Project Butterfly:

Allegheny County Fetal and Infant Mortality Review

Annual Report

(2022, 2023, 2024)

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Executive Summary

Fetal and infant deaths in Allegheny County are indicators of the general health of communities, the quality of maternal and infant care systems, and the social and structural inequities that families continue to face. The Allegheny County FIMR program is a community-based, multidisciplinary effort led jointly by the Allegheny County Health Department, Healthy Start Pittsburgh, and UPMC Children's Hospital of Pittsburgh to investigate causes and circumstances of fetal and neonatal deaths, identify system gaps, and provide actionable recommendations to drive improvement.

The Allegheny County FIMR reviewed several fetal and neonatal death cases reported by birthing facilities from 2022 to 2024. Data indicate that Allegheny County's fetal death rate dropped from 8.3 per 1,000 live births in 2016 to 5.7 in 2020, then increased to approximately 8.0 in 2022, nearly reaching the state average. Neonatal death rates fluctuated between 4.0 and 4.6 per 1,000 live births from 2016 through 2020, reaching a peak of 5.6 in 2021 before decreasing to 3.5 in 2022.

Despite these improvements, disparities persist: Black families in Allegheny County continue to bear a significantly higher burden of fetal and neonatal mortality as compared to White families, a situation that reflects ongoing systemic inequities in access, quality of care, and the social determinants of health.

Multiple related medical, behavioral, and social contributors to poor pregnancy outcomes were identified by the FIMR CRT. The most common medical contributors were preterm labor, hypertensive disorders (including preeclampsia), infection, perinatal asphyxia, and diabetes. Behavioral health issues, such as depression, anxiety, and substance use, were commonly noted, again pointing to the need for integrated mental health during and after pregnancy. Social and structural contributors included housing instability, financial stress, intimate partner violence, and a lack of continuous care.

Other relevant factors that influenced the outcome were issues in care coordination, including late initiation of prenatal care, missed appointments because of transportation or scheduling barriers, inconsistency in provider communication, and lack of doula involvement. The gaps in health education, along with limited shared decision-making, further reflected opportunities to improve patient-centered, trauma-informed, and culturally competent care.

In response to these findings, the Community Action Team and Clinical Action Collaborative moved forward several key initiatives that were developed from Case Review Team recommendations:

• Community Blood Pressure Monitoring: Implemented in high-priority neighborhoods, including but not limited to Wilkinsburg, North Side, and Hill District, to reduce hypertension-related complications of pregnancy.

• Count the Kicks Campaign: County-wide education and awareness regarding fetal movement monitoring to help reduce stillbirths and further improve timely clinical response.

• Trauma-Informed Care Implementation: A cross-sector strategy to develop safer, more compassionate care environments for families who experience loss or adversity.

Recognizing that data alone cannot tell the full story, FIMR has placed family engagement and story collection as a priority to ensure that lived experiences inform systemic change. In 2024, the program took a pause from interviewing families to reconceptualize its approach to becoming more trauma-informed, inclusive of fathers, and accessible through digital and community-based methods. These efforts leverage family voices in amplifying their experiences and integrating their perspectives into program planning and recommendations.

As the work of the FIMR program continues, so too does the emphasis on root cause inequities, strengthening care coordination, and empowering community-led solutions. As public health, healthcare, and community partners engage with one another, Allegheny County is closer to a shared vision that all pregnancies are supported, every loss is honored, and every family has equitable opportunities for healthy beginnings.

Technical Glossary

Fetal Death: A Fetal Death in Pennsylvania is defined by the Vital Statistics Law as the expulsion or extraction from its mother of a product of conception after 16 weeks of gestation, which shows no evidence of life after such expulsion or extraction."

This does not include deaths as a result of induced termination of pregnancy.

https://www.pa.gov/en/agencies/health/health-statistics/health-statistics-a-to-z/fetal-deaths---health-statistics-a-to-z. html

Neonatal death: The death of a live-born baby within the first 28 days of life, regardless of the gestation.

Live birth: The complete expulsion or extraction of a product of human conception with evidence of life at any gestation. Evidence of life:

o Breathing

o Beating of the heart

o Pulsation of the umbilical cord

o Definite movement of voluntary muscles

Infant death: Any death, at any gestation, that occurs after live birth until 1 year of life.

- Early neonatal death :0-6 days of life
- Late neonatal death:7-27 days of life
- Post neonatal death-28-364 days of life

Induced abortion: An induced abortion or induced termination of pregnancy is the purposeful interruption of pregnancy with the intention other than to produce a live born infant or to remove a dead fetus, and which does not result in a live birth.

Miscarriage: Any fetal death occurring before 20 weeks of gestation.

Stillbirth (or IUFD): Fetal loss that occurs 20 weeks or greater.

Abbreviations:

FIMR-Fetal Infant Mortality Review

ACHD-Allegheny County Health Department

CRT- Case Review Team

CAT-Community Action Team

CAC- Clinical Action Collaborative

Background

Fetal and Infant Mortality Review (FIMR) is a community-based, action-oriented process to improve services, systems, and resources for women, infants, and families. FIMR brings a multidisciplinary community team together to examine confidential, de-identified cases of fetal and infant deaths. Fetal & Infant Mortality Review – The National Center for Fatality Review and Prevention Review of individual cases helps teams understand medical care practices and families' various stresses, including but not limited to financial, food insecurity, behavioral health disorders, violence exposure, and racism, that may have impacted maternal and child outcomes.

Fetal and Infant Mortality Review (FIMR) programs operate across 26 states in the U.S., with approximately 148 active teams working to understand and address the causes of fetal and infant deaths. In Pennsylvania, FIMR initiatives are currently based in Philadelphia and Allegheny County.

https://viz.fatalityreviewdata.org/t/Public/views/FIMRProfile_17285876079920/MapofPrograms?%3Aembed=y&%3AisGuestRedirectFromVizportal=y

The Allegheny County FIMR is a collaborative effort co-led by the Allegheny County Health Department, Healthy Start Pittsburgh, and UPMC Children's Hospital of Pittsburgh. This vital work is supported through federal Title V funding, which enables the team to engage in case reviews, identify systemic issues, and advocate for community-driven solutions to improve maternal and infant health outcomes.

Composition of the Team

The purpose of the Allegheny County Fetal and Infant Mortality Review (FIMR) is to understand and prevent stillbirths, pregnancy losses, and neonatal deaths. The FIMR program is founded on the concepts of health equity and community collaboration, and it mobilizes a diverse group of people who are passionately concerned about maternal and infant welfare. This group brings together public health workers, health care providers, organizational leaders, and community members, allowing each person to share their viewpoint and life experiences. They jointly explore the local circumstances of fetal and neonatal deaths to discover what factors might underline these losses.

We seek to find methods that may be effective yet culturally sensitive to the community in question. Dealing with the root causes of fetal and neonatal mortality serves best when not restricted to incidents but analyzed in terms of the larger systems surrounding health. Be it access to quality prenatal care, housing stability, or a level of education, the Allegheny County FIMR aims to transform based on the voices of the greatly affected. The end goal is

to see a decline in fetal and neonatal mortality rates while improving health standards for all pregnant women and babies in the sphere of our community.

To conduct the work, FIMR functions with three interrelated teams:

- Case Review Team (CRT),
- Community Action Team (CAT),
- Clinical Action Collaborative (CAC).

FIMR Case Review Team (CRT)

The responsibility of the Case Review Team (CRT) specifically ties into the fetal and neonatal mortality review process. The goal of the team is to study fetal and infant deaths within Allegheny County to identify the barriers and look for systems that might help support families further, with the end goal of preventing future losses.

Each case reviewed is an opportunity to learn more about the medical, social, and systemic factors contributing to that particular family's experience. A well-rounded view of the case helps detect patterns for areas of opportunity improvement and relevant and effective solutions within the community.

What the review involves?

- Careful information collection from medical, hospital, and vital records by a trained nurse or medical abstractor.
- A voluntary parental story collection, when possible, to include the family's voice and lived experience.
- A detailed, de-identified review of each case by the CRT.

Possible Sources of Data Include:

- Vital records (birth and death certificates)
- Prenatal, delivery, neonatal, pediatric, and autopsy records
- Hospital and physician documentation
- Records from Healthy Start, WIC, home visits, and other available social service programs

Key Questions the CRT Seeks to Answer:

- Was there a provision of care and services for the family?
- Were there any gaps in the system that may have impacted the outcome?
- What lessons can be learned to help other families access and benefit from available community resources?

Responsibilities of CRT:

- Analyzing case summaries for identifying:
    - Barriers to access
    - Gaps in care
    - Trends in service provision
    - Existence and effectiveness of community resources
- Recording potential improvement sites
- Sharing findings with the Community Action Team (CAT) and Clinical Action Collaborative (CAC) so they can drive actions and interventions based on those findings.

In this collaborative, open, and respectful process, the CRT can highlight opportunities for change, contributing meaningfully to the county's work in improving maternal and infant health outcomes.

Parental Interviews

As part of the ongoing Fetal and Infant Mortality Review (FIMR) process, we respectfully invite parents who have recently experienced a fetal or early neonatal loss to voluntarily share their stories, if and when they feel ready.

Hearing directly from families gives us insight that no chart or report can provide. Parents are the only ones who can truly describe how they were treated, what helped, what did not, and how the experience affected them. These personal reflections help us understand how effective existing medical and social services are, and where they need to improve.

About the Interview:

- Generally, one and a half to two hours is spent in conversations. However, parents can pull out of the interview at any time they wish to do so.
- Interviews can be conducted in the families' homes or any other private area, which can be small yet comfortable.

- Anyone can accompany them, support people, or even children.
- Strictly confidential and identifying information will never be shared. Family members' names, hospitals, or providers will never appear. Only the story is told without personal identifiers.
- Partnering with hospitals and birthing centers continues to ensure that the process supports respect.

These interviews serve as a vital component of our work, ensuring that the lived experiences of families inform and guide our community s response to fetal and infant loss.

Community Action Team (CAT)

The Community Action Team is the aspect of FIMR that undertakes further steps towards action after learning lessons from case reviews. It comprises different individuals from different backgrounds, including community leaders, service providers, health professionals, and other concerned people, in the well-being of families in Allegheny County.

The core function is to provide inputs to develop opportunities to educate the community and provide outreach to implement recommendations.

These efforts are meant for the community, for people receiving services, and for those who provide them. The group meets regularly to discuss what is happening, what is needed, and how to improve.

What does CAT do?

- It identifies strategies to address concerns revealed during the review of cases.
- It helps create clear and practical educational tools and programs that meet local needs.
- It brings different organizations and people together to work towards common goals.
- It focuses on realistic and respectful solutions for people served.

Hence, the Community Action Team helps ensure families' experiences are taken to practical transformation, whether related to service resources or communications about them. The voices of those most impacted shape their grassroots work.

Clinical Action Collaborative

Following a recommendation from the December 2024 FIMR Retreat, the FIMR Clinical Action Collaborative (CAC) was initiated in collaboration with Healthy Start to foster clinical accountability and improve birth outcomes for Black families in Allegheny County.

The CAC was built on the belief that real change can only happen when the clinical community is involved in solutions that focus on equity. The need for the CAC was borne out of a perceived need to promote more effective communication and collaboration between the medical and community.

This initiative brings together healthcare providers, hospital leadership, public health practitioners, and community partners to develop action-oriented strategies to address disparities identified from FIMR case reviews. The CAC is more than just a meeting — it's a space where trust grows and insights from FIMR lead to real changes in the community.

The goals of the Clinical Action Collaborative are founded upon equity, partnership, and healing. To advance this work, we have five priority areas:

- Strengthening clinical partnerships to maintain a constant collaborative relationship between hospitals, public health departments, and community-based organizations.
- Adequately increasing the visibility of the FIMR within clinical systems so that providers become informed and invested in the review process and findings.
- Providing respectful, constructive, and actionable feedback processes to share FIMR recommendations with clinical sites.
- Educating caregivers on culturally competent and trauma-informed practices to enable them to consider the family's needs with compassion and humility.
- Initiating programs that support birthing justice based on the real experiences and needs of Black birthing people in our communities.

