Working to Address the Tragedy of Stillbirth: Implementation Recommendations

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Executive Summary

In 2022, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) convened a group of federal government, academic, nonprofit, and clinical experts to collect information on stillbirth, which is the loss of a fetus at 20 weeks or more of gestation.[1] To prevent these deaths and provide better care to families who have a stillborn infant, the U.S. Department of Health and Human Services (HHS)—which includes the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), and the Indian Health Service (IHS)—established the Stillbirth Working Group (WG) of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development's (NICHD) National Advisory Child Health and Human Development (NACHHD) Council. As mandated by Congress, the WG focused on current barriers to collecting data on stillbirths throughout the United States, communities at higher risk of stillbirth, the psychological impact and treatment for mothers following stillbirth, and known risk factors for stillbirth.[2]

Based on key findings, the WG developed recommendations with the following objectives: guide future efforts to improve recordkeeping, data collection, and analysis about stillbirths; address disparities in stillbirth risk; better support families after stillbirths occur; and ultimately reduce the U.S. stillbirth rate through research and prevention efforts.

The WG released its final report to HHS, *Working to Address the Tragedy of Stillbirth*, on March 15, 2023. Recommendations included the following: improve the quality of vital statistics, surveillance, and epidemiologic data on stillbirth at the local, state, and national levels; use insights from improved epidemiologic data and conduct additional research to explain and ultimately address disparities in stillbirth and identify prevention opportunities; conduct implementation research and develop culturally sensitive interventions to support families who have experienced stillbirth; and create and support a full research agenda—including research on known and unknown risk factors and physiologic mechanisms—to support the development of interventions to prevent stillbirth.

The Consolidated Appropriations Act of 2023 (P.L. 117-328) included language for the WG to continue its activities by focusing on three topics that Congress mandated it to address:

- Current knowledge on stillbirth and prevention
- Areas of improvement for data collection
- Current resources for families impacted by stillbirth

Based on key findings in each area, the WG developed recommendations for reducing the U.S. stillbirth rate and improving care for those who experience stillbirth. In this work, multiple collaborators will play vital roles, including federal agencies, states, professional societies, public health agencies, researchers, clinicians, families, and advocates.

For a fourth topic, Congress asked HHS to address next steps to gather data and lower the rate of stillbirth in the United Sates. Because this issue crosscuts the other three focus areas, it was addressed by each subgroup.

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[1] *Eunice Kennedy Shriver* National Institute of Child Health and Human Development. (2023, August 25). *Stillbirth*. U.S. Department of Health and Human Services, National Institutes of Health. https://www.nichd.nih.gov/health/topics/stillbirth

[2] Consolidated Appropriations Act of 2022 (P.L. 117-103).

Summary of the WG Findings

The WG held a total of three meetings in 2023 and 2024, during which it heard from a broad range of experts. To identify key findings, the WG was divided into three subgroups to address each of the three focus areas: Identifying Current Knowledge on Stillbirth and Prevention, Improving Data Collection, and Identifying Current Resources for Families Affected by Stillbirth. The WG also identified several general recommendations that are relevant across more than one focus area, such as the burden on communities at higher risk of stillbirth. These findings are summarized below.

One key theme across the three focus areas was lack of standardization across states and territories. Without standard terminology and reporting practices, data cannot be collected uniformly, which slows the advancement of knowledge and prevention efforts. The lack of standard training for bereavement also hinders health care professionals' ability to work with affected families in ways that convey and promote empathy. This is vital to enable the work of determining the possible cause by securing the families' consent to additional data collection efforts—such as blood tests, genetic testing, placental examination, and perinatal autopsy.

Each subgroup also highlighted different aspects of standardization based on its mandate.

Current Knowledge of Stillbirth and Prevention

- Lack of routine perinatal autopsy and placental examination leads to incomplete pathology/histology information. Complete information could improve understanding of the causes of stillbirth and potential avenues of prevention.
- Genetic testing is often not done because of the cost and logistical challenges.
- Perinatal audits[3]—the process of capturing information on the causes of stillbirth and analyzing the quality of care received in a no-blame, interdisciplinary setting to guide action to prevent similar deaths in the future—are not routinely performed.

Data Collection

- Surveillance and medical definitions (including gestational age and birthweight criteria, which vary by state) for stillbirth, pregnancy loss, and miscarriage are not currently standardized; therefore, data collection is inconsistent.
- Clinical data collected from multiple sources—e.g., electronic health records (EHRs), monitoring data, imaging studies, genetic testing, pregnancy experience, patient history—are not integrated and linked across datasets, so that all information could be accessible for research and stillbirth prevention.
- There is a lack of uniform training of individuals who complete fetal death certificates, which hinders accurate recordkeeping.
- Currently, a fetal death certificate must be filed within days of a fetal death, before results of a full workup are available. Workups may better identify causes of death. Full-workup death results are often not incorporated into the fetal death certificate, as formal legal amendment is not needed. Thus, information from the delivery and from subsequent testing may be delayed and not integrated into the fetal death certificate.

[3] Kerber, K. J., Mathai, M., Lewis, G., Flenady, V., Erwich, J. J. H. M., … Pattinson, R. (2015). Counting every stillbirth and neonatal death through mortality audit to improve quality of care for every pregnant woman and her baby. *BMC Pregnancy Childbirth, 15*(Suppl 2), S9. doi:10.1186/1471-2393-15-S2-S9

Resources for Families

- There is not always appropriate care at the time of bereavement, which is vital to meet the needs of families.
- Health care professionals often lack standard training in, among other things, cultural sensitivity on how to speak empathetically with bereaved parents and families.
- Local and national resources are insufficient to support families who have experienced stillbirth, especially in smaller hospitals with limited resources.
- Health care professionals are inadequately trained regarding stillbirth.

