ENDING PREVENTABLE BABY DEATHS

An action plan for Ireland

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The **Pregnancy Loss Research Group** leads national research to better understand pregnancy loss experiences and impacts, and the development of resources and evidence-informed advice and interventions, to improve health care (quality) and health and social outcomes for women, babies, families and communities. It is based within the Department of Obstetrics and Gynaecology and the INFANT Research Centre at University College Cork.

www.ucc.ie/pregnancyloss

The **National Perinatal Epidemiology Centre (NPEC)** collaborates with each of the 19 Irish maternity services to translate clinical audit data and epidemiological evidence into improved maternity care for families in Ireland. It is based in the Department of Obstetrics and Gynaecology, University College Cork and is funded by the Department of Health through the Health Service Executive (HSE).

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Féileacáin (Stillbirth & Neonatal Death Support Ireland) was formed in 2009 and registered as a charity in 2010 (CHY – 19635). Féileacáin is a not-for-profit organisation and receives no funding from central Government, relying instead on the support of their community and the families who avail of their services. Féileacáin is dedicated to supporting those affected by the loss of a baby. Their vision is the prevention of avoidable deaths of babies.

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List of abbreviations

CSO	Central Statistics Office
HSE	Health Service Executive
ICD-PM	International Classification of Diseases – Perinatal Mortality
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
MECC	Making Every Contact Count
MN-CMS	Maternal and Newborn Clinical Management System
NHS	National Health Service
NPEC	National Perinatal Epidemiology Centre
NWIHP	National Women and Infants Health Programme
PLRG	Pregnancy Loss Research Group
PMMERT	Perinatal Mortality and Morbidity Review Tool
PMRT	Perinatal Mortality Review Tool
RCPI	Royal College of Physicians of Ireland
SIDS	Sudden Infant Death Syndrome
SPHE	Social, Personal and Health Education
UCC	University College Cork

Ending Preventable Baby Deaths: An Action Plan for Ireland

SUMMARY

Perinatal deaths, including stillbirths and early neonatal deaths, remain a major public health issue in Ireland, affecting around 300 families each year[i]. Ireland continues to rank poorly internationally in terms of its perinatal death rate – 20th out of 24 countries in Europe in 2021 (1) and findings from the National Perinatal Mortality Clinical Audit indicate that rates have remained largely unchanged over the past decade (2). When deaths due to congenital anomalies are excluded from overall figures, an annual average of around 200 perinatal deaths remain (2). This figure provides an indication of the scale of perinatal deaths where improvements in prevention, clinical care, communication, and system-level responses may have the greatest potential to reduce avoidable pregnancy loss.

Reductions in stillbirth rates in Australia and the UK due to targeted prevention efforts also show that some baby deaths are preventable, not unavoidable tragedies. Political leadership, commitment, and targeted investment could reduce the number of baby deaths, but unlike other countries (such as Australia and the UK) Ireland has no action plan to end preventable baby deaths. Preventing baby deaths is not only affordable but cost-effective, with every dollar invested delivering more than triple the return by reducing medical, economic, and legal costs, while saving families and society from lifelong emotional and financial hardship (3). Available evidence from Ireland, Australia and the UK also demonstrates that people want to receive information about risk factors for baby deaths, and in a sensitive and accessible way (4).

While many baby deaths are preventable, we are limited in predicting all adverse pregnancy outcomes through screening and monitoring. Further research and investment is needed to enhance prevention efforts and is an important pillar of this action plan. A common misconception is that stillbirths are primarily due to issues with medical care, the baby or pregnant woman (5). However, the most common causes of stillbirth are problems with the placenta (2), which can affect any pregnancy but are currently difficult to detect due to lack of research in this area (6). Further, 3 in 10 stillbirths occur at term, when babies are considered fully developed and ready for birth. A small but important number of unexpected baby deaths also occur in labour or because of events during labour (2). As such, all pregnancies carry some level of risk of ending in loss, even when no specific risk factors are identified, and this is an important message and component to factor into prevention efforts.

Over the last decade there has been significant progress in enhancing the care that people receive in the 19 maternity hospitals/units around the time a baby dies, particularly through the implementation of the National Standards for Bereavement

[i] NPEC Perinatal Mortality Clinical Audit. Available at https://www.ucc.ie/en/npec/clinical-audits/perinatalmortalitynationalclinicalaudit/

Care following Pregnancy Loss and Perinatal Death[ii]. In tandem with ensuring that people receive the best bereavement care after pregnancy loss, there is a duty to create the conditions to prevent deaths that are avoidable. Perinatal deaths should be investigated because conducting a systematic review of each case is essential for understanding why babies die, identifying modifiable factors, improving care and safety for women and infants. When perinatal deaths occur, however, the systems and processes surrounding them can at times become fragmented, with different actors operating within separate remits and priorities. This can limit opportunities for shared learning, prevention, and collective action. However, there is now a clear opportunity for Government, public bodies, clinicians, researchers, experts by experience and support organisations, civil society, the public and others to work together in a more coordinated way to reduce preventable baby deaths.

This action plan is grounded in the recognition that meaningful progress depends on collaboration across sectors, aligned leadership, and shared responsibility. This vision aligns closely with the Department of Health's own strategy to improve population health and wellbeing through high-quality services and effective use of health system resources, as well as with broader public health and prevention efforts[iii]. It complements existing national frameworks, particularly the National Maternity Strategy: Creating a Better Future Together (2016–2026)[iv], the Women's Health Action Plan (2024–2025)[v], the National Strategy for Women and Girls (2025-2030)[vi] and the Health Service Executive (HSE) Public Health Strategy (2025-2030)[vii].

Beyond the primary goal of ending preventable baby deaths, this action plan will also impact on maternity care, experiences and outcomes more broadly.

By increasing public awareness of pregnancy risk factors such as smoking, obesity and high blood pressure, and by promoting positive health behaviours such as taking folic acid before and in early pregnancy, a public health campaign can also help reduce wider complications including gestational diabetes, preterm birth, pre-eclampsia, neural tube defects and low birth weight. These conditions are associated not only with perinatal mortality but also with significant short- and long-term health, social and economic consequences for mothers and babies, as well as sustained health system resources. Reducing preterm birth is central to any strategy aimed at lowering stillbirth and

[ii] Originally published in 2016; version 2 was published by the HSE in 2022. Available at https://pregnancyandinfantloss.ie/hse-national-standards-for-bereavement-care-following-pregnancy-loss-and-perinatal-death/

[iii] Department of Health Statement of Strategy 2025-2028. Available at https://www.gov.ie/en/department-of-health/publications/department-of-health-statement-of-strategy-2025-2028/

[iv] National Maternity Strategy – Creating a Better Future Together 2016-2026. Available at https://www.gov.ie/en/department-of-health/publications/national-maternity-strategy-creating-a-better-future-together-2016-2026/

[v] Women's Health Action Plan 2024-2025 Phase 2: An Evolution in Women's Health. Available at https://www.gov.ie/en/department-of-health/publications/womens-health-action-plan-2024-2025-phase-2-an-evolution-in-womens-health/

[vi] National Strategy for Women and Girls 2025 – 2030. Available at https://www.gov.ie/en/department-of-children-disability-and-equality/campaigns/national-strategy-for-women-and-girls-2025-2030/

[vii] HSE Public Health Strategy 2025-2030. Available at https://about.hse.ie/news/hse-launches-new-public-health-strategy-2025-2030/.

neonatal mortality, as it remains one of the leading causes of neonatal death. Implementing more precise risk stratification based on current clinical knowledge ensures that existing healthcare resources are more effectively managed. Funding new research will bridge current knowledge gaps, leading to more targeted risk stratification models that will potentially allow for the reduction of interventions and a more efficient use of healthcare resources overall.

This action plan focuses on ending preventable baby deaths, specifically focusing on perinatal deaths which include stillbirths and early neonatal deaths. We use these terms across the document in various ways. We refer specifically to stillbirth in certain places where our focus involves targeted action or where the research applies to this specific area. We have used the term baby deaths rather than perinatal deaths as the overall framing of this action plan and associated messaging is targeted at a broad audience. We also acknowledge that while second trimester pregnancy loss (i.e. the loss of a pregnancy between 13 and 23 weeks' gestation) is beyond the scope of this action plan, there are many overlapping factors in cause, management, care experiences and outcomes. Investigation, registration, data collection and research in the area of second trimester pregnancy loss is vital.

This five-pillar, evidence-informed action plan sets out how to end preventable baby deaths in Ireland, focusing on 1) Public Awareness & Education; 2) Risk Awareness & Communication; 3) Best Care, Every Time; 4) Ongoing Review of Baby Deaths; 5) Driving Research Informed Care.



Pillars of 'Ending Preventable Baby Deaths: An Action Plan for Ireland'.

PILLAR 1: Public Awareness & Education

Enhance knowledge and awareness of risk factors related to baby deaths within the general population and before and during pregnancy.

Implement a national public health campaign to promote evidence-informed actions for safer pregnancies and to support women and families to make informed decisions within their circumstances. Enhance public awareness and education around baby death prevention through a variety of settings, including healthcare, schools and the media.

- **1.a** Appoint a clinical public health lead within the Health Service Executive (HSE) with responsibility for pregnancy and pre-conception health.
- **1.b** Develop information resources for both the public and healthcare professionals for use in healthcare settings and beyond, including fact sheets that explain the main risk factors for baby deaths and outline practical, supportive actions that women, families, healthcare professionals can take to address these risks.
- **1.c** Design and implement a public health campaign to raise awareness about risk factors and prevention strategies.
- **1.d** Develop tailored strategies to engage groups experiencing health inequalities, including those facing barriers to care, language, or requiring psychosocial support.
- **1.e** Incorporate education about fertility and pregnancy loss into school curricula.
- **1.f** Evaluate the implementation and effectiveness of the public health campaign and its related strategies and adapt as needed on an ongoing basis.

PILLAR 2: Risk Awareness & Communication

Ensure risks in pregnancy are assessed consistently by healthcare professionals and communicated clearly and with sensitivity within healthcare settings.

Strengthen the capacity of healthcare professionals to identify, screen and discuss risk factors for baby deaths and preterm birth with women and families, to support behaviour change, and to ensure that antenatal management plans, including monitoring and timing of birth, are developed in partnership to achieve the best possible outcomes for women and babies.

- **2.a** Develop a standardised list of risk factors to guide healthcare conversations.
- **2.b** Reform medical and midwifery curricula to include education about prevalence and prevention of baby deaths.
- **2.c** Incorporate guidance into national antenatal education standards to support healthcare professionals in promoting health / health behaviours with pregnant women and to discuss risk factors, stillbirth prevention, and options for antenatal care and delivery in antenatal education standards and settings.

2.d Adapt the 'Making Every Contact Count' (MECC) programme[viii] to include education on baby death prevention.
2.e Develop communication and education materials for healthcare professionals and update antenatal education standards.
2.f Evaluate healthcare professional education and communication initiatives on an ongoing basis.

PILLAR 3: Best Care, Every Time

Deliver consistent, high-quality, evidence-informed care for every pregnancy.

Support the implementation of national clinical guidelines developed through the National Clinical Guideline Programme in Obstetrics and Gynaecology[ix], including: administration of antenatal corticosteroids, reduced fetal movements, fetal growth restriction, gestational diabetes, preterm birth, multiple pregnancy and timing of birth at term, with required algorithms, flow charts, patient information leaflets and education/training (in partnership with HSE public health leads, the National Women and Infant Health Programme (NWIHP) leads, clinical and academic experts, and experts by experience).

3.a Provide targeted supports and structures to enhance national and regional implementation of relevant national clinical guidelines, including ongoing monitoring and evaluation across all 19 maternity hospitals/units.
3.b Resource national coordination and support for guideline implementation including a dedicated implementation lead.
3.c Develop and implement clinical decision support tools/clinical algorithms to support implementation of national clinical guidelines.
3.d Evaluate and audit guideline implementation and examine the effectiveness of the clinical decision support tools and related quality improvement initiatives.

PILLAR 4: Ongoing Review of Baby Deaths

Make maternity services safer through ongoing review of baby deaths and learning, to implement recommendations and drive care improvements.

Establish a standard regional and national approach to the review of baby deaths, ensuring meaningful involvement of bereaved parents in the review process, and using findings to drive continuous improvements in care.

[viii] https://healthservice.hse.ie/staff/training-and-development/making-every-contact-count-training-programme/
[ix] The National Clinical Guidelines are a programme of work agreed between the National Women and Infants Health Programme (NWIHP) in the HSE and the Institute of Obstetricians and Gynaecologists of the Royal College of Physicians in Ireland. https://www.rcpi.ie/Faculties-Institutes/Institute-of-Obstetricians-and-Gynaecologists/National-Clinical-Guidelines-in-Obstetrics-and-Gynaecology

4.a Ensure there are robust processes in each maternity hospital/unit to review baby deaths, with regional reporting of findings, and action plans/learning events as appropriate.
4.b Develop the Perinatal Mortality and Morbidity Review Tool (PMMERT) for all perinatal death case reviews alongside a new process for stillbirth review that involves parents (via the ACHIEVE project[x]).
4.c Evaluate and refine the use of the new PMMERT process through implementation and ongoing review of the baby death review process in all maternity hospitals/units.
4.d Report findings annually at regional level, including the status of implementation of recommendations, from PMMERT nationally and to the Minister for Health.
4.e Improve Coronial processes to reduce delays, improve communication with families and clinicians, and ensure Coronial findings inform care improvements.

PILLAR 5: Driving Research Informed Care

Invest in research for better policy, practice, and outcomes.

Invest in research to develop screening and diagnostic tools to identify pregnancies/ babies at risk of perinatal death, preterm birth and other adverse pregnancy outcomes, thereby enabling targeted intervention to improve outcomes. Research is crucial for improving care, support and understanding the causes of baby deaths, and should involve all interest holders, including clinicians, researchers, experts by experience and support organisations.

5.a Invest in research aligned with priorities outlined within this action plan through national research funders including the Health Research Board, Research Ireland and Enterprise Ireland.
5.b Aligned with 5.a, invest in researchers/clinician researchers and research systems to create the supportive environments required to deliver, high-quality, timely research as part of learning health systems, academic health sciences systems, and research ecosystems.
5.c Develop a theory-based behaviour change intervention to address the modifiable risk factors for stillbirths and an associated implementation strategy (via the RELEVANT project[xi]).
5.d Advance pathological and clinical studies and invest in research structures to understand the biological causes of baby deaths and preterm births and develop screening, prediction and diagnostic tools.
5.e Investigate how inequities lead to adverse outcomes and address barriers to high-quality care.

