG Alliance for Innovation on Maternal Health (AIM) modules to improve maternal outcomes (this also could be done through PQC4ME).
	  o ACOG's Emergencies in Clinical Obstetrics (ECO).

RECOMMENDATIONS	EXAMPLES OF SPECIFIC IMPLEMENTATION STEPS

2.3 Identify and implement perinatal risk assessment and screening tools, and resources to address the results of the assessments and screenings.	• Identify tools that are evidence-based, if possible; develop and test new tools, as needed.
	• Develop guidance and training on the use of the tools, including documentation of the screening and results in the medical record (e.g., EMR).
	• Identify topics such as the following to be covered:
	  o Clinical/genetics risk assessments.
	  o Depression and other mental health conditions.
	  o Substance use.
	  o Domestic violence.
	  o Newborn screening and immunizations.
	  o Oral health.
	  o Social determinants of health (e.g., transportation, housing, food insecurity).
	  o Assessment of language and cultural needs of new and vulnerable populations.
	• Mental health and substance use co-morbidities.
	• Create and disseminate a comprehensive package of risk assessment and screening tools.

Strategy 3 Workforce and Training	

3.1 Design and implement strategies/models to fill the identified workforce shortages (clinical, mental health, substance use) across the state.	• Use the study to identify the specific workforce shortages and locations to target (Recommended Action 2.2).
	• Select, develop and implement strategies and models:
	  o Telehealth, including assessment of broadband capabilities, provider interest and target areas for telehealth.
	  o Clinical rotations of community-based providers through the Level III/IV hospitals to increase their knowledge and skills.
	  o Clinical training program related to deliveries in non-traditional settings such as Emergency Rooms in rural hospitals and Maine Emergency Medical Services.
	  o New or enhanced care coordination programs and services.
	  o Midwifery Advanced Practice RN program.
	  o Identification and pursuit of federal workforce shortage programs and funding for medically underserved areas.

RECOMMENDATIONS	EXAMPLES OF SPECIFIC IMPLEMENTATION STEPS

3.2 Design, implement, and evaluate trainings for perinatal providers.	• Determine the timing, frequency, modalities, target audiences (e.g., obstetricians, pediatricians, midwives, nurses, social workers, care coordinators/community health workers, multidisciplinary groups), and topics such as:
	
	  o Screening procedures, tools, resources and referral mechanisms (e.g., social determinants of health, mental health, substance use, domestic violence and oral health).
	
	  o Cultural sensitivity and structural and implicit bias in caring for diverse/vulnerable populations (e.g., persons of different races/ethnicities, immigrants, low income persons and those living in rural areas—also see Recommended Action 1.6).
	
	  o Reproductive life planning using existing tools such as One Key Question ("Would you like to be pregnant in the next year?").
	
	  o Other topics such as infant mortality, the Maine Perinatal System of Care, trauma-informed care, family engagement/ shared decision-making, breastfeeding, and telehealth to link primary and specialty care providers for consults and education.
	
	  o Identify training materials using available existing national and state materials, if available and desirable; ensure that the messaging in the trainings is consistent with messaging from public and private sector organizations in Maine.
	
	  o Design and conduct evaluations of the trainings.

3.3 Design, implement and evaluate trainings for providers who see perinatal populations, but whose focus is not perinatal populations.	• Determine the timing, frequency, modalities, target audiences (e.g., primary care providers, substance use and mental health providers, staff from state agencies such as the Office of Child and Family Services), and topics such as:
	
	  o Mental health – safe medications to take during pregnancy; and the signs, symptoms, and prevalence of depression and other mental health conditions during and after pregnancy.
	
	  o Risks of substance use, including marijuana, during pregnancy on the woman and infant; and the risks of relapse post-pregnancy.
	
	  o Connections between pregnancy and domestic violence.
	
	  o Reproductive life planning such as One Key Question.
	
	  o Obesity and pregnancy.

RECOMMENDATIONS	EXAMPLES OF SPECIFIC IMPLEMENTATION STEPS

3.4 Design, implement and evaluate trainings or modules on perinatal topics for students.	• Determine methods, specific target audiences (e.g., medical, nursing, social work and public health students) and topics such as:
	  o Reproductive and perinatal epidemiology.
	  o Perinatal System of Care in Maine.
	  o Cultural competency and structural and implicit bias in perinatal care.
	  o Perinatal programs and services.

Strategy 4 Referrals, Coordination and Collaboration	
4.1 Establish written procedures and agreements for maternal and neonatal referrals and transports between community-based birth hospitals and providers, and Level III/IV hospitals.	• Include in the procedures and agreements: the specific steps to make referrals and set up the transports through EMS; and ongoing communications between the referring and accepting providers during the hospital stay and at discharge. • Monitor and report referral and transport activity on a regular basis. • Also see 1.2 above.
4.2 Establish and implement mechanisms for referrals to community-based programs and services such as Early Intervention (EI) at perinatal care sites (hospitals and practices).	• In collaboration with community-based service providers, establish written procedures for referrals. • Document referrals made in the patient's medical record.
4.3 Coordinate and collaborate (including the sharing of results) on perinatal activities such as PQC4ME QI (Quality Improvement) projects at the birth hospitals and birth centers	• Determine the forums, timelines, and specific activities to report; report on activities.
Strategy 5 Family Engagement and Education	
5.1 Conduct and assess provider trainings on family engagement and shared decision-making.	• See implementation steps outlined in 3.3 above.

RECOMMENDATIONS	EXAMPLES OF SPECIFIC IMPLEMENTATION STEPS
5.2 Create a comprehensive package of maternal/family education materials.	• Identify the topics to be covered in the package of education materials (e.g., breastfeeding, family planning, safe sleep, postpartum depression, etc.). • Develop guidance for providers about how and when the materials are distributed.

Strategy 6 Public Policies and Programs

6.1 Design and implement an analysis of eligibility (including opportunities for expanding eligibility), participation, services and costs for public policies and programs that can optimize maternal and infant outcomes.	• Identify the programs/policies to analyze (e.g., MaineCare, Public Health Nursing, Maine Families, SNAP, WIC, TANF, EI). • Conduct analyses and produce report of findings.
6.2 Examine payment strategies, provider performance incentives and quality improvement initiatives to improve birth outcomes and lower costs.	• Identify the payment strategies, provider performance incentives and QI initiatives to analyze (e.g., MaineCare and commercial insurers). • Conduct analyses and produce report(s) of findings.
6.3 Implement and evaluate evidence-based public social media campaigns on select perinatal topics.	• Identify the target audiences (e.g., women of reproductive age; pregnant and post-partum women and their families; low, medium, and high risk women) and the topics to be covered (e.g., safe sleep practices (already underway), tobacco and other substance use, postpartum depression) • Develop and implement the campaigns using existing national and state materials, if available and desirable; ensure messaging is consistent with messaging from public and private sector organizations. • Evaluate the campaign(s).

RECOMMENDATIONS	EXAMPLES OF SPECIFIC IMPLEMENTATION STEPS
6.4 Ensure that eligible women and their families receive the services that promote optimal birth outcomes.	• Clarify and streamline referral processes for public programs available to Maine families (e.g., PHN, Maine Families, MaineCare, SNAP, WIC, TANF, EI). • Produce regular reports on program enrollments, and periodic reports on clinical outcomes and costs.
6.5 Design and implement a website of perinatal resources.	• Create a plan to develop (or enhance an existing website) and maintain a website; plan should include: the content, staffing and funding needed. • Identify resources such as: Eat Sleep Console, Snuggle ME, Cribs for Kids, Text4Baby, Period of Purple Crying, Up, Up and Away, etc.; and links to national and regional organizations; screening tools, and best practices. • Implement the website and develop a continuous marketing and communications plan to assure optimal access and use of resources.
Strategy 7 Assessment, Monitoring and Evaluation	
7.1 Assess the effectiveness of new and enhanced models and activities using QI methods and data collection, and/or other appropriate evaluation methods.	• Design and implement evaluations of new and enhanced models. • Use PQC4ME to engage hospitals, rural health centers, birth centers and others to test and evaluate QI interventions; disseminate and scale effective interventions.
7.2 Develop and distribute regular public heath reports or dashboards of maternal and infant outcomes.	• Determine the content of the reports/dashboards and sources (e.g., Vital Statistics, Maine and national Kids Count reports, America's Health Rankings Maternal and Child Health reports, triennial Maine State Community Health Needs Assessment reports, etc.). • Develop and implement a dissemination plan that includes the reporting frequency, and presentations at meetings such as the PQC4ME.

RECOMMENDATIONS	EXAMPLES OF SPECIFIC IMPLEMENTATION STEPS
7.3 Enhance the MFIMR panel reviews and reporting.	• Increase the number of infant deaths reviewed by the MFIMR panel (HRSA recommends that state with fewer than 100 annual deaths review all deaths). • Review all fetal deaths (for policy changes and education)—e.g., knowledge gap re: ACOG/SMFM resuscitation at threshold of viability; and the 2013 home birth deaths. • Produce and disseminate annual reports of the reviews.
7.4 Improve Vital Statistics data, including accuracy, timeliness and reporting.	• Identify changes to be made and timeline for making changes, including the development of an electronic system of fetal deaths.

Summary

Through this project, we were able to describe the trends in births and IM in Maine over the period 2000–2017. We identified the primary causes, and many associated demographic, clinical and other risk factors. We explored the perceptions of a diverse group of experts from across the state about the risk factors they think are important, and how Maine's existing system of perinatal care is working and how it can be improved. Finally, we identified recommendations that address the findings of the report and if implemented, will improve Maine's IMR as well as birth outcomes overall.