General WG Recommendations

Some recommendations were endorsed by at least two of the three subgroups or were applicable to more than one of the three focus areas. Among the recommendations in this category were the following:

- Standardize data reporting and collection to promote accurate and consistent surveillance.
- Support population-based surveillance such as expanding the CDC Pregnancy Risk Assessment Monitoring System (PRAMS) Stillbirth Project (Study of Associated Risks of Stillbirths [SOARS] survey) to capture diverse voices of those experiencing stillbirth in jurisdictions with high stillbirth burden.[4]
- Explore artificial intelligence (AI) and machine learning (ML) as ways to improve risk prediction and stratification based on existing data, ensuring that sensitive health care information is safeguarded.
- Create tools to educate patients and health care professionals on risk factors for stillbirth.
- Create standardized training, appropriate infrastructure, and resources so that a complete stillbirth workup (e.g., completion of autopsy, placental pathology, genetic studies) can become more widespread and standards of care can be more uniform.
- Create infrastructure for perinatal audits to enable analysis and discussion of stillbirth and further identification of risk factors, as well as possible prevention strategies.
- Support research on how structural, institutional, and interpersonal racism contribute to inequalities in stillbirth rates, the offering and completion of stillbirth workups, differential access to health care opportunities, quality of care after stillbirth, and bereavement care.[5]

[4] Centers for Disease Control and Prevention. (n.d.). *Pregnancy Risk Assessment Monitoring System (PRAMS)*. U.S. Department of Health and Human Services. https://www.cdc.gov/prams/index.html

[5] Debbink, M. P., Stanhope, K. K., & Hogue, C. J. R. (2024). Racial and ethnic inequities in stillbirth in the U.S.: Looking upstream to close the gap: Seminars in perinatology. *Seminars in Perinatology, 48*(1), 151865. doi:10.1016/j.semperi.2023.151865

Recommendations by Focus Area

More detailed recommendations are provided in the full report, but these indicate the most salient findings from specific subgroups:

Identifying Current Knowledge of Stillbirth and Prevention

- Address health disparities and the social determinants of health (SDOH) that contribute to stillbirth, to allow for stillbirth prevention strategies.
- Support population-based stillbirth surveillance, especially in jurisdictions with high stillbirth rates.
- Provide access to high-quality prenatal care and postpartum care to optimize pregnancy and to prevent stillbirth.
- Initiate additional research to develop stillbirth prevention bundles that focus on patient and provider education, including public health measures such as advising people to cease tobacco use; helping people achieve a healthier body mass index; optimizing management of chronic medical conditions such as diabetes and hypertension; and inducing labor.
- Link maternal and fetal medical records to enable research, surveillance, and detection.

Improving Data Collection

- Collect, transform, integrate, and maintain EHRs and other pertinent datasets in a format appropriate for future use in AI and ML to create a maternal child health data ecosystem that serves as a major resource for research on stillbirth and other adverse pregnancy outcomes.
- Bridge the gap between data available at delivery and data available after the completion of stillbirth workup.
- Link EHRs to death certificate data to facilitate accurate and complete data collection related to stillbirth.
- Support CDC's population-based case-control study, the Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS), which collects data on causes and risk factors.
- Enhance regionalization of stillbirth evaluation through telehealth, the creation of Stillbirth Centers of Excellence, and HRSA's existing investments with the Fetal and Infant Mortality Review through the National Center for Fatality Review and Prevention.
- Provide state field representatives with ongoing, in-person training on the collection of national fetal death data.
- Encourage providers to use guidance documents and e-learning tools prepared by the National Center for Health Statistics (NCHS) to support data providers.
- Educate hospital personnel on using a flowchart developed by NCHS to understand fetal death certificates.
- Provide personnel training to improve overall fetal death data accuracy and completeness and to ensure the filing of amendments (e.g., for autopsy results) as needed.

Identifying Current Resources for Families Affected by Stillbirth

- Give families resources that provide relevant information relating to various aspects of the stillbirth experience and hospitalization. This should include information on the hospital stay and the birth process for individuals who know that they are delivering a

stillborn child, available tests for stillbirth workup, and how the results of those tests will be communicated with families after discharge from the hospital.
- When providing information on available tests for stillbirth workup, highlight that results could help determine the cause of death and help with subsequent pregnancy planning. This could include both national and local resources.
- Have perinatal mental health care professionals, social workers, and bereavement doulas available to support families.
- Ensure that the process of recovery from delivery is respectful:
    - Mark the patient's door as well as the paper/EHR to indicate to other staff that an infant's death has occurred.
    - Provide information about ways to memorialize or honor the infant, disposition of the body, and normal grief and bereavement.
    - Encourage families to see and hold their infant while respecting those who decline.
    - Create photos, videos, or other mementos of the infant for families to take home.
- If perinatal autopsy is permitted, emphasize that the baby will be treated with care and respect.
- Address the physical needs of the person giving birth.
- Provide frequent postpartum follow-up and include an emphasis on grief and mental health support.
- Create standards of care for health care professionals and others who might regularly interact with families who experience stillbirth, such as social workers and chaplains:
    - Encourage professional societies to consider integrating bereavement stillbirth materials as part of standards of care.
    - Create workshops on stillbirth for stakeholders in professional organizations.
    - Establish and require medical training education related to stillbirth, which includes bereavement and culturally specific training, for those working in prenatal, labor, and postpartum care. Encourage and make available training for willing providers.
    - Create resources for providers who may need emotional support caring for families that experience stillbirth.
- Develop research on the following areas relevant to patient care:
    - The most effective interventions for mental health of bereaved parents and families
    - Bereavement practices that prioritize marginalized groups in a culturally appropriate manner
    - Ways to discuss stillbirth with patients as part of routine prenatal care before stillbirth occurs
    - The economic impact of stillbirth for families and societies, including short- and long-term costs and direct and indirect costs
    - The most effective ways to train health professionals about respectful care
- Design and model awareness campaigns for stillbirth that are based on campaigns for sudden infant death syndrome (SIDS) and premature births. Also, examine whether lessons learned after suspected SIDS deaths can be applied to stillbirth.
- Make the costs of stillbirth workups more affordable, including access to fetal autopsy and genetic testing (optimal when done by a perinatal pathologist).
- Expand work leave after stillbirth.
- Expand awareness of legal options after stillbirth (e.g., memorial birth certificates).