[x] ACHIEVE – Appraise and CHange PerInatal Mortality EVEnts: Structured evaluation and implementation of a national perinatal mortality review tool for Ireland. Available at: https://www.ucc.ie/en/pregnancyloss/researchprojects/achieve/
[xi] The RELEVANT (REducing stiLlbirth through bEhaViour chAnge iNtervenTions) Project. Available at https://www.ucc.ie/en/pregnancyloss/researchprojects/relevant/

5.f Maintain and strengthen the National Perinatal Epidemiology Centre (NPEC) Maternal and Fetal Classification System[xii], ensuring compatibility with international frameworks (such as ICD-PM: International Classification of Diseases to Perinatal Mortality), and aligning with the work of the International Stillbirth Alliance improving global cause-of-death classification and reducing the proportion of unexplained stillbirths.

5.g Better understand and enhance communication around pregnancy and baby loss and related risk factors across society, including within political, public and clinical spheres.

[xii] NPEC Maternal and Fetal Classification System. Available at https://www.ucc.ie/en/npec/clinical-audits/perinatalmortalitynationalclinicalaudit/annualreport2023/npecmaternalandfetalclassificationsystemdefinitions/

BACKGROUND

Perinatal mortality, which includes stillbirths and early neonatal deaths (see Box 1), remains a major challenge worldwide. In 2021, an estimated 1.9 million stillbirths occurred globally, alongside over 2 million neonatal deaths, with progress in reducing these figures far slower than for maternal or child mortality overall (7,8).

Box 1. Explaining baby deaths

In this document, baby deaths refer to perinatal deaths, which include:

Stillbirths: In Ireland, until recently, a stillbirth was defined as the birth of a baby showing no signs of life at or after 24 weeks' gestation and/or with a birthweight of 500 grammes or more. This legal definition was revised in September 2024. It lowered the threshold to a baby born with no signs of life at or after 23 weeks of pregnancy and weighing 400 grammes or more. The rates presented in this document (i.e. for 2023) are based on the older definition of stillbirth in Ireland.

More information: https://www.gov.ie/en/department-of-social-protection/services/registering-a-stillbirth-in-ireland/

Neonatal death: Refers to the death of a live-born baby within the first 28 completed days after birth, regardless of the baby's birthweight or gestational age. The term *early neonatal deaths* includes all baby deaths occurring within the first 7 days of life, while *late neonatal deaths* include baby deaths occurring from day 7 to day 28.

Note: All live-born babies in Ireland are legally registerable with the General Register Office (GRO), regardless of gestational age. However, legal definitions of stillbirth and reporting thresholds for perinatal mortality are determined by gestational age and/or birthweight criteria, as outlined above. As such, some extremely preterm live-born babies who subsequently die may be registered as neonatal deaths but may not always be included in perinatal mortality rate calculations depending on the definition applied in national reporting. In addition, Ireland's Central Statistics Office (CSO) published figures for stillbirths are acknowledged as understated, as they include only registered deaths.

This section provides an overview of why action is needed to end preventable baby deaths (perinatal deaths) in Ireland. Data on rates of stillbirth and early neonatal death are provided and associated risk factors are outlined. Prevention initiatives in other countries are discussed. How this action plan was developed, in addition to its purpose and scope, is then described.

Notes on language:

- A glossary is provided at the end of this document which explains some of the terms used, as well as research projects and national and international organisations referenced, throughout.
- Throughout this Action Plan, we use the terms "woman" and "women". While it is primarily cisgender women who experience pregnancy, we aim to be inclusive of anyone who can become pregnant, including transgender and non-binary people.

Perinatal death rates and risk factors

The Perinatal Mortality National Clinical Audit led by the National Perinatal Epidemiology Centre (NPEC) reports on all perinatal deaths that occur each year. In Ireland, the most recent Perinatal Mortality National Clinical Audit (2023) reported a stillbirth rate of 2.9 per 1,000 births (158 babies), alongside an early neonatal death rate of 1.4 per 1,000 live births (77 babies), giving a combined perinatal mortality rate of 4.3 per 1,000 births (235 babies) (2). To put this into context, this is consistently higher than the number of people who tragically died on Irish roads each year over the last 15 years (9). While the chance of live birth generally improves as pregnancy progresses, the risk of stillbirth begins to rise at week 33 (10), with 25-34% of stillbirths in Ireland occurring at term (37–41 weeks) (2), the period generally considered safest for delivery.

While baby death rates have declined over recent decades, progress has slowed in recent years and, in some cases, the figures remain higher than in previous reporting periods (Figure 2).

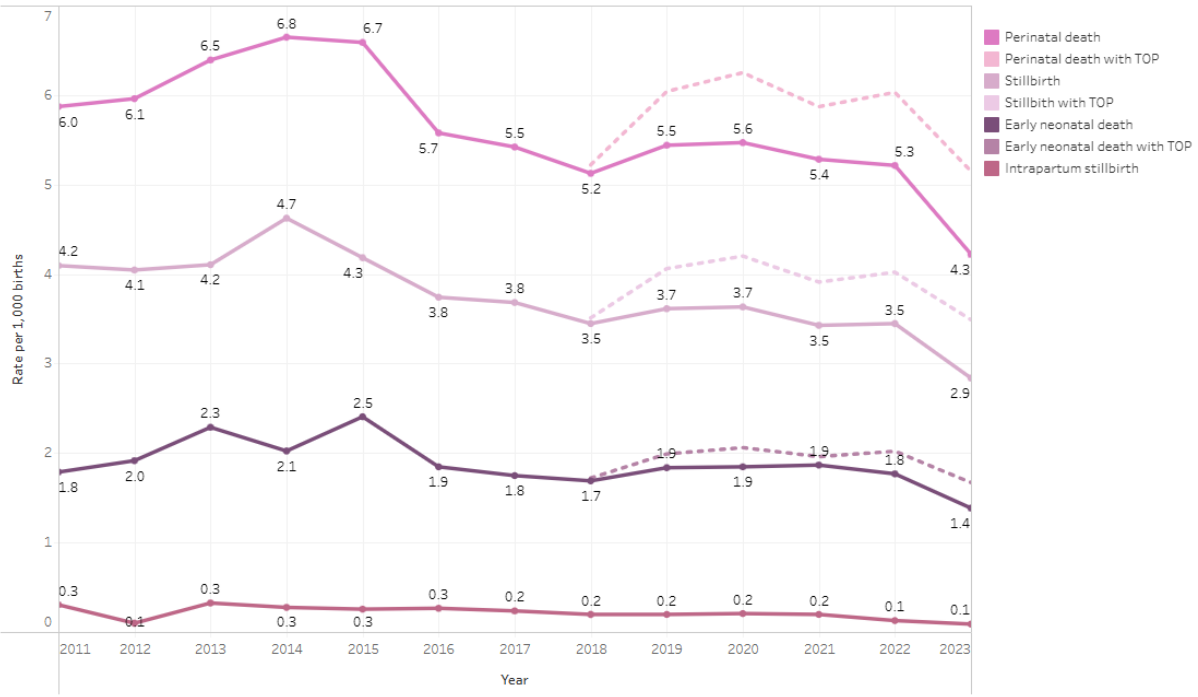


***Figure 2: Trends in perinatal mortality rates in Ireland, 2011-2023. Extracted, with permission, from the Perinatal Mortality National Clinical Audit in Ireland - Annual Report 2023* (2)**

Note: How perinatal deaths are classified and reported in Ireland has evolved over recent years. Since 2019, deaths after termination of pregnancy are excluded from perinatal mortality rate calculations. Congenital anomaly–related deaths are fewer in NPEC's audit due to increased access to all termination of pregnancy services. These shifts should be considered when comparing trends over time.

A wide range of factors have been associated with baby deaths, spanning sociodemographic, medical, obstetric, pregnancy-related, fetal, and behavioural domains. Persistent inequalities in perinatal deaths also exist, with higher rates observed among women experiencing social or economic disadvantage and among minority groups including Black women and Irish Travellers. Using Irish data, Robinson et al. (2025) found that women from minority ethnic groups experienced a 41% higher risk of perinatal death compared with white women (RR 1.41, 95% CI: 1.00–1.99) (11).

Preterm birth is consistently described as a leading cause of neonatal and infant deaths worldwide, particularly before 32 weeks' gestation. Globally, 5-18% of pregnancies end in preterm birth (that is, before 37 week's gestation), and in Ireland, it is estimated this figure is around 7% of pregnancies (12). Many preterm births are caused by underlying pathologies such as placental disease, fetal growth restriction and fetal anomalies. Survival of extremely preterm babies (<28 weeks) has increased steadily in the last two decades with greater willingness to offer, and improved, neonatal intensive care (13,14). According to the British Association for Perinatal Medicine, 8 in 10 babies born at 22 weeks will die, compared to 3 in 10 at 24 weeks, and 1-2 in 10 at 26 weeks (13). These are the outcomes that are seen on average, and for any individual baby, their risk may be lower or higher than this, depending on a variety of factors. Reducing preterm birth is therefore central to any strategy that aims to lower stillbirth and neonatal death rates.

Box 2 summarises the main categories of risk factors for stillbirths (15), drawing on national and international evidence, and provides a framework that underpins the actions proposed across subsequent sections of this action plan. These risk factors will be described in more detail under PILLAR 3: Best Care, Every Time. It is important to note that these risk factors have a broader impact than stillbirth, including on low-birth weight, preterm birth and neonatal death.

The first umbrella review to systematically synthesise, appraise, and grade the available evidence globally on risk factors for neonatal death, published in The Lancet in late 2025 identified 54 distinct risk factors (16). Evidence indicated an increased risk of neonatal death associated with maternal age ≥35 years, low occupational status, prenatal opioid exposure, maternal overweight and obesity, history of stillbirth, maternal death, severe maternal morbidity, hypertensive disorders of pregnancy, haemorrhagic disorders, anaemia in pregnancy, preterm birth and low birth weight (16). Factors identified as modifiable included preterm birth, low birth weight, antenatal care uptake, maternal overweight and obesity, and medical comorbidities such as hypertensive disorders of pregnancy, and anaemia (16).

Box 2. Risk factors for stillbirth (15)

Categories		Main risk factors for stillbirth
Sociodemographic factors		Maternal age
		Ethnic minorities
		Socioeconomic status
Medical factors	Maternal medical factors	Hypertension
		Diabetes
		Thyroid disorders
		Bacterial and viral infections
		Maternal weight
		Mental health conditions
	Obstetric history	Parity
		Previous history of pregnancy loss/stillbirth
		Previous preterm birth
		Multiple pregnancies
		History of caesarean birth
		Use of assisted reproductive technologies
	Pregnancy complications and fetal factors	Fetal growth restriction
		Placental insufficiencies
		Pregnancy length
		Changes in fetal movements
Behavioural factors		Smoking
		Alcohol and illicit drug use
		Use of medical drugs and supplements
		Sleep practices
		Antenatal care attendance

Risk factors for baby deaths are addressed in different ways across the five pillars of this action plan, including Public Awareness and Education (PILLAR 1), Risk Awareness and Communication (PILLAR 2), and Best Care, Every Time (PILLAR 3).

Notwithstanding the importance of identifying and managing risk factors, baby loss prevention is complex. **All pregnancies, even seemingly 'healthy' ones, carry some level of risk, even when no specific risk factors are identified.** Limitations remain in predicting all adverse outcomes through screening and monitoring. By way of illustration, over a 12-year period in Ireland, the average age of women who had a stillbirth was 31.7 years, fewer than a quarter smoked, or had a BMI of 30 or over. Half of the babies who died were average-sized, indicating even 'healthy' babies are at risk (17). More research is needed (PILLAR 5) to assist with risk prediction. In tandem, there is much we can do to end preventable baby deaths.

Making the case for prevention: evidence from international prevention initiatives

Evidence from other high-income countries demonstrates that a substantial proportion of baby deaths are preventable with timely, evidence-informed interventions often called care bundles.

A care bundle is a structured set of evidence-informed clinical interventions designed to be implemented together to prevent baby deaths. The core philosophy is that while each individual action is helpful, applying them as a unified "bundle" significantly improves the safety and consistency of maternity care. The UK and Australia have achieved reductions in stillbirth rates of around 20% following implementation of the *Saving Babies' Lives Care Bundle* (18) and the *Safer Baby Bundle* (19) respectively (20–23). Elements covered in the bundles include: smoking cessation, improved detection and management of fetal growth restriction, maternal sleep position, awareness of decreased fetal movements, and appropriate timing of birth. The UK's bundle was later expanded to include reducing preterm births and management of pre-existing diabetes, in 2019 (Version 2) and 2025 (Version 3), respectively (24,25). In the UK, staff reported positive experiences of implementing the care bundle, noting it supported clinical decision making (21,26). Furthermore, in Australia, the majority of pregnant women reported a positive experience during both pregnancy and labour, feeling both listened to and included in their care decisions (27).

Preventing baby deaths is not only affordable but cost-effective, with every dollar invested delivering more than triple the return by reducing medical, economic, and legal costs, while saving families and society from lifelong emotional and financial hardship (3). The economic burden of baby deaths is substantial, extending far beyond the immediate tragedy. It includes increased healthcare use, long-term parental mental health needs, lost productivity at work, and significant costs from litigation (28,29). Preventative measures such as improved antenatal care, safer sleep campaigns, and early identification of risks are low-cost, evidence-informed, and already proven in some countries to reduce stillbirths (22,23,25,27). Improving antenatal care also brings wider benefits, including better detection and treatment of risks that overlap with fetal growth restriction, preterm birth, and maternal mortality. While there are some costs involved in implementing such programmes—for example, the *Saving Babies' Lives Care Bundle* in the UK was estimated at £166,000 per stillbirth prevented (30)— these must be weighed against the far greater costs of doing nothing. Medical litigation alone is extremely expensive, with the US spending an average of $26 million annually over the past decade compared with just $12 million directed to stillbirth research (31). In Ireland, medico-legal cases related to baby deaths already contribute to an unsustainable financial trajectory for the health system (32).

Understanding why babies die is essential for identifying opportunities for prevention, improving clinical care, and guiding research priorities.

Perinatal deaths should be investigated because systematic review of each case is essential for understanding why babies die, identifying modifiable factors, improving

care and safety for women and babies, and providing transparent, compassionate answers:

- To understand why the baby died
- To identify modifiable factors and improve the quality of care
- To address inequalities and system failures
- To support bereaved parents and hospital staff
- To inform learning, policies, guidelines, and future pregnancies and associated care (33–35).

In Ireland, National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death (36) and stillbirth clinical guidelines (34) position perinatal death investigation (including autopsy, placental pathology, genetics, and case review) as integral to high-quality care.

Contemporary perinatal death review programmes explicitly seek adaptable factors in antenatal, intrapartum, neonatal, organisational, and social care, and use these to generate recommendations for service improvement, facilitating learning and improvements in care to end preventable baby deaths (35). Confidential enquiries give an impartial expert assessment on perinatal deaths and supply feedback at a system level, whereas local reviews identify unit-specific issues and provide essential feedback (to bereaved families and frontline staff) (35,37). To accomplish a factual, informative local perinatal mortality review, clinical staff and bereaved families should always be involved in local hospital reviews (38–40). Findings from structured reviews feed directly into clinical guideline development, prevention strategies, training priorities, and research agendas, closing the loop from an individual death to system-level learning (35,41).