While recognizing that the gaps and needs identified in this report are real and substantive, we clearly heard that many are committed to not only improving Maine's IMR but birth outcomes for all infants and families across the state. It is our hope that the findings and recommendations will help inform and guide the process of engagement and action.

Appendices

Appendix A: Glossary of Definitions and Acronyms

1. Adequacy of Prenatal Care Measure (Kotelchuk Index) - Index that measures both the timing of initiation of prenatal care and whether the number of recommended visits occur.

2. Birth weight
   - ELBW (Extremely low birth weight) – Less than 1000 grams
   - VLBW (Very low birth weight) – Less than 1500 grams
   - MLBW (Moderately low birth weight) – 1500-2499 grams
   - LBW (Low birth weight) – Less than 2500 grams
   - NBW (Normal birth weight) – 2500+ grams

3. Causes of infant death
   - Congenital Anomalies or Birth Defects - structural, functional or biochemical abnormalities, regardless of cause and irrespective of any known genetic or environmental association(s), that may interfere with normal growth or development. Examples include neural tubes defects such as anencephaly and spina bifida, and heart defects such as critical congenital heart disease.
     - Prematurity-related causes – ICD codes related to prematurity, low birth weight. and conditions related to prematurity/low-birth weight such as premature rupture of the members, respiratory distress and multiple births. List developed by the National Institute of Children's Health Quality (NICHQ).
     - Infections – Includes a broad range of diseases that are considered communicable or transmissible – both viral and bacterial.
     - Injuries – Includes a broad range of injuries such as car accidents, drowning and inhalation of chemicals.
     - Other perinatal conditions – Includes a range of conditions not included in the prematurity-related causes such as maternal transmission of medications and other substances, and injuries resulting from the delivery.
     - SIDS/SUID – Sudden unexplained death of an infant younger than one year old. Term SUID is used before investigation of the cause of death.
     - Others – Includes all other causes not specified above.

4. Food insecurity - the state of being without reliable access to enough affordable, nutritious food.

5. Hospital level of care (AAP, ACOG: Guidelines for Perinatal Care, 2017)
   - Level I (Basic Care) – Facility that provides care of low-risk women with uncomplicated singleton term pregnancies with a vertex presentation who are expected to have an uncomplicated pregnancy.
   - Level II (Specialty Care) – Facility that provides Level 1 care and care for appropriate high-risk antepartum, intrapartum or post-partum conditions to those directly admitted or transferred from another facility.

- Level III (Subspecialty Care) – Facility that provides Level 2 care plus care of more complex medical conditions, obstetrical complications and fetal conditions.
- Level IV (Regional Perinatal Centers) – Facility that provides the highest level of care to the highest risk women, including those with severe maternal cardiac conditions or those requiring surgeries.

6. Infant Mortality Rate (IMR) – deaths per 1000 live births
   - Neonatal death – death in the 1st 27 days of life
   - Early neonatal death – death in the 1st 6 days of life
   - Post-natal death – death during the period 28 – 364 days of life

7. Kitagawa decomposition analysis – Analytic method that quantifies the contribution of changes in the distribution of and/or rates of a predictor to the overall difference in an outcome between two time periods, two demographic groups, two geographic areas, etc.

8. Maine Child Death and Serious Injury Review Panel – Multidisciplinary team that reviews cases of child death and serious injury with a focus on improving the safety and care of children in Maine; it was established in statute in 1992.

9. MFIMR (Maternal, Fetal, Infant Mortality Review) Panel – A team at the Maine CDC that reviews and reports on cases of maternal, fetal and infant deaths with a goal of strengthening resources and enhancing system and policies to improve maternal and child outcomes; the panel is in state statute.

10. NICU (Neonatal Intensive Care Unit) – Located in Level III/IV hospitals, these units provide the highest level of care to the sickest neonates.

11. One Key Question – Tool used in clinical practice to assist women in making their plans for contraception.

12. PPOR (Perinatal Periods of Risk) – Multi-phase, multidisciplinary approach for monitoring and examining the causes of infant and fetal death; the PPOR approach allows states and communities to identify the "risk periods" in which infant and fetal deaths are higher than would be expected.

13. Perinatal regionalization – Strategy to improve maternal and neonatal outcomes, particularly the reduction of infant mortality, by establishing systems designating where infants are born or transferred according to the level of care they need at birth.

14. PRAMS (Pregnancy Risk Assessment Monitoring System) - CDC-supported surveillance data collected by the states through maternal questionnaires post-birth.

15. Prematurity -birth before 37 weeks gestation
    - Extreme prematurity – birth before 32 weeks

16. Race – As reported by the parent on the State of Maine birth certificate parent worksheet

- AIAN: American Indian/Alaska Native
- API: Asian Pacific Islander
- Black – Black or African American
- White
- Other

17. SNAP (Supplemental Nutrition Assistance Program) – Formerly known as Food Stamps, a federal program that provide food-purchasing assistance to low-income individuals and families living in the US.

18. TANF (Temporary Assistance for Low-Income Families) – A federal program that provides cash assistance to low income families in the US.

19. WIC (Women, Infant and Children) – A federal special supplemental nutrition program that provides federal grants to states for supplemental foods, health care referrals, and nutrition education for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women, and to infants and children up to age five who are found to be at nutritional risk.

Appendix B: Examples of National and State Strategies to Reduce Infant Mortality

Policy Approaches

Policies can include payment (Medicaid and commercial insurers) that influences the use of health care services, as well as those that impact other factors such as income, childcare, food security, transportation, housing, etc.

1. **State Medicaid Payment Reform Strategies to Improve Birth Outcomes (** *National Association for State Health Policy, 2017)* **http://nashp.org/state-medicaid-payment-reform-strategies-promote-improved-birth-outcomes**
   - Oklahoma Case Study: The Oklahoma Health Care Authority created the Cesarean Section Quality Initiative to reduce elective C-sections 15.6%, resulting in significant cost savings to the state.
   - Tennessee Case Study: The TennCare program (Medicaid) implemented a perinatal episode of care (EOC) strategy as part of the Tennessee Health Care Innovation Initiative; the perinatal EOC focused on women with low to medium risk pregnancies and includes care provided during pregnancy, delivery and postpartum care. Goals are to control costs, patient centered care by rewarding providers who deliver cost effective, high value care; outcome showed a 3.4% reduction in medical care costs over 1 year.
   - Wisconsin Case Study: The Wisconsin Department of Health Services (Medicaid) implemented the Obstetric Medical Home Program, which targets high risk pregnant women to reduce birth disparities through effective, coordinated, comprehensive and quality maternity care. Results included an increase in the rate of postpartum visits from 61.4% to 85.5% over 1 year.

2. **State Policy Options (National Association for State Health Policy and the deBeaumont Foundation, 20xx)** **https://nashp.org/**
   - **A toolkit for state officials that includes policies on:**
     - Targeted care for those at greatest risk
     - Safe sleep
     - Smoking cessation
     - Preconception/interconception care
     - Promote full-term births
     - Social factors

3. **Increase WIC Program Enrollment (Vermont Agency of Human Services, Department of Health, 2019)** **https://legislature.vermont.gov/assets/Legislative–Reports/WIC–Legislative–Report-2019.pdf**
   https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2837444/ *Impact of WIC Participation on Infant Mortality and Racial Disparities* (American Journal of Public Health, 2010)

   The Special Supplemental Nutrition Program for Women, Infants and Children (WIC) is a federal program, administered by the states, to assure healthy pregnancies, healthy birth outcomes, and healthy growth and development for women, infants and children up through age 5 who are at nutrition risk. WIC caseloads have been decreasing nationally, and Vermont implemented a project to determine contributing factors and strategic solutions such as expanding access to clinic services in rural communities, eliminating "proof of pregnancy" documentation to expedite enrollment, and establishing partnerships with medical providers to schedule appointments in the medical home, to improve WIC enrollment and retention. These strategies were informed by outreach to program participants and nonparticipants.

Programmatic Approaches

4. **Virginia BabyCare:** http://www.vdh.virginia.gov/mount-rogers/maternal-and-child-health/baby-care/
   - The Virginia Department of Medical Assistance (Medicaid) launched BabyCare in 1987 and added case management in 1991. BabyCare integrates behavioral risk screening, case management, expanded prenatal services, and requires provider enrollment. Outcomes documented include improved birth outcomes, increased use of wraparound services and lower costs.

5. **High Risk Pregnancy Program (formerly Arkansas Angels):** https://angels.uams.edu/ and https://angels.uams.edu/wp-content/uploads/sites/81/2019/10/1904180-2019-Angels-annual-report_SchaffnerFINAL–DRAFT.pdf

   Targeted at all women in Arkansas who are at risk for a complicated pregnancy, this comprehensive program provides evidence-based guidelines, research, health care education, and a 24 x 7 call center. Outcomes include reductions in infant mortality rates, high rates of patient satisfaction (for use of telemedicine services to reduce travel in rural areas among many other outcomes); partners include University of Arkansas Medical School, the Arkansas Department of Human Services, and the Arkansas Medical Society.

6. **Project WIN (Women Inspired Neighborhood Network), Henry Ford Health System (Michigan):** https://www.henryford.com/about/community-health/win/infant-mortality for women ages 18-35
   - A mortality rate among black babies that was twice that of white babies led Henry Ford and its partners to launch WIN in 2011 to build a comprehensive system of care for women 18-35 in Detroit and connect them with community resources. Using community health workers and certified nurse midwives among other strategies, the program achieved the following outcomes between 2016 and 2019: no infant deaths under the age of one; increases in average birth weight and term; reductions in low birthweight and preterm babies; 94% of mothers initiated breastfeeding, and 91% of babies in safe sleeping positions for the first three months after birth.