Background

Introduction

Each year, about 21,000 U.S. families experience a stillbirth—the death of a baby before or during delivery at 20 weeks or more of gestation.[6] Stillbirth is not only a tragedy for parents and families but also a major public health concern.

Although the total U.S. stillbirth rate has generally declined since 1990, it has shown little change in recent years, and disparities have persisted across racial and ethnic groups.[7] In 2015, the U.S. stillbirth rate—after 28 weeks, to enable international comparison—was 23rd out of 49 high-income countries.[8] And in a 2016 study published in *The Lancet* medical journal, the annual percentage stillbirth rate reduction in the United States from 2000 to 2015 was lower than all but one of the other 48 high-income countries.[9] In 2022,[10] the overall fetal mortality rate[11] at 20 or more weeks of gestation was 5.45 deaths per 1,000 births (live and stillbirths).[12] Stillbirth rates among non-Hispanic Native Hawaiian or other Pacific Islander and non-Hispanic Black women are more than twice what they are for non-Hispanic White women. Stillbirth rates in American Indian and Alaska Native communities are also considerably higher than the national average.[13] By maternal age, fetal mortality rates are highest among those who give birth when they are either younger than age 15 or older than age 39.[14] By jurisdiction, stillbirth rates in 2022 for those at 20 weeks of gestation or more were highest (7.0 or higher) in Alabama, Arkansas, District of Columbia, Georgia, Mississippi, and Nevada and lowest (less than 4.0) in Massachusetts, New Mexico, Vermont, and West Virginia.[15]

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[6] Centers for Disease Control and Prevention. (2024, May 15). *Data and statistics on stillbirth*. U.S. Department of Health and Human Services. https://www.cdc.gov/stillbirth/data-research/

[7] Gregory, E. C. W., Valenzuela, C. P., & Hoyert, D. L. (2023). Fetal mortality: United States, 2021. *National Vital Statistics Reports, 72*(8), 1–21.

[8] Heazell, A. E. P., Holland, F., & Wilkinson J. (2023). Information about fetal movements and stillbirth trends: Analysis of time series data. *BJOG, 130*(8), 913–922.

[9] Flenady, V., Wojcieszek, A. M., Middleton, P., Ellwood, D., Erwich, J. J., Coory, M., … Goldenberg, R. L.; Lancet Ending Preventable Stillbirths Study Group; Lancet Stillbirths in High-Income Countries Investigator Group. (2016). Stillbirths: Recall to action in high-income countries. *The Lancet, 387*(10019), 691–702.

[10] National Center for Health Statistics. (2024, June 4). *Fetal Death 2022*. Hyattsville, Maryland: National Center for Health Statistics. Available at: http://www.cdc.gov/nchs/data_access/VitalStatsOnline.htm. Accessed May 20, 2024.

[11] This is a comparable term to stillbirth and may be used interchangeably in the document.

[12] Gregory, E. C. W., Valenzuela, C. P., & Martin, J. A. (2023, November). Fetal mortality in the United States: Final 2020–2021 and 2021–Provisional 2022, Report No. 32. *Vital Statistics Rapid Release.* Hyattsville, Maryland: National Center for Health Statistics.

[13] Gregory, E. C. W., Valenzuela, C. P., & Martin, J. A. (2023, November). Fetal mortality in the United States: Final 2020–2021 and 2021–Provisional 2022, Report No. 32. *Vital Statistics Rapid Release.* Hyattsville, Maryland: National Center for Health Statistics.

[14] Gregory, E. C. W., Valenzuela, C. P., & Hoyert, D. L. (2023). Fetal mortality: United States, 2021. *National Vital Statistics Reports,* 72(8), 1–21.

[15] Gregory, E. C. W., Valenzuela, C. P., & Martin, J. A. (2023, November). Fetal mortality in the United States: Final 2020–2021 and 2021–Provisional 2022, Report No. 32. *Vital Statistics Rapid Release.* Hyattsville, Maryland: National Center for Health Statistics.

The number of stillbirths in the United States yearly is higher than the number of live-born infants who die before their first birthday.[16] Advocates and parents say that the devastating effects of stillbirth are often overlooked and underappreciated. This report is designed to increase awareness, identify issues that need addressing, and suggest areas of research and potential solutions.

Congressional Mandate, the Formation of the WG, and WG Activities in 2023

The fiscal year (FY) 2022 Consolidated Appropriations Act (P.L. 117-103) included funds and language for the U.S. Department of Health and Human Services (HHS) to establish a task force to address the burden of stillbirth on U.S. families by examining the following issues:

- Current barriers to collecting data on stillbirths throughout the United States
- Communities at higher risk of stillbirth
- The psychological impact and treatment for mothers following stillbirth
- Known risk factors for stillbirth

To address this issue, HHS requested that NICHD form the Stillbirth Working Group (WG) of Council, a subgroup of NICHD's National Advisory Child Health and Human Development (NACHHD) Council.

The FY 2023 Consolidated Appropriations Act (P.L. 117-328) provided an additional $1 million to continue the WG and address the following issues:

- Current knowledge on stillbirth and prevention
- Areas of improvement for data collection
- Current resources for families impacted by stillbirth

The fourth topic that Congress asked HHS to address was next steps to gather data and lower the rate of stillbirth in the United States. This issue cuts across the other three and was addressed by each group.