In Ireland, perinatal deaths reviews are currently carried out in a number of ways at local, regional, national and international levels, with input from clinicians, clinical/academic experts, and inconsistently involving bereaved parents (42). Review of perinatal deaths is encompassed in the HSE's Incident Management Framework (43) which advises on the types of serious reportable events (SREs) to be reviewed in the hospital setting, including perinatal deaths. While most Irish maternity units adopt the Incident Management Framework guidance for perinatal death reviews, the review system is not standardised or transparent (37).

Standardised perinatal death review systems exist in several countries around the world, including the UK, the Netherlands and New Zealand (35). These countries follow a structured process for evaluating perinatal deaths with the help of a standardised review tool. Implementing a standardised review system in Ireland may help improve and prioritise national learning from preventable perinatal deaths. This may help to reduce future similar deaths from occurring and promote quality improvement initiatives in the Irish maternity services.

In Ireland, all baby deaths are reported to NPEC by the 19 maternity hospitals/units. Such detailed national audit data provide critical insight into the main causes of baby deaths, even if this does not clinically review care. Box 3 summarises the leading causes

of baby deaths (stillbirths and early neonatal deaths) based on findings from NPEC's Perinatal Mortality National Clinical Audit (2).

Box 3. Main causes of baby deaths

Stillbirths

- Placental and cord conditions: Placental insufficiency, maternal or fetal vascular malperfusion, and cord pathology are the leading causes
- Congenital and chromosomal anomalies: Structural or chromosomal anomalies (e.g. multiple anomalies, aneuploidy)
- Pregnancy complications: Antepartum or intrapartum haemorrhage and fetal growth restriction
- Fetal conditions: Conditions affecting fetal development or function
- Unexplained causes: Cases where no clear cause is identified after full investigation.

Early neonatal deaths

- Congenital anomalies: Most deaths result from major congenital or chromosomal anomalies, particularly affecting the cardiovascular system
- Respiratory disorders: Pulmonary immaturity and respiratory failure following preterm birth
- Neurological disorders: Hypoxic-ischaemic encephalopathy and other brain injury related to birth complications or prematurity
- Other causes: Infection, metabolic disorders, or complications of extreme prematurity.

Increasing the uptake of practice- and policy-relevant research and audit across pregnancy loss

Since 2012, the Pregnancy Loss Research Group (PLRG) has been conducting practice- and policy-relevant research across all forms of pregnancy loss, contributing significantly to improved understanding of risks, care needs and parental experiences. The National Perinatal Epidemiology Centre (NPEC), established in 2006, also plays an essential role by delivering national clinical audits and applied perinatal research that can inform quality improvement initiatives across maternity services in Ireland.

Challenges remain, however, in ensuring the uptake of evidence into routine practice, consistent data collection, across the 19 maternity hospitals/units and securing sustainable funding to address identified knowledge gaps (see actions 5.c to 5.g under PILLAR 5). Various barriers to knowledge translation across all forms of pregnancy loss have been identified through the PLATFORM Project (see Box 4). They include stigma and

taboo, lack of awareness and understanding, the lack of priority afforded to pregnancy loss in at a political level and in policy which has ripple effects across other areas (44).

Box 4. PLATFORM – Pregnancy Loss knowledge trAnslaTion FOR iMpact (43)

Led by the PLRG, in partnership with the Irish Hospice Foundation.

- National research initiative focused on enhancing the translation of pregnancy loss research into policy and practice in Ireland.
- Brought together researchers, key civil society partners, experts by experience and other knowledge users to identify barriers and facilitators to effective knowledge translation in this field.
- Aimed to address long-standing gaps in policy impact and practice change by developing activities and outputs to promote greater awareness, uptake and use of research evidence across health, community and policy settings.
- Contributed to increased public and policymaker awareness of pregnancy loss, informed the development of dissemination and engagement strategies, and supported efforts to influence healthcare service delivery and funding.
- Completed between December 2021 and July 2023 and funded by the Irish Research Council through its New Foundations Awards.

This Action Plan draws on the work and expertise of both the PLRG and the NPEC (and other sources, documented in the next section), to bridge the gap between research, policy and practice, and to generate action to end preventable baby deaths.

Development, purpose and scope of this action plan

'Ending Preventable Baby Deaths: An Action Plan for Ireland' is an evidence-informed action plan, developed through collaboration between NPEC and the PLRG at University College Cork (UCC) (see list of Working Group members in Appendix 1).

This evidence-informed action plan draws on national and international research, behavioural science, clinical guidelines, and lessons from successful care bundles and strategies implemented in other high-income countries. It complements existing national frameworks, particularly the National Maternity Strategy: Creating a Better Future Together (2016–2026) (45), the Women's Health Action Plan (2024–2027) (46), the National Strategy for Women and Girls (2025-2030) (46) and the HSE Public Health Strategy (2025-2030) (47). *Ending Preventable Baby Deaths* also aligns closely with the Department of Health's own 2025-2028 strategy to improve population health and wellbeing through high-quality services and effective use of health system resources, as well as with broader public health and prevention efforts (48).

While there are many actions that could contribute to the goal of ending preventable baby deaths, **this action plan focuses on priority measures that can be implemented now**. These actions are not exhaustive but represent an important starting point. The action plan will need to be reviewed and updated over time to ensure continued relevance, to adapt as actions are completed, and to respond to evidence about their impact.

This document is intended as a strategic, evidence-informed framework for action rather than a fully operational implementation plan. It does not assign formal ownership, targets, or timelines for delivery. Implementation of the actions outlined — including prioritisation, sequencing, resourcing, and the development of timelines and performance indicators — will require national policy leadership and coordination, led by Government and the Department of Health, in partnership with the HSE (including the NWIHP and other named HSE programmes) and relevant interest holders.

It is envisaged that this action plan could inform the establishment of a dedicated national lead and/or working group to support coordinated implementation and monitoring over time. Where appropriate, the authors will continue to support learning, research, and dialogue to inform progress in this area.

Introduction to the five pillars of Ending Preventable Baby Deaths

Five interconnected pillars form **'Ending Preventable Baby Deaths: An Action Plan for Ireland'** (Figure 1).

Each pillar represents a core domain of coordinated action, from public awareness and professional communication to clinical care, learning, and research.



Figure 1: Pillars of 'Ending Preventable Baby Deaths: An Action Plan for Ireland'.

Ending Preventable Baby Deaths

This action plan sets out to reduce preventable baby deaths in Ireland through coordinated public health messaging, improved professional education, standardised clinical practice, and structured learning from perinatal deaths, as well as prioritisation of research funding for knowledge gaps.

Implementation of the identified actions should be adequately resourced, evidence-informed, and consistently standardised across services, while allowing some flexibility in how all maternity units/hospitals operationalise the recommendations according to their specific context.

The following sections provide further details about the five interconnected pillars of action. Together, they summarise what has been achieved to date and what remains to be done. While not exhaustive, they focus on the areas where coordinated national effort is achievable and can have the greatest impact.

PILLAR 1: Public Awareness & Education

Meaning and relevance

A wide range of factors have been associated with baby deaths, including maternal medical conditions, maternal characteristics, fetal and placental factors, sociodemographic circumstances, and behavioural influences (as discussed in pages 9-13). Risks can be reduced through approaches that strengthen an individual's capability, opportunity, and motivation for healthy behaviours during pregnancy, as well as through actions that support healthcare professionals and maternity services to identify, communicate, and respond to risk effectively. While some factors can be influenced through information and the provision of supports and environments that enable safer practices (e.g. sleeping position, smoking cessation), others depend on timely recognition of pregnancy warning signs and proactive communication and partnership with healthcare professionals in decisions about antenatal care, birth/delivery planning (including timing and/or mode of birth), and follow-up care. Importantly, many determinants of perinatal mortality lie beyond individual control and require coordinated system-level action to address social, economic, and service-related inequities.

Public health awareness campaigns can contribute to ending preventable baby deaths by increasing awareness and knowledge – amongst people who are pregnant or who are thinking about pregnancy, health professionals, and the public more broadly. As pregnancy loss does not always receive the same visibility as other areas of women's health, prevention opportunities are missed. Much research (4,44,49–53), and indeed a recent Sands-UK and Tommy's 2025 policy summary report, has reinforced the need for greater public awareness of baby deaths (54).

A public health campaign should support the communication of risk factors, including medical conditions, socioeconomic factors, and pregnancy complications, to ensure that women are accurately informed and adequately supported during the pre-conception period, antenatal care and birth/delivery. Addressing both modifiable and non-modifiable risks through sensitive, tailored and consistent messaging is essential to reduce baby deaths. Furthermore, because adverse outcomes can occur in any pregnancy, the public health campaign should also acknowledge that baby deaths may occur even when no specific pregnancy risk factors have been identified.

Public health messaging on pregnancy and baby loss must be designed carefully to avoid stigma or unintended blame (55). Communications that focus solely on individual behaviours can lead women and families to feel responsible for outcomes that are often outside their control (56). The national public health campaign should therefore promote supportive, compassionate, and inclusive messages that emphasise shared responsibility across society, the healthcare system, and those in positions of influence and decision-making, while supporting women and families to make informed decisions within their circumstances. Ensuring that necessary supports and/or services are available and sign-posted to is also an important aspect of public health campaigns.

National and international evidence

Multiple initiatives internationally have acknowledged that a large proportion of stillbirths in high-income countries are avoidable and have developed public health awareness campaigns to inform the population about these risks and risk reduction. Some examples of these initiatives are the Scottish Patient and Safety Programme Maternity and Children Quality Improvement Collaboration (57). In Australia, the *Safer Baby Bundle* (19) educated women on how to reduce their risk of stillbirth across five key areas. The Australian public awareness campaign – *Still Six Lives* – which aligns with the *Safer Baby Bundle* messaging had significant reach and resulted in increased awareness of key messages: baby's movements, quit smoking and going-to-sleep on side (23,58). The UK's NHS *Saving Babies' Lives Care Bundle* covers two areas for enhanced public awareness – reducing smoking and raising awareness of reduced fetal movement (25). Multiple countries have run campaigns covering single topics, for example *Counts the Kicks* (United States) (59) and *Sleep on Side* (New Zealand) (60). The *Counts the Kicks* campaign about reduced fetal movements and stillbirth prevention was associated with reduced stillbirth rates (61).

There are also lessons to be drawn from experiences around public health communications regarding sudden infant death syndrome (SIDS or 'cot death'). As a result of targeted action, information about reducing the risk of SIDS is shared as part of antenatal care and deaths (in Ireland) have fallen from 150 to fewer than 20 annually (62,63). This shows that communication around difficult topics such as ways to avoid preventable deaths during across preconception, pregnancy and postpartum periods, is possible and has meaningful impacts, and in the case of SIDS, is embedded in routine practice.

How the public access health information has evolved, and many women now seek pregnancy-related information online for a range of reasons, often alongside or prior to consulting with healthcare professionals (64). Concerningly, the quality of pregnancy information online varies (65–67). A recent study found that half of Google search results in Ireland contain misinformation about reduced fetal movements (68), an important pregnancy warning sign that should prompt immediate attendance and assessment at a maternity hospital/unit. To counteract misinformation and low-quality information online, it is important that all women are provided with reliable and accurate information about risk factors, pregnancy warning signs and decisions regarding antenatal care, mode of delivery and timing of birth by trusted sources, including through health and maternity services/professionals and public health bodies. The HSE Health App, which is widely used and considered a trusted source by many pregnant women in Ireland, provides an important existing channel through which evidence-informed pregnancy information and updates could be delivered in a consistent and accessible way[xiii].

In Ireland, issues around knowledge, awareness, education and availability and quality of sources of information regarding stillbirth and modifiable behavioural risk factors have been identified in both people who use maternity services and healthcare professionals (49–51,65). Further, several studies have shown limited awareness of how

[xiii] https://www2.hse.ie/health-app/

specific behaviours are linked to adverse pregnancy outcomes (4,49–51). This lack of knowledge can affect women's perception of risk, including their susceptibility to it and the severity of the risk, and their ability to adopt protective behaviours. Confusion is often compounded by inconsistent or conflicting messages from different sources of information (4,49–51,65). However, while awareness and knowledge are important, they are insufficient, as behaviour change is complex and shaped by a range of individual, social, and system-level factors. This highlights the importance of designing evidence-informed interventions that address the multiple influences on behaviours (52).

While much research in Ireland has focused on modifiable risk factors, there is also a need to ensure that all risks, such as pre-existing health conditions, pregnancy complications, pregnancy warning signs, ethnicity, socioeconomic factors, or advanced maternal age, are appropriately discussed and integrated into public health messaging and antenatal education. In addition, women should be informed that every pregnancy, even seemingly 'healthy' ones, carries some level of risk, even when no specific risk factors are identified, and that limitations remain in predicting all adverse outcomes through screening and monitoring. Over a 12-year period in Ireland, the average age of women who had a stillbirth was 31.7 years, fewer than a quarter smoked, or had a BMI of 30 or over. Half of the babies who died were average-sized, indicating that even perceived healthy babies are at risk (17). A common misconception is that stillbirths are primarily due to issues with medical care, the baby or mother (5). However, the most common causes of stillbirth are problems with the placenta (2), which can affect any pregnancy but are currently difficult to detect (6).

Clear and balanced communication about this uncertainty is essential to support women to feel confident in raising concerns or changes they notice and discussing them promptly with their healthcare team (69). Available evidence from Ireland, Australia and the UK demonstrates that people want to receive information about risk factors for perinatal death, and in a sensitive and accessible way (4,69–71).

Actions proposed for Ireland

1.a Appoint a clinical public health lead within the HSE with responsibility for pregnancy and pre-conception health.

Currently, there is no single designated public health lead within the HSE accountable for pregnancy, pre-conception care, risk communication and prevention of baby deaths. The absence of such leadership has resulted in fragmented responsibility across different HSE programmes (maternity services, child health, health promotion, health service improvement, health and wellbeing, chronic disease prevention, health inequalities, patient safety). This fragmentation has contributed to gaps in national coordination and public understanding, as many women remain unaware of key risk factors or preventative actions during pregnancy.

Establishing a dedicated clinical public health lead would provide clear oversight, coordination, and accountability for national strategies aimed at reducing preventable baby deaths. The creation of this role would ensure that public health messaging about

pregnancy and pregnancy loss is consistent, evidence-informed and nationally coordinated.

To support implementation, the following resources are required:

- Appointment of a dedicated clinical public health lead within the HSE: this role could be held by a clinical public health specialist with suitable expertise. The creation of this post would require permanent allocated funding.
- Team support for national lead including an available research team to facilitate data analysis, knowledge user engagement and project management support.
- Creation of structures for collaboration and alignment across key HSE programmes — including the NWIHP, Healthy Eating and Active Living, Tobacco Control, Healthy Childhood, Health Inequalities and Social Inclusion, Sláintecare, and Healthy Ireland — to ensure that public health, pre-conception health and pregnancy initiatives are coherent, mutually reinforcing, and supported by consistent messaging.