Quality Improvement Approaches

Quality improvement efforts to address infant mortality have been implemented in NC, CA, MA, IL and other states, as well as a national 19-state QI initiative funded by HRSA (CoIIN). These initiatives have been shown to be effective strategies to engage primary and specialty care providers and others in addressing issues of local importance, informed by data and use of evidence-based QI processes.

7. **National Institute for Children's Health Care Quality (NICHQ):** https://www.nichq.org/
   - **NICHQ served as a national center for technical assistance (training, data infrastructure, online community, etc.) for the 19-state COIIN, funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration. NICHQ produced an IM toolkit** https://www.nichq.org/resource/infant-mortality-coiin-prevention-toolkit **and has published numerous issue briefs** https://www.nichq.org/project/collaborative-improvement-and-innovation-network-reduce-infant-mortality-infant-mortality **on topics such as increasing the use of LARC in Medicaid.**

8. **Northern New England Perinatal Quality Improvement Network (NNEPQIN):** https://www.nnepqin.org/

   NNEPQIN is a voluntary consortium of more than 40 organizations involved in perinatal care, including hospitals and health systems, state health departments, midwifery organizations and the March of Dimes; the mission is to improve perinatal care throughout New England through professional education, developing best

practice guidelines, and benchmarking and use of QI parameters. Maine has established a statewide perinatal QI initiative (PQC4ME) that intends to coordinate and support NNEPQIN, but currently lacks funding.

9. **Collaborative Learning and Quality Improvement in Public Health (CoIIN):** https://mchb.hrsa.gov/maternal-child-health-initiatives/collaborative-improvement-innovation-networks-coiins **CoIINs are a multistate quality improvement initiative to address infant mortality. Published results credit the peer to peer learning network, platform for collaborative learning, and data sharing.**

State Approaches

In 2018, the infant mortality rate in Georgia (7.6 per 1,000 live births) exceeded rates in Florida and Maine (both 6.2 per 1,000 live births), while New Hampshire and Vermont led the nation with the lowest state infant mortality rates (3.9 per 1,000 live births). While these states have undertaken similar strategies to reduce infant mortality, they differ markedly in terms of demographics, social determinants, leadership, partnerships/collaboration and allocation of resources.

10. **Georgia (Milbank Memorial Fund Quarterly):** https://www.milbank.org/wp-content/uploads/2017/10/Reducing-Infant-Mortality-in-Georgia-and-Florida.pdf **Georgia improved from 43rd to 31st in its state infant mortality rate between 2007 and 2012.**
    - **The success of this effort was attributed to four factors: stakeholder engagement, champions and leadership (including the Department of Public Health Commissioner), data-driven strategies, and partnerships that focused on postnatal care.**

11. **Florida (Milbank Memorial Fund Quarterly):** https://www.milbank.org/wp-content/uploads/2017/10/Reducing-Infant-Mortality-in-Georgia-and-Florida.pdf Florida improved from 33rd to 25th in its state infant mortality rate between 2007 and 2012. Key lessons from this initiative included creation of the Healthy Start program to identify all women with high risk pregnancies and provision of targeted care; federal, state and local partnerships; sustainability and champions through changes in political leadership; and a focus on disparities.

12. **New Hampshire: (personal communication with Victoria Flanagan, Dartmouth-Hitchcock and Rhonda Siegel and Carolyn Fredetter, Department of Health and Human Services, NH Child Fatality and Sudden Unexpected Infant Death Review Programs, respectively, November, 2019)**

13. **Vermont: (personal communication with Breena Holmes, MCH, VT Dept of Health, September 2019).** https://www.med.uvm.edu/vchip/vrphp
    Vermont Child Health Improvement Program, Vermont Regional Perinatal Health Project, is a high quality academic health care resource for education, skills, competencies and quality improvement in perinatal health care, partnering with the Vermont Department of Health, community hospitals and multidisciplinary teams to facilitate timely, effective, and patient-centered health care in rural settings. Actions include statewide statistics conferences to review perinatal outcomes data against key maternal and newborn quality indicators, maternal/newborn transport conferences, and regular meetings of nurse managers from community hospitals to review policy and best practices, regionalization for high risk pregnancy care, Nurse-Family Partnership (home visiting); prioritized treatment for opioid-exposed pregnant women and infants; and early entry into prenatal care.

Appendix C: Advisory Committee Members

Name	Organization
Claire Berkowitz	Mid-coast Maine Community Action
Ed Doherty	March of Dimes
Maryann Harakall	Main CDC
Dr. Gregory Hardy	Stephens Memorial Hospital
Helen Hemminger	Maine Children's Alliance
Bobbi Johnson	Maine Child Welfare Services
Evelyn Kieltyka	Maine Family Planning
Stephanie LeBlanc	Oxford County Mental Health Services
Dr. Dora Mills	MaineHealth
Denise Osgood	Maine CDC
Megan Perry	Westbrook Police Department
Dr. Alan Picarillo	Maine Medical Center
Michelle Probert	MaineCare
Julie Redding	Community Caring Collaborative
Danielle Rideout	Westbrook Police Department
Dr. Tracy Stevens	Northern Light Eastern Maine Medical Center
Elyssa Wynne	Maine Office of Child and Family Services

Appendix D: Key Informants Interviewed

Name	Organization
Amanda Brown	Inland Hospital
Kate Downing	Maine CDC/Public Health Nursing
Dr. Mark Flomenbaum/ Lindsey Chasteen	Maine Medical Examiner's Office
Nancy Green	Maine Medical Center
Dr. Gregory Hardy	Stephens Memorial Hospital
Dr. Jennifer Hayman	Maine Medical Center
Evelyn Kieltyka	Maine Family Planning
Pamela Lahaye	Maine Children's Trust/Maine Families
Dr. Christian Litton	Maine Medical Center
Sue Mackey Andrews	Maine Resilience Building Network
Dr. Peter Manning	Southern Maine Medical Center
Maryanne McDormand/ Lisa Stout/Anne Lang	Portland Public Department/Public Health Nursing
Dr. Dora Mills	MaineHealth
Marc Minkler	Maine Emergency Medical Services
Gregory Mitchell	Maine State Police
Mark Moran	Northern Light Eastern Maine Medical Center
Jan Morrisette	Formerly, Maine CDC/Public Health Nursing
Dr. Jay Naliboff	Formerly, Franklin Memorial Hospital
Elizabeth Neptune	Pleasant Point Health Center
Alane O'Connor	Maine General Hospital
P Lynn Ouellette	Private Psychiatric Practice
Dr. Alan Picarillo	Maine Medical Center
Julie Redding	Community Caring Collaborative
Lisa Sockabasin	Wabanaki Public Health
Francine Stark	The Maine Coalition to End Domestic Violence
Matthew Stone	Bangor Daily News
Alfred Wakeman	Downeast Hospital
Kelly Wheeler/Rebecca Sucy	AWHONN/Reddington-Fairview Hospital
Marjorie Withers	Formerly, Community Caring Collaborative
Elyssa Wynne	Maine Office of Child and family Services

Appendix E: Quantitative Research Questions for the Maine CDC Vitals Statistics

1. How did the <u>number of births, the number of deaths and the IMR</u> in the state change over period 2000- 2017?

2. How did the distribution of births and deaths, and the IMR change over the period 2000-2017 by location?
   - County of maternal residence
   - Rurality of maternal residence
   - Place of birth – hospital, birth center, home, other

3. How did the distribution of infant death by age of death (early neonatal, neonatal and post-neonatal) change over the period?

4. Did the <u>causes of infant mortality</u> change over the period 2000-2017?
   - Prematurity-related causes
   - SIDS/SUID
   - Congenital Anomalies
   - Injuries
   - Infections
   - Other – describe

5. Did the causes of infant mortality change from the periods 2000-2004 to 2013-2017?

6. How did the distribution of births and deaths, and the IMR change over the period 2000-2017 by the following established risk factors?
   - Prematurity
   - Low Birthweight (LBW and VLBW)
   - Race
   - Ethnicity
   - Maternal age
   - Maternal education
   - Maternal marital status (2014-2017, data not available prior to 2014)
   - Adequacy of prenatal care
   - Delivery insurance = MaineCare/Medicaid)2014-2017, data not available prior to 2014)
   - Plurality
   - Maternal smoking during pregnancy (2014-2017, data not available prior to 2014)

7. During which of the four risk period groups – maternal health and prematurity, maternal care, newborn care, and infant health – were excess infant and fetal deaths more likely to occur during the period 2014-

2017? (This question was answered through a PPOR (Perinatal Periods of Risk) analysis. The steps in this analytic approach are described in Appendix F).

8. What was the impact of gestational age and rurality on the IMR between 2000-2004 and 2013-2017? (This question was answered through a Kitagawa decomposition analysis, which is described in Appendix G).

9. Where there changes in the distribution of births and deaths in Level 3 and Level 1 hospitals, and at home over the period 2000-2017 overall, and by county and rurality?

10. Where there changes in the distribution of deaths by age of death in Level 3 and Level 1 hospitals, and at home over the period 2000-2017 overall, and by county and rurality?

11. Were there changes in the per cent of VLBW newborns born in Level 3 hospitals over the period 2000- 2017 overall, and by county and rurality?

12. Where there changes in the causes of deaths in Level 3 and Level 1 hospitals, and at home over the period 2000-2017 overall, and by county and rurality?

Appendix F: Key Informant Interview Guide

Introduction

I am working with Quality Counts/Qualidigm and a group of public health and perinatal health experts on a research project studying IM in Maine. Although in 1996, Maine ranked #1 with the lowest Infant Mortality Rate (IMR) in the US, the state's rank dropped significantly over the next two decades to a ranking of 37th in 2014.