In 2023 and 2024, the WG convened three sessions for presentations from researchers, families, and advocates. The WG also heard reports from the three subgroups that had been established to address the three congressionally mandated questions, with next steps to gather data and lower the rate of stillbirth.

Members of the WG

The WG has 27 members and three ad hoc consultants. Members are affiliated with federal agencies or outside specialty organizations (e.g., the March of Dimes, the American College of Obstetricians and Gynecologists [ACOG], the Society for Maternal–Fetal Medicine [SMFM]). Members had a variety of relevant areas of expertise in, among other things, maternal and fetal medicine, genetics, and pathology. Along with NIH, the WG included federal partners such as CDC, HRSA, and IHS. NICHD Council members Lucky Jain, M.D., M.B.A., from Emory University, and Uma M. Reddy, M.D., M.P.H., from Columbia University, served as co-chairs. Four of the WG members have also given birth to stillborn children, bringing vital lived experience to the proceedings. Members are listed in Appendix II.

[16] Ely, D. M., & Driscoll, A. K. (2023). Infant mortality in the United States, 2021: Data from the period linked birth/infant death file. *National Vital Statistics Reports, 72*(11), 1–19.

Findings and Recommendations

Three subgroups were formed to address each of the congressionally mandated topics: stillbirth prevention and strategies, improvement of data collection, and enhancement of resources for families affected by stillbirth.

Many of the same recommendations emerged from one or more of the subgroups. Common themes included the need to standardize data collection and reporting; exploring new technologies such as artificial intelligence (AI) and machine learning (ML); creating a stillbirth prevention bundle (similar to those already developed in other countries) to educate patients and providers on modifiable risk factors; creating standardized training so that a complete stillbirth workup, including autopsies, genetic, and blood tests, is performed; and conducting perinatal audits after stillbirths so that specific protocols can be developed following fetal deaths. Each of these general themes will be discussed in turn.

Developing standardized methods to collect and report data are important at both the clinical and policy levels. Clinically, standardized reporting methods ensure that past instances of stillbirth can be assessed to evaluate lessons learned based on similar cases. At a policy level, standardized reporting methods are important for surveillance purposes, enabling accurate epidemiological studies to be conducted. The importance of standardized recordkeeping was emphasized by both the stillbirth prevention strategies subgroup and the improving data collection subgroup. The following were among the recommendations to improve standardization:

- Rely on definitions of standard data elements from ACOG.
- Use contemporary data collection methods, such as EHRs and national datasets, monitoring, imaging, genetic testing, and pregnancy experience recording and linkage to national datasets.
- Pursue active surveillance to standardize and obtain fetal death records, medical records, and perinatal autopsy results.
- Ensure that perinatal autopsy requests are made in culturally competent ways.
- Encourage the work being conducted by the National Center for Health Statistics (NCHS) Fetal Death Data Quality Improvement Workgroup.
- Expand the Study of Associated Risks of Stillbirth (SOARS) to multiple sites to capture diverse voices of those experiencing stillbirth in jurisdictions with high stillbirth burden.

Both the prevention strategies subgroup and the improving data collection subgroup recommended **harnessing the capabilities of AI and ML**. AI and natural language processing methods allow for analysis of granular and comprehensive data available in the EHR—including imaging, fetal monitoring, and genetic and lab testing beyond standard baseline pregnancy risk factors—to develop risk prediction models for stillbirth and related adverse pregnancy outcomes. AI could be combined with biomarkers and imaging to stratify risk based on pregnancy risk factors, decreased fetal movement, and fetal growth restriction; to be most effective, these stratification efforts should be applied to the entire population. AI and ML could be used to develop risk scores for stillbirth and to improve the management and follow up after stillbirth. It is important to note that successful AI and ML rely on reliable data, because these tools also have the risk of perpetuating social biases if not explicitly built to avoid those biases.

Creating a bundle of care to educate practitioners and patients on modifiable risk factors was recommended by more than one subgroup. International examples include Australia's Safer Baby Bundle and the United Kingdom's Saving Babies' Lives Care Bundle. As members of the

Stillbirth Prevention Subgroup observed, factors that could be considered in a bundle created for the United States might include the following:

- Smoking and marijuana cessation, and optimization of body mass index before conception
- Improved screening, detection, and management of fetal growth restriction.
- Wider use of low-dose aspirin
- Reduction of intrapartum hypoxia
- Improved risk stratification for decreased fetal movement

All three subgroups recommended **greater availability and utilization of perinatal autopsies and other tests**. To achieve this, more standardized training for health care providers and support to cover the financial costs for families who cannot afford autopsy may be necessary. Currently, autopsies are performed adequately in only about 20% of stillbirth cases in the United States. Yet this procedure, coupled with placental histopathology, can be informative. The cost is not always covered by insurance, however. Genetic tests are also useful, but making these more widespread poses logistical and financial challenges. Other diagnostic tests may also be beneficial. The following strategies were proposed to implement these recommendations:

- Centralizing perinatal autopsies and histopathology at tertiary care centers or using centralized interpretation of slides and images
- Centralizing genetic testing with relay of information back to health centers
- Finding a way for payors to cover perinatal pathology evaluation
- Developing appropriate language for providers to discuss the benefits of testing with patients, including blood tests, noninvasive options, and genetic counseling
- Increasing the number of pathologists who are appropriately trained to conduct perinatal autopsies, which will improve data collection on stillbirth causes

Perinatal audits should be performed. These have been used in other countries to determine the cause of stillbirths so that preventive measures could be taken. The results of these audits could be discussed by multidisciplinary panels of experts and patients, and the findings could be used to develop programs to evaluate stillbirths. This recommendation of regular evaluation of stillbirths was endorsed by both the stillbirth prevention subgroup and the data collection subgroup.