1.b Develop information resources for both the public and healthcare professionals for use in healthcare settings and beyond, including fact sheets that explain the main risk factors for perinatal deaths and outline practical, supportive actions that women, families, healthcare professionals can take to address these risks.

To support implementation, the following resources will be required:

- Leadership by NWIHP and HSE Public Health with collaboration from HSE Health and Wellbeing, NPEC, PLRG and experts by experience.
- Development of resources for each key clinical pregnancy risk factor associated with stillbirth and neonatal death, as described in PILLAR 3, including reduced fetal movements, fetal growth restriction, preterm birth, gestational diabetes, multiple pregnancy and timing of birth at term:
    - Fact sheets for healthcare professionals and the public
    - Information for the public (specific to each clinical element)
    - Tailored information and guidance for both women and healthcare professionals on managing pregnancies with identified risk factors associated with preventable baby deaths.
- Designated funding for graphic design and translation services to ensure the resources are accessible in multiple languages and formats.
- Support with digital and print dissemination through all maternity hospitals/units, general practice clinics, community healthcare services and other channels such as the HSE website.
- Partnerships with major digital platforms and media outlets (e.g. search engines and social media services) to ensure accurate, evidence-informed pregnancy information is prioritised online, and to counter misinformation through coordinated messaging with HSE digital channels.

1.c Design and implement a public health campaign to raise awareness about risk factors and prevention strategies.

The Department of Health, HSE Public Health and HSE Communications could lead this work, with input from PLRG and NPEC, experts by experience, and parent organisations such as Féileacáin. Messaging around risk factors must be clear, consistent, supported by evidence and come from trusted sources.

The development of this new campaign should include patient and public involvement and experts by experience to ensure acceptability, clarity and sensitivity. Messaging should also reinforce that: 1) all pregnancies carry some level of risk, and women and families should be supported and encouraged to raise concerns, with healthcare professionals and services ensuring those concerns are taken seriously and acted upon; 2) there are changes that can be made and supported before and during pregnancy to reduce risk; 3) there are pregnancy warning signs that women should look out for (e.g. reduced fetal movements) and 4) there are risk factors that may lead to closer monitoring during pregnancy or decisions about best timing of birth.

NWIHP, supported by HSE Public Health, HSE Digital and with input from PLRG and NPEC, should coordinate the development and ongoing maintenance of clear, accessible online content on risk factors for baby deaths. This should include integration into platforms already used by the public, such as MyChild.ie[xiv] or HSE Social Inclusion's 'My Health, My Language' platform (72). However, at present, there is no designated specific public health lead within the HSE to oversee this work, a gap that Action 1.a seeks to address.

To support implementation, the following resources will be required:

- Establishing a clear editorial and clinical review process, including knowledge users (including experts by experience, members of the public, clinicians), so that all information resources for the public and healthcare professionals are appropriate, accurate, consistent, and evidence-informed.
- Designated funding for medical/scientific writers and graphic designers to develop accessible content that is suitable for different levels of literacy and cultural backgrounds. Designated funding for translation and accessibility support services to ensure materials are inclusive is also required.
- IT technical capacity provided by HSE Digital to ensure access to distribution channels including digital platforms (e.g. HSE website and social media, HSE Health App, HSE My Health) and healthcare settings (e.g. primary care clinics and maternity hospitals/units).
- Funding for dissemination of information including marketing budget to run social media/digital, radio/TV and outdoor (e.g. bus shelters, billboards) campaigns, and printing of resources (e.g. booklets/leaflets and posters) for distribution in healthcare settings.

[xiv] https://www2.hse.ie/my-child/

1.d Develop tailored strategies to engage groups experiencing health inequalities, including those facing barriers to care, language, or requiring psychosocial support.

To reduce inequities, maternity and wider health services must implement strategies to identify and support women at higher risk due to limited access to care, language or literacy barriers, or complex psychosocial circumstances. These strategies should be guided by a standardised national approach with clear oversight and coordination, while also drawing on local data to identify equity-owed groups who are disproportionately affected by adverse outcomes. They should embed principles of cultural safety and trauma-informed care to ensure that all interactions are respectful, responsive, and free from bias or re-traumatisation. These approaches should be designed and implemented in collaboration with experts by experience and the public more broadly to ensure they are appropriate, relevant, and responsive to local needs, and can be applied universally.

To support implementation, the following resources will be required:

- Leadership by all maternity hospitals/units with support from NWIHP and HSE Social Inclusion.
- Establishing partnerships with community organisations.
- Development of culturally and linguistically appropriate materials, co-designed with communities and HSE Social Inclusion.
- Use national and local maternity data (including datasets such as the Irish Maternity Indicator System and Maternity Patient Safety Statements), together with insights from staff and community partners, including experts by experience, to identify at-risk groups and inform targeted actions at local, regional, and national levels.
- Designated funding to access graphic design and translation services.
- Training for staff on cultural safety, trauma-informed care and social risk identification delivered through a combination of induction for new staff, integration into medical and midwifery training programmes, and accessible ongoing modules via HSELanD[xv] for all maternity and community-based staff, including primary care

1.e Incorporate education about fertility and pregnancy loss into school curricula.

The Department of Education and Youth, in collaboration with the Department of Health and the HSE should resource and scale up initiatives such as the SPRING Study (Supporting PRegnancy & reproductive health INformation for teenaGers)[xvi]. The project, developed by the PLRG in partnership with students and teachers, has created age-appropriate, co-designed educational materials covering reproductive health, fertility, and pregnancy loss (73). In addition, the RCSI's "Debunking the Myths"[xvii] provides another example of how evidence-informed, collaborative approaches can improve

[xv] HSeLanD: The Irish Health Service's national online learning and development portal. https://www.hseland.ie/

[xvi] www.ucc.ie/en/pregnancyloss/researchprojects/spring

[xvii] debunkingthemyths.ie

sexual health awareness and understanding of reproductive health among young people (74). Continuing to support and expand such initiatives will help normalise open discussion about fertility, pregnancy, and loss from an early age and enhance perinatal death prevention efforts.

To support implementation, the following resources will be required:

- Provide specialist coordination and expertise to integrate reproductive health, and pregnancy loss education within the curriculum (including Social, Personal and Health Education, or 'SPHE') and through whole-school health promotion approaches, in line with Department of Education frameworks.
- Co-designing age-appropriate teaching materials, informed by initiatives like the SPRING study, through collaboration with students, parents, teachers, healthcare professionals, and an appointed education or health promotion lead. Materials should align with SPHE and whole-school health promotion approaches to ensure relevance, inclusivity, and responsiveness to diverse needs.
- Provision of training and resources for teachers on delivering this content sensitively and effectively.
- Establish collaboration structures between the Department of Education and Youth (including Oide[xviii], the national support service for teacher professional development; Education Support Centres[xix]; and teacher-training programmes), the HSE, and academic partners such as the PLRG and NPEC to scale up this programme nationally.
- Develop evaluation tools to assess acceptability, effectiveness and implementation (among students, teachers, parents and wider school community) over time.

1.f Evaluate the implementation and effectiveness of the public health campaign and its related strategies and adapt as needed on an ongoing basis.

Evaluation is critical to ensure that public health campaigns and awareness initiatives are effective, equitable, and embedded within health and social care systems. A national evaluation framework should therefore be established to monitor implementation, assess effectiveness, and guide ongoing refinement.

Evaluation should include process indicators such as the reach of campaigns, engagement with resources, and healthcare professional uptake, as well as outcome indicators such as changes in knowledge and awareness of risk factors, and uptake of protective behaviours (for example, attending all recommended antenatal appointments, reducing smoking and alcohol use in pregnancy, maintaining side-sleeping in late pregnancy, and timely presentation for reduced fetal movements). Annual evaluation reports should be coordinated nationally, with NPEC, PLRG and HSE

[xviii] oide.ie
[xix] www.esci.ie

Public Health leading analysis and reporting in collaboration with NWIHP and the Department of Health.

To support implementation, the following resources will be required:

- Development of a national evaluation framework with standardised indicators and tools.
- Funding to conduct evaluation activities such as surveys and audits.
- Dedicated technical expertise in behavioural science, implementation science and evaluation should be secured to support the design and analysis of the evaluation strategy, alongside meaningful input from knowledge users (including women, families, and healthcare professionals) to ensure that evaluation measures are underpinned by relevant knowledge and expertise.

PILLAR 2: Risk Awareness & Communication

Meaning and relevance

Building on public awareness efforts described in PILLAR 1, this pillar focuses on ensuring that healthcare professionals have the knowledge, confidence, and system supports needed to communicate and manage risk effectively (75). Education and training interventions for healthcare staff have a significant impact on patient care and outcomes in various healthcare settings (76). Ongoing education, training, and continuing professional development are essential to ensure that healthcare professionals are equipped to provide evidence-informed care, identify risks and early signs of complications, and respond effectively to the individual needs of pregnant women.

National and international evidence

Studies from Ireland have shown that communication and knowledge regarding stillbirth, risk factors, causes of stillbirth and how to reduce risk through modifying behaviours is poor (4). In one Irish study, over half of first-time parents could not identify any stillbirth risk factors, with many attributing deaths to unavoidable problems with the baby or to issues with medical care (5). Similarly, other studies found that bereaved parents had not been informed of the possibility of stillbirth during pregnancy, even in pregnancies classified as 'high-risk'(77). Parents in Ireland and other countries feel that the possibility of stillbirth, and stillbirth prevention strategies, should be discussed during antenatal care (4,69). In a recent study, women reported not getting any information regarding behavioural risks or behavioural habits during their antenatal care, however, most women expressed that they would welcome that information if given in a sensitive manner (4). Similar findings regarding preterm birth show that while parents are often interested in knowing their personal risk, healthcare professionals often withhold this information due to fear of causing anxiety (78).

It is important that the pregnancy risk profile is shared accurately and clearly, as the risk assessments made by women and healthcare professionals do not always align; specifically, women may feel that professionals overstate the risk (79). In a survey conducted with healthcare professionals working in maternity services, only half of respondents were able to identify the definition of stillbirth in Ireland correctly (75). Maternal weight was the risk factor that healthcare professionals found most difficult to discuss, and time constraints were identified as a major barrier to both providing education and supporting behaviour change (75). Further, only around half of the respondents felt confident to inform women about health behaviours and stillbirth risks (75).

Evidence also suggests that communication gaps extend beyond stillbirth prevention to other aspects of antenatal care, particularly around timing of birth and the rationale for key investigations or interventions (80,81). Many women report limited understanding of why interventions such as induction of labour, monitoring for pre-eclampsia, or testing

related to advanced maternal age are recommended (81–84). Studies show that women often perceive induction as something they are told to do rather than a shared decision, while healthcare professionals may feel ill-equipped to explain the relative risks and benefits of induction or its alternatives (80–82). Similar communication challenges are described in relation to hypertensive disorders and chronic conditions, where women report being unprepared for complications and wanting clearer information and greater involvement in decision-making (83,85).

These findings highlight the importance of strengthening healthcare professionals' communication skills and providing decision-support tools that enable open discussions about risks, benefits, and timing of birth options. Improving shared decision-making - supported by written information, visual aids, and structured communication training - can help women understand the purpose of investigations and interventions, build trust, and promote informed decisions that contribute to preventing baby deaths (71). Evidence from Ireland also shows that existing education for obstetricians has largely focused on communication and bereavement care after stillbirth, with little emphasis on risk communication or prevention, underscoring a gap in preparing clinicians to support stillbirth reduction efforts (86).

Regarding training on behaviour change, in Ireland, healthcare professionals have access to an online and in person training called *Making Every Contact Count* (MECC) Programme[xx]. This training, developed and introduced by HSE Health and Wellbeing, provides healthcare professionals with an introduction to behaviour change, aiming to offer a foundation in behaviour change theory and techniques with a patient-centred approach. However, these modules are not focused on pregnancy risk factors or pregnancy outcomes. For example, even though the benefits of not engaging in substance use during pregnancy are discussed, no mention of baby deaths is made as a possible outcome.

While MECC provides a valuable framework for opportunistic health promotion, a recent critique has highlighted the paradox that its wide policy adoption has often outpaced evidence of meaningful impact on health outcomes or equity (87). The commentary warns that behaviour-focused frameworks risk placing responsibility primarily on individuals while overlooking structural and social determinants of health. In this context, adapting MECC for baby death prevention should form only one component of a broader, multi-level approach that combines individual-level conversations with system-level supports, clear referral pathways, and evaluation of equity impacts. Additional, dedicated training tailored specifically to pregnancy and the prevention of baby deaths may also be required to address the specific communication and behaviour change challenges in maternity care. This module nonetheless provides an opportunity to train healthcare professionals in behaviour change and behavioural risk factors for health, and it could be adapted to the specific context of baby death prevention by

[xx] https://healthservice.hse.ie/staff/training-and-development/making-every-contact-count-training-programme/

integrating findings from the RELEVANT project[xxi], which explored behavioural risk factors for stillbirth (88) (see Box 5), and other evidence from the literature.

Findings from a survey led by the PLRG show that doctors and midwives encounter pregnancy loss and stillbirth very early in their careers (75), which emphasises the need for early education regarding baby death prevention. Furthermore, Hennessy and O'Donoghue conducted a review of Medical and Midwifery Curricula as part of the implementation of the National Standards for Bereavement Care following Pregnancy Loss and Perinatal death (89). They concluded that there were varied mentions of various aspects of pregnancy loss across curricula, mostly within midwifery BSc and higher diploma programmes, and medical curricula to a much lesser extent (89).

However, there remains limited structured education on prevention, specifically on communicating pregnancy risks, recognising early warning signs, and supporting women to act on concerns. Evidence from a very recent evaluation of the Australian *Safer Baby Bundle* found that implementing structured conversations about stillbirth risk in routine antenatal care, supported by healthcare professional training and co-designed resources, contributed to improved confidence among professionals and more consistent discussion of risk and prevention measures (69).

Box 5. RELEVANT Project – Reducing stillbirth through behaviour change interventions

Led by the PLRG, funded by Science Foundation Ireland (Phase 1) and supported by NPEC (Phase 2)

- National research programme focused on risk factors for stillbirth (e.g. sleep position, antenatal attendance, smoking, weight management and substance use), funded by Science Foundation Ireland.
- Phase 1 (completed): Reviews of evidence and online information, qualitative research with women, and survey of healthcare professionals' communication practices.
- Phase 2 (underway): Co-design and development of an evidence-informed behaviour-change intervention with clinicians and people from diverse backgrounds.
- Aim: Create a scalable, equitable intervention to support safer behaviours in pregnancy and inform national stillbirth prevention policy and practice.