The Collaborative embodies a paradigm shift in our approach to perinatal health: rather than just interpreting outcomes, it assumes some responsibility for changing them. By bridging clinical care with the wisdom of the community, the CAC is setting the groundwork for fairer, more person-centered systems of care.

FIMR Case Identification and Review Process in Allegheny County

Whenever a fetal or neonatal death occurs, birthing facilities notify the health department, submitting an intake form through Qualtrics for the collection of basic information necessary for initial case selection. The reported cases are compiled in a tracking sheet maintained with a focus on filtering for deaths in Allegheny County.

Each case is then scored by using a standardized scoring sheet, which takes into consideration several factors such as:

- Gestational age
- Birthweight
- Timing of death (whether it is fetal or neonatal)
- Race
- Prenatal care status
- Presence of chromosomal anomalies
- Evidence of perinatal asphyxia
- Maternal history of preeclampsia, diabetes, or smoking
- Prior neonatal losses
- Known maternal history of mental health illness

Cases with higher scores will be more likely to be reviewed. However, beginning in 2024, we prioritized reviewing **Black fetal and neonatal deaths** due to the observed historical Allegheny County black/white disparity.

The selected cases have their complete medical records requested from the birthing facilities through a standardized medical records request form. This is supplemented with records from DHS and partner organizations such as Healthy Start, Nurse-Family Partnership (NFP), and others to give a complete perspective regarding the family's life.

From the collation of all of these data, a detailed case summary is prepared and reviewed at the monthly Case Review Team (CRT) meeting.

Note: The fetal and neonatal deaths reported to the health department represent only a subset of all such deaths that occur in Allegheny County.

Overview

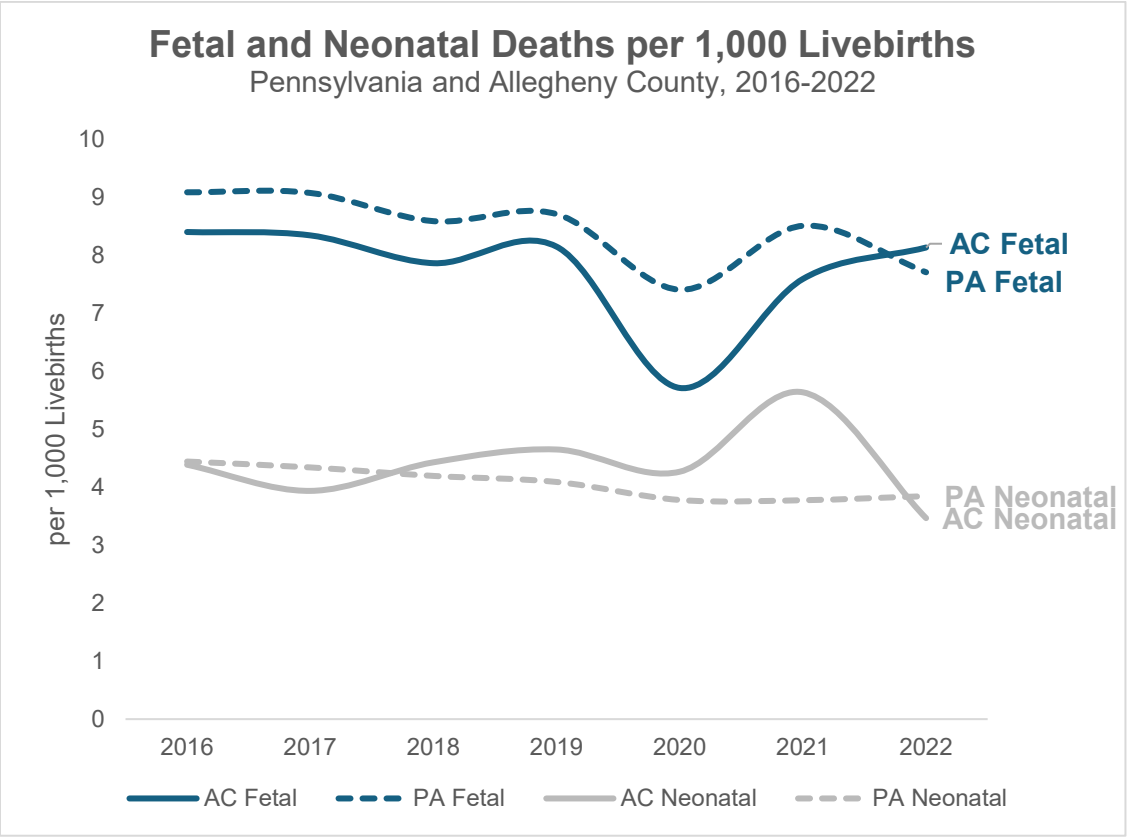


Figure 1: Fetal and Neonatal Deaths per 1000 Livebirths in Pennsylvania and Allegheny County, 2016-2022

According to the PA vital statistics report from 2016 to 2022, Allegheny County generally had lower fetal death rates than Pennsylvania, with a sharp drop to 5.7 per 1,000 live births in 2020 compared to the state's 7.4, before rising to nearly match the state at approximately 8.0 in 2022. Neonatal death rates in Allegheny were similar to the state's early on but spiked to 5.6 in 2021, while Pennsylvania stayed steady around 3.8.

In Allegheny County, fetal death rates remained consistently high, starting at around 8.3 per 1000 live births in 2016, dipping sharply to 5.7 in 2020, and rising again to approximately 8.0 by 2022. Neonatal death rates ranged from 4.0 to 4.6 per 1,000 live births between 2016 and 2020, before increasing significantly to 5.6 in 2021and again dropping to around 3.5 in 2022.

Such disconcerting patterns necessitated looking deeper into systemic factors responsible for poor outcomes. High fetal and neonatal mortality rates often point toward broader issues in the healthcare and social support systems, including disparities in access to quality prenatal and postpartum care, maternal mental health services, housing and food security, health insurance coverage, and the implications of structural racism on health outcomes.

Allegheny County established a Fetal and Infant Mortality Review (FIMR) program to tackle these somewhat complex and interlinked issues. The FIMR program looks at the statistics and the families who have affected lives, raises their voices, and works on their behalf toward the betterment of life for mothers, babies, and families everywhere in the county.

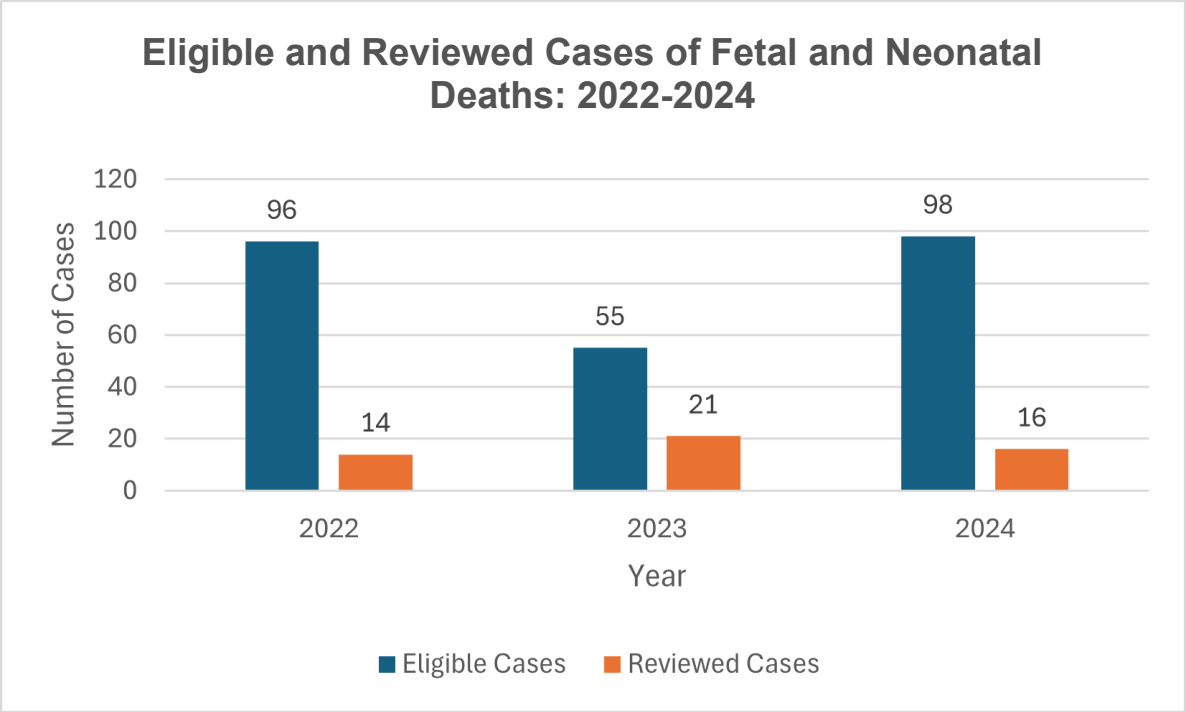


Figure 2: Eligible and Reviewed Cases of Fetal and Neonatal Deaths: 2022-2024

Figure 2 displays the number of eligible and reviewed cases of fetal and neonatal deaths in Allegheny County for the years 2022, 2023, and 2024. Eligible cases are those that are only filtered for Allegheny County residents. This is representative of the fetal and neonatal deaths that were reported to the health department through intake forms and do not represent the total number of such deaths that occurred in Allegheny County in a given year. Over the three years, the rates of eligible cases remained consistent, with a slight drop in 2023, with 67 eligible cases. Regarding the reviewed cases, the three-year period has remained consistent with an increase in the number of cases reviewed in 2023 (21).

The health department continuously collaborates with birthing facilities throughout the County to strengthen the identification and review processes. In this way, we can ascertain that even more cases are rightly identified and reviewed to understand better the responsive strategies that may be developed to prevent future loss and promote health equity for all families in Allegheny County.

Fetal And Neonatal Deaths

The data is sourced from the intake forms submitted by the birthing facilities and recorded in a tracking sheet by the health department.

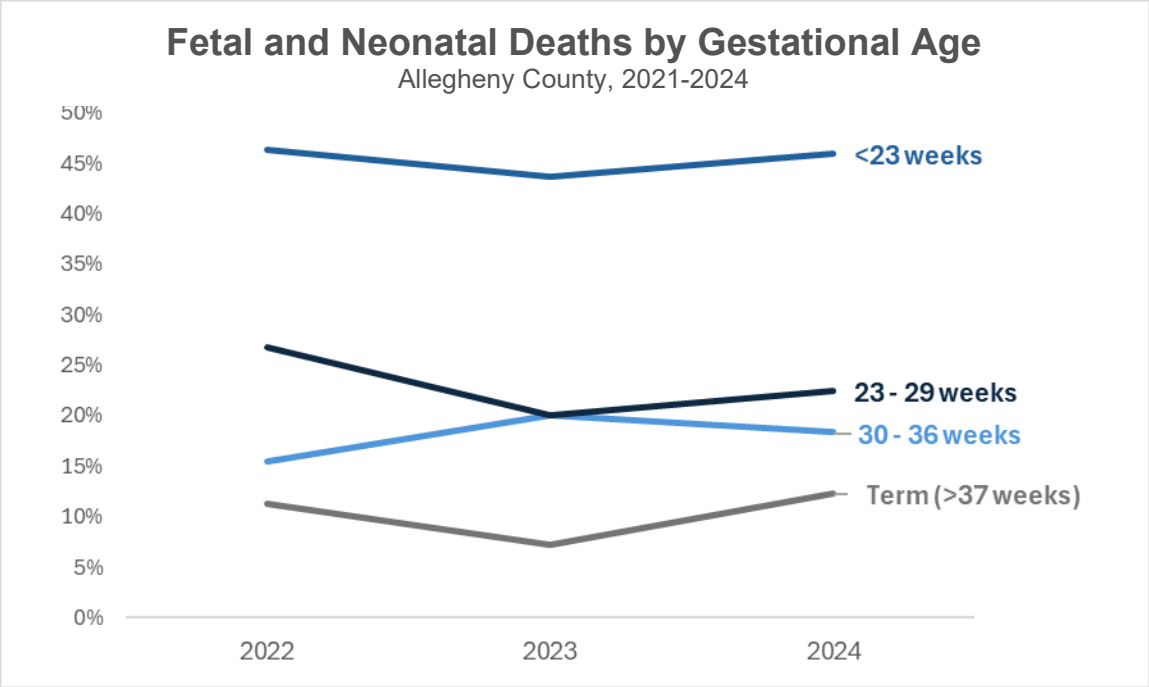


Figure 3: Fetal Deaths by Gestational Age

The graph presents fetal mortality rates in Allegheny County from 2022 to 2024 by gestational age. The significant observations are:

- **Early Gestation High Mortality**: The percentage of fetal death in pregnancies of gestational age under 23 weeks is astoundingly high, starting at about 47% in 2022 and slowly declining to about 46% by the year 2024.