Research ways to reduce the health disparities in stillbirth, which disproportionately affect Black, Indigenous, and other populations of color in the United States.[17] By addressing upstream issues such as racial residential segregation, the race and ethnicity gaps in stillbirth may be lessened. Data measures can be tested to see how chronic stress associated with racism affects stillbirth[18,19]; PRAMS samples could include a standardized questionnaire. Differences in postpartum care would also benefit from research that examines populations that are not predominantly White. This research can help to address the effects of structural, institutional, and individual racism that contribute to the varying stillbirth rates.

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[17] Debbink, M. P., Stanhope, K. K., & Hogue, C. J. R. (2024). Racial and ethnic inequities in stillbirth in the U.S.: Looking upstream to close the gap: Seminars in perinatology. *Seminars in Perinatology, 48*(1), 151865. doi:10.1016/j.semperi.2023.151865

[18] Kim, S., Im, E.-O., Liu, J., & Ulrich, C. (2020). Maternal age patterns of preterm birth: Exploring the moderating roles of chronic stress and race/ethnicity. *Annals of Behavioral Medicine, 54*(9), 653–664. doi:10.1093/abm/kaaa008

[19] Deichen Hansen, M. E. (2021). Predictors of preterm birth and low birth weight: A person-centered approach. *SSM—Population Health, 15*, 100897. doi:10.1016/j.ssmph.2021.100897

Other recommendations were specific to individual subgroups.

Stillbirth Prevention and Strategies

Beyond recommending standardization of data collection and training, the stillbirth prevention and strategies subgroup had more specific suggestions relating both to clinical practice and research:

- Consider conducting research on timing of delivery to develop personalized recommendations on the optimal time. Induction of delivery may be offered at 39 weeks per ARRIVE trial results.[20]
- Address health disparities and the SDOH that contribute to stillbirth to allow for stillbirth prevention strategies.
- Support population-based stillbirth surveillance—especially in jurisdictions with high stillbirth rates.
- Provide access to high-quality prenatal care and postpartum care to optimize pregnancy and to prevent stillbirth.
- Initiate additional research to develop stillbirth prevention bundles that focus on patient and provider education, including public health measures such as advising people to cease tobacco use; helping people achieve healthier body mass index; optimizing the management of chronic medical conditions such as diabetes and hypertension; and inducing labor as appropriate.
- Link maternal and fetal medical records to enable research, surveillance, and detection.
- Consider creating a stillbirth registry and collecting stillbirth biospecimens.
- Consider universal use of low-dose aspirin according to the United States Preventive Services Task Force guidelines.[21]

Improving Data Collection

This subgroup broke down responses into clinical, surveillance, research, policy, and education/training recommendations. Many of the clinical and surveillance recommendations were similar to those from the stillbirth and prevention strategies subgroup, with a focus on standardizing measures and conducting surveillance. However, specific recommendations were made related to research, policy, and education/training. The recommendations on research and policy are the following:

- Collect, transform, integrate, and maintain EHR and other pertinent datasets in a format appropriate for future use in AI and ML to create a maternal child health data ecosystem that serves as a major resource for research on stillbirth and other adverse pregnancy outcomes.

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[20] Committee on Obstetric Practice and Committee on Practice Bulletins—Obstetrics. (2018, August). *Clinical Guidance for Integration of the Findings of The ARRIVE Trial: Labor Induction Versus Expectant Management in Low-Risk Nulliparous Women*. American College of Obstetricians and Gynecologists. https://www.acog.org/clinical/clinical-guidance/practice-advisory/articles/2018/08/clinical-guidance-for-integration-of-the-findings-of-the-arrive-trial

[21] United States Preventive Services Task Force. (2021, September 28). *Final Recommendation Statement: Aspirin Use to Prevent Preeclampsia and Related Morbidity and Mortality: Preventive Medication*. U.S. Department of Health and Human Services. https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/low-dose-aspirin-use-for-the-prevention-of-morbidity-and-mortality-from-preeclampsia-preventive-medication

- Bridge the gap between data available at delivery and data available at workup completion. Specifically, focus data standardization and quality improvement on reporting, follow up, and workup of stillbirths.
- Design a case-control study with data for prevention measures, maternal experience evaluation, and ascertainment surveillance.
- Enhance regional stillbirth evaluation through telehealth, the creation of Stillbirth Centers of Excellence, and the Fetal and Infant Mortality Review.
- Improve and develop quality indicators for evaluation, counseling, bereavement services, and follow up.
- Conduct regular audits to improve the quality of data collection.

The recommendations on education are the following:

- Provide state field representatives with ongoing, in-person training for national fetal death data.
- Encourage providers to use guidance documents and e-learning tools developed by NCHS.
- Educate hospital personnel on using a flowchart developed by NCHS to understand fetal death certificates.
- Provide personnel training to improve overall fetal death data accuracy and completeness and to ensure the filing of amendments (e.g., for autopsy results) as needed.

Enhancing Resources for Families Affected by Stillbirth

This subgroup discussed how uniform standards and better training for providers could improve care for bereaved parents and families. Appropriate care at the time of stillbirth is vital for the grieving process and for preventing poor outcomes later.[22,23] In the United Kingdom and Australia, extensive standards of care for stillbirth have been developed[24,25] and could serve as a model for future efforts in the United States.

Sensitive conversations need to occur on stillbirth diagnosis, the birth process itself, care after stillbirth, workup after stillbirth, and postpartum care. The subgroup also had recommendations for implementation, research, and advocacy.