Although Maine has seen some improvement in recent years – with a 2015 rank of 31st and a 2016 rank of 20th, the rank is still well below what it once was, and behind the other northern New England states. The purpose of this project is to gain knowledge and insights into the causes of Maine's IMR, and develop recommendations to address the causes and lower Maine's IMR.

As part of this research, I am conducting interviews with key informants like you across the state.
In the interviews, I will cover a range of topics and would like to <u>learn from you and get your insights</u> on these topics.

I will be asking you questions about known primary and secondary drivers of IM – including medical, social, behavioral and demographic risk factors; access to perinatal and other health and social services; and changes in programs, policies and reporting that many have impacted IM in Maine. I also would like to hear about any successful local, state and/or national strategies that you know about and think may be used or adapted in Maine.

A report of the findings is planned to be issued in late 2019 or early 2020.

You may not be able to answer all the questions so we will just <u>skip the questions you cannot answer</u>.

I expect the interview to take about 60 minutes and would like to record the session to make sure that I do not miss any of the information you provide. The interview transcriptions will only be available to my Research Associate and me. No individual responses will be identified in our report. Is it okay if I record the call?

Do you have any questions before I begin?

Background

First, I would like to get some background information about your work experience and other related experience such as participation in committees that you have had <u>working with pregnant/post-partum women and infants and/or on issues related to infant and fetal mortality</u>.

1. What is your current position and organization?
2. What previous related positions or roles have you had?
3. What areas of the state have you worked in or have knowledge about?
4. What populations have you worked with? (e.g., residents of rural areas, those living in poverty, MaineCare recipients, different racial/ethnic/religious groups, immigrants, Native Americans)

Before we begin the questions, some background on IM and the specific areas I will explore with you in the questions:

- The five major <u>primary</u> drivers of infant mortality in Maine and the broader US are: low birthweight/prematurity, maternal pregnancy complications, birth defects, SIDS, and injuries.
- Several <u>risk factors/secondary drivers</u> have been found to be associated with these primary causes. These include smoking and other substance use, safe sleep practices, social determinants of health, mental health, trauma, domestic violence, as well as limited access to care and services due to a number of factors such as geography, race and culture; health care system issues, and policies and programs.

Risk Factors/Secondary Drivers

5. How significant do you think substance use (SU) is in IM in Maine? On a scale from 1-5, with 1=lowest contributor, 5=highest contributor), how would you rate the effects of the different substances on IM?
   a. Tobacco cigarettes
   b. Electronic cigarettes
   c. Marijuana
   d. Opioids
   e. Other substance(s) (e.g., Kratom) Describe: _____

6. For <u>each</u> of the substances just named: (note: screening for use – not lab testing)
   a. Do you think the <u>use of the different substances</u> varies by geography AND/OR different populations? How?
   b. Do you think pregnant and post-partum (PP) women are <u>routinely screened</u> during pregnancy & the PP period for SU? Is screening for some of these substances done more often than for others?
      - If a direct care provider:
        o Do you routinely screen your patients for all of some of these substances? Which?
        o Do you have screening tool(s) that you use?
        o Does your EMR have a prompt for SU screening?
        o About how many times over the past year did you ID SU during pregnancy or PP period? Which substances?
        o Are there any barriers to screening?
        o What are your usual actions when screening is positive?
   c. What <u>treatments</u> for the different substances are available?
      - Does availability vary by geography AND/OR different populations? How?
      - If a provider:
        o Do you make referrals to services?
        o Do women who you refer receive treatment?
        o What are the barriers to receiving SU services? Is stigma a factor?
        o How do you follow-up to determine if treatment is occurring?
   d. What do you think are the best approaches to decrease SU during the <u>pre-conception</u>, pregnancy, and post-partum periods including prevention and reducing PP relapse rates?

7. Do you think that safe sleep practices (sleeping on back, no co-sleeping) are being used by families in Maine?

    a. Do you think there are differences in safe sleep practices by geography AND/OR among different populations?

    b. Are caregivers providing pregnant and post-partum women with information about safe sleep practices? What information?

- If you are a direct care provider:
  - Do you discuss breastfeeding and safe sleep practices?
  - Do you routinely provide information about safe sleep to families? If yes, what information?
  - How do you follow-up with families about sleep practices?

    c. Do you know if/how birth hospitals are addressing breastfeeding and safe sleep practices? (e.g., what are lactation consultants telling women? Are hospitals doing any modeling re: safe sleep? Are hospitals referring families to Cribs for Kids (available thru Maine Families)?

8. Do you know of any current, planned or past campaigns or (educational) initiatives related to smoking cessation during pregnancy and/or safe sleep practices <u>in Maine</u>?

    a. Can you describe these efforts, including where and when they happened?

    b. Do you refer pregnant women to smoking cessation programs?

9. Do you know of any other successful smoking or safe sleep initiatives that have been used elsewhere (e.g. in other parts of the country) that could be used/adapted in Maine?

10. Social determinants of health (SDoH) have become an increasing area of focus in examining poor health outcomes, including infant mortality. It is thought that SDoH, which include the complex interactions between social and physical environments, health services and structural and societal factors, are thought to be responsible for most health equities. I am going to list some SDoH, and would like you to respond to several questions:

- Poverty/low-income
- Homelessness/unstable housing
- Hunger/food insecurity
- Un-/under-employment
- Low education level
- Lack of adequate health insurance

- How significant a role do you think these SDoH play a in IMR? Some more than others?
- Do you think SDoH are addressed in perinatal care through screening, referral and other methods? How?
  - If you are a direct care provider:
    - Do you screen for SDoH? --Which ones?
    - Is there a screening tool that you use? Are there prompts in your EMR?
    - Are there any barriers to screening? What?
    - Do you have any ideas about how SDoH may be addressed, or better addressed to improve birth outcomes?

11. Do you think mental health (MH)/trauma- <u>including ACES</u>, play a significant role in infant in Maine? How?

a. Are there particular conditions that play a bigger role than others?

b. Do you think that mental health/trauma -- including post-partum depression -- is addressed in perinatal care and services through screening and other methods? How?
- If you are a direct care provider:
  - Do you routinely screen for mental health/trauma?
  - Is there a screening tool that you use? What tool?
  - Are there any barriers screening?
  - Do you routinely make referrals for clients with MH/Trauma/ACES history?

c. Are there available mental health services for pregnant and post-partum women?
- Does the availability of these services vary by geographic location AND/OR for different populations?

d. Do women whom you have referred for MH/trauma services receive them (e.g., is there a feedback loop)?

e. How does stigma affect the diagnosis, care and treatment of pregnant and post-partum women with mental health conditions/trauma?

12. Do you think domestic violence (DV) plays a significant role in infant and fetal mortality, and prematurity and low birthweight in Maine? How?

a. Do you think that DV is more prevalent in certain geographic areas AND/OR among different populations? Explain.

b. Do you think DV is addressed in perinatal care and services through screening and other methods? How?
- If you are a direct care provider:
  - Do you routinely screen for DV?
  - Is there a screening tool that you use? What tool?
  - Are there any barriers to screening?
  - Over the past year, approximately how many women did you identify with DV?

c. Are there available services to address DV in pregnant and post-partum women, and does the availability of these services vary by geographic location AND/OR for different populations?
- Do you refer these women to DV services?
- Did the women referred receive the services?

d. What are the barriers to identifying DV among pregnant and post-partum women, and to women receiving services?

13. Race (Black vs. White) has been consistently found to be associated with adverse birth outcomes. Immigration status (both undocumented and documented) also has been emerging as an issue due to increased limitations on access to services, and cultural differences in accessing and receiving care has been identified as a factor. In the State of Maine, how significant do you think each of these factors are in IM?

a. Race

b. Immigration status

c. Culture differences

Perinatal System of Care in Maine

The next questions focus on the system of perinatal care for pregnant and post-partum women, and infants in Maine; and access to this care. The elements of a perinatal system of care that we will cover in these questions include:

- o Access to birth hospitals, including those with advanced levels of care, as needed
- o Access to providers
    - Community-based general providers - OBs, NMs, PEDs,
    - Access to Specialists – MFMs, Neonatologists, Pediatric Surgeons, as needed
- o Referral mechanisms, including transport, to high-risk care, as needed
- o Coordination of care between referring and accepting providers/facilities
- o Access to community-based services, such as mental health and home visiting
- o System is client-centered and shared decision-making is integral to all aspects of care

The goal of an effective system of perinatal care is to ensure all pregnant and post-partum women and their infants receive the RIGHT care in the RIGHT place at the RIGHT time to ensure the best possible outcomes for women and infants of all risk status—low-risk, med-risk and high-risk women and infants.

Literature has shown that aspects of the perinatal system of care since as place of birth/LOC affect outcomes.

14. How well do you think the perinatal system of care is working in Maine?
    a. Are there any elements of the system (refer above) that are missing or not working well?
        - Are there enough hospitals in the needed locations? (e.g., rural areas)
        - Are there enough providers–including generalists and specialists available when and where needed?
        - Do providers have the volume of births available to remain current in knowledge and skills?
        - Are there enough community-based services available where and when needed?
        - Are there clear and effective referral mechanisms in place?
        - Is care coordinated across providers/facilities?
        - Do you think the system is client- (not provider-) focused?
        - Is there diversity in the provider population to reflect the populations cared for?
    b. Are there any women and/or infants who are "falling through the cracks?" Who?
    c. Are there any other gaps?