Thus, current evidence highlights the need to strengthen education and training for maternity-care professionals in Ireland, ensuring consistent, evidence-informed communication about stillbirth risks and prevention strategies throughout antenatal care. These findings also indicate that existing training opportunities do not adequately address pregnancy-specific risks or communication about stillbirth. This serves to

[xxi] RELEVANT: REducing stiLlbirth through bEhaViour chAnge iNtervenTions. www.ucc.ie/en/pregnancyloss/researchprojects/relevant

highlight that the opportunity to educate healthcare professionals during their training is being missed (89). Evidence from other healthcare contexts shows that structured tools and cognitive aids support clear communication, recall, and patient safety (90,91). Integrating these approaches into maternity care would strengthen professional practice and improve parents' understanding of stillbirth risks and prevention strategies.

These actions proposed should strengthen, not only healthcare professionals' communication skills, but also the systems, policies and organisational supports that enable consistent, equitable discussions about risk and prevention across settings.

Actions proposed for Ireland

2.a Develop a standardised list of risk factors to guide healthcare conversations.

A standardised list of risk factors for stillbirth, preterm birth and early neonatal death should be produced to encourage both identification of risk and continuous risk assessment during pregnancy. This list should be available at booking and in all antenatal appointments to encourage continuous risk assessment. The list should be integrated into eHealth records and paper charts. Development could be supported through collaboration between NWIHP, HSE Public Health and maternity hospital/unit clinical leads, with NPEC contributing audit findings and evidence reviews.

To support implementation, the following resources will be required:

- Development of standardised list of risk factors including/using review of national clinical guidelines, national audit findings, input from clinicians and experts by experience and the public.
- Integration of the list into the Maternal and Newborn Clinical Management System (MN-CMS) and antenatal documentation paper charts.
- Print and digital dissemination of the risk factor list across maternity hospitals/units, with appropriate and ongoing funding.
- Training for healthcare professionals on how to use the list for ongoing risk review. The purpose of this list is to guide meaningful conversations with women, support the early recognition of risk, and ensure timely, appropriate follow-up care. Training should focus not only on completing the checklist, but on using it as a foundation for person-centred care.
- Continuous review and update of the list to ensure new evidence is reflected in practice.
- Updating antenatal care electronic health records (MN-CMS) and paper-based documentation charts to prompt and record health promotion and risk factors discussions.
- Strengthen system-level supports to enable consistent risk communication, including standardised prompts in electronic medical records, adequate consultation time, integrated referral pathways, and leadership endorsement, so that healthcare professionals are supported and empowered to deliver preventative messages effectively and equitably.

2.b Reform medical and midwifery curricula to include education about prevalence and prevention of baby deaths.

Medical schools, midwifery programmes, and postgraduate training schemes should embed structured teaching on the prevalence and prevention of baby deaths, as well as the identification and management of all relevant risk factors. This should include identification of medical conditions (e.g. hypertension, obesity), pregnancy specific factors and complications (e.g. parity, gestational diabetes), pregnancy warning signs (e.g. reduced fetal movements), modifiable behavioural factors (e.g. smoking, sleep position, delayed or non-attendance at antenatal care visits), and wider sociodemographic factors and social determinants of health (e.g. age, poverty, housing, access to care, language or literacy barriers), and that all pregnancies, even seemingly 'healthy' pregnancies, are at risk of stillbirth or other adverse outcomes.

Teaching should present current evidence, highlight both individual-level and system-level opportunities for prevention, and include communication skills training. Content should be co-designed with experts by experience and delivered through creative and interactive methods such as simulation workshops and reflective case-based learning, supported by practical communication frameworks and debriefing tools. Opportunities for interprofessional education, involving pharmacy, dietetics, and other allied health disciplines, should also be incorporated to promote collaborative, team-based approaches to the prevention of baby deaths. Training for doctors in postgraduate obstetrics and gynaecology programmes should also be prioritised, in collaboration with the Royal College of Physicians of Ireland (RCPI), to ensure that prevention and communication skills enabling the conversations through antenatal care are embedded throughout specialist training.

To support implementation, the following resources will be required:

- Curriculum review and revision by academic leads from all institutions delivering medicine and midwifery curricula in collaboration with relevant professional regulatory bodies such as the Irish Medical Council and the National Midwifery Board of Ireland, clinical experts, public health professionals, and experts by experience and the public.
- Development of standardised teaching materials.
- Training for academic staff and clinical educators to support teaching and learning in sustainable, consistent and sensitive ways.
- Dedicated curriculum time across undergraduate and postgraduate programmes.
- Mechanisms to ensure consistency across Irish universities and clinical training sites.

2.c Incorporate guidance into national antenatal education standards to support healthcare professionals in promoting health / health behaviours with pregnant women and to discuss risk factors, stillbirth prevention, and options for antenatal care and delivery in antenatal education standards and settings.

The HSE and NWIHP should review and update national antenatal education standards (92) to include clear guidance on how healthcare professionals can address behavioural risk factors and promote maternal health, highlight stillbirth warning signs during pregnancy and how risk factors can impact antenatal care and delivery decisions. This should include practical examples, and conversation prompts to support routine discussion of risk factors like smoking, sleep position, and antenatal care attendance, seeking immediate assessment of reduced fetal movements, and examples of where specific modes or timing of birth should be discussed based on individual risk factors such as advanced maternal age, obesity or substance use. Furthermore, the standards should clarify that all pregnancies even seemingly 'healthy' ones are at risk of stillbirth and other adverse outcomes.

Healthcare professionals should incorporate risk factors and stillbirth reduction strategies in their discussions with women during routine antenatal care appointments. This integration could be supported by updating electronic (e.g. MN-CMS) and paper-based documentation, with leadership from maternity hospitals/units and oversight from NWIHP and HSE Public Health.

To support implementation, the following resources will be required:

- A dedicated working group to review antenatal education standards, including midwives, clinical leads, health promotion experts and people who use maternity services/experts by experience.
- Development of conversation guides or scripts to support consistent, sensitive communication which can be tailored to individual needs.
- Incorporating prompts into all antenatal-booking forms to support discussion of risk factors — medical conditions (e.g. hypertension, obesity), pregnancy specific factors and complications (e.g. parity, gestational diabetes), pregnancy warning signs (e.g. reduced, fetal movements), modifiable behavioural factors (e.g. smoking, sleep position, delayed or non-attendance at antenatal care visits), and wider sociodemographic factors and social determinants of health (e.g. age, poverty, housing, access to care, language or literacy barriers).
- Providing healthcare professionals with training sessions to build communication skills and confidence to discuss behavioural risk factors with women and to support women with behaviour change.
- Including specific reference to reduced fetal movements in all educational and clinical guidance materials, aligned with current national and international guidelines and online resources to enhance awareness, timely recognition, and appropriate management.
- Providing healthcare professionals with training sessions to build communication skills and confidence to partner with women to agree plans for antenatal care and delivery based on risk assessment.

- Producing tools to support and monitor the inclusion of risk communication in antenatal care.
- Protected time for maternity staff to allow for meaningful conversations with women during antenatal visits and enhanced abilities to refer to specialist services where needed (e.g. weight management, smoking cessation, gestational diabetes management).

2.d Adapt the 'Making Every Contact Count' (MECC) programme to include education on baby death prevention.

For healthcare professionals already in practice, continuing professional development opportunities are essential. As previously mentioned, the HSE's *Making Every Contact Count* (MECC) programme provides a recognised framework for promoting behaviour change across healthcare settings. While MECC primarily focuses on behavioural factors such as smoking, alcohol use, diet, and physical activity, its principles could be adapted or complemented by a maternity-specific training module to support communication about pregnancy-related risks and stillbirth prevention.

Embedding baby deaths content into MECC would require substantial modification but offers a practical and familiar platform for maternity staff. Alternatively, a dedicated training course could be developed, building on the approach taken in Australia through the *Safer Baby Bundle* education programme[xxii], which integrates evidence-informed risk communication, shared decision-making, and behavioural support into routine antenatal care, with scope for integrated content or add-on modules specifically focused on equity-owed groups.

To support implementation, the following resources will be required:

- Adaptation of MECC training modules to include risk factors for baby deaths and preventive measures.
- A working group including behavioural experts, clinicians and experts by experience to co-develop/adapt content.
- Designated funding for module development, technical production and promotion.
- Protected time for maternity staff and relevant community-based staff, including in primary care, to complete training.
- Establishing an evaluation framework to assess effectiveness of training (uptake, outcomes - including impact on practice).

[xxii] https://learn.stillbirthcre.org.au/

2.e Develop communication and education materials for healthcare professionals and update antenatal education standards.

Effective communication is essential to ensure that risk factors are discussed clearly, sensitively, and consistently throughout pregnancy care.

Structured communication resources and education materials should be developed to support healthcare professionals in discussing stillbirth risk factors clearly, sensitively, and consistently, and to ensure that women and families receive accurate and accessible information. Updating antenatal education standards by the HSE and NWIHP could provide clear guidance on promoting maternal health and discussing stillbirth risk factors, supported by conversation guides and prompts. Existing work, such as NWIHP's *Supporting People Experiencing Pregnancy and Infant Loss* module currently being developed for HSELanD (focused on bereavement care following pregnancy loss), could be built upon as part of a broader suite of modules that also includes dedicated training on risk factors, prevention, and sensitive risk communication.

In parallel, collaboration with NPEC, PLRG and experts by experience could support the production of information resources, including leaflets, infographics, fact sheets, and digital materials, tailored for both the general population and for pregnancies that are at higher risk of stillbirth. Ensuring these resources are culturally appropriate and available in multiple languages will be essential for equity.

To support implementation, the following resources will be required:

- Commissioning and financial resourcing of communication tools (scripts, videos) and information resources, designed in collaboration with experts with experience and other relevant knowledge users.
- Development of structured communication tools including sample conversation scripts and prompts for common clinical scenarios, short videos demonstrating best practice communication, scenario-based role play training for teams.
- Dedicated funding to support design, translation, and dissemination across print and digital platforms.
- Integration of new resources into training platforms, local training days, and antenatal education standards.
- A structured dissemination plan across all maternity hospitals/units, general practice and community-based antenatal care settings, including services working with equity-owed groups (e.g. community health workers supporting Traveller women during pregnancy).

2.f Evaluate healthcare professional education and communication initiatives on an ongoing basis.

Evaluation should focus both on the implementation of training and resources, and on their impact on professional practice and women's experiences of antenatal care. Evaluation could be led jointly by NWIHP and NPEC/PLRG, in collaboration with ongoing evaluation through medical and midwifery schools as well as maternity hospitals/units.

This should include process indicators such as engagement with resources, and healthcare professional uptake, as well as outcome indicators such as changes in knowledge and awareness of risk factors, and uptake of education programmes.

To support implementation, the following resources will be required:

- Development of a national evaluation framework with standardised indicators and tools.
- Funding to conduct evaluation activities such as surveys and audits.

Dedicated technical expertise in behavioural science, implementation science and evaluation should be secured to support the design and analysis of the evaluation strategy, alongside meaningful input from knowledge users (including women, families, and healthcare professionals) to ensure that evaluation measures are underpinned by relevant knowledge and expertise.

To support implementation, the following resources will be required:

- Development of evaluation indicators such as:
    - Proportion of staff attending MECC programmes (including maternity-specific adaptations, where available) and completing HSELanD modules.
    - Healthcare professionals' knowledge and confidence in discussing risk factors.
    - Availability and uptake of communication tools and resources across maternity hospitals/units.
    - Women's reported awareness of, and satisfaction with information received in antenatal care regarding risk factors.
- Periodic surveys of healthcare professionals and people who use maternity services to measure knowledge, attitudes, and practice.
- Designated funding and technical expertise for data analysis, behavioural evaluation, and independent review where appropriate.
- Mechanisms to feed evaluation findings back into training programmes, antenatal education standards, and resource development to support continuous improvement.

PILLAR 3: Best Care, Every Time

Meaning and relevance

In this action plan, 'best care' means evidence-informed, up-to-date care, delivered consistently and equitably across all maternity services and evolving as new evidence becomes available.

This pillar focuses on the key clinical risk factors associated with stillbirth and with other adverse pregnancy outcomes, including low birth weight, preterm birth and neonatal death. These clinical factors, together with the other types of risk factors addressed elsewhere, should also be reflected in public health initiatives and incorporated into educational materials and other interventions.

The clinical risk factors include (See Box 2):

- Reduced fetal movements
- Fetal growth restriction
- Gestational diabetes and pre-existing diabetes
- Preterm birth
- Multiple pregnancy
- Pregnancy at term (i.e. at or over 37 weeks).

Evidence from existing care bundles shows that these risk factors represent the clinical areas with the strongest evidence currently for reducing the risk of stillbirth (19,25). As evidence and practice continue to evolve, these priorities should be regularly reviewed and refined to ensure alignment with emerging research and clinical guidance.

National and international evidence

Reduced fetal movements

Reduced fetal movements have been associated with an increased risk of adverse perinatal outcomes and interventions, including stillbirth, fetal growth restriction, induction of labour, instrumental birth and caesarean section. A recent meta-analysis reported that reduced fetal movements was associated with a more than 3-fold increase in stillbirth (OR 3.44 95% CI 2.02 to 5.88, 23 studies, 513124 participants I^2=84%) (93). Placental conditions are a common cause of perinatal deaths and reduced fetal movements can be a warning sign that the placenta is not functioning as it should (94–96) - sometimes the only warning sign. Reduced fetal movements have been associated with anomalies in placental structure and function, suggesting that placental insufficiency is the pathological cause of death in these cases (94–96). While the Irish National Perinatal Mortality National Clinical Audit does not collect routine data on reduced fetal movements, specific placental conditions, such as fetal and maternal vascular malperfusion, have been consistently identified as the leading cause of stillbirth over the years (97).

Fetal growth restriction

Fetal growth restriction is associated with a range of adverse outcomes including stillbirth, pre-eclampsia, placental abruption, preterm birth, neonatal mortality, hypoglycaemia, hyperbilirubinaemia, necrotising enterocolitis, respiratory morbidity, hypothermia and intraventricular haemorrhage (98,99). Emerging evidence further links fetal growth restriction with increased long-term risks of cardiovascular disease, type 2 diabetes and other chronic metabolic conditions in offspring, as well as elevated maternal cardiovascular risk in later life, highlighting its implications beyond the perinatal period (100–102). Fetal growth restriction is also associated with neurodevelopmental disorders and metabolic syndromes (98,99). Identifying fetal growth restriction cases accurately is central to reducing mortality and morbidity. While a diagnosis of fetal growth restriction increases the risk of stillbirth by 2.4 times compared to pregnancies without fetal growth restriction, the risk is elevated by 19.8 times when growth restriction is undiagnosed (103).