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[22] Ellis, A., Chebsey, C., Storey, C., Bradley, S., Jackson, S., Flenady, V., … Siassakos, D. (2016). Systematic review to understand and improve care after stillbirth: A review of parents' and healthcare professionals' experiences. *BMC Pregnancy and Childbirth, 16*(16). doi:10.1186/s12884-016-0806-2

[23] Kirkley-Best, E., & Kellner, K. R. (1982). The forgotten grief: A review of the psychology of stillbirth. *American Journal of Orthopsychiatry, 52*(3), 420–429. doi:10.1111/j.1939-0025.1982.tb01428.x

[24] Flenady, V., Oats, J., Gardener, G., Masson, V., McCowan, L., Kent, A., … Khong, Y.; Perinatal Society of Australia and New Zealand (PSANZ) Care Around the Time of Stillbirth and Neonatal Death Guidelines Group. (2020). *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death (version 3.4).* Canberra: National Health and Medical Research Council (NHMRC) Centre of Research Excellence in Stillbirth. https://learn.stillbirthcre.org.au/wp-content/uploads/2024/01/CASaND-Guideline-2024-1.pdf

[25] Royal College of Obstetricians & Gynaecologists. (2010). *Late intrauterine fetal death and stillbirth. Green-top Guideline No. 55*. https://www.rcog.org.uk/media/0fefdrk4/gtg_55.pdf

At the time of diagnosis, caregivers should do the following:

- Display empathy (i.e., understand and respect parental choices regarding the stillborn baby).[26]
- Refer to the stillborn infant as a baby and use the name if one has been given.[27,28]
- Provide families with the following information about their delivery hospitalization: items they may need or want in the hospital; what to expect around the delivery; what the baby might look like at birth; options for pain management; information on a cuddle cot, if one is available; options for parenting activities (e.g., reading the baby a book, bathing them, dressing them); and options for mementos and photography.[29]
- Make a bereavement health care professional (e.g., doula, social worker) available to support families during their hospital stay.

Regarding the birth process itself, a main decision is whether to have a vaginal or cesarean delivery. Vaginal birth is recommended for most birthing people because of the faster recovery afterward, but some may prefer a cesarean delivery to avoid the experience and potential trauma of actively giving birth to a deceased infant. This decision involves a sensitive conversation that should include discussing the risks for future childbearing after a cesarean delivery.[30]

After delivery, the following steps are recommended to those who provide care to the birthing parent:

- Put the patient in a recovery area away from other pregnant people and the sounds of live-born infants.
- Place a marker on the door so that health care providers will know that the death of an infant has occurred.
- Conduct a religious ceremony if it is desired.
- Support the parents' decision to hold or not hold the baby.[31]
- Support the parents' decision to engage in parenting activities if they choose.

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[26] Royal College of Obstetricians & Gynaecologists. (2010). *Late intrauterine fetal death and stillbirth. Green-top Guideline No. 55*. https://www.rcog.org.uk/media/0fefdrk4/gtg_55.pdf

[27] Flenady, V., Oats, J., Gardener, G., Masson, V., McCowan, L., Kent, A., … Khong, Y.; PSANZ Care Around the Time of Stillbirth and Neonatal Death Guidelines Group. (2020). *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death (version 3.4).* Canberra: NHMRC Centre of Research Excellence in Stillbirth. https://learn.stillbirthcre.org.au/wp-content/uploads/2024/01/CASaND-Guideline-2024-1.pdf

[28] Royal College of Obstetricians & Gynaecologists. (2010). *Late intrauterine fetal death and stillbirth. Green-top Guideline No. 55*. https://www.rcog.org.uk/media/0fefdrk4/gtg_55.pdf

[29] Flenady, V., Oats, J., Gardener, G., Masson, V., McCowan, L., Kent, A., … Khong, Y.; PSANZ Care Around the Time of Stillbirth and Neonatal Death Guidelines Group. (2020). *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death (version 3.4).* Canberra: NHMRC Centre of Research Excellence in Stillbirth. https://learn.stillbirthcre.org.au/wp-content/uploads/2024/01/CASaND-Guideline-2024-1.pdf

[30] Royal College of Obstetricians & Gynaecologists. (2010). *Late intrauterine fetal death and stillbirth. Green-top Guideline No. 55*. https://www.rcog.org.uk/media/0fefdrk4/gtg_55.pdf

[31] Flenady, V., Oats, J., Gardener, G., Masson, V., McCowan, L., Kent, A., … Khong, Y.; PSANZ Care Around the Time of Stillbirth and Neonatal Death Guidelines Group. (2020). *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death (version 3.4).* Canberra: NHMRC Centre of Research Excellence in Stillbirth. https://learn.stillbirthcre.org.au/wp-content/uploads/2024/01/CASaND-Guideline-2024-1.pdf

- Create photos, videos, or other mementos of the stillborn child.[32,33]

For postpartum workup, the following recommendations are made:

- Create resources to help parents better understand how the information collected from tests and exams can help to determine the cause of their infant's death.
- Identify any immediate health concerns for the birthing parent, and guide management for subsequent pregnancies.
- Set expectations for how results of these tests will be communicated to the family.
- Be explicit that testing may not determine causes of death but emphasize that testing is the best thing that can be done to determine causes. Emphasize that the baby will be treated with care and respect.[34]

For postpartum care, the following recommendations are made:

- Address the physical needs of the person giving birth.
- Provide information on recovery from childbirth, especially for first-time parents. This could include resources (and staff) that address milk production, physical recovery from childbirth, and postpartum depression.
- Risk of depression is high in parents who have experienced stillbirth. Provide close postpartum follow up and mental health support for grief, trauma, and depression.
- Provide national and local resources for support, such as the following:
    - Local support groups (in-person and virtual)
    - Therapists who specialize in perinatal loss and grief
    - Books (especially for grieving siblings)
    - Local and national bereavement support organizations
    - Guidance on how parents can talk about the family's loss with their children, other family members, and friends
    - Instructions on how family and friends can help
    - Resources to plan a funeral or a memorial service, including available financial assistance
    - Pathology consultation
    - Keepsakes and mementos
    - Processes to obtain documentation, such as a Certificate of Birth Resulting in Stillbirth or a fetal death certificate
    - Websites and social media resources (e.g., the Maternal Mental Health Leadership Alliance Resource)
    - Crisis hotlines (e.g., the National Maternal Mental Health Hotline)
- Encourage states to consider the availability of stillbirth tax credit