- **A Moderate Increase in Mid-Gestation Deaths:** For 23-29 weeks, the fetal deaths did increase slightly over the years, peaking in 2022, and then declining again in 2023.
- **Stable Late Preterm Deaths:** The 30-36 weeks percentage is relatively stable, starting from 15% in 2021 and increasing marginally to around 17% in 2024.
- **Lowest Mortality at Full Term:** After 37 weeks, fetal deaths have always been the least, remaining around 10%, with a slight dip towards 2023.

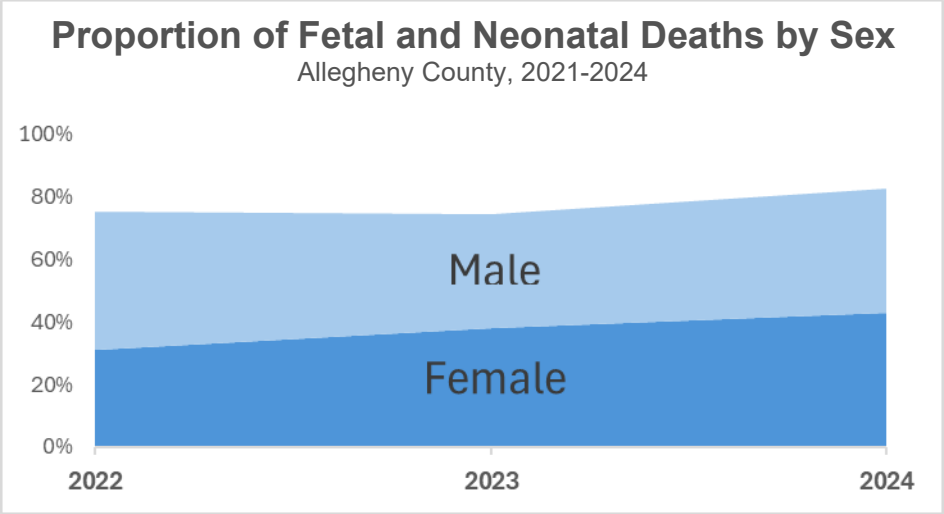


Figure 4: Proportion of Fetal Deaths by Sex

- **Male Fetal Deaths Dominate:** For the entire three-year period, the total male fetal deaths have consistently exceeded those of female fetal deaths.
- **Gradual Increase Over Time:** For both sexes of fetal deaths, the slight ascending trend noticed might be suggestive of changing environmental, medical, and/or socioeconomic factors**.**
- **Relative Stability in Gender Distribution:** Although there is a slight increase in total fetal deaths, the relative proportion of male and female fetal deaths at any given time has remained relatively constant.

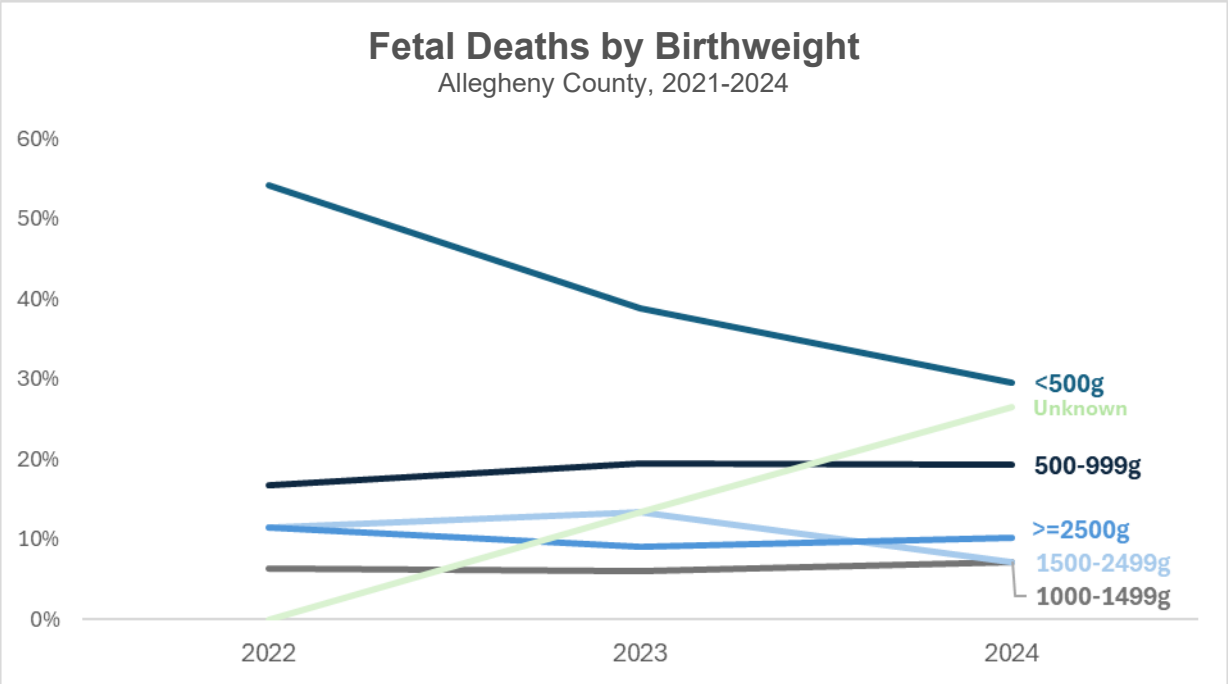


Figure 4: Fetal Deaths by Birthweight

- Fetal deaths among infants weighing <500g were high in 2022, at ~56%. This has decreased over the years to approximately 30% in 2024. However, the increasing proportion of cases with unknown weight- rising from none to nearly 30%- may complicate any trend analysis.
- The 500-999g category shows ~16% in 2022, spiking in 2023, then decreasing to ~20% in 2024.
- For 1000-1499g, 1500-2499g, and ≥2500g categories, minimal fluctuations were observed, not exceeding 10% for the years in consideration.

This only reconfirms that fetal mortality is a rare incidence in babies with higher birthweight and that low birthweight remains a foremost risk factor for fetal demise.

Fetal and Neonatal Conditions

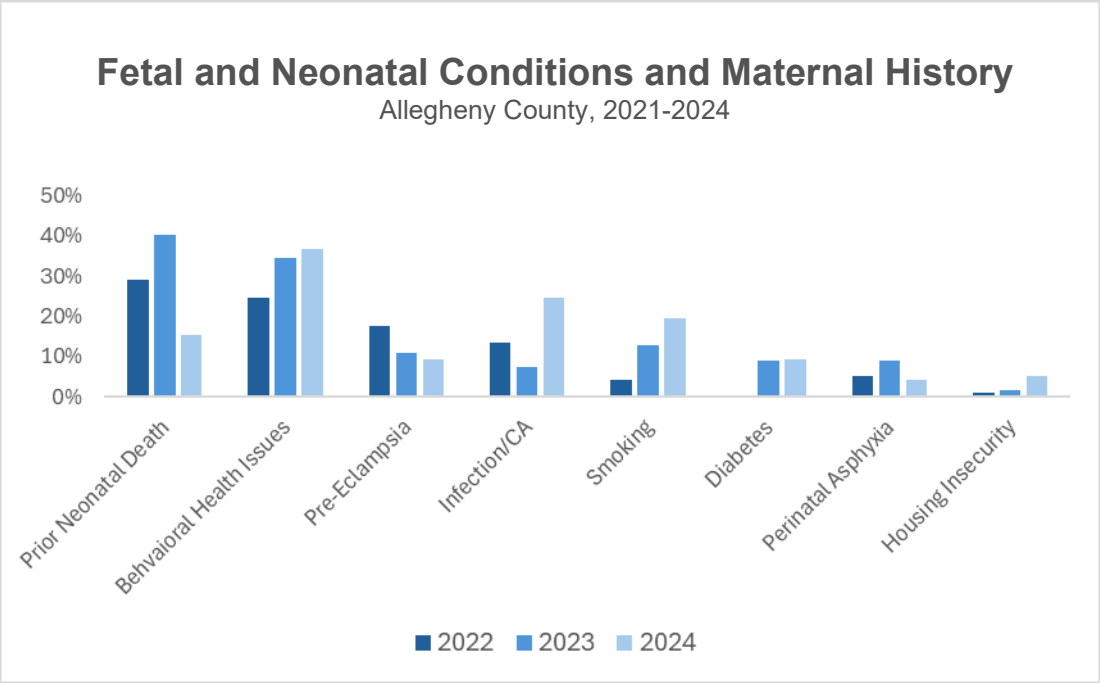


Figure 5: Fetal Conditions and Maternal History

This "Fetal and Neonatal Conditions and Maternal History" diagram gives a multidimensional view (2022-2024) of various maternal and fetal health indicators in Allegheny County. This data is taken from the information provided on the intake forms reported to the county, which, as previously stated, do not represent all of the fetal deaths in the county for this period.

Observations:

Prior neonatal death rates were decreasing in 2022, spiked in 2023, and decreased significantly in 2024, which may suggest that maternal health interventions have a positive impact. However, further analysis is needed to confirm this.

Behavioral Health

Behavioral Health Issues surged in 2023 and 2024, indicating a need for improved behavioral services and support.

Pre-Eclampsia

There is a decline in cases of Pre-Eclampsia, suggesting potentially effective intervention.

Infection/Congenital Anomalies

Infection/Congenital Anomalies have spiked in the year 2024, which could be linked to broader healthcare disparities or emerging environmental influences affecting maternal health.

Smoking

Smoking has increased drastically in 2024, which could reflect an emerging trend in maternal lifestyle or perhaps stressors.

Diabetes

The trend for diabetes exhibits a stable pattern with minimal variation from year to year.

Perinatal Asphyxia

Perinatal asphyxia exhibited a sharp increase in 2023, followed by a decline in the subsequent year, which may indicate improved prenatal screenings, enhanced birth practices, etc.

Housing Insecurity

Housing Insecurity has been observed at low levels throughout the years, except for the year 2024, when it is slightly higher, which may indicate new challenges such as economic shifts, policy changes, and rising rent costs.