Gestational diabetes and pre-existing diabetes

Pre-existing diabetes in pregnancy has also been associated with an increased risk of stillbirth (37 studies; pooled odds ratio [OR] 3.74, 95% CI, 3.17–4.41, I^2=82.5%), especially maternal type 2 diabetes (104). A systematic review and meta-analysis covering 7.5 million pregnancies found that gestational diabetes is associated with pregnancy complications including low one minute Apgar score and preterm birth (105). Gestational diabetes has also been studied as a possible risk for stillbirth. However, a recent meta-analysis concluded that given the heterogeneity in the literature, that there is not enough available data to establish this relationship (106). While the overall findings suggest that gestational diabetes does not increase the risk of stillbirth, the absolute risk of stillbirth *was* increased when restricting analysis to only include late stillbirths and studies published before 2013 (106). This is in accordance with the findings of a case control study conducted in England which found that women at risk of gestational diabetes that are not screened have a 44% increased risk of late stillbirth over those not at risk (107).

Preterm birth

Spontaneous preterm birth is one of the main causes of perinatal mortality (108). According to the latest Very Low Birthweight Infants in the Republic of Ireland Report 2021/2022, the risk of mortality is 73% for babies born at 23 weeks' gestation, 31% for babies born at 24-27 weeks and 6% for babies born between 28-31 weeks (109). Similarly, the Perinatal Mortality National Clinical Audit Report 2023 shows that early neonatal deaths are concentrated in births between 22-27 weeks of gestation (rates over 150 per 1000 live births), and 74% of babies that died had a birthweight of less than 2.5kg (2). Survival rates have improved due to advances in neonatology care and the utilisation of antenatal corticosteroids and surfactant. Children born preterm (i.e. before 37 weeks) are at a higher risk of lower academic achievement and health conditions in adulthood including cardiovascular, endocrine/metabolic, respiratory, renal, neurodevelopmental, and psychiatric disorders Opportunities remain for prevention and early identification (110,111).

To this effect, the UK – via the *Saving Babies' Lives Care Bundle* – has implemented risk stratification tools in routine clinical practice, clear referral pathways for women at risk of preterm birth, standardised care protocols for threatened preterm labour, and education packages for healthcare professionals (25).

In Ireland, the current Model of Care for Neonatal Services, published in 2015 (and due to be updated in 2026), recommends that infants born before reaching a gestational age of 28 weeks should ideally be delivered at one of the four tertiary (level 3) neonatal centres (112). However, about 10% of these infants are born in peripheral centres every year (109) suggesting that not all pregnancies at risk of preterm birth are identified and subsequently do not receive specialised care at a tertiary centre which is essential to improving survival rates. Analysis of NPEC data also shows that a considerable proportion of twin deaths with major congenital anomalies or birth before 28 weeks' gestation occur in non-tertiary hospitals (113). Antenatal education should include communication about preterm birth risk and the importance of the specialised services at tertiary centres.

Multiple pregnancy

Twins account for around 10% of all baby deaths, despite representing only 3-4% of total births in Ireland (113). Multiple pregnancies are associated with an increased risk of stillbirth, which increases after 37 weeks of gestation for dichorionic twin pregnancies and after 36 weeks for monochorionic pregnancies (114). This aligns with Irish data; a recent study from data spanning from 2011 to 2022 found that the perinatal mortality rate was 17.3 per 1000 births for twins, which was 3.1 times higher than for singletons (113). Similarly, findings from the Perinatal Mortality National Clinical Audit have consistently highlighted multiple pregnancy as a risk factor for baby deaths over the years (2). According to the 2025 Euro-Peristat study**,** differences in multiple births explained 0.03 per 1000 births of Ireland's above-average stillbirth rate in 2021 (1). NPEC's data shows that spontaneous preterm birth was the leading cause of early neonatal death in monochorionic twin pregnancies and the second main cause in dichorionic twin pregnancies in Ireland (113).

Timing of birth at term and post-term

Making appropriate decisions regarding the timing of birth is another aspect to consider in preventing baby deaths. Post-term pregnancy (41+0 weeks and beyond) is a stillbirth risk factor (34), with Irish clinical guidelines recommending induction of labour for uncomplicated pregnancies at 41+0 weeks and individualised management plans for those who decide not to be induced (115). There are very few post-term stillbirths (on or after 42 weeks) in Ireland, with none recorded in 2023 (2).

However, it is not only post-term pregnancies that are at risk. The peak risk period is at term (37 to 41 weeks) (116). The risk of stillbirth starts to rise from about 33 weeks (10,116) and several large observational studies have shown that the risk rises steadily from 37 weeks (117). In Ireland, 29% of stillbirths occur at term (between 37 and 41 weeks) (2) - when the baby is fully developed, highlighting the importance of careful decision-making about timing of birth and ongoing monitoring in term pregnancies.

Timing of birth is therefore an important tool in stillbirth prevention as there is no additional risk of newborn death when delivering between 38 and 41 weeks (117) and caesarean births are less likely with induction at 39 weeks (118). This approach is reflected in Australian policy, where reducing stillbirths at term is a key priority and a core element of the *Safer Baby Bundle* (19). The timing-of-birth component of the bundle aims to reduce stillbirths at or near term while avoiding unnecessary intervention and associated adverse outcomes, through improved screening for risk factors and shared decision-making around timing of birth (19).

Current clinical practice

The National Clinical Guidelines in Obstetrics and Gynaecology are a programme of work agreed between the NWIHP and the RCPI's Institute of Obstetricians and Gynaecologists. While over 20 clinical guidelines related to pregnancy have been published since 2023, the level of adherence and barriers to their implementation across maternity hospitals/units are unknown. For example, as discussed previously, most babies with fetal growth restriction are not diagnosed with this condition antenatally and the opportunity to manage their care effectively is missed, even though clinical guidelines on fetal growth restriction exist since 2014, with the most recent guideline published in 2025 (99).

The current Guideline Programme does not have specific resourced implementation supports, and there is no standardised national process for reporting or review of each guideline's published auditable standards. Actions within this pillar focus on enhancing and standardising care nationally by focusing on guideline implementation as an important starting point.

Actions proposed for Ireland

3.a Provide targeted supports and structures to enhance national and regional implementation of relevant national clinical guidelines, including ongoing monitoring and evaluation across all 19 maternity hospitals/units.

Maternity hospitals/units should review existing service provision against the relevant guidelines (see Box 6), identifying necessary resources required to implement the recommendations provided.

Local multidisciplinary clinical teams, senior executive and clinical management teams in each maternity hospital/unit are ultimately responsible for the adoption and implementation of guidelines within their area of responsibility.

Box 6. National Clinical Practice Guidelines relevant to preventing/reducing baby deaths[xxiii]

- Reduced fetal movements (119)
- Fetal Growth Restriction – Recognition, Diagnosis and Management (99)
- Induction of Labour (115)
- Antenatal corticosteroids to reduce neonatal morbidity and mortality (120)
- Stillbirth – Prevention, Investigation, Management and Care (34)
- Prevention of Early-Onset Group B Streptococcal Disease in Term Infants (121)
- Fetal Heart Rate Monitoring (122)
- Assisted Vaginal Birth (123).

Note: Any updates to the listed guidelines, or the publication of additional guidelines relevant to preventing baby deaths, over the course of the Action Plan should also be considered.

A dedicated clinical guideline implementation lead and local staff member are required to support all maternity hospitals/units to confirm which recommendations have been implemented, identify any barriers, and support a clear path to complete implementation, to standardise high-quality care across all hospitals/units.

To support implementation, the following resources are required:

- Appointment of implementation leads or champions in each maternity hospital/unit and/or HSE Health Region(s) under the national co-ordination of the NWIHP and National Clinical Guideline Programme Team, to coordinate the local rollout of national clinical guidelines and associated quality-improvement initiatives, supporting staff engagement, training, and follow-up on actions identified through audit.
- Protected time for clinical and audit staff to conduct data collection and reporting on adherence to relevant national clinical guidelines and stillbirth prevention actions, using electronic health record systems or platforms managed by NPEC (e.g. REDCap), to support local audit, national reporting, and continuous quality improvement.
- Establishment of multidisciplinary quality improvement (QI) teams in each maternity hospital/unit, with protected time and funding to review current practice against national clinical guidelines, coordinate local implementation of recommendations, oversee data collection and audit processes, and lead follow-up actions to address identified gaps in care.
- Guidance on developing quality improvement initiatives specific to this area, accompanied by practical implementation tools such as self-assessment checklists, staff training materials, audit templates, and care pathways aligned with national guidelines.

[xxiii] Guidelines available at https://www.rcpi.ie/Faculties-Institutes/Institute-of-Obstetricians-and-Gynaecologists/National-Clinical-Guidelines-in-Obstetrics-and-Gynaecology

- Processes to support the timely adoption of updated national clinical guidelines into local practice.
- Dedicated funding to support the printing and distribution of lay summaries and information linked to national clinical guidelines, ensuring that up-to-date, evidence-informed materials are available in all maternity hospitals/units and relevant community settings for people during pre-conception, antenatal and pregnancy care, as well as the public more broadly.

3.b Resource national coordination and support for guideline implementation including a dedicated implementation lead.

National clinical guidelines relevant to prevention of baby deaths (see Box 6) are already reviewed and updated regularly through the National Clinical Guideline Programme typically every three years or sooner if new evidence or priority issues arise. This process is coordinated by NWIHP and the National Clinical Guideline Programme Team.

The priority now is to strengthen national coordination, communication, and implementation support so that updated national guidelines are consistently embedded in clinical practice across all maternity hospitals/units.

To support implementation, the following resources will be required:

- Appoint a dedicated and resourced national clinical guideline implementation lead whose role would be to support the implementation of guidelines nationally, regionally and locally. This would involve evaluating implementation, identifying factors that influence implementation and developing and implementing appropriate implementation strategies (see related actions 3.c and 3.d).
- Continue the structured national process for periodic review and revision of relevant clinical guidelines through the National Clinical Guideline Programme, coordinated by NWIHP and the National Clinical Guideline Programme Team.
- Ensure input from multidisciplinary healthcare professionals, researchers, and people who use maternity services during guideline updates to ensure guidelines are relevant and fit for purpose.
- Strengthen dissemination mechanisms so that all maternity hospitals/units receive updated guidelines promptly, with clear summaries of key changes and implications for practice. This could include the development of a dedicated online guideline hub, providing a single, easily accessible source for current guidance, resources, and implementation tools.
- Develop and maintain training programmes to support guideline implementation, including e-learning modules, in-person workshops, and case-based learning sessions.
- Provide protected time for maternity staff to engage in training and incorporate updated recommendations into routine care.

3.c Develop and implement clinical decision support tools/clinical algorithms to support implementation of national clinical guidelines.

To enhance risk assessment for each one of the clinical risk factors, it is proposed to produce decision support algorithms or 'risk' flow charts and risk factor checklists. These resources will include different strategies based on the individual-level of risk of each pregnant woman and should be integrated in the electronic health record or paper charts through structure templates as appropriate. The decision support algorithms will aim to reduce variability in care, adhere to clinical national guidelines and prompt appropriate escalation based on individuals risk factors. Integration into electronic health records (MN-CMS) and paper charts will help embed this approach into routine practice and reduce variation in care.

To support implementation, the following resources will be required:

- Establishment of a working group to co-design tools, involving obstetricians, midwives, neonatologists, IT, experts by experience and any other relevant knowledge users.
- Development of tailored decision support algorithms for each clinical aspect and including user testing and validation before national rollout.
- Integration into MN-CMS and national paper charts with structured fields, prompts, and escalation alerts. This should include embedded links or prompts to relevant referral pathways and supports when risks are identified (e.g. specialist clinics, smoking cessation, medical social work referral, mental health supports), so that documentation directly enables action.
- Provision of training for clinicians on the use of the tools and on how to communicate risk and discuss resulting care decisions with women in a clear, sensitive, and shared decision-making approach.
- Establishment of ongoing review mechanisms to ensure the tools remain aligned with national clinical guidelines and audit findings and that they are implemented in practice.

3.d Evaluate and audit guideline implementation and examine the effectiveness of the clinical decision support tools and related quality improvement initiatives.

A structured national evaluation framework should be developed to measure the effectiveness of clinical decision support tools and quality improvement initiatives. Evaluation should consider both process outcomes (such as adoption of guidelines, staff adherence, and use of decision support tools) and clinical outcomes (such as detection of fetal growth restriction, response to reduced fetal movements, or timing of birth decisions).

Routine clinical audits should be embedded at maternity hospital/unit level and coordinated nationally. Standardised audit tools and templates, aligned with national clinical guidelines, will support consistent data collection and reporting across maternity services. This work could be coordinated by NWIHP and NPEC, in collaboration with maternity hospitals/units.

To support implementation, the following resources will be required:

- Co-development of standardised evaluation tools for each clinical guideline, including measures assessing communication and information-sharing with women and families within HIQA's national care experience programme.
- Establish and maintain a standardised national audit reporting structure, whereby maternity hospitals/units measure key auditable standards for each relevant national clinical guideline and report these data nationally to NPEC.
- Establish monitoring systems to assess the adoption, and adherence to updated guideline recommendations across all maternity hospitals/units, and to identify where additional support or clarification is needed.
- Protected time and resources for staff to complete audit and evaluation of guideline targets such as detection of fetal growth restriction, timely assessment of reduced fetal movements, smoking cessation referral rates or proportion of women offered/accepting induction of labour at recommended gestational ages.
- Integration of key indicators into national data systems (MN-CMS, NPEC audits) to support consistent national reporting and benchmarking.
- IT and data-management support to generate local and national dashboards, and ensure timely feedback to clinical and governance teams, mirroring systems used in the UK's *Saving Babies' Lives Care Bundle* (25) and Australia's *Safer Baby Bundle* (19).
- Designated funding for data analysis and evaluation expertise.
- Mechanisms to ensure findings from evaluations and audits inform updates to national guidelines, training programmes, and local service improvements.

PILLAR 4. Ongoing Review of Baby Deaths

Meaning and relevance

All baby beaths should be investigated because systematic review of each case is essential for understanding why babies die, identifying modifiable factors, improving care and safety for women and babies. Structured in-depth clinical reviews of baby deaths are an essential component in high-quality maternity care systems. These reviews provide an opportunity to assess and reflect on the care provided, identify potential contributing factors or areas of improvement, and support learning to prevent recurrence of a similar event (41). The latter is the main objective of ongoing reviews of baby deaths and the ultimate goal of this action plan.

Perinatal death reviews can also give bereaved parents a sense of acknowledgement and help them understand why their baby died, which may support their grieving and inform decisions in relation to any future pregnancies (40). These review processes must be designed to be sensitive, transparent, and inclusive of parents' perspectives.

National and international evidence

International evidence reinforces the importance of structured perinatal death reviews. A comparative synthesis conducted in 2021 examined stillbirth review processes across high-income countries. The study identified wide variation in practice in terms of structure, timing and parental involvement. Findings highlight that best practice for stillbirth reviews include adopting a multidisciplinary approach, using a structured national tool, including parents in the process, and availing of a system for escalation and dissemination of findings and learning points (35,41). This work, led by researchers at the PLRG and NPEC, demonstrated the need for a respectful, flexible system that includes bereaved parents in their baby's perinatal death review (40) Parental involvement is not currently a routine part of perinatal death review processes in Ireland (39,40).