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[32] Flenady, V., Oats, J., Gardener, G., Masson, V., McCowan, L., Kent, A., … Khong, Y.; PSANZ Care Around the Time of Stillbirth and Neonatal Death Guidelines Group. (2020). *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death (version 3.4).* Canberra: NHMRC Centre of Research Excellence in Stillbirth. https://learn.stillbirthcre.org.au/wp-content/uploads/2024/01/CASaND-Guideline-2024-1.pdf

[33] Royal College of Obstetricians & Gynaecologists. (2010). *Late intrauterine fetal death and stillbirth. Green-top Guideline No. 55*. https://www.rcog.org.uk/media/0fefdrk4/gtg_55.pdf

[34] Flenady, V., Oats, J., Gardener, G., Masson, V., McCowan, L., Kent, A., … Khong, Y.; PSANZ Care Around the Time of Stillbirth and Neonatal Death Guidelines Group. (2020). *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death (version 3.4).* Canberra: NHMRC Centre of Research Excellence in Stillbirth. https://learn.stillbirthcre.org.au/wp-content/uploads/2024/01/CASaND-Guideline-2024-1.pdf

- Create standards of care for other professionals, such as social workers and chaplains, who might regularly interact with families experiencing stillbirth.

To implement these recommendations, the Enhancing Resources for Families Affected Subgroup recommends the following:

- ACOG as well as SMFM should integrate bereavement support stillbirth materials into new standards of care in partnership with psychology, social work, or other mental health provider organizations.
- Workshops on stillbirth should be created for stakeholders such as ACOG; SMFM; the American Board of Obstetrics & Gynecology (ABOG); the Association for Women's Health, Obstetric, and Neonatal Nurses (AWHONN); the American Academy of Family Physicians (AAFP); and the American College of Nurse-Midwives (ACNM).
- Continuing health care provider education should be established related to stillbirth.

For topics requiring future research, the Enhancing Resources for Families Affected Subgroup recommends the following:

- Bereavement practices prioritizing marginalized groups with higher stillbirth rates
- Patient information needs
- The most effective mental health support after stillbirth, with a focus on trauma, self-blame, and grief processing
- How to discuss stillbirth with all patients as part of routine prenatal care
- The economic impact of stillbirth for families and societies, including short- and long-term costs and direct and indirect costs

The outcome of this research may justify creating additional resources on bereavement care and the training of clinicians.

The Enhancing Resources for Families Affected Subgroup also offers these advocacy suggestions:

- Design awareness campaigns modeled on sudden infant death syndrome (SIDS) and premature births.
    - Educate the public and families of childbearing age that stillbirth occurs more frequently than is commonly believed.
    - Raise awareness of warning signs and potential preventability.
    - Discuss the risk of stillbirth within routine prenatal care.
    - Empower expectant parents with information and encourage open dialogue between patients and providers around stillbirth risks and prevention measures.
- Make the costs of stillbirth workup more affordable, including access to autopsy and genetic testing.
- See whether lessons learned from autopsy after suspected SIDS death can be applied to stillbirth.
- Expand work leave after stillbirth.
- Expand awareness of legal recognition and support after stillbirth (e.g., state income tax credits, memorial birth certificates).

Conclusion

In 2022, NICHD convened a group of federal government, academic, nonprofit, and clinical experts to collect information on stillbirth. Based on those findings, the WG developed a set of recommendations to improve data collection tools, address disparities, better support families that experience stillbirth, and reduce the U.S. stillbirth rate through research and prevention efforts, which are detailed in the *Working to Address the Tragedy of Stillbirth* report. Spurred by those recommendations, research investments have been made in fetal diagnostic and monitoring technologies to directly measure parameters of fetal health status during the late antepartum and/or intrapartum periods of pregnancy. Moreover, efforts are underway through collaboration among clinical research networks to align existing data collection efforts to record stillbirths and other adverse fetal outcomes. Detailed records, collected by combining these registries, may yield important insights into the causes of, risk factors for, and mechanisms underlying stillbirth. Finally, there are plans to develop a Stillbirth Consortium to expand research in this area.

Building upon the recommendations in the previous report, opportunities exist to implement the strategies outlined in this report through the following activities: encourage federal and state multiagency collaboration; build partnerships with professional societies, academics, researchers, advocates, and public health organizations, both nationally and internationally; and engage families who have experienced stillbirth.

Appendix 1: Task Force Congressional Mandate

Report language accompanying Consolidated Appropriations Act of 2023 (P.L. 117-328).

Stillbirth Task Force. —The Committee provides an additional $1,000,000 for the Secretary to bolster the work for the Stillbirth Task Force. The task force should continue to include the CDC, NIH, outside specialty organizations, and maternal and fetal medicine specialists. The task force should work through the Office of the Secretary to identify current knowledge on stillbirth and prevention, areas of improvement for data collection, current resources for families impacted by stillbirth, and next steps to gather data and lower the rate of stillbirth in the United States. The Committee directs the Secretary to provide a report within 120 days of the date of enactment of this Act on the progress of the task force (H. Report: 117-403).

Senate Explanatory Statement - *Stillbirth Task Force.* —The agreement includes an increase of $1,000,000 for this activity as described under this heading in House Report 117–403.