	Total (2022-2024)	2022		2023		2024	
		Cases	%	Cases	%	Cases	%
Total	249	96	-	55	-	98	-
Gestational Age							
Term (>37 weeks)	27	11	11.3%	4	7.3%	12	12.2%
30 - 36 weeks	44	15	15.5%	11	20.0%	18	18.4%
23 - 29 weeks	59	26	26.8%	11	20.0%	22	22.4%
<23 weeks	114	45	46.4%	24	43.6%	45	45.9%
Unknown	1	0	0.0%	0	0.0%	1	1.0%
Birthweight							
<500g	101	52	54.2%	20	36.4%	29	29.6%
500-999g	48	16	16.7%	13	23.6%	19	19.4%
1000-1499g	15	6	6.3%	2	3.6%	7	7.1%
1500-2499g	24	11	11.5%	6	10.9%	7	7.1%
>=2500g	27	11	11.5%	6	10.9%	10	10.2%
Unknown	0	0	0.0%	9	13.4%	26	26.6%
Time of Death							
< 4 days	204	90	93.8%	38	69.1%	76	77.6%
4-28 days	21	5	5.2%	9	16.4%	7	7.1%
Unknown	24	1	1.0%	8	14.5%	15	15.3%
Sex							

Female	93	30	31.3%	21	38.2%	42	42.9%
Male	101	42	43.8%	20	36.4%	39	39.8%
Unknown	48	24	25.0%	9	16.4%	15	15.3%
Maternal Race							
Asian	9	6	6.3%	1	1.8%	2	2.0%
Black/African American	104	36	37.5%	33	60.0%	35	35.7%
Latin X	5	3	3.1%	1	1.8%	1	1.0%
Southwest Asian, Middle Eastern, or North African	9	8	8.3%	0	0.0%	1	1.0%
White	112	39	40.6%	20	36.4%	53	54.1%
Unknown	10	4	4.2%	0	0.0%	6	6.1%
Insurance Type							
Private	68	-	-	22	40.0%	46	46.9%
Public	69	-	-	27	49.1%	42	42.9%
No Insurance	6	-	-	1	1.8%	5	5.1%
Unknown	17			17	25.4%	0	0.0%
Infection/Congenital Anomaly							
Yes	41	13	13.4%	4	7.3%	24	24.5%
No	198	82	84.5%	47	85.5%	69	70.4%
Unknown	16	0	0.0%	0	0.0%	0	0.0%
Prenatal Care							
Yes	228	89	92.7%	53	96.4%	86	87.8%
No	19	7	7.3%	2	3.6%	10	10.2%
Perinatal Asphyxia							
Yes	14	5	5.2%	5	9.1%	4	4.1%
No	226	91	94.8%	47	85.5%	88	89.8%
History of Pre-eclampsia							
Yes	32	17	17.7%	6	10.9%	9	9.2%
No	215	79	82.3%	49	89.1%	87	88.8%
History of Diabetes							
Yes	14	0	0.0%	5	7.5%	9	9.2%
No	233	96	100.0%	50	74.6%	87	88.8%
Unknown	12	0	0.0%	12	17.9%	0	0.0%
History of Smoking							
Yes	45	7	7.3%	19	19.4%	19	19.4%
No	239	89	92.7%	75	76.5%	75	76.5%
Unknown	0	0	0.0%	0	0.0%	0	0.0%
Prior Neonatal Death							
Yes	58	28	29.2%	15	15.3%	15	15.3%
No	234	68	70.8%	83	84.7%	83	84.7%
History of Behavioral Health Issues							
Yes	96	24	25.0%	36	36.7%	36	36.7%
No	194	72	75.0%	61	62.2%	61	62.2%

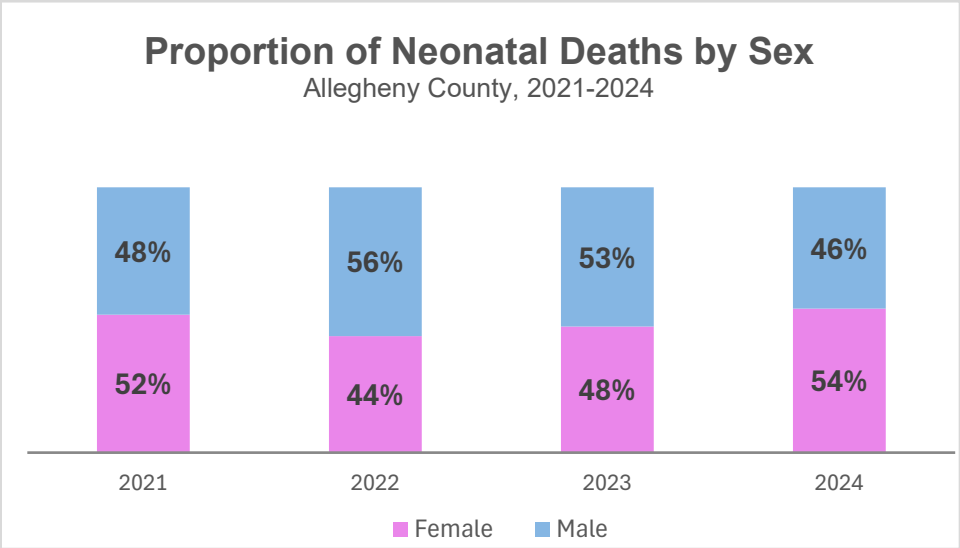
Unknown	0	0	0.0%	0	0.0%	0	0.0%
Housing Insecurity							
Yes	11	1	1.0%	5	5.1%	5	5.1%
No	279	95	99.0%	92	93.9%	92	93.9%
Initiation of Prenatal Care							
1st Trimester	103	-	-	63	64.3%	63	64.3%
2nd Trimester	20	-	-	14	14.3%	14	14.3%
3rd Trimester	2	-	-	1	1.0%	1	1.0%
Unknown	20			0	0.0%	0	0.0%

It was also identified that fetal and neonatal deaths in Allegheny County for the years between 2022 and 2024 were recorded only in specific zip codes. Mostly, they emphasized Coraopolis (15108), Pittsburgh (15219), Ross Township (15237), and Forest Hills (15221). Some neighborhoods have been under greater stress than others. The other part reveals that while most zip codes had only one report, Coraopolis had almost 12 reports. Among the municipalities, Coraopolis is experiencing a higher number of fetal deaths. The pattern shows the necessity of looking more closely into communities that bear the heaviest burden, understanding the underlying issues, and tailoring investment, resources, and support to targeted areas.

Neonatal Deaths

The data presented here is based on the line list the ACHD regularly receives from the state health department.

Figure 6:



Proportion of Neonatal Deaths by Sex

Figure 6: Proportion of Neonatal Deaths by Sex Shows the distribution of neonatal deaths by gender over four years in Allegheny County, from 2021 to 2024. There are fluctuations in the proportions of male and female deaths each year. For instance, in 2022, male deaths were above female deaths; the above percentage being 56% to 44%. In 2024, however, the trend was reversed, with female deaths accounting for 54% as opposed to 46% for males. These represent changes that might suggest some biological, health, or socioeconomic difference that changes neonatal mortality by sex.

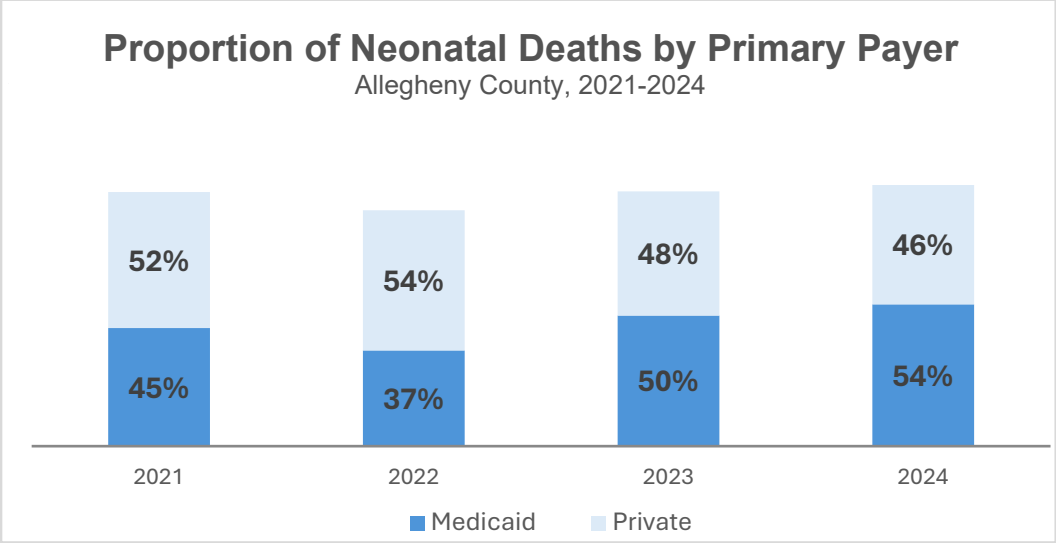


Figure 7: Proportion of Neonatal Deaths by Primary Payer

Figure 8 represents the percentage of neonatal deaths by primary payer type in Allegheny County from 2021 to 2024, indicative of a significant shift in healthcare coverage patterns for affected families. Back in 2021, deaths were nearly evenly split between Medicaid and private payers, with 45% Medicaid and 52% private. However, in 2022, private insurance climbed to 54%, and Medicaid climbed to 37%. An interesting reversal occurred in 2023 and 2024, with Medicaid expanding predominantly, from 50% to 54%, respectively, while private insurance decreased to 48% and 46%.

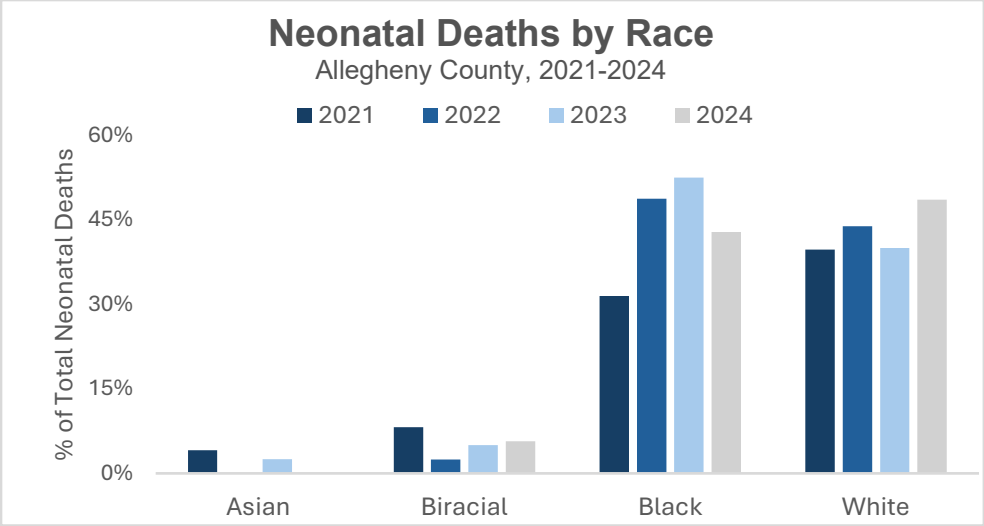


Figure 8: Neonatal Deaths by Race

Figure 9 shows neonatal deaths by race in Allegheny County from 2021 to 2024. Despite only making up 20% of the population, Black neonates consistently exhibited the highest proportion of mortality across all years, with a peak observed in 2023. White neonates also comprise a large share but increase even further by 2024. The figures for Biracial and Asian neonates are much smaller overall. The disproportionately higher mortality among Black neonates compared to other racial groups underscores the persistent racial inequities in neonatal health outcomes. It provokes a more serious inquiry into its cause, such as systemic inadequacies in access to health care, socioeconomic considerations, or even environmental ones. This racial disparity has driven our decision to focus more on complete reviews of black deaths.

Readdressing these inequities is vital for county neonatal health equity and preventing avoidable deaths.