At national level, in 2025, NWIHP commissioned NPEC to develop the National Perinatal Quality Care Review (NPQCR). The NPQCR is proposed as a confidential, consent-based national review process that applies only to perinatal deaths meeting specific inclusion criteria. IN proposals, and where parental consent is provided, relevant medical records are anonymised and reviewed by an independent multidisciplinary expert panel using agreed national standards. The NPQCR is not intended to replace local hospital reviews, but to provide additional, system-level learning by examining patterns across cases. Families and healthcare professionals will not be identifiable in national outputs, and findings will be synthesised by NPEC into national reports to inform quality improvement, prevention efforts, and policy. At the time of writing of this action plan, the NPQCR has not commenced, but is planned by NWIHP to start in 2026.

In contrast, routine perinatal death review should be embedded within everyday clinical governance at hospital level. In Ireland, a standardised data collection tool — the

Perinatal Mortality and Morbidity Evaluation and Review Tool (PMMERT) — has been developed and piloted through collaboration between NPEC and the NWIHP to support routine review of selected perinatal mortality and morbidity events (such as neonatal encephalopathy and intrapartum death)[xxiv]. PMMERT is intended to be used by maternity hospitals/units as part of their standard review processes, enabling consistent documentation, reflection, and local quality improvement. While PMMERT is currently in use in some units, and for selected intrapartum perinatal mortality events, it has not yet been formally published, evaluated, or implemented nationally.

Internationally, the Perinatal Mortality Review Tool (PMRT), developed by MBRRACE-UK, provides an example of a mature, nationally supported routine local review system (124). The PMRT has been associated with more consistent and higher-quality reviews, improved identification of modifiable factors, and national synthesis of learning through published reports. It also includes structured guidance and materials to support parental engagement in local review processes.

The ACHIEVE project[xxv] (See Box 7), funded by Féileacáin and led by the Pregnancy Loss Research Group (PLRG) with experts by experience, is evaluating and refining the use of NPEC's PMMERT for all perinatal deaths. This includes antepartum stillbirths, with a particular focus on developing and testing a structured pathway for parental involvement throughout the stillbirth review process, drawing on recent Irish research on review quality and parent inclusion (37,39,40).

Box 7. The ACHIEVE project - Appraise and change perinatal mortality events: Structured evaluation and implementation of a national perinatal mortality review tool for Ireland

Led by the PLRG, in collaboration with NPEC

- National research project focused on the evaluation and refinement of the Perinatal Mortality and Morbidity Evaluation and Review Tool (PMMERT) to support structured, consistent review of stillbirths and other perinatal mortality events in Irish maternity hospitals/units
- Funded by Féileacáin, with support from the INFANT Research Centre, UCC College of Medicine and Health, Ireland South Women & Infants Network, and NPEC
- Builds on Irish and international research identifying the need for a national perinatal death review system with defined team composition, timelines, and parental involvement
- Key activities include evidence synthesis, assessment of barriers and facilitators to implementation, development of the PMMERT tool for review of all stillbirths, and pilot testing in selected maternity hospitals/units

[xxiv] https://www.ucc.ie/en/npec/resources/npecdatahub/perinatalmortalityandmorbidityeventreviewtool/
[xxv] https://www.ucc.ie/en/pregnancyloss/researchprojects/achieve/

- Aim: to inform future national implementation of a standardised, high-quality perinatal mortality review process in Ireland.

Actions proposed for Ireland

4.a Ensure there are robust processes in each maternity hospital/unit to review baby deaths, with regional reporting of findings, and action plans/learning events as appropriate.

At hospital or unit level, perinatal death reviews should be embedded as routine, multidisciplinary clinical governance activities, in a supportive interdisciplinary setting, with clearly defined triggers, timelines and outputs. Local reviews require relatively modest infrastructure compared with national enquiries but are pivotal for identifying unit-specific contributory factors and providing feedback to both frontline staff and bereaved families (36,41).

Well-managed clinical perinatal mortality meetings, essential for clinico-pathological classification of cause of death and discussion of future pregnancy management, when inclusive and explicitly oriented towards system learning, can foster open discussion of care standards and support implementation of change (125). Structured investigation of both clinical care and system factors rather than narrow attribution of cause alone is important, and hospitals/units also need to situate death review findings within broader quality-improvement programmes and according to national frameworks

To support implementation, the following resources will be required:

- All hospital/units should have access to a multidisciplinary guideline-informed clinical-perinatal mortality meeting, where case discussions of perinatal deaths lead to recommendations for future pregnancy care, as well as learning notices for frontline staff. This requires investment in perinatal pathology structures at regional level and leadership from hospital management to prioritise regional working arrangements.
- A nationally co-ordinated system using a standard format for all perinatal death reviews locally and regionally would help to ensure that all local and regional perinatal death reviews in Ireland are of the same standard and depth and follow the same structure.
- To complete local reviews, the multidisciplinary review team needs to have the appropriate resources available, including protected time, managerial and administrative support, with appropriate training for hospital staff who are participating in reviews.
- Establishment of a nationally coordinated learning platform to collate themes, recommendations, and action plans arising from local and regional perinatal death reviews. This platform should enable structured national reporting of learning, support transparency for parents and the public, and facilitate cross-site quality improvement while maintaining appropriate governance and confidentiality safeguards.

4.b Develop the Perinatal Mortality and Morbidity Review Tool (PMMERT) for all perinatal death case reviews alongside a new process for stillbirth review that involves parents (via the ACHIEVE project).

While PMMERT has been developed has been developed by NPEC and NWIHP, and is in use in some settings, there is currently no nationally approved, standardised process for stillbirth review using PMMERT, nor has the tool or associated review process been formally evaluated. Further resources are therefore required to support the development, standardisation, implementation, and evaluation of PMMERT and its related processes, including agreed procedures and training for staff.

To support implementation, the following resources will be required:

- National implementation oversight of the PMMERT tool with continued technical and research input from NPEC and PLRG.
- Development of national guidance for PMMERT use and for the revised PMMERT process, including review team composition and approach, timelines, reporting of findings.
- Administrative support, IT infrastructure and protected time for the teams conducting the reviews in any new e.g. NPQCR process.
- Developing a structured approach to parental involvement in all stillbirth reviews (via the ACHIEVE Project[xxvi]) with the objective of:
  - Developing clear guidelines and structured opportunities for parental engagement through the process.
  - Providing resources and support for parents.
  - Training healthcare professionals on how to facilitate this process.
  - Evaluating the impacts for everyone of parental involvement in reviews.

4.c Evaluate and refine the use of the new PMMERT process through implementation and ongoing review of the baby death review process in all maternity hospitals/units.

NPEC, with oversight from NWIHP, should coordinate a structured evaluation of PMMERT use, including audits of tool completion, quality, and multidisciplinary input. Structured feedback from local clinical teams and bereaved parents should be gathered to refine the tool and review process.

To support implementation, the following resources will be required:

- Designing a standardised evaluation framework including criteria for completeness, data quality and multidisciplinary team participation.
- Establishing of feedback mechanisms for bereaved parents to assess their involvement in the expanded PMMERT process and how it could be improved.

[xxvi] ACHIEVE – Appraise and CHange PerInatal Mortality EVEnts: Structured evaluation and implementation of a national perinatal mortality review tool for Ireland.
https://www.ucc.ie/en/pregnancyloss/researchprojects/achieve/

4.d Report findings annually at regional level, including the status of implementation of recommendations, from PMMERT nationally and to the Minister for Health.

Ensure annual reporting and dissemination of findings from the PMMERT review process including learning points and identified actions. Reports should be shared with healthcare professionals, clinical governance teams, policymakers (e.g. Department of Health), support organisations and advocacy groups to inform quality improvement initiatives.

NWIHP should produce annual national reports which document the findings, recommendations and status of implementation of recommendations from PMMERT findings, highlighting modifiable factors and learning themes. These reports should be shared with the Department/Minister for Health, as well as through HSE clinical and regional networks, audit leads, and published online (i.e. made publicly available).

Maternity hospitals/units should also receive unit-specific feedback to support local action planning, with support from NWIHP and Quality & Patient Safety leads.

To support implementation, the following resources will be required:

- Designated resources for data collection and analysis to support national and unit-level reporting.
- Annual PMMERT reporting and dissemination plan, led by NWIHP, outlining progress on implementing recommendations, new actions added, and updated priorities. Reports and learning notes should be issued to the Department of Health, HSE Regional Executive Officers, Clinical Directors/Masters and Directors of Midwifery/Nursing of maternity hospitals/units, and frontline staff through targeted briefings to support accountability and continuous learning.
- Establishment of a process to identify and prioritise focused audit topics based on findings from the new PMMERT process.

4.e Improve Coronial processes to reduce delays, improve communication with families and clinicians, and ensure coronial findings inform care improvements.

In Ireland, all baby deaths are *mandatorily reportable* to the Coroner under the Coroners Act (1962), as amended by the Coroners (Amendment) Act 2019 (126). While this requirement ensures independent oversight, it can also lead to delays in post-mortem examinations, which in turn delays results communicated to families, and to clinicians (40). The cause of death may be omitted from the Perinatal Mortality National Clinical Audit if an Inquest is planned and held after the annual audit is published. The delay in communication of results and changes in communication with clinicians as a result of the Coronial process can be distressing for bereaved families and slows and impedes the care improvement cycle.

To support implementation, the following resources will be required:

- To ensure timely availability of Coronial investigations/findings to inform care planning for women and families:
    - A legislative or policy review, in consultation with the Department of Justice and the Coroner's Service, to explore options for expedited post-mortem report authorisation and more efficient pathways, particularly in antepartum stillbirth cases.
    - Development of clear, accessible information for parents about Coronial review processes, including parental involvement and review timelines.
- To ensure Coronial findings inform service-level and national care improvements:
    - Mechanisms to ensure findings and recommendations from Coronial Inquests are shared efficiently with maternity services, including directly to Clinicians, and integrated into PMMERT reviews and the Perinatal Mortality National Clinical Audit should be put in place.
    - A national process to review all Coronial recommendations across different maternity hospitals/units should be considered to examine common issues that arise and determine where national action might be required.

PILLAR 5: Driving Research Informed Care

Meaning and relevance

High-quality evidence is necessary to understand why perinatal deaths occur, identify mechanisms or tests to improve risk stratification, identify at-risk babies accurately, develop effective interventions to end preventable baby deaths and improve care experiences and outcomes more broadly. Internationally, women's health research, and pregnancy loss and stillbirth research, has been consistently under-prioritised, with organisations such as Sands (UK) and the World Health Organization recognising this gap and issuing clear calls for investment and coordinated action (8,127,128).

Research into pregnancy and baby loss is often poorly integrated into policy and practice, underscoring the need for sustained funding, clearer research priorities, and stronger systems to translate evidence into action (44). In Ireland's national perinatal mortality audit, a cause of death is reported as identified in 94% of perinatal deaths (2). However, research translating known causes of death to prevention strategies appears unprioritised.

Research priorities under this pillar should be closely aligned with the objectives of the Women's Health Action Plan (46) and the National Maternity Strategy (45) and any future iterations of these frameworks, as well as with the wider international calls/research prioritisation strategies (23,25,70,129–131), ensuring that new evidence directly informs national policy implementation and service planning.

Investment in the generation of research and implementation of research findings drives progress across all areas of perinatal health: from understanding biological causes, such as placental dysfunction or preterm birth, to addressing behavioural and social determinants of health, and understanding and tackling inequities. It also drives innovation in screening, diagnostics, and treatment, and ensures that public health messaging and clinical guidelines are based on the best available evidence.

Research must be rapidly completed with evidence turned into practical tools, clear communication, and policies that reduce risks and improve safety for families. Research should be developed in partnership with all knowledge users, including women, pregnant people, families, and bereaved parents, to ensure that it is relevant, appropriate, and grounded in lived experience and needs. Progress will also depend on interdisciplinary collaboration, drawing on clinical, social, behavioural, data and implementation science expertise, to ensure that new knowledge leads to effective, equitable and scalable changes in practice.

National and international evidence

As outlined above (see Box 2), research has identified several leading contributors to perinatal death, including placental dysfunction, fetal growth restriction, and complications of preterm birth (132,133). Advances in antenatal surveillance, risk stratification, and neonatal care have helped reduce mortality in high-income countries,

yet important gaps remain in identifying which pregnancies are most at risk and in ensuring consistent application of evidence-informed interventions (117,134). As discussed previously, stillbirth can occur in seemingly 'healthy' pregnancies with limited risk factors identified. While issues with the placenta are a leading cause of perinatal deaths, there are currently limited tests to understand if it is functioning effectively during pregnancy. Research gaps mean that at-risk pregnancies may not be identified.

In several high-income countries, stillbirth and perinatal mortality research has been prioritised through the establishment of dedicated national research centres and coordinated research programmes, for example, the Centre of Research Excellence in Stillbirth in Australia[xxvii] and the Tommy's Maternal and Fetal Health Research Centre in the UK[xxviii]. These centres have accelerated progress by bringing together multidisciplinary expertise, sustained funding, and strong links between research, clinical practice, and policy. More recently, the United States launched a coordinated national effort[xxix], which includes the University of Utah Stillbirth Center of Excellence[xxx] among its founding partners, to advance understanding of the causes of stillbirth and improve prevention. A similar coordinated research system does not yet exist in Ireland; while international research provides valuable insights, many challenges are context-specific, and there is also an opportunity to harness national expertise to both address priorities within the Irish context and contribute leadership at an international level.

In high-income countries, most neonatal deaths now relate to extreme prematurity or congenital anomalies (135). Survival has improved thanks to advances in perinatal care, but outcomes for very preterm babies remain a concern (135,136). Research is still needed to optimise pathways of care for preterm babies and babies with complex medical needs, and to better understand long-term outcomes.

There is strong evidence of inequities in perinatal outcomes in Ireland (11,137). Socioeconomic disadvantage, ethnicity, and lack of access to antenatal care remain consistent predictors of higher perinatal mortality (6,136,138). Understanding and addressing these inequities through focused research is essential to achieving improved outcomes.

Behavioural risk factors—including smoking, inadequate antenatal attendance, and sleep practices—are also associated with perinatal mortality (15). Public health initiatives such as safe sleep campaigns have shown impact, yet awareness and uptake of protective behaviours remain uneven (50,51,139). Research into acceptable and effective behaviour change interventions during pregnancy is also needed to strengthen prevention efforts, as similar approaches in other high-income countries (for example, the UK and Australia) have demonstrated reductions in stillbirth rates following the implementation of structured behaviour-change programmes such as the *Saving Babies' Lives Care Bundle* (21,25) and *Safer Baby Bundle* (19,22) as previously mentioned. Importantly, further research is required to inform the design and

[xxvii] www.stillbirthcre.org.au
[xxviii] https://www.tommys.org/our-research/our-research-centres/tommys-maternal-and-fetal-health-research-centre
[xxix] www.nih.gov/news-events/news-releases/nih-launches-consortium-reduce-risk-stillbirth-us
[xxx] medicine.utah.edu/obgyn/utah-stillbirth-center

implementation of such interventions to ensure communication and education are appropriate, equitable, and do not reinforce stigma or contribute to unintended harms. Drawing on implementation science will also be crucial to support the uptake, scalability, and long-term sustainability of recommended interventions and actions.