Appendix 2: Stillbirth Working Group of Council Members

Co-Chairs

Lucky Jain, M.D., M.B.A., Emory University

Uma M. Reddy, M.D., M.P.H., Columbia University, representative of the American College of Obstetricians and Gynecologists

Members

RADM Wanda D. Barfield, M.D., M.P.H., CDC

Joanne Cacciatore, Ph.D., M.S.W., Arizona State University; stillbirth parent

CAPT Amanda Cohn, M.D., CDC

Ada Dieke, Dr.P.H., M.P.H., CDC

Donald Dudley, M.D., University of Virginia

Andrew Fullerton, M.P.P., March of Dimes

Karen Gibbins, M.D., MSCI, Oregon Health & Science University; stillbirth parent

Katherine Gold, M.D., M.S.W., M.S., University of Michigan

Cynthia Gyamfi-Bannerman, M.D., M.S., University of California (UC) San Diego School of Medicine

Isabelle Horon, Dr.P.H., CDC

Denise Jamieson, M.D., M.P.H., University of Iowa

Stephanie Leonard, Ph.D., M.S., Stanford University

Jenna Nobles, Ph.D., University of Wisconsin–Madison

Tina Pattara-Lau, M.D., FACOG, Indian Health Service

Jennita Reefhuis, Ph.D., CDC

George Saade, M.D., Eastern Virginia Medical School

Mikyong Shin, Dr.P.H., M.P.H., RN, CDC

Robert M. Silver, M.D., University of Utah Health Sciences Center, representative of the Society for Maternal–Fetal Medicine

Catherine J. Vladutiu, Ph.D., M.P.H., Health Resources and Services Administration

Maeve Wallace, Ph.D., M.P.H., Tulane University School of Public Health & Tropical Medicine

Ronald J. Wapner, M.D., Columbia University

Jill Wieber Lens, J.D., University of Iowa College of Law; stillbirth parent

Monica H. Wojcik, M.D., M.P.H., Boston Children’s Hospital

Debbie Haine Vijayvergiya, The 2 Degrees Foundation; stillbirth parent

Monica Longo. M.D., Ph.D., NICHD

Ad Hoc Consultants

Alison Cahill, M.D., MSCI, The University of Texas at Austin

Carol J. Hogue, Ph.D., M.P.H., Emory University

Mana Parast, M.D., Ph.D., University of California, San Diego

Appendix 3: Stillbirth Working Group of Council Meetings

The WG held two public sessions to gather information on its topics of focus. This appendix lists the topics covered and the experts who presented at each session.

October 31, 2023: First Meeting

- Welcoming Remarks
  - Alison Cernich, Ph.D., NICHD, Deputy Director
- Overview of Stillbirth Working Group Report to Congress: Summary of Findings and Recommendations
  - Lucky Jain, M.D., Co-chair, Emory University School of Medicine, Department of Pediatrics
  - Uma Reddy, M.D., M.P.H., Co-chair, Columbia University Irving Medical Center; American College of Obstetricians and Gynecologists Representative
- Current and New Activities CDC Stillbirth Activity Update
  - Jennita Reefhuis, Ph.D., CDC, Branch Chief, Division of Birth Defects and Infant Disorders
- NICHD Stillbirth Activity Update
  - Monica Longo, M.D., Ph.D., NICHD, Pregnancy Perinatology Branch
- Resources for Families Impacted by Stillbirth
  - Debbie Haine Vijayvergiya, Working Group Member and Advocate
- NIH Portfolio Analysis: Research Literature Update
  - Sarah Glavin, Ph.D., NICHD, Deputy Director, Office of Science Policy, Reporting, and Program Analysis

January 24, 2024: Second Meeting

- Welcoming Remarks
  - Diana W. Bianchi, M.D., Director, NICHD
- Opening Speaker: Strategies for Predicting Risk of Pregnancy Complications and Reducing Stillbirths
  - Gordon Smith, M.D., Ph.D., D.Sc., FRCOG, FMedSci, University of Cambridge, U.K.
- Stillbirth Prevention and Strategies WG Recap
  - Robert Silver, M.D., Division of Maternal–Fetal Medicine, University of Utah Health Sciences Center
- Strategies to Prevent Stillbirth
  - Alexander Heazell, M.B.Ch.B.(Hons), Ph.D., MRCOG, Division of Developmental Biology and Medicine, University of Manchester, U.K.
- Prevention of Stillbirth: Role of Audits
  - Jan Jaap Erwich, M.D., Ph.D., University of Groningen, Netherlands
- In Utero Program
  - Sarah Stock, M.D., Ph.D., In Utero, Wellcome Leap; University of Edinburgh
- Addressing Stillbirth in Australia: Video Remarks
  - Vicki Flenady, Ph.D., M.Med.Sc., National Health and Medicine Research Council Centre for Research Excellence in Stillbirth, Brisbane, Australia
- Improving Data Collection WG Recap
  - George Saade, M.D., Eastern Virginia Medical School
- Machine Learning and Its Application in Stillbirth
  - Tetsuya Kawakita, M.D., M.S., Eastern Virginia Medical School

- Data-Driven Strategies to Augment Maternal Health Delivery
    - Vesela P. Kovacheva, M.D., Ph.D., Harvard Medical School
- Improving Data Collection Through AI
    - Noémie Elhadad, Ph.D., Columbia University
- Enhancing Resources for Families Affected by Stillbirth WG Recap
    - Jill Wieber Lens, J.D., University of Arkansas School of Law
    - Karen Gibbins, M.D., M.S.C.I., Oregon Health & Science University
- Hearing Our Stories: Exploring Provider Empathy for Families Experiencing Stillbirth
    - Nicole Alston, M.S.W., Columbia University
- Improving Surveillance for the Hidden Half of Fetal–Infant Mortality
    - Lauren Christiansen-Lindquist, Ph.D., M.P.H., Emory University
- Supporting Bereaved Parents Experiencing Pregnancy and Infant Loss
    - Kathleen Massmann, M.S., Healing Moments Counseling