15. What has been the effect of maternity service closures on access to antepartum and post-partum care?
    a. Are women getting less care and fewer services or delayed care?
    b. What areas have been the hardest hit?
    c. Where do the women who used to deliver in the closed units now give birth? What are the challenges? (e.g., travel, childcare)

16. How do home births fit into the Maine's perinatal system of care?
    a. Do you think these births have had any impact on birth outcomes in Maine?
    b. Are the criteria for home births clear and appropriate?

17. What changes/improvements do you think should be made to the state's perinatal system of care?

Next, questions about more specific care and services:

18. Do you think women have access to AND receive pre-conception care/contraceptive counseling AND prenatal care in their communities?

    a. Is there differential <u>access</u> across different geographic areas of the state AND/OR for different demographic groups? Explain.

    b. Do pregnant women have access to AND receive the full range of prenatal/genetic testing?

    c. What are the barriers to receiving pre-conception and prenatal care and testing? (e.g., availability of providers, insurance)?

19. Do you think the risks – numbers and types – of pregnant women have changed over the past decade? If yes, how? (e.g., more obesity, hypertension, diabetes)?

    a. Are there geographical and demographic differences in the changes in risk status?

20. For <u>pregnant women needing high-risk obstetrical care</u> including those with chronic and pregnancy- related conditions such as asthma, chronic and gestational hypertension, obesity, pre-eclampsia/eclampsia, chronic and gestational diabetes; and those carrying multiple fetuses or fetuses with diagnosed or suspected congenital anomalies:

    a. Are there geographic AND/OR demographic differences in access?

    b. Are there referral mechanisms in place?

    c. Are there barriers to receiving high-risk care? (e.g., geography, transportation, insurance)?

    d. How is care coordinated between the referring provider and the high-risk provider?

    f. For women who need to be transported, what is the process, and how is it working?

    g. Is there support and education for women to help them follow care recommendations?

21. Do <u>high-risk newborns</u> have access to and receive neonatal care and management, and pediatric surgery as needed? If not, why not?

    a. Does access vary by area of the state AND/OR by demographics?

    b. Are there referral mechanisms in place?

    c. Are there barriers to receiving high-risk care? (e.g., geography, transportation)

    d. How is care coordinated between the referring provider/pediatrician and the high-risk providers?

    e. Is there a newborn transport service, and if yes, how is it working?

    f. Is there parental support and education to ensure parents understand and participate in care and recommended follow-up of sick babies?

22. Do pregnant and post-partum women and their infants have access to <u>community and support services,</u> such as home visiting and public health nursing?

    a. Do women/infants who are eligible for these services receive them? If not, why not?

    b. If you are a direct care provider for pregnant and post-partum women:

        • Do you make referrals to Cradle ME and/or PH nursing? If not, why not?

        • Do the women you refer to Cradle ME receive home visiting services? If not, why not?

        • Do you talk to women during their pregnancy about community support after the baby is born?

c. What are the challenges or barrier for women receiving home visits and/or other community- based services?
- Are the eligibility criteria clear and appropriate (e.g., are they too stringent or onerous in applying?)
- Are there enough of these services?
- Are the services provided in a timely manner?
- Are there geographic areas and/or different populations where access and receipt of these services is most and least available?

23. Do you think there are class, social-economic or other biases in perinatal care? What are the specific biases and how are they manifested?
    a. Do you think the biases you identified are more often found in particular areas of the state -- where – AND/OR toward specific populations – who?
    b. How do these biases impact care and outcomes?

Changes in Perinatal Policies, Programs and Reporting

24. Have there been any changes in state or local policies or programs (such as the birth defects program that began in 2005) that have impacted access to or receipt of preconceptual, perinatal, neonatal, or infant care and services?
    a. What specific policies and programs in what parts of the state were changed?
    b. When did the changes occur?
    c. How have the changes – if any – affected the families you interact with?

25. Have there been any changes in public health or other health care reporting that have impacted data collection and results related to infant mortality and other adverse birth outcomes?
    a. What specific policies and programs in what parts of the state were changed?
    b. When did the changes occur?
    c. Is there any data not collected that you think could be instrumental to improving IM rates?

Final Questions

26. Living in rural areas has often been cited as a risk factor for IM. Recognizing that there are many factors associated with living in rural areas that increase IM – many of which we just discussed—what do you think are the aspects of rurality that are most important to address to improve birth outcomes?

27. If you had to identify the top 1-2 causes of infant deaths in Maine, what would they be?
    a. Do you have suggestions about how to addresses these causes?
    b. Do you know of any other national, other state and/or local strategies/programs that have been successful in lowering infant that are applicable to Maine?

28. Do you know others in the state that you think it is important that we speak with?

29. Do you have any final questions or thoughts about what we have discussed?

Appendix G: Other Research Questions Explored Through Other Sources

Research Questions/Available Questions	Sources
Did the women: (2016-2017) • Use THC during most recent pregnancy • Use THC since baby born • Have depression during pregnancy • Have post-partum depression symptoms • Experience domestic violence during pregnancy by husband or partners • Have baby most often laid on back Did the women drink EToH during the last 3 months of pregnancy (2008-2017)	Maine CDC PRAMS
What were the causes of infant deaths related to unsafe sleep practices referred to the Medical Examiner's Office in 2013-2017?	State Medical Examiner's Office
What were the volumes of transports to the Northern Light Eastern Maine Medical Center and Maine Medical Center NICUs? From what hospitals were the babies transferred?	Northern Light Eastern Maine Medical Center and Maine Medical Center NICUs
Among SIDS/SUID deaths, how many associated with unsafe sleep practices/tobacco and alcohol use? Where did deaths occur?	Maine Medical Center and Maine CDC unsafe sleep research
Were there changes in the enrollments for infants under one from 2013 **to 2017 in SNAP, TANF**, WIC?	Maine Children Alliance
OCFS reports on babies w/ NAS symptoms or FAS disorders (2012-2018)	Kids Count
	Interviews with Other States

Appendix H: Description of Kitagawa Decomposition Analysis

Kitagawa Decomposition Analysis of IM rate change, 2000-2004 and 2013-2017:

Kitagawa decomposition is an analytic method that quantifies the contribution of changes in the distribution of and/or rates of a predictor to the overall difference in an outcome between two time periods, two demographic groups, two geographic areas, etc. In the case of infant mortality, a decomposition approach can help clarify the extent to which an increase (or decrease) in mortality is due to a change in the prevalence of a risk factor (e.g. preterm birth) or a change in survival outcomes among infants with that risk factor. We examined the impact of gestational age and rurality on the increase in the infant mortality rate in Maine between 2000-2004 and 2013-2017 using the Kitagawa decomposition technique.

Gestational age

In 2013-2017, infant mortality increased among infants at all gestational ages (Table 1 and Figure 1).

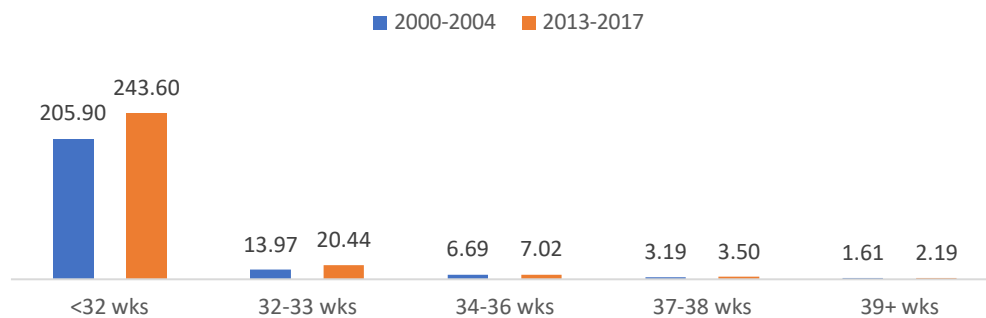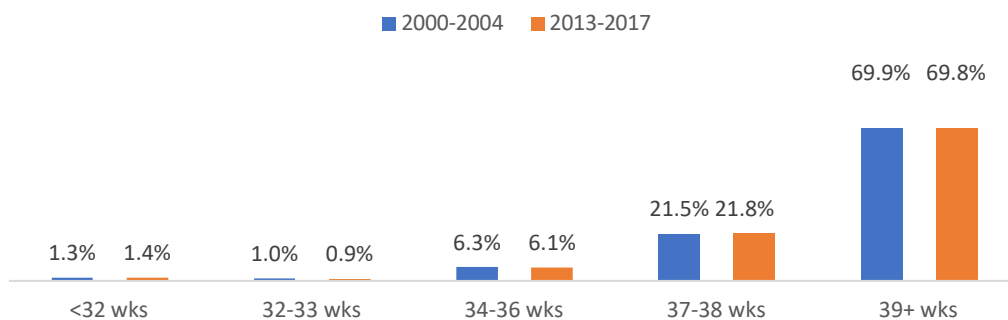## Figure 1. IMR per 1,000 live births by gestational age

■ 2000-2004　■ 2013-2017

	<32 wks	32-33 wks	34-36 wks	37-38 wks	39+ wks
2000-2004	205.90	13.97	6.69	3.19	1.61
2013-2017	243.60	20.44	7.02	3.50	2.19

Figure 2. Percent of births by gestational age

■ 2000-2004　■ 2013-2017

	<32 wks	32-33 wks	34-36 wks	37-38 wks	39+ wks
2000-2004	1.3%	1.0%	6.3%	21.5%	69.9%
2013-2017	1.4%	0.9%	6.1%	21.8%	69.8%

These changes in the gestational age distribution contributed close to 6% of the overall increase in infant mortality in the later period; the remainder was due to poorer overall survival among infants at all gestational ages.