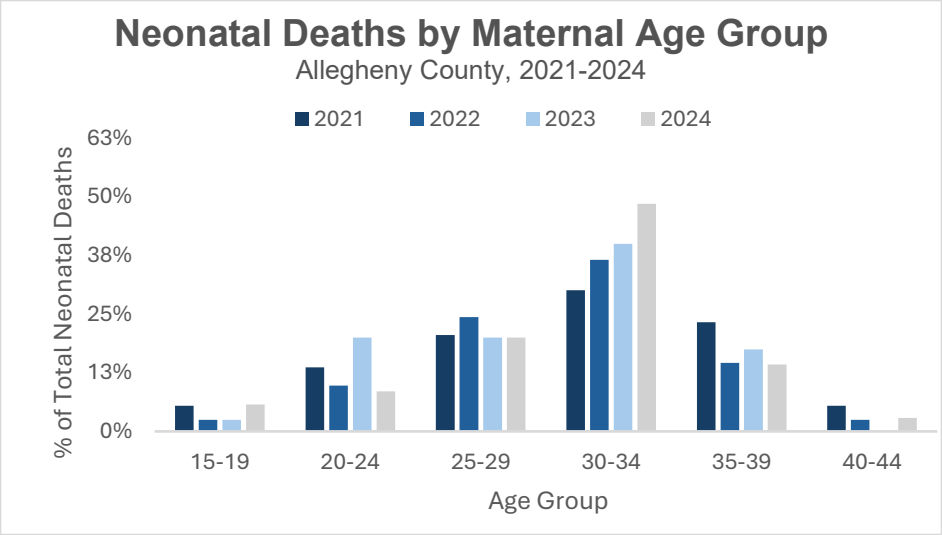


Figure 9: Neonatal Deaths by Maternal Age Group

Figure 10 shows the trends regarding the death of a neonate by maternal age group in Allegheny County from 2021 to 2024. This indicates that the age group 30-34 is consistently the most affected in terms of neonatal death. This particular age group hits an all-time high in the year 2024, representing about 50% of neonate deaths for that year. Following this, the 25-29 and 35-39 age groups also represent significantly high numbers of deaths, while the youngest (15-19) and oldest (40-44) maternal age groups report the lowest percentages over the years.

This pattern highlights the need to allocate and strengthen resources within healthcare systems and interventions, specifically targeting maternal age groups at increased risk for poor neonatal outcomes, with the goal of improving neonatal health across the county.

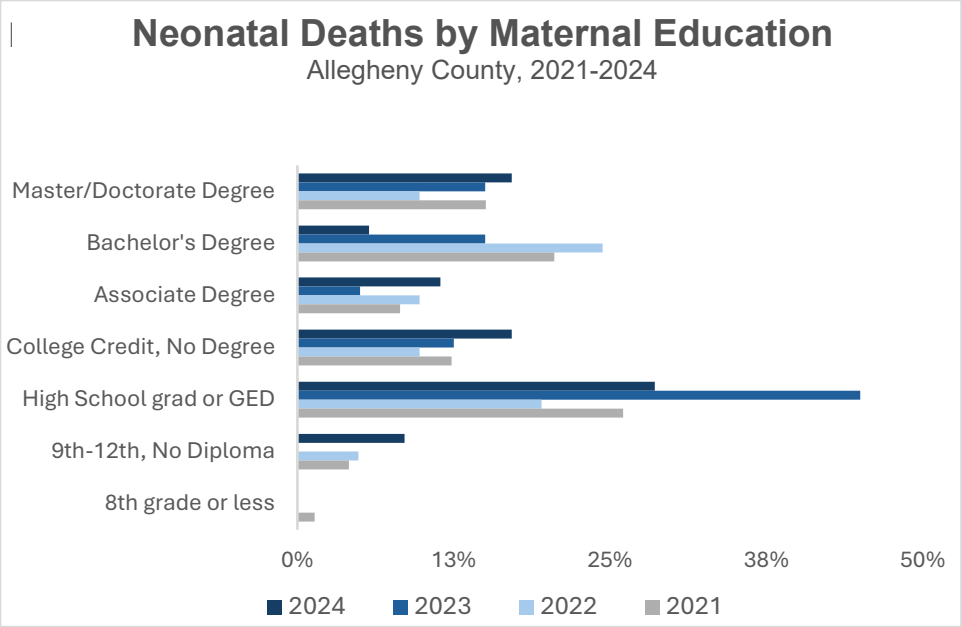


Figure 10: Neonatal Deaths by Maternal Education

Figure 11 examines the association between maternal educational attainment and neonatal deaths. Mothers with a high school education or GED qualifications consistently have shown the highest percentage of neonatal deaths, reaching their peak in 2023 of almost 50% of the total neonatal deaths for that year. At the same time, mothers with the highest educational levels ("Master/Doctorate Degree") are revealed to exhibit low percentages during these four years. Therefore, further enlightening and supporting education's social potential. This phenomenon also frames maternal education's influence on the outcomes related to the newborn. It thus brings to mind the important role education might play towards health equity and reduction in neonatal mortality rates.

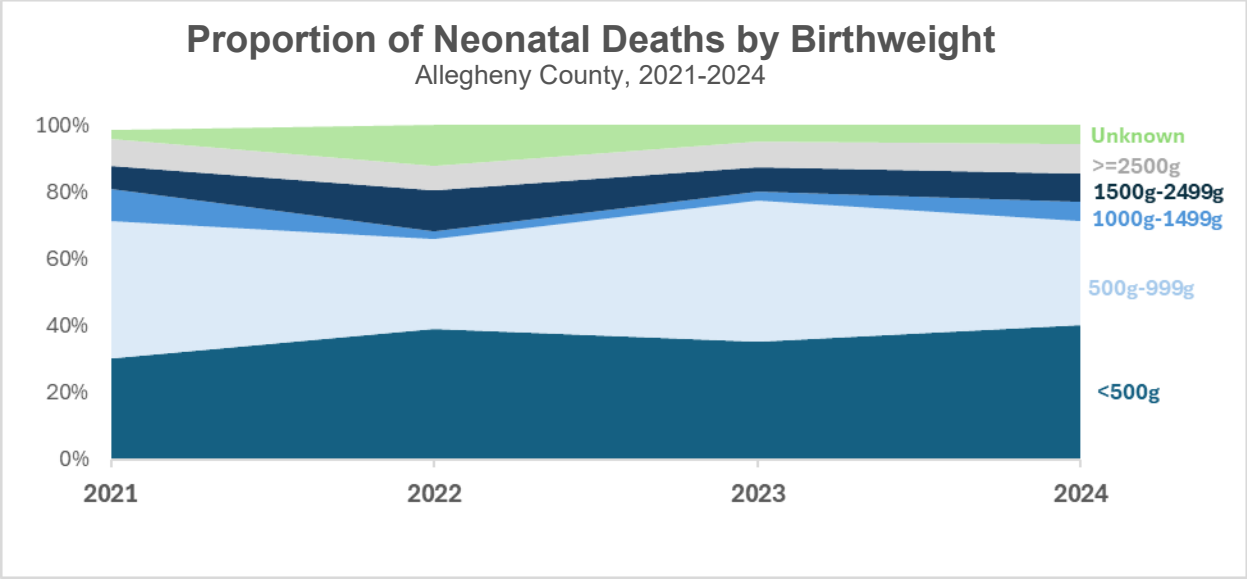


Figure 11: Proportion of Neonatal Deaths by Birthweight

Figure 12 looks at the distribution of neonatal deaths in Allegheny County in 2021-2024 concerning birthweight categories. Babies weighing less than 500 grams almost always have a significant share of neonatal deaths, as shown by the fact that for every year in these four years, they represent at least a quarter of total neonatal deaths. Thus, showing extremely low birthweight infants have very high mortality risks. This is followed by the 500–999 grams category, representing a significant portion of the total neonatal deaths for this period. Neonates in the 1000–1499 grams group moderately affect the total numbers, while every year the proportions of mortality for 1500-2499 grams neonates and >=2500 grams or more neonatal groups represent the smallest number of total deaths.

The data indicates that birth weight is the most critical factor influencing neonatal survival. Extremely low birth weight (< 1000 g) is a significant determinant of neonatal death and is often a consequence of organ systems that are not mature, and many medical complications that invariably accompany them. Such observations highlight the critical need for specific medical care for high-risk very low-birth-weight newborns, maternal public health initiatives to improve maternal wellbeing, and reduce the causes of premature birth. Alleviation of these associated risk factors will generally translate into significant mileage in reducing the neonatal mortality rate in the county.

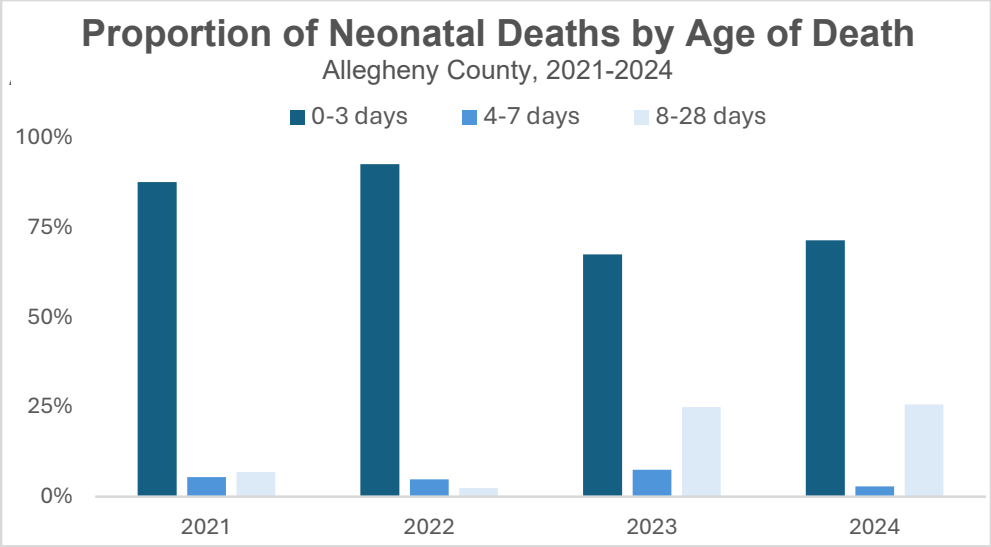


Figure 12: Proportion of Neonatal Deaths by Age of Death

Figure 13 explores the proportion of neonatal cases in Allegheny County from 2021 to 2024, by age at death. It is seen that most of the neonatal deaths generally occur between 0 and 3 days after birth, as shown by this age group representing around 75% of total deaths in the respective year. This category accounts for the largest share of cases in all four years. Intriguingly, in 2023, deaths in this time frame dropped to around 60%. A significant increase in deaths occurred between 8 and 28 days from 2023 to 2024.

This data indicates that the early postnatal period constitutes a critical window for medical care and possibly intervention effectiveness in reducing neonatal mortality. This suggests a reason to develop early neonatal care services and decrease health outcome disparities.

Potential Contributors to Poor Pregnancy Outcomes

From 2022 to 2024, various medical and non-medical conditions have been identified as frequently associated with poor pregnancy outcomes in Allegheny County. Each represents a significant challenge in maternal-fetal health and warrants understanding, as proper intervention could improve care and prevention efforts.

Medical Contributions

Medical	Number of Reviewed Cases
Abruption	4
Diabetes	2
Incompetent Cervix	0
Infection	3
Cord Accident	3
Preeclampsia/Chronic Hypertension	4
Previa	1
Preterm Labor	5
P/PROM	5
Previous Fetal/Infant Loss	4
Previous Preterm Delivery	3
STD	0
Multiple Gestation	2
Obesity	3

Table 1: Possible Medical Contributions to Reviewed Fetal and Neonatal deaths in the year 2023

Previable labor or ruptured membranes

Sometimes, labor begins too early or the membranes rupture before the fetus is developed enough to survive outside the womb. This is known as previable labor or previable rupture of membranes, and the risk of fetal or neonatal death is specific (or 100%). The fetus simply isn't ready to live outside the uterus. The causes can vary and may include injury, structural issues with the cervix, or unknown factors that lead to early rupture. When this happens too soon, the protective amniotic sac is compromised, leaving the fetus vulnerable and with minimal chances of survival.

Intrauterine Fetal Death with Preeclampsia

Preeclampsia affects people who are pregnant, happens mostly later on in the pregnancy, and this leads to an increase in blood pressure and damage to organs such as the liver and kidneys. When it is severe and uncontrolled, blood and delivery of nutrients to the fetus can be significantly restricted. Most of the time, noticeable symptoms are not seen until complications already exist, so taking care of high-risk pregnancies is very important through monitoring during prenatal visits.