The contribution of changes in distribution was more pronounced at specific gestational ages. In 2013-2017, there were more infants born at less than 32 weeks and at 37-38 weeks (Figure 3).

Figure 3. Change in the proportion of births between 2000-2004 and 2013-2017
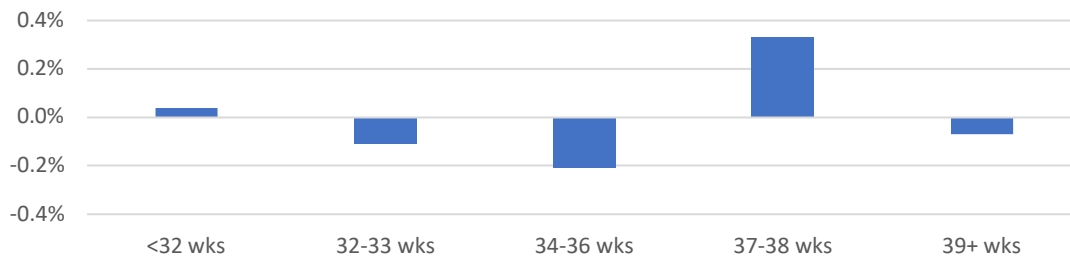

These increased proportion of infants born at less than 32 week and those born between 37-38 weeks accounted for 15.1% and 14.1%, respectively, of the increase in mortality among infants at these gestational ages (Table 1 and Figure 4). In 2013-2017 there were fewer infants born at 32-33 and at 34-36 weeks, However, infants born at these ages died at a higher rate in 2013-2017 relative to 2000-2004. There was essentially no change in the distribution of infants born at full term, thus all of the increase in mortality of these infants in 2013- 2017 was due to worse survival outcomes among full term infants in 2013-2017 (Figure 4).

Table 1. Kitagawa decomposition of change in infant mortality by gestational age group, Maine, 2000-2004 vs. 2013-2017

Gestational Age	Mortality rate 2000-2004	Mortality rate 2013-2017	Total change due to GA distribution (%)	Total change due to GA specific mortality (%)
<32 wks	205.9	243.6	15.1%	84.9%
32-33 wks	13.97	20.44	-42.2%	142.2%
34-36 wks	6.69	7.02	-235.5%	335.5%
37-38 wks	3.19	3.50	14.1%	85.9%
39+ wks	1.61	2.19	-0.3%	100.3%

Figure 4. Kitagawa decomposition of change in infant mortality by gestational age group, Maine, 2000-2004 vs. 2013-2017
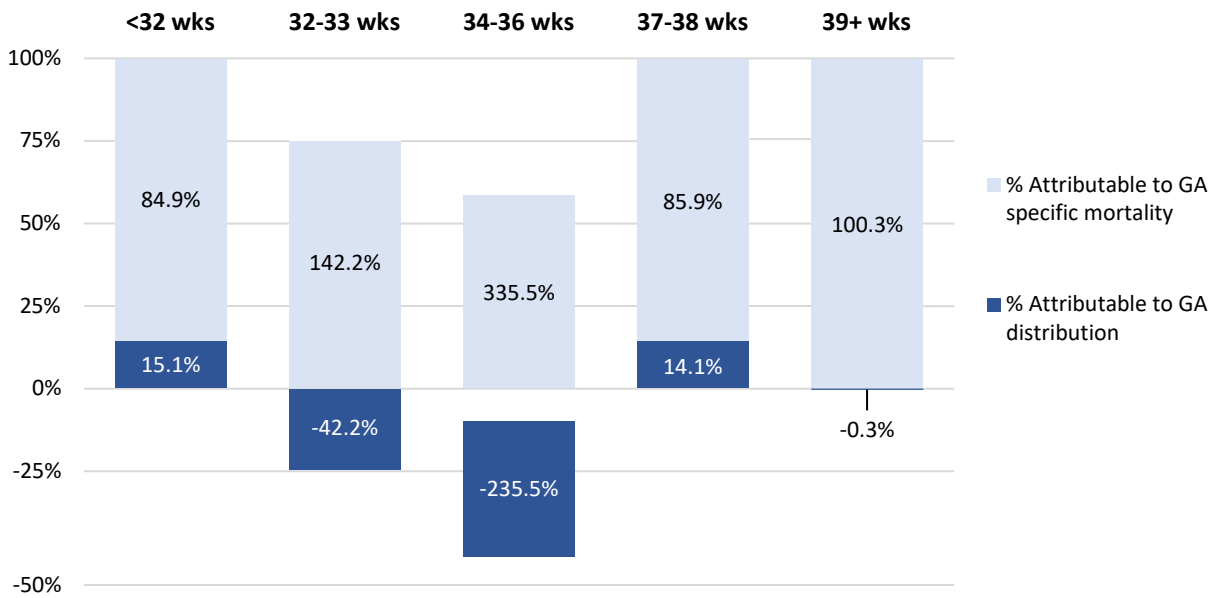

Rurality of maternal residence

Shifts in the residential distribution of births between 2000-2004 and 2013-2017 played a minimal role in the overall increase in infant mortality between the two time periods. While there was an increase in the number of births to mothers residing in urban areas, and a corresponding decrease in the number of births to mother residing in rural areas, between the two time periods, both groups experienced worse survival outcomes in the later time period.

The mortality rate among urban infants in 2013-2017 was 6.5 deaths per 1,000 live births compared to 4.9 per 1,000 in 2000-2004 (Table 2). About 14% of the increase in mortality among urban infants was attributable to an increase in the number of urban births, while the remainder was due to worsening survival outcomes among urban infants (Table 2). The overall infant mortality increase among rural infants between the two time periods was less in absolute terms (5.2 per 1,000 in 2000-2004 vs. 6.3 per 1,000 in 2013-2017). However, as rural births declined in the later time period, those infants who were born in rural areas during the later period had even worse survival outcomes relative to their urban counterparts (Table 2 and Figure 5).

Table 2. Kitagawa decomposition of change in infant mortality by maternal rural/urban residence, Maine, 2000-2004 vs. 2013-2017

Maternal residence	Mortality rate 2000-2004	Mortality rate 2013-2017	Total change due to residence distribution (%)	Total change due to residence specific mortality (%)
Urban	**4.86**	**6.48**	**13.9%**	**86.1%**
Rural	**5.18**	**6.31**	**-14.4%**	**114.4%**

Figure 5. Kitagawa decomposition of change in infant mortality by maternal rural/urban residence, Maine, 2000-2004 vs. 2013-2017
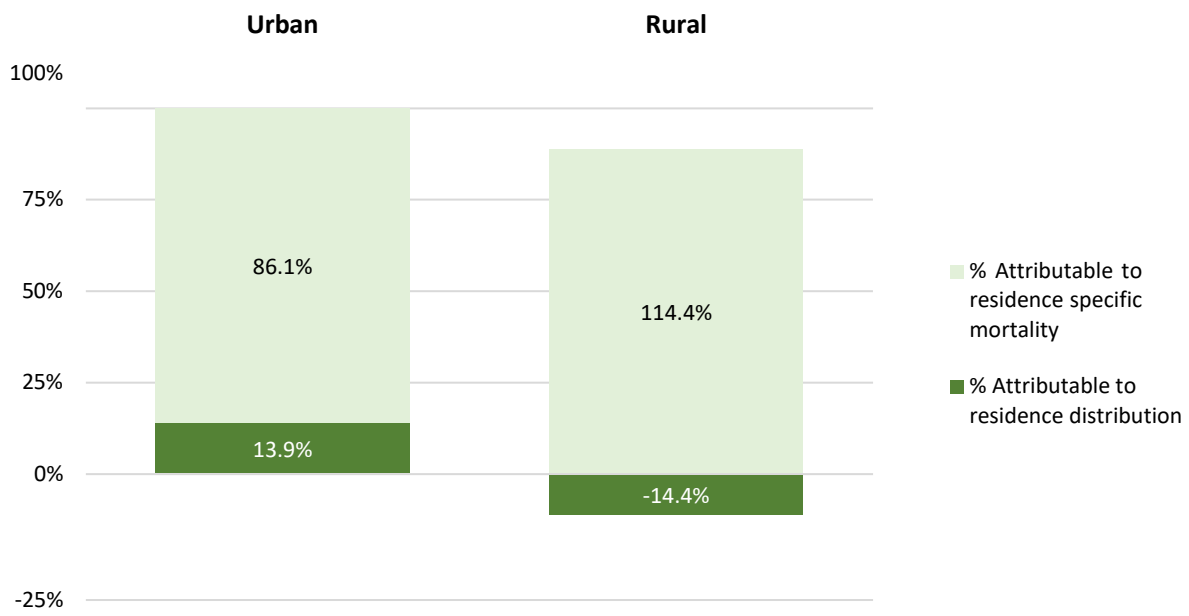
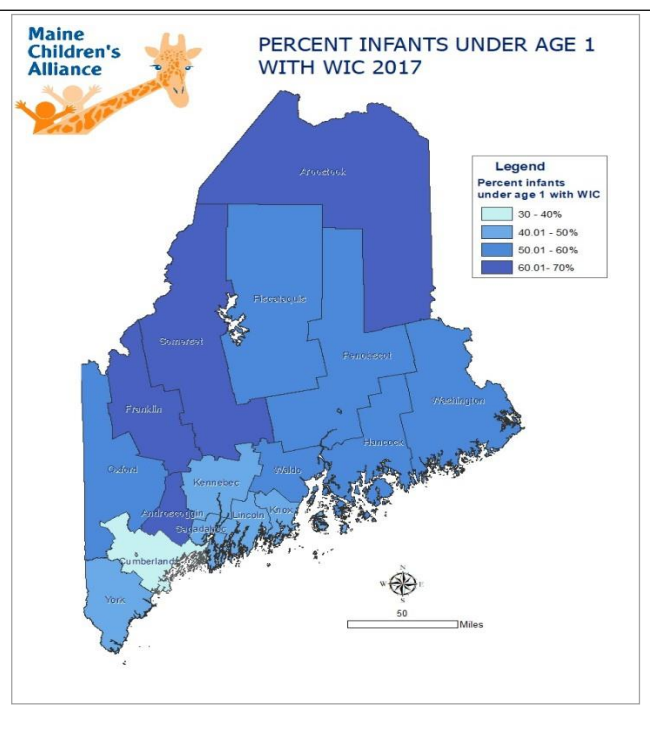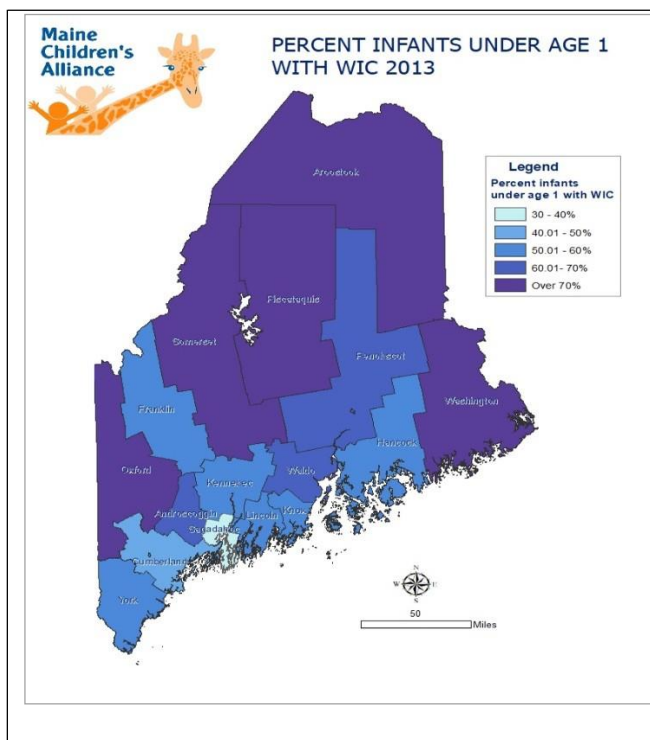# Appendix I: Description of the PPOR (Perinatal Periods of Risk) Analysis

Perinatal Periods of Risk (PPOR) is a multi-phase, multi-disciplinary approach for monitoring and examining causes of infant and fetal deaths. The PPOR approach allows states and communities to identify the "risk period(s)" in which infant and fetal deaths are higher than would be expected. A key element of the first phase of PPOR is the creation of a feto-infant mortality map in which infant and fetal deaths are divided into four risk period groups based on the age and birthweight of the infant at death. The four risk groups are:
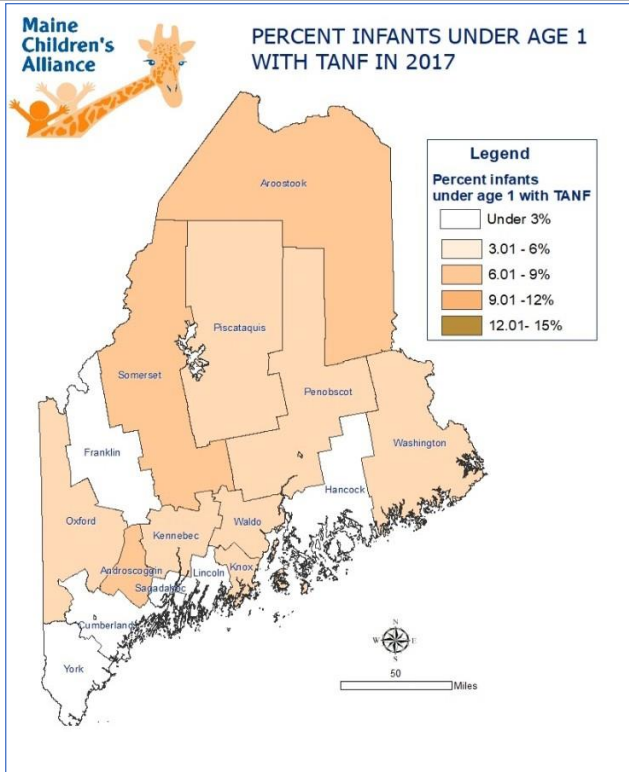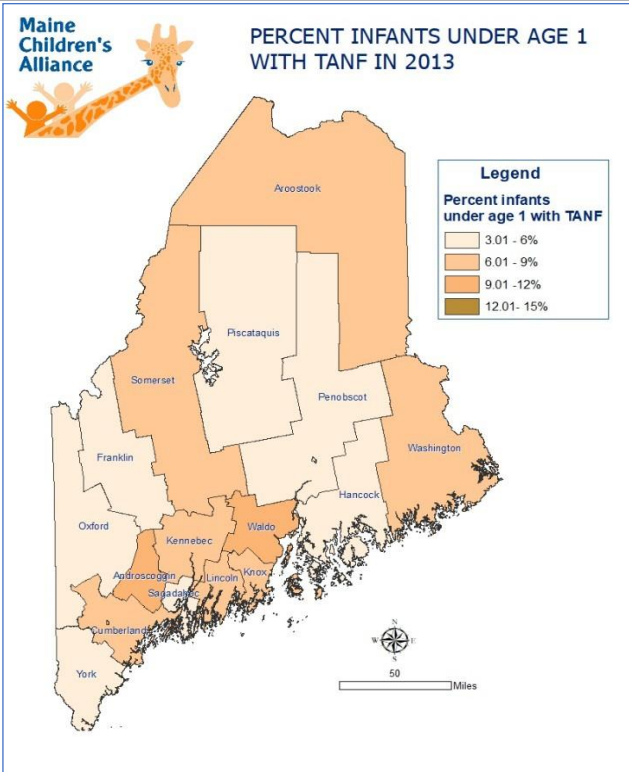
- Maternal Health and Prematurity (deaths of fetuses and infants weighing 500-1499g): Factors contributing to fetal and infant deaths in this period include preconception health care; preconception health behaviors, such as tobacco use; and timely access to prenatal care.
- Maternal Care (deaths to fetuses weighing 1500g or more): Factors contributing to fetal demise in this period include access to appropriate prenatal care and high-risk obstetric care, as well as proper management of chronic maternal health conditions.
- Newborn Care (deaths to infants age 0-27 days weighing 1500g or more): Factors contributing to infant deaths in this period include risk-appropriate neonatal medical care.
- Infant Health (deaths to infants age 28-365 days, weighing 1500g or more): Factors contributing to infant deaths during this period include a range of social and environmental factors, such as access to safe sleep environments, maternal mental health, access to breastfeeding support, and family violence.

In 2019, Maine CDC's Maternal and Child Health Program developed a feto-infant map using vital records data (births, infant deaths and fetal deaths) from 2014-2017. Following the PPOR phase 1 analysis guidelines, a reference population (e.g., lower risk group) was chosen and compared to other infant and fetal deaths (e.g., higher risk group). The selected reference group was white mothers between the ages of 24-34 who had completed at least some college education. Nationally, this demographic group generally experiences the best birth outcomes. The infant mortality rate of the reference group was subtracted from the infant mortality rate of all other women to determine the excess mortality in each period of risk.

Source: Sappenfield, WM, Peck, MG, Gilbert, CS, Haynatzka, VR and Bryant, T. 2010. Perinatal Periods of Risk: Analytic Preparation and Phase I Analytic Methods for Investigating Feto-Infant Mortality. Maternal and Child health Journal. 9)2): 199-205.

Appendix J: Maps of WIC, SNAP and TANF Enrollments: 2013 and 2017

PERCENT INFANTS UNDER AGE 1 WITH TANF IN 2013

PERCENT INFANTS UNDER AGE 1 WITH TANF IN 2017

Appendix K: References

1. U.S. Department of Health and Human Services, Healthy Resources and Services Administration, Maternal and Child Health Bureau, Child Health USA 2014. Rockville, Maryland, 2014.

2. CDC 2017 Infant Mortality Rates by State. Available at: https://www.cdc.gov/nchs/ pressroom/sosmap/infant_mortality_rates/infant_mortality.htm.

3. U.S. Census Bureau. Sex by Age. Universe: Total population. 2017 American Community Survey 1-Year Estimates. [cited 4-4-19]; Cited 4-4-19; Available at: https://factfinder.census.gov/bkmk/table/1.0/en/ACS/17_1YR/B01001/0400000US23|0500000US23005|05 00000US23031|310M300US12620|310M300US30340|310M300US38860

4. Center for Workforce Research and Information. County Profiles. Available at: http://www/main.gov/labor/cwri/county-economic-Profiles/countyProfile.

5. Catalano, A., Bennet, A. et al. (2017). Implementing CDC's Level of Care Assessment Tool (LOCATe): A National Collaboration to Improve Maternal and Child Health. Journal of Women's Health. 26(12): 1265-1269. Doi:10.1089/jwh.2017.6771.

6. McLeroy, K. R., Bibeau, D., Steckler, A., et al. (1988). An ecological perspective on health promotion programs. Health Education Quarterly. 15: 351–377.

7. Zip Code Rural-Urban Commuting Areas Geographic Taxonomy. Available at: http://ruralhealth.und.edu/ruca.

8. Crosswalk to NE rural definition: NE Rural Health Roundtable. Rural data for action: a comparative analysis of health data for the NE region. Second edition, October 2014.