Term Fetal Distress

Problems could arise during labor and delivery, even during a full-term pregnancy. Fetal distress usually refers to conditions indicating that, during labor, the baby is not getting adequate oxygen. This could be observed on a fetal heart monitor, which shows abnormal heart rates. Causes include problems with the umbilical cord, ruptured uterus, or stress from labor that is either long or difficult. If these signs of distress are not recognized and acted upon quickly, fetal demise can occur.

Cord Accident

The umbilical cord is the lifeline between the baby and the placenta, supplying oxygen and nutrients to sustain the baby. Sometimes the cord gets compressed, twisted, knotted, or wrapped tightly around the baby s neck. Such accidents can abruptly interrupt the oxygen supply to the baby, leading to fetal death.

Chromosomal Anomalies

Chromosomal anomalies are genetic issues that arise when there is an unusual number or structure of chromosomes. These anomalies can interfere with normal fetal development and are a frequent cause of miscarriage and fetal loss. Many chromosomal anomalies occur randomly during the formation of reproductive cells and are not inherited, though the risk increases with maternal age. When a fetus has a chromosomal anomaly, the body may naturally terminate the pregnancy, or the fetus may die later in life due to critical developmental complications.

Intrauterine Rupture

Intrauterine rupture is an emergency that is hazardous when the wall of the uterus is torn apart, usually during labor. The condition is primarily seen in individuals with previous cesarean sections or surgeries on the uterus, but it can also occur in those without these risk factors. Upon the rupture of the uterus, the fetus may almost immediately be cut off from the oxygen supply. Unless rapid surgical intervention is done, both the mother and unborn child are in danger.

Preterm with Postnatal Infection

Babies born before 37 weeks of pregnancy are considered preterm, which means that their immune systems are too immature to fight infections. Once a preterm baby becomes infected after birth, the condition can be overwhelming for their already-fragile body. Bacteria, viruses, or fungi that a full-term infant efficiently fights off can cause an infection that's lethal to a preterm newborn, describing illnesses like sepsis. Despite advances in neonatal intensive care, infections remain a significant and sometimes deadly complication for these tiny babies.

Preterm with Respiratory Compromise

Lungs are among the last organs that mature in the fetus; thus, those born very early often need help breathing. Respiratory compromise means that the newborn's lungs fail to provide enough oxygen to the body, which can result in respiratory failure, even with intensive support involving ventilators and oxygen. Conditions like Respiratory Distress Syndrome continue to plague preterm infants and remain one of the leading killers today, especially among those born extremely preterm.

Previable Preterm

Some babies are born earlier than viability, usually at 22 to 24 weeks, before their systems are fully functional. These births are previable. In these circumstances, the body systems are too underdeveloped for life outside to be sustained, and even the most potent support cannot change the outcome. These infants don't stand a chance, living just a few minutes to hours after their birth.

Intrauterine Infection

Intrauterine infection occurs when an infection is within the uterus during pregnancy, caused mainly by bacteria, viruses, or other pathogenic agents. Infections can travel across the placenta, affect the fetus, causing inflammation, and eventually lead to the destruction of organs. Depending on the severity of infections, one may encounter preterm labor, intrauterine growth restriction, or even stillbirth. After birth, the newborn might develop complications, such as sepsis, which can be potentially fatal.

Premature Rupture of Membranes (PROM)

The amniotic sac is broken early, rendering the mother and fetus prone to infections, and this often leads to preterm labor. The early rupture of membranes may severely limit fetal maturation of vital organs, especially the lungs, heightening the chances of stillbirth or neonatal complications.

Previous Fetal or Neonatal Loss

A history of fetal or neonatal loss appeared as a strong risk factor for subsequent pregnancy loss. Families with these prior losses are often faced with a complex set of emotional and medical issues. In addition, the probable underlying conditions, whether genetic, anatomical, or unknown, may extend across pregnancies, thus compounding risks despite the best possible efforts with surveillance and intervention.

Preeclampsia and Chronic Hypertension

Chronic hypertension and preeclampsia are some of the most alarming disorders in women. These maternal disorders lead to restriction of fetal growth and chronic hypoxia, which can lead to preterm delivery and subsequent death. Although prenatal monitoring techniques have been improved, hypertensive disease remains an ailment to both mother and child.

Placental Abruption

Reports of different cases reviewed had placental abruption, a sudden complete disconnection of the placenta from the uterine wall. Such a sudden cutoff of oxygen and nutrient supply usually causes either instantaneous fetal death or critical morbidity of the neonate.

Previous Early Delivery

Recurrent preterm labor and complications like death of the fetus are significantly increased with a prior early delivery due to cervical insufficiency, infection, or uterine anomalies that raise the chance of repeating such events.

Obesity

Pregnancy complications related to obesity include gestational diabetes, hypertensive disorders, fetal macrosomia, and stillbirth. Physiological effects of obesity complicate prenatal assessments and may sometimes mask emerging problems until they become critical.

Multiple Gestation (e.g., Twins, Triplets)

Multiple gestation pregnancies (i.e., twins, triplets, etc.) have inherent increased risks. They are more prone to end up in preterm labor, fetal growth restrictions, and placental complications. Their management, though closer monitoring, would still be a big challenge given the competing needs of more than one fetus.

Diabetes (Pre-existing and Gestational)

Preexisting diabetes and gestational diabetes, or those diagnosed for the first time during pregnancy, increase the risk of specific adverse outcomes. Poorly controlled blood sugar levels have been associated with congenital anomalies, macrosomia, intrauterine fetal demise, and respiratory complications in newborns. Although the newer and better-managed protocols in diabetes care have shown remarkable improvement, challenges remain.

Placenta Previa

In many instances, placental previa occurs when a placenta covers some part or the whole cervix. This condition poses a threat of heavy maternal bleeding, and most often, the indication for a cesarean section before term delivery. In cases where the bleeding could not be controlled, the fetus unfortunately suffered a loss.

Care Coordination Issues

Continuity of Care/Care Coordination	Number of Reviewed Cases
No Prenatal Care	2
Late Entry Into Prenatal Care	4
Missed Appointments	3
Lack of Coordination of Care	2
Lack of Appropriate Referrals	0
Poor Provider-to-Provider Communication	3
Services Inconvenient to Access	0
No Doula	17

Table 2: Possible Continuity of Care/Care Coordination in Reviewed Fetal and Neonatal Deaths in the year 2023

No Prenatal Care

There were numerous cases where no prenatal care was documented during the entire duration of pregnancy. Missing out on prenatal care would mean missing significant chances for detecting and treating risk factors early. Conditions like hypertension, infections, and even fetal growth restrictions can go unnoticed and, when they do surface, are very life-threatening to mother and baby at the same time.

Late Prenatal Entry

Some families could be enrolled in prenatal services during the second or third trimester. Various factors contributed to delays in seeking care, such as lack of insurance and transport barriers to accessing health services, mistrust of the health services systems, and multi-demand lifestyles.

Frequent Missed Appointments

Every visit missed is an opportunity lost for monitoring fetal growth, addressing maternal health issues, providing health education, and so forth. Some missed visits result from logistical problems, like work schedules and transport. Others are tied to more systemic barriers, like difficulty scheduling visits or a lack of culturally sensitive care.

Poor Provider-to-Provider Communication

Several cases highlighted missed communications between providers, particularly during key transition periods like referral from a primary care setting to a consultation appointment with a specialist or handovers during labor and delivery. Poor communication can leave unacceptable gaps in care, lead to delays in diagnosis, and result in loss of critical pieces of information that, in the end, adversely impact outcomes for mothers and infants.

No Documentation of Doula Support

Although increasing evidence indicates that continuous labor support by trained doulas significantly enhances birth outcomes, only a few cases reviewed indicated doula involvement. Families, especially those facing social or systemic stressors, can substantially benefit from the advocacy and emotional support offered by doulas navigating the health system. In many cases, the absence of this support denotes missed opportunities for enhancing patient-centered care.

Behavioral Health Issues Identified in Fetal and Infant Loss

Mental Health

Mental Health Issues	Number of Reviewed Cases
History of Mental Illness Before Pregnancy	10
Depression/Mental Illness During Pregnancy	11
Depression/Mental Illness Postpartum	5
No Depression Screen Documented	0

Table 3: Possible Mental Health Contributions to Reviewed Fetal and Neonatal Deaths in the Year 2023

There were many cases of mental health-related issues, including depression, anxiety, bipolar disorder, and other psychiatric illnesses. Pregnancy can be a difficult time for emotional health. It can result in undermined self-care, declining adherence to prenatal care, and an inability to manage stress, with possible implications for fetal growth if mental health problems go unrecognized or poorly managed. Some families reported delays in availing timely mental health services, while others cited stigma or fear of judgment as hindrances to seeking help. Maternal mental health has a significant implication for pregnancy outcomes, thus necessitating delicate screening and integrated access into perinatal mental health resources.

Substance Use

Substance Use Issues	Number of Reviewed Cases
Tobacco Pre-Pregnancy	8
Tobacco During Pregnancy	4
Alcohol Pre-Pregnancy	6
Alcohol During Pregnancy	3
Illicit Drugs Pre-Pregnancy	4
Illicit Drugs During Pregnancy	3
Prescription Drugs Pre-Pregnancy	0
Prescription Drugs During Pregnancy	0

Table 4: Possible Substance Use Contributions to Reviewed Fetal and Neonatal Deaths in the year 2023

Usage of substances such as tobacco, alcohol, opioids, and other drugs was recognized in several cases. Substance abuse during pregnancy can be harmful to the fetus and related risks of miscarriage, stillbirth, premature birth, and symptoms in the neonate due to opioids' effects on the developing fetuses.

Social Issues

Social Issues	Number of Reviewed Cases
Lack of Family/Partner Support	1
Lack of Community Support	0
Housing Issues	6
Food Insecurity	1
Maternal or Paternal Incarceration	1
Family Discord	5
Intimate Partner Violence	2
Exposure to Community Violence	0
Transportation Issues	0
Financial Stressors	3
Uninsured	0

Table 5: Possible Social Issue Contributions to Reviewed Fatal and Neonatal Deaths in the Year 2023

Housing Instability

Many other families in our review experienced housing instability during pregnancy. Some were in shelters; some stayed temporarily with family or friends; others faced eviction. Unstable housing triggers constant stress and may interrupt access to prenatal care, nutrition, and rest, which are required for a healthy pregnancy.

Food Insecurity

Accessing sufficient, nutritious food was an ongoing challenge for families. Some reported meal skipping, going to food pantries, or making agonizing choices between purchasing food and paying bills. Poor maternal nutrition correlates strongly with adverse pregnancy outcomes, including preterm birth and low birth weight. Food insecurity brings emotional burdens that are hard enough for these women.

Discord in Families

Family conflicts could occur between partners or parents and other family members and within multigenerational households. This was another layer of difficulty for many mothers. Family discord leads to emotional withdrawal, maternal stress, and lack of access to needed support after birth and during pregnancy. The cases show that unresolved conflict diminishes mothers' ability to engage in prenatal care and prepare for a new baby or family addition fully.

Financial Stressors

Even if mothers did have jobs, the burden of inadequate pay, job turnover, lack of paid leave, and paying out-of-pocket for healthcare drove stressors to excess. The pressure of finance has often put mothers in positions where they have been forced to delay their prenatal visits, not fill their prescriptions, or find an appropriate means of paying for transportation. Such chronic stress remains firmly linked with subpar health outcomes for both mother and fetus.

Lack of Partner Support

In several cases, mothers described feeling alone without a supportive partner, family, or friends to lean on. Isolation contributes to depression, missed medical appointments, and difficulty in preparing for the baby's arrival.

Intimate Partner Violence

Sadly, intimate partner violence (IPV) was detected in some of the cases. Experiences ranged from emotional abuse to beating, even during pregnancy. IPV endangers both maternal and fetal safety, but it injects an additional sense of danger, wherein women may not report health problems or even seek prenatal care. Violence affects every aspect of maternal and infant health.