9. U.S Department of Health and Human Services (US DHHS), Centers of Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Division of Vital Statistics (DVS). Linked Birth /Infant Death Records 2007-2017, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program, on CDC WONDER On-line Database. Accessed at http://wonder.cdc.gov/lbd-current.html

10. Kotelchuck, M. (1994). An Evaluation of the Kessner Adequacy of Prenatal Care Index and a Proposed Adequacy of Prenatal Care Utilization Index. American Journal of Public Health, 84(9): 1414–1420.

11. Kids Count. Maine DDS. Maine Office of Child and Family Services (the number of drug-affected babies born in a year); state of Maine Office of Vital Statistics (for the number of births in Maine per previous calendar year).

12. Prevalence of Selected Maternal and Child Health Indicators for Maine, Pregnancy Risk Assessment Monitoring System (PRAMS), 2016-2017. Available at: https://www.cdc.gov/prams/prams-data/mch-indicators/states/pdf/2018/Maine-508.pdf.

13. Communications with Jenn Hayman, MD; Kelley Bowden, Maine CDC/Maine Medical Center.

14. Association of State and Territorial Health Officials (2014). Fact Sheet – Perinatal Regionalization. Available at: astho.org/Programs/ASTHO-Perinatal-Regionalization-Fact-Sheet/

15. Maine Children's Alliance. Enrollment of Maine Infants in WIC, SNAP and TANF.

Appendix L: Authors, Report Contributors, and Operations Team Members*

Katherine Flaherty, ScD, MA, Katherine Flaherty Consulting, LLC, lead author*
Dr. Katherine Flaherty has more than 25 years of experience in public health, with a focus on maternal and child health (MCH). Her experience has included strategic planning, program and policy development and implementation, and research and evaluation. Dr. Flaherty has specific expertise in Medicaid, health equity, women's health, perinatal regionalization, and quality improvement. Currently, she is the Principal, Katherine Flaherty Consulting, LLC, and is a Lecturer in MCH policy at Tufts University School of Medicine. From 2010-2014, Dr. Flaherty was a Principal Associate in the Public Health and Epidemiology Practice at Abt Associates where she led MCH and health prevention initiatives and was the Co-Director of the Scientific Resource Center for the US Preventive Services Task Force. For two years, Dr. Flaherty led the HRSA Infant Mortality Collaborative Improvement and Innovation Network (CoIIN) in 19 Southern and Midwestern states. In addition to her work at Abt Associates, Dr. Flaherty worked within the Partners Healthcare System where she focused on Medicaid and perinatal policies and programs and led the Perinatal and Child Health Division at the Massachusetts Department of Public Health. She has a Bachelor' degree from Wellesley College, a master's degree from Boston University and a Doctor of Science degree from the Harvard T.H. Chan School of Public Health.

Amy Belisle, MD, MBA, Maine Department of Health & Human Services, formerly Quality Counts/Qualidigm*
Dr. Amy Belisle is currently the Chief Child Health Officer in the Maine Department of Health and Human Services. Prior to this position. She was a Senior Medical Director at Quality Counts, a Division of Qualidigm, and the Director of Child Health Quality Improvement at Maine Quality Counts and the Maine Child Health Improvement Partnership (ME CHIP). Dr. Belisle attended Harvard University and the University of Vermont College of Medicine. She received her MBA from Lehigh University. She completed her Pediatric Residency at the Barbara Bush Children's Hospital at Maine Medical Center in 2002. She returned to the state in 2007 after serving in the Air Force at Yokota Air Base (AB) Japan and Andrews AFB for four years. When she was stationed at Yokota AB in Japan she was as a general pediatrician for 2 years and then served as a Flight Surgeon and was the Flight Commander of the Flight Medicine Flight overseeing the Flight Medicine Clinic and the Immunization Clinic her last year. From 2007-2010, Dr. Belisle was a Pediatric Hospitalist at Central Maine Medical Center (CMMC) in Lewiston, Maine. Dr. Belisle is a member of the Board of the Maine Chapter of the American Academy of Pediatrics (AAP). Dr. Belisle has extensive experience leading quality improvement efforts including helping to lead the four-year learning collaborative, First STEPS (Strengthening Together Early Preventive Services) as part of the Maine Improving Health Outcomes for Children Program (IHOC)/CHIPRA grant. She has worked to improve the care of substance exposed infants through the Snuggle ME Project since 2010. In 2015-16, Dr. Belisle served as an Interim Program Director for several adult health quality improvement projects for 18 months including the Chronic Pain Collaborative, Year 2; the Chronic Disease Improvement Collaborative, Years 1 and 2, and the Improving Medication Assisted Treatment in Primary Care. In 2016-18, she served as the Program Director for the Caring for ME Program and Child Health. Currently, she is one of the Senior Medical Directors leading for the Caring for ME Program at QC which is working to address the opioid crisis in the state of Maine. As part of this work, she served as a Medical Director on the *Perinatal Substance Use Disorder ECHO*.

Kelley Bowden, MS, RN*

Kelley Bowden is the Perinatal Outreach Nurse Coordinator for the State of Maine. After graduating from the University of Southern Maine with her bachelor's degree in nursing, she joined the Maine Medical Center NICU staff. Kelley then went on to earn a certificate from Georgetown University as a Neonatal Nurse Practitioner. After working in the NICU for 18 years, she left to become a chart abstractor for the Maine Birth Defects Program and assumed the outreach position in 2004. Kelley completed her master's degree in nursing at USM in 2005.

Kayla Cole, CSR-MS, Quality Counts/Qualidigm*

Kayla grew up in Maine and attended the University of Maine, Orono for her undergraduate studies. Shortly after graduating, Kayla began her career working for the Maine Women Infants and Children Nutrition Program (WIC) serving as the Vendor and Data Services Manager. She spent several years working with the grocery stores in Maine that accept WIC as well as the USDA to ensure adherence to federal regulations as well as identifying future technology needs of the program. In 2013, she transitioned into the field of Information Technology and served as a Certified Scrum Master on agile software development teams. After several years of leading Agile teams, Kayla achieved her Scrum Professional Certification from the Scrum Alliance. Kayla began working for Quality Counts in January of 2017 and now serves as a Lead Project Manager for Child Health, Substance Use Disorder, and ECHO initiatives at Quality Counts.

Deborah Deatrick, MPH, Consultant, formerly Mainehealth*

Deb Deatrick is currently a public health consultant. Until 2019, she was Senior Vice President for Community Health Improvement at Mainehealth (MH), the largest nonprofit integrated health system in Northern New England, a position she held for 20+ years. At MaineHealth, she led and oversaw the system's strategic population health initiatives in access to care, tobacco, obesity, child health and other priorities. Deb has worked in both private and public sectors including the Maine Bureau of Health and the University of Maine System. Prior to coming to Maine, she held positions at Baylor College of Medicine in Houston and the University of Michigan Center for Postgraduate Medical Education. She holds undergraduate and graduate degrees from the University of Michigan.

Fleur Hopper, MSW, MPH

Fleur Hopper is a Research Associate at the University of Southern Maine's Cutler Institute for Health and Social Policy, where she provides epidemiologic and evaluation support to state and federally funded public health programs, including Maine CDC's Maternal and Child Health program. Prior to joining the Cutler Institute, Fleur worked as a mental health clinician for over a decade. She received her MSW from Boston College School of Social Work and her MPH from the University of Southern Maine.

Erika Lichter, ScD*

Erika Lichter is an Associate Research Professor at the University of Southern Maine's Muskie School for Public Service and has worked as the lead Maternal and Child Health Epidemiologist (MCH) for the State of Maine since 2005. Dr. Lichter has a doctorate in maternal and child health from the Harvard School of Public Health with concentrations in epidemiology and biostatistics. As the lead MCH Epidemiologist in Maine, she directs a team charged with creating and supporting public health efforts related to MCH at the state's health department. Specifically, within the Maine CDC, she has worked with the Maine Injury Prevention Program, Maine Youth Suicide Prevention Program, Maine WIC Program, Maine Title V Program, Children with Special Health Needs (CSHN), Women's Health, Public Health Nursing, and the Office of Performance Improvement. Dr. Lichter is also

currently the lead evaluator of the Maine Families Home Visiting Program. She has expertise in data translation, quantitative and 15 qualitative data analysis, program evaluation, and applied epidemiology.

Cindy Mervis, MPH

Cindy Mervis has 25+ years of epidemiology experience in state, federal, university and nonprofit settings. She has been at the University of Southern Maine since 2004, where her work has focused on maternal and child health. Her areas of expertise include public health surveillance, data analysis, program evaluation, needs assessment, and dataset linkages. She has an MPH from Emory University.

Nell Tharpe, CNM, CRNFA, MS, FACNM, Perinatal & Women's Health Consultant*

Nell Tharpe obtained her Certificate in Nurse--Midwifery from the State University of New York in 1986, her Master of Science degree in Midwifery from Philadelphia University in 2003. After more than 20 years in active practice, Nell turned to postgraduate education. Nell's passion is bridging the gap between clinical practice and emerging evidence. Her focus is on teaching and writing to foster the highest quality women's health care in every practice setting. Nell was an MCH consultant at the Maine CDC from 2012-2015, where she became active in promoting quality initiatives across the state.

Nell is the original author of the widely used midwifery text *Clinical Practice Guidelines for Midwifery and Women's Health*, recently released in its 5th edition. She is an adjunct professor at Jefferson (Philadelphia University + Thomas Jefferson University) and offers workshops as an independent Perinatal and Women's Health Consultant.