Incarceration

Incarceration, exclusive focus on the mother or another person of direct concern, was another social factor that disrupted stability. Loss through incarceration brought about separation, financial difficulties, and emotional burdens. Concerning incarcerated mothers, prenatal care was affected, and, likely, the added stress associated with incarceration would also increase health risks. On the other hand, if the mother's partner or co-parent were incarcerated, the ensuing instability, in turn, would have negatively impacted the health and resource access of the mother herself.

Health Care System Issues

Quality of Care Issues	Number of Reviewed Cases
OB or Neonatal Standards Not Met	2
Lack of Appropriate Education	7
Lack of Referral to Appropriate Provider	1

Table 6: Possible Contributions of Quality-of-Care Issues to Reviewed Fetal and Neonatal Deaths in the year 2023

Lack of Referral to Appropriate Provider

Another critical issue that has come up is either not referring pregnant individuals or sometimes not taking them to the appropriate specialists when referred. In a few cases, women with risk factor symptoms like high blood pressure or diabetes, or showing symptoms like early labor, did not receive the timely referral to specialist obstetricians or maternal-fetal medicine (MFM) providers. This can lead to unmanaged conditions that worsen pregnancy outcomes, including fetal distress, preterm birth, and even stillbirth.

Lack of Effective Education

Effective patient education becomes crucial to helping an individual make informed choices regarding their health and the health of their unborn child. However, in various selected instances, it was observed that the information provided to mothers about prenatal care, warning signs during pregnancy, and newborn care was either partial or ineffective. Such gaps in knowledge leave mothers unprepared to recognize complications, thus missing opportunities for early intervention.

In some instances, mothers were not fully informed about the signs of preeclampsia, preterm labor, or other pregnancy-related complications. Without clear instructions about what to look for and precisely when to seek help, mothers may not seek timely medical attention, and outcomes will suffer for both mother and baby. Making education available,

culturally competent, and tailored to each patient's specific needs is one of the most crucial elements toward better health outcomes.

Obstetrics or Neonatal Standards Not Met

Some instances of obstetric and neonatal standards not being upheld were also noted. These include failures in adequately monitoring fetal heart rates during labor, managing postpartum hemorrhage, and failing to provide timely neonatal resuscitation when indicated. Such lapses in care could have catastrophic consequences for situations in which there is a risk for the immediate health of the mother or the neonate. For instance, an absence of appropriate monitoring procedures for labor or non-adherence to protocol may have severe, even catastrophic, results of birth asphyxia, brain injury, and death. Correct action in these cases and adherence to the guidelines are viewed not only as best practices but as paramount to ensure that those most vulnerable, especially those who develop complications, receive the highest care possible.

Patient Provider Communication Issues

Patient-Provider Communication Issues	Number of Reviewed Cases
Language Barriers Not Addressed	0
Evidence of Disrespectful Care	0
Lack of Shared Decision Making	2
Patient Dissatisfaction	3

Table 7: Possible Contributions of Patient-Provider Communication Issues to Reviewed Fetal and Neonatal Deaths in the Year 2023

Patient Dissatisfaction

Many cases show how dissatisfied patients were with the care they received. In some cases, women were unhappy because they felt as though they were not being acknowledged, heard, or listened to by their health care providers; subsequently, they suffered from frustration, anxiety, and sometimes delayed or missed care. In contrast, some mothers were outraged by how their issues were addressed when asking for help to treat pregnancy-related symptoms such as pain, swelling, or strange movements of fetuses.

Patients' perceptions of their issues being trivialized or not addressed can gradually erode their trust in the health care system. It leads to non-adherence to treatment, that is, missed appointments, non-compliance with follow-ups, and ultimately poor health outcomes.

Lack of Shared Decision-Making

Involvement of shared decision-making represents important characteristics of patient-centered care. A good number of cases report that the providers made health care decisions entirely, without being adequately consulted or respecting the patient. Some reported that they were never told about possible risks or benefits from specific procedures or interventions. In addition, they were not given any time to discuss their choices before making major decisions. Other cases revealed significant labor and delivery decisions quite unilaterally made by the health care provider, sometimes leaving the mother feeling deprived of normal processes or overwhelmed.

It comprises a very significant aspect of effective care: patient engagement. Without giving a biocentric link to health-related decisions, it would lead to nonadherence to treatment plans, the patient becoming more anxious, and lower satisfaction with care received. On the contrary, shared decision-making enables an open discussion, trust-building, and a more individualized treatment approach- all those playing a very essential role for better outcomes, both for mothers and infants.

Family Planning	Number of Reviewed Cases
Lack of Contraception Education	2
Unintended Pregnancy	0
Undesired Pregnancy	12
Short Interpregnancy Interval	0

Table 8: Possible Contributions of Family Planning Issues to Reviewed Fetal and Neonatal Deaths in the Year 2023

Bereavement Issues	Number of Reviewed Cases
No Bereavement Offered	0

Table 9: Possible Contributions of Bereavement Issues to Reviewed Fetal and Neonatal Deaths in the Year 2023

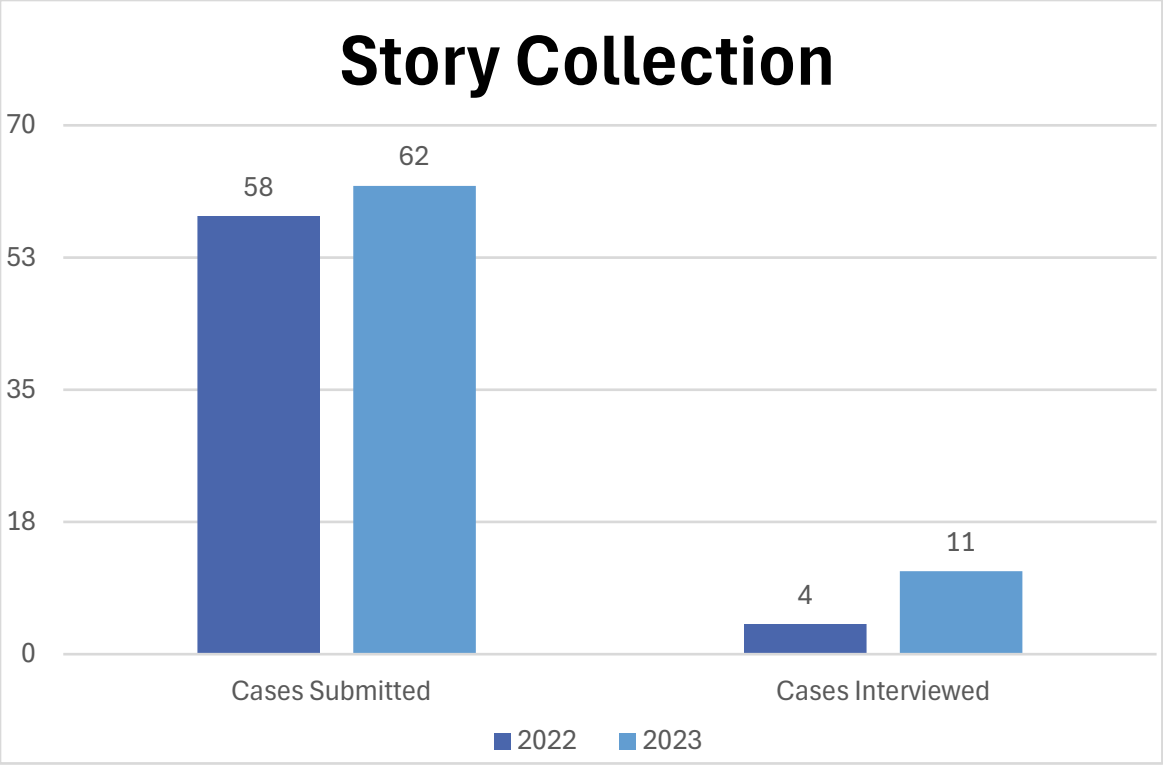


Figure 13: Story Collection

Figure 14 illustrates the number of cases submitted for FIMR and the number of completed cases in 2022 and 2023. In 2022, 58 cases were successfully submitted for interviews, of which only four were eventually conducted. The number of cases submitted in 2023 increased marginally to 62, but the number of interviews conducted increased to just 11. This considerable difference between submitted and conducted cases reflects several challenges in the story collection process.

Primarily, the most challenging aspect of interviewing families has had to do with the emotional burden they are carrying following the loss of a loved one. The possible issues of re-traumatization, as well, tend to discourage many families from participating. Besides this, the team was hampered from finding many families due to obsolete contact information and an inability to follow up. Language constraints and scheduling challenges due to an inadequate number of trained interviewers might also have hampered the total completion of interviews. In a few instances, it was a case where families were initially willing but later declined because of emotional trauma or a change in circumstances.

In 2024, no interviews were conducted, having temporarily halted the process to reflect on changing our strategy for collecting stories. It has meant re-evaluation of the methods for being more trauma-informed, equitable, and respectful of family needs. There's also been a minimal response from the community at this time, making engagement much more difficult. In the coming year, we hope to restore faith and create a more welcoming and culturally rich way of collecting stories from these communities.

Family Interviews/ Story Collection: A Vital Piece of the Puzzle

Interviews conducted with the family are a key component of the Fetal and Infant Mortality Review (FIMR) process. While medical records are valuable data sources concerning health problems, treatment, and outcomes, these records often miss the scope of the family experience. The narratives from family interviews speak to a deeper appreciation of the emotional, social, and contextual advantages that might either support or deteriorate health outcomes for mothers and infants. Such interviews bring in the voices of the people who had, first and foremost, the direct experience of the pregnancy and the care of the infant: the family members, who allow a fuller story to be told with a few more dimensions.

Medical records seem limited to many families, focusing only on clinical matters such as diagnosis, treatments, and medical procedures. However, the real-life experience of pregnancy, birthing, and aftercare is complex and multifaceted, with multiple layers of emotions, support systems, cultural beliefs, and personal struggles that are often invisible in the clinical setting. This multidimensional aspect of pregnancy and infant death is illuminated by family interviews, which appreciate the real-life experience with an emotional context. The families engage in open and candid conversations about their perspectives on the hurdles they faced, the care they received, how the loss might have affected them, and support (or lack thereof) from health care providers, family, and communities.

Shifting Toward Fatherhood Engagement

Historically, the FIMR story collection has been directed toward mothers as the direct caregivers seen through the pregnancy and childbirth process. However, over the years, we've realized that fatherhood matters equally for the health and well-being of both mother and infant. Fathers, too, are much affected by the pregnancy complications, neonatal loss, and grief. The emotional burden carried alongside their perspectives regarding the care process provides essential scope to understand the broader family dynamic.

In late 2024, we started engaging fathers directly in our interviews rather than the traditional practice of interviewing mothers. Fathers are often profoundly affected by the stress and pain that come with pregnancy complications and loss. When mothers are overwhelmed by

medical care and grief, it can impact not only their mental health but also the well-being of their partners and families. Involving fathers in the family interview creates a better understanding of coping with the relationship and motherhood, and how involvement or lack thereof affects a family.

Parenting is one of the essential facets of family health. Including fathers in our story collection is vital to understanding family health. It emphasizes the need to involve both mothers and fathers to gain a more complete and holistic view of fetal and infant mortality.

Revamping the Survey: Making It More Inclusive

A significant update to the FIMR survey was made in 2024, building on an earlier version created in 2022. One of the key changes introduced was to make the study more inclusive of all family members, especially fathers' experiences, while also addressing the varied backgrounds and identities of the families we serve. The original survey chiefly addressed maternal experiences, thus inadvertently constraining our outlook on the broader family impact. With the revision, we sought to ensure that many voices and perspectives would be represented in the family narrative.

Changes included the introduction of questions regarding fathering involvement, family dynamics, and support from other systems, such as extended family or community. More culturally sensitive sections were named, considering the diverse cultural and economic contexts in which our families live. The goal was to ensure that the survey reflected the realities of all family members, acknowledged their experiences, and promoted a more inclusive approach to data collection.

Building Community Through Family Interviews

One key task for family interviews is strengthening their community and connection. These interviews are about gathering information, establishing trust, and creating an environment where families feel heard, valued, and understood. Telling personal stories can be healing for families and empower them with a sense of validation and connection through their mutual experiences.

An effort is made to create a supportive and non-judgmental atmosphere during the interviews. This helps families feel at ease to discuss their innermost thoughts and feelings, their experiences of losing a child. Over the years, we have found such discussions

therapeutic while building more community networks within the FIMR program and in the wider social group of the families.

Active listening and conversing with families would help them build relationships with others with similar life issues and challenges. This commonality of experience is essential for healing and resilience-building for both the mother and father. This reminder goes a long way to show families that they are not alone in their journey.

Connecting with Families in the Future: New Media Approaches

There are some exciting developments in the new things we are doing toward our future vision -the possibility of using new media to reach out to families. This is very important to us as we consider the fact that most families today are almost dependent on digital media for their needs and services. This has set the stage for us to create a technology-based process that will assist in conducting interviews in a way that would be more accessible, using elements such as online surveys and video calls to collect family narratives under a more flexible and comfortable scenario. In addition, we are launching a new website where families can easily share their stories, further enhancing accessibility and engagement.
These new media approaches will enable us to go beyond traditional communication methods with families, particularly those who find it difficult to leave their homes for in-person interviews. Our multiple options will allow different families to share their stories, making sure that everyone will have an opportunity to be heard, regardless of their circumstances: this is undoubtedly more inspiring.

Improving Positive Outcomes and Grieving Together

The main objective of the entire FIMR process is to ensure positive outcomes for families. This generally means looking into all aspects of maternal and infant deaths that go beyond medical and health-related conditions into emotional and social features. The interviews we conduct are intended to help families process their grief, build resiliency, and find strength in each other and with their communities.

Grieving approaches differ from one family to another since grief is a profoundly personal experience. Therefore, our team grieves with families as it recognizes their pain, provides assistance, and assures them that they are not alone. This may include referral to grief counselors, connections to support groups within the community, or just a compassionate presence.

Through active engagement in a nurturing environment with families all along their journey, we can understand their experiences and help them on their way to healing and hope.

Rationales for Recommendations

CRT's recommendations are ideas shaped by real experiences, not only by statistics or checklists: real griefs, real yearnings to do better, real life stories. Below, we furnish explanations of why an individual recommendation stands out. We aim to create a situation where each individual, family, and community is given a fair opportunity for the healthiest pregnancy and life after loss.

Bereavement check-ins before the 6-week appointment (1–2-week follow-up)

After a pregnancy or baby loss, these early weeks can feel so alone, lonely, and confusing. Six weeks is just too long a wait! A simple 1- to 2-week follow-up check-in call or even a visit would allow families a moment in the light to feel seen and supported when it matters most. This early check-in will help with detecting depression or anxiety while they are still small and manageable.

Blood pressure should always be recorded

Blood pressure problems during pregnancy and postpartum can creep up silently and cause real damage if no one is watching for them. With every session, recording blood pressure ensures that subtle warning signs do not go unnoticed. An elementary act that can save lives: careful monitoring will catch problems before they get serious.

Providers should do a social risk assessment

A pregnant person struggling with housing, food, safety, or even attending appointments may experience adverse health impacts. When providers inquire about social risks, it helps complete the picture of understanding the patient and may also connect mothers to resources they were unaware they could access.

Find and recommend inclusive care spaces for Black and LGBTQ+ families

Not all doctors' offices or hospitals feel welcoming to everyone. Black families and LGBTQ+ families often face discrimination or may feel invisible when seeking quality care. Finding clinics and doctors who genuinely respect their clients can make the difference between continuing care and walking away from it.

Track missed appointments and make more care connections

Usually, there is a reason patients cannot come to their appointments. In most cases, that reason is serious: not having a ride, being unable to take time off work, or fear of another negative experience based on past visits. Outreach to find out why and offer help instead of simply marking it as a "no-show" could keep someone from falling through the cracks.

Increase education about fetal movement

One of the best indicators of a healthy pregnancy is the baby's movement, but not everyone understands what that means. Gas bubbles or muscle twitches can feel similar, and some may not be aware of the difference. Teaching families early on how to recognize healthy fetal movements and when it's necessary to contact a doctor if there's a change in the baby's movements could save lives through early intervention.

Trauma-informed care at every single level

Many patients bear emotional scars from past experiences — sometimes from hospitals, sometimes from their personal lives. If the front desk staff, the nurses, and the doctors show compassion, understanding, and patience, the chances of a patient trusting them grow considerably. This type of care is necessary to treat people without fear or judgment.

Help patients learn how to advocate for themselves

Some find it easy to ask questions while others do not, perhaps due to past disrespectful treatment or ignorance. Teaching patients that their voice matters in a clinical setting can improve their experience tremendously. It can be a lifesaver since the patient may feel empowered to speak up regarding a patient safety issue.

Make sure insurance covers genetic testing after fetal loss.

Genetic testing can help explain why a fetal loss occurred, especially in cases where chromosomal abnormalities are suspected, but it can be costly. Families often do not have funds for it to be paid out of pocket after having traversed such painful switching events. If Medicaid and private insurance covered this testing, it would relieve a burden from many families and benefit them in planning their futures.

Create a funding program to help with medical bills after fetal loss

Medical bills can become a significant burden, especially following a loss. No family should bear the weight of debt on top of their grief. A program that covers some of these costs could make a massive difference in the healing process, allowing families to focus on recovery without the added stress of financial worries.

Focus on reducing disparities for Black birthing individuals

Black women giving birth are much more likely to face complications and losses regardless of their job, education, or ability to pay for insurance. It is not about individual choice, but profound historical injustice embedded in the health care system. We will see the same disastrous outcomes until we truly begin to invest in closing these gaps.

These are only beginning recommendations. Time and devotion are needed to really change society, along with listening — not only to one set of data but also the voices of the families who tell us their stories. We take each small step toward a future where every pregnancy is safe, every family is supported, and nobody is alone as they experience loss. We hope these actions will lead to stronger, kinder, safer systems for all.

Data Collection Limitations

While the findings from this report provide critical insights into fetal and infant mortality trends in Allegheny County, a number of limitations affect the completeness and generalizability of the data:

Incomplete Case Capture:
Not all fetal and neonatal deaths in Allegheny County are reported through the FIMR intake process. The data reflect only those cases reported by birthing facilities and do not include all deaths that occurred during the review period.

Variability in Data Quality:
The intake forms and medical records submitted by facilities varied in their completeness and accuracy. Missing or inconsistent fields in particular areas, such as maternal behavioral health, social determinants, and prenatal care, limit the precision of trend analyses.

Delays in Record Acquisition:
Medical records from hospitals and partner agencies may arrive late, delaying case reviews and thus causing data gaps for specific years, especially for the most recent reporting period.

Limited Family Interview Data:
Family interview participation rates were low due to emotional distress, contact challenges, and limited interviewer capacity. As a result, qualitative insights from affected families are limited in this report.

Unknown or Missing Variables: Increasing proportions of cases with "unknown" entries, for example, on birthweight, gestational age, or insurance type, limit the extent to which robust subgroup analyses can be performed and may obscure emerging trends.

Non-representativeness of the sample: Because the reviewed cases have been prioritized based on specific criteria, such as race, gestational age, or case scoring, this sample may not be representative of all fetal and neonatal deaths in the county.

Cross-Year Comparability: Changes in reporting systems, facility engagement, and scoring methods over time may limit year-to-year comparability of findings and trends. Despite these limitations, data collected and analyzed through FIMR continue to form a unique and valuable foundation for understanding and addressing the complex factors driving fetal and infant mortality in Allegheny County. Continued improvement in case reporting, interagency data sharing, and engagement with families is required to enhance completeness and quality in future reviews.

Community Action Team

Based on the recommendation of CRT, our Community Action Team is working on three major solutions, specifically focusing on black births:

1) Community Blood Pressure Monitoring

2) Count the kicks campaign

3) Trauma-informed care.

Community blood pressure monitoring.

Goals: The initiative aims to raise awareness and educate community members on blood pressure management, specifically focusing on areas such as Wilkinsburg, North Side, and Hill District through:

1. Targeted Outreach: Working with community organizations and leaders to maximize local impact.

2. Trainer Identification: Recruit and train skilled professionals to teach blood pressure education well

3. Community-training Partnerships: Partner with trusted local organizations to host blood-pressure awareness/theme events.

Funding and Resources: The maternal health innovation grant from Pennsylvania is made possible by the Jewish Healthcare Foundation, which supports blood pressure campaign initiatives. These funds will be allocated to key areas such as educational materials, community training sessions, and heart health kits for engagement.

With proper blood pressure management, it is possible to reduce the complications experienced in pregnancy and lead to healthier pregnancies and better maternal and infant outcomes. CAT intends to tackle systemic disparities and lay the groundwork for community-level health improvements for years.

Count the Kicks Campaign

The Count the Kicks (CTK) campaign aims to reduce stillbirth rates and improve fetal health outcomes through community mobilization and education. It is one of the evidence-based programs that encourage parents to make regular observations of the movements of a fetus after a certain number of weeks (28 for low-risk pregnancies and 26 for those at high risk). These activities should elicit early signs of complications, allowing for timely medical attention.

Key Strategies:

1. Awareness Building: By storytelling and addressing some misconceptions, CTK enables an understanding that fetal movement monitoring can be a reliable measure of health.
2. Access for Communities: The program ensures parents can access numerous educational resources, including a multilingual app and low-cost services.
3. Equity-Focused: The program puts an emphasis on working with Black communities toward the reduction of disparities in stillbirths, which are observed to be disproportionately high in these communities.

Impact Potential: Nationwide, it is said that stillbirth occurs in 1 out of every 77 births and 1 out of every 100 Black births, with a rate of 5.59 per 1,000 births in Pennsylvania. CTK has demonstrated efficacy in reducing stillbirths by 39% over five years in Iowa! If implemented here in Allegheny County, it could save as many as 239 lives yearly.

Next Steps for Implementation:

- Campaign rollout throughout the county using digital media and educational tools.
- Training community leaders to distribute materials and educate parents.
- Engage stakeholders, particularly health care providers, to foster clinical buy-in and outreach.

Count the Kicks thus becomes an example of a working intervention with a clear path towards local implementation that is proactive and equitable in reducing mortality and enhancing maternal and infant health outcomes in Allegheny County.

Trauma-Informed Care

Trauma is not uncommon at all. Many people bear the burden of harm done to them through interpersonal violence, loss, systemic oppression, or natural disasters, and such experiences often affect their present ability to cope with the world. Trauma-Informed Care is an intervention that aims to transform environments regarding trauma and actively promote safety, healing, and empowerment.

Objectives :

1. Understanding the Prevalence and Impact of Trauma

Trauma is a common thread through the lives of many patients. The CDC-Kaiser ACE Study found that almost two-thirds of respondents had experienced at least one adverse childhood experience (ACE) involving neglect, abuse, or household dysfunction, with more than one in five reporting three or more. Understanding such prevalence allows caregivers to view the trauma in light of empathy and insights into behaviors.

2. Recognizing Signs and Symptoms of Trauma

Trauma can show up as anxiety, depression, hypervigilance, somatic complaints, or difficulty with trust formation. These symptoms are often responses from past trauma rather than standalone disorders.

Trauma-informed care providers identify these signals as trauma-like responses to past harm rather than problems to be solved.

3. Implement Policies and Practices Based on Trauma-Informed Knowledge

Trauma-informed practice includes modifying one's communication style, rearranging the physical setting, and providing clients with choices whenever possible. It is about providing a safe physical, emotional, and psychological environment where individuals feel respected, empowered, and supported in their healing process without fear of re-traumatization.

4. Resist Causes of Re-traumatization

Even those systems intended to help could nonetheless create trauma. Constant reflection, the hallmark of TIC, discourages practices that inadvertently trigger or marginalize individuals.

Community Action Team (CAT) and Clinical Action Collaborative (CAC) plan to implement trauma-informed care across the clinical and community sectors.