Ireland has a well-established national perinatal mortality audit system, coordinated by the NPEC, which produces high-quality data and valuable insights (97). Strengthening the translation of these audit findings into service improvements remains a key research and policy priority.

Actions proposed for Ireland

5.a Invest in research aligned with priorities outlined within this action plan through national research funders including the Health Research Board, Research Ireland and Enterprise Ireland.

Sustained investment through national funders (e.g. Department of Health - Health Research Board, Department of Further and Higher Education, Research, Innovation and Science - Research Ireland) and participation in European and global funding programmes will be essential to address knowledge gaps and translate evidence into policy and practice, e.g. through updated national guidelines and clinical practice through NWIHP.

To support implementation, the following resources will be required:

- Ensuring the specific areas in this action plan are considered within future funding calls / research priority areas put forward by funding bodies and by Government (e.g. Department of Health, Women's Health Taskforce).

5.b Aligned with 5.a, invest in researchers/clinician researchers and research systems to create the supportive environments required to deliver, high-quality, timely research as part of learning health systems, academic health sciences systems, and research ecosystems.

Creating, sustaining and scaling structures to support researchers/clinician researchers and research systems is vital to delivering, high-quality, timely research in relation to aid efforts to end preventable baby deaths, and improve health more generally. There is a role for Government, public funding bodies, the health services and others in this regard.

There are other opportunities for progress, as an Academic Health Sciences System[xxxi] is developing in Ireland - a fully coordinated partnership between a university and a healthcare system, designed to deliver quality care alongside teaching, training, research and innovation incorporating the full spectrum of the healthcare workforce.

[xxxi] https://www.ucc.ie/en/academichealthsciences/system/

To support implementation, the following resources will be required:

- Explicitly adopt a learning health system linked to Sláintecare[xxxii] and universal healthcare, so research is seen as core infrastructure rather than a discretionary activity, with recognition of research time and expectations.
- Expand and adapt research career frameworks to support embedded researcher / clinician researcher roles and including early- and mid-career development.
- Use models from learning health systems and implementation research, where researchers are co-located in services and jointly line-managed to support change and system learning.

5.c Develop a theory-based behaviour change intervention to address the modifiable risk factors for stillbirths and an associated implementation strategy (via the RELEVANT project).

Researchers from the PLRG and NPEC, in collaboration with behavioural experts from the School of Public Health at UCC, are currently developing a theory and evidence-informed behaviour change intervention to address the modifiable risk factors for stillbirth, including smoking, alcohol and substance use, sleep position, antenatal care attendance and weight management behaviours. This work will provide the evidence base, tools, and implementation guidance needed to support healthcare professionals in PILLAR 2, where identifying risk and supporting behaviour change form key components of routine antenatal care.

To support implementation, the following resources will be required:

- Piloting the behaviour change intervention in a maternity hospital/unit to evaluate feasibility, acceptability, and impact prior to wider implementation, followed by a hybrid implementation–effectiveness trial to assess outcomes and inform national scale-up.
- Protected time for healthcare professionals to train and deliver the intervention components as part of routine care.
- Training for maternity staff and community-based healthcare services on behavioural risk factors, sensitive communication and referral pathways.
- Reinforcing referral structures to existing supports (e.g. smoking cessation officers, addiction services, diabetes clinics).

5.d Advance pathological and clinical studies and invest in research structures to understand the biological causes of baby deaths and preterm births and develop screening, prediction and diagnostic tools.

Further research is needed to deepen understanding of the biological mechanisms that underlie baby deaths. In particular, placental dysfunction, fetal growth restriction, and congenital anomalies remain central but incompletely understood contributors. The

[xxxii] https://www.gov.ie/en/department-of-health/publications/sl%C3%A1intecare-publications/#slaintecare-action-plan-2023

NPEC, in collaboration with pathology departments and maternity hospitals/units, should strengthen placental pathology data collection to build a clearer picture of causes and mechanisms.

In parallel, the development and validation of novel screening tools and biomarkers is required to better identify babies at risk, enabling earlier and more targeted interventions to improve outcomes. Current screening methods detect only a proportion of at-risk pregnancies. Research has shown that uterine artery Doppler screening detects less than 50% of fetal growth restriction (140) and that selective ultrasonography identifies only 20% of small-for-gestational-age infants (141). This highlights the need for improved predictive tools. Strengthening this evidence base would support more precise risk stratification and inform national guidelines for monitoring and intervention. Research in this area should be integrated within existing international collaborations, and appropriately funded, to ensure consistency and comparability.

To support implementation, the following resources will be required:

- Investment in placental pathology services and perinatal post-mortem capacity within the public maternity and pathology services in Ireland, potentially supported through cross-jurisdictional collaboration and mixed funding models, including targeted staff training and infrastructure at key centres to ensure timely access for all maternity hospitals/units.
- Development of a national biobank for perinatal tissue and clinical samples to support ongoing research, including funding for biomarker and diagnostic studies, in collaboration with relevant national bodies such as the National Biobanking Working Group and regulatory authorities, to ensure alignment with existing governance and consent frameworks for human biobanking.
- Strengthening of national post-mortem and placental histology data collection and reporting systems/processes led by the HSE in collaboration with NPEC and hospital pathology services, to ensure findings are standardised, accessible, and used to inform prevention.
- Mechanisms to ensure rapid translation of findings into clinical practice and guideline updates, such as formal feedback loops between pathology services and NWIHP and scheduled reviews of national guidelines informed by emerging evidence.
- Investment in coordinated national research infrastructure and multidisciplinary expertise in placental pathology and stillbirth prevention, aligned with international best practice.
- In the longer term, Ireland could establish a national centre of excellence in placental and stillbirth research to match leading programmes in the UK, Australia, and Canada, with scope to explore all-island collaboration and shared research infrastructure where appropriate.

5.e Investigate how inequities lead to adverse outcomes and address barriers to high-quality care.

This work should be led by the HSE National Social Inclusion Office, NPEC, PLRG and academic research groups in collaboration with community organisations, members of the public, and maternity hospitals/units supporting the findings of the Migrant Women & Ethnic Minority Group Experiences Project[xxxiii] (Box 8).

Box 8. Migrant Women & Ethnic Minority Group Experiences in Maternity Care

- The Migrant Women & Ethnic Minority Group Experience Project examines migrant and ethnic minority women's experiences of the Irish maternity services, and system-level factors that contribute to inequities in care.
- Project findings show persistent national gaps in the collection of ethnicity data, and in communication support tailored to these women. A lack of structured, culturally responsive care continues to discourage optimal engagement with the services.
- When maternity systems cannot accurately identify who is using the services, or communicate effectively with them, they cannot monitor or address potential inequities. As a result, preventable risks for some mothers and babies remain unaddressed.
- Change requires coordinated, system-level action that supports the implementation and evaluation of targeted models of care.
- The next steps of this project involve piloting improved ethnicity data collection processes aligned to the latest Central Statistics Office categories per national guidance, improving linguistic support, and working alongside women from migrant and ethnic minority backgrounds to inform national practice.

Recent national analyses have demonstrated disparities in perinatal mortality across ethnic groups in Ireland (11,142), indicating that inequities in care are also reflected in adverse outcomes. Findings from the National Perinatal Mortality Clinical Audit have similarly identified the over-representation of certain groups, including women from minority ethnic backgrounds and Irish Travellers, among perinatal deaths (2).

Addressing the structural barriers identified through this project is therefore an important component of efforts to reduce preventable baby deaths.

Research should focus on identifying which groups are disproportionately affected, understanding barriers to accessing and engaging with maternity care, and evaluating interventions designed to improve equity of access and outcomes. Findings must be rapidly translated into policy and service delivery through the Department of Health and NWIHP.

[xxxiii] https://www.ucc.ie/en/npec/research/qualityimprovement/memproject/

To support implementation, the following resources will be required:

- Expand and scale up the Migrant Women & Ethnic Minority Group Experience Project across Ireland, ensuring representation of diverse migrant and ethnic minority populations in the research structures, to collect robust data on their maternity and perinatal care experiences, identify systemic barriers, and inform tailored interventions and policies.
- Enhance analysis of perinatal audit data by demographic and socioeconomic variables — including improved capture of ethnicity and integration of a national deprivation index — coordinated by NPEC, with reporting at both national and regional (maternity hospital/unit or hospital group/health region) levels to identify and address inequities.
- Funding for evaluation and implementation of equity-focused interventions, including strengthened interpreting services, co-designed services and supports, and more flexible and accessible antenatal care pathways, to improve access and outcomes for migrant and ethnic minority populations.
- Mechanisms within HSE and the Department of Health to translate research findings into responsive policy with sufficient/appropriate resource allocation.

5.f Maintain and strengthen the NPEC Maternal and Fetal Classification system[xxxiv], ensuring compatibility with international frameworks (such as ICD-PM), and aligning with the work of the International Stillbirth Alliance improving global cause-of-death classification and reducing the proportion of unexplained stillbirths.

Ireland already has a robust classification system used for perinatal deaths[xxxv] developed and implemented by NPEC through the Perinatal Mortality National Clinical Audit. This provides a strong foundation for understanding causes of death and informing prevention. However, ongoing refinement is needed to ensure Irish data remains aligned with emerging international standards, supports standard and consistent interpretation across all maternity hospitals/units, and maximises its value for both research and clinical practice.

Work should therefore focus on maintaining and strengthening the NPEC classification system, ensuring compatibility with international frameworks (such as ICD-PM: International Classification of Diseases to Perinatal Mortality), and specifically aligning with the work of the International Stillbirth Alliance[xxxvi] on improving global cause-of-death classification and reducing the proportion of unexplained stillbirths (143).

[xxxiv] NPEC Maternal and Fetal Classification System. Available at https://www.ucc.ie/en/npec/clinical-audits/perinatalmortalitynationalclinicalaudit/annualreport2023/npecmaternalandfetalclassificationsystemdefinitions/

[xxxv] https://www.ucc.ie/en/npec/clinical-audits/perinatalmortalitynationalclinicalaudit/annualreport2023/npecmaternalandfetalclassificationsystemdefinitions/

[xxxvi] https://www.stillbirthalliance.org/

To support implementation, the following resources will be required:

- Continued investment in the NPEC Perinatal Mortality Audit and its classification system.
- Ongoing review and refinement of the classification framework to reflect international best practice.
- Training and guidance for clinicians to ensure consistent application across all maternity hospitals/units.
- Technical support to integrate classification data with MN-CMS and other national data systems.
- Mechanisms to ensure findings from classification are used systematically in policy, audit, and prevention strategies.

5.g Better understand and enhance communication around pregnancy and baby loss and related risk factors across society, including within political, public and clinical spheres.

Undertake interdisciplinary research to examine and improve how pregnancy loss and related risks are communicated within maternity services and in with the wider public. This should go beyond information provision alone to consider who delivers messages, how they are delivered, in what contexts, and how power, stigma, and institutional norms shape communication. Improved communication is needed not only to support women and families, but also to inform healthcare practice, public understanding, and decision-making among those with responsibility for policy, service planning, and system improvement in relation to preventable baby deaths. Research should ensure that communication approaches are accurate, accessible, sensitive, and equity focused.

To support implementation, the following resources will be required:

- Dedicated funding for mixed-methods interdisciplinary research and co-design activities (e.g. Department of Health, Health Research Board; Department of Further and Higher Education, Research, Innovation and Science, Research Ireland).
- Expertise from service users, maternity clinicians, behavioural science, implementation science, linguistics, discourse analysis, law.
- Mechanisms to support integration of findings into clinical guidance, education, and practice across the health system and wider public sphere, including through the HSE (e.g. NWIHP, Social Inclusion, Healthy Childhood Programme), the Department of Health and other relevant Government Departments, public bodies, and public-facing channels such as media and civil society organisation.

CONCLUSION

This document outlines the **actions** needed to end preventable baby deaths in Ireland. **It focuses on priority measures that can be implemented now**. The action plan will need to be reviewed and updated over time to ensure continued relevance and progress in reducing baby deaths.

This action plan has been conceptualised building on successful international care bundles, as well as multidisciplinary research, clinical and lived experience from the Irish context.

The proposed pillars/priority areas of our Action Plan to End Preventable Baby Deaths are:

- **PILLAR 1: Public Awareness & Education |** Enhance knowledge and awareness of risk factors related to baby deaths within the general population and before and during pregnancy.
- **PILLAR 2: Risk Awareness & Communication |** Ensure risks in pregnancy are assessed consistently by healthcare professionals and communicated clearly and with sensitivity within healthcare settings.
- **PILLAR 3: Best Care, Every Time** | Deliver consistent, high-quality, evidence-informed care for every pregnancy.
- **PILLAR 4: Ongoing Review of Baby Deaths |**Make maternity services safer through ongoing review of baby deaths and learning, to implement recommendations and drive care improvements.
- **PILLAR 5: Driving Research Informed Care |** Invest in research for better policy, practice, and outcomes.

There are multiple challenges associated with implementing a proposal like this at national level in Ireland. These challenges relate not only to differences in hospital/unit size, staffing levels, and access to specialised services and resources across hospitals, but also to the wider system context in which change is delivered. Achieving meaningful, sustained progress will require political commitment and Government support, as seen in other countries that have prioritised stillbirth prevention, together with adequate resourcing and long-term investment. The newly established Cross-Party Oireachtas Group on Pregnancy and Infant Loss[xxxvii] can play an important role in building momentum, raising awareness, and ensuring continued political attention.

This document is intended as a strategic, evidence-informed framework for action rather than a fully operational implementation plan. The latter will require national

[xxxvii] www.ucc.ie/en/pregnancyloss/policyandadvocacy/cross-partyoireachtasgroup

policy leadership and coordination, led by Government and the Department of Health, in partnership with the HSE (including the NWIHP and other named HSE programmes) and relevant interest holders. There is a role for a **dedicated national lead and/or working group** to support coordinated implementation and monitoring over time.

It is also important to recognise that pregnancy and infant loss does not always receive the same visibility as other areas of women's health, and stigma or discomfort around discussing baby deaths can limit both public and political engagement. Addressing these barriers through **clear communication, public education, and active leadership will be essential**.

NWIHP will play a key role in leading implementation, supported by local maternity clinical teams, hospital management, and academic partners, while ensuring that local needs, possibilities, and limitations are acknowledged in designing an implementation strategy that works across all maternity hospitals/units. **The action plan needs national standardisation, despite regionalisation, to ensure people receive the best care, regardless of where they live or their means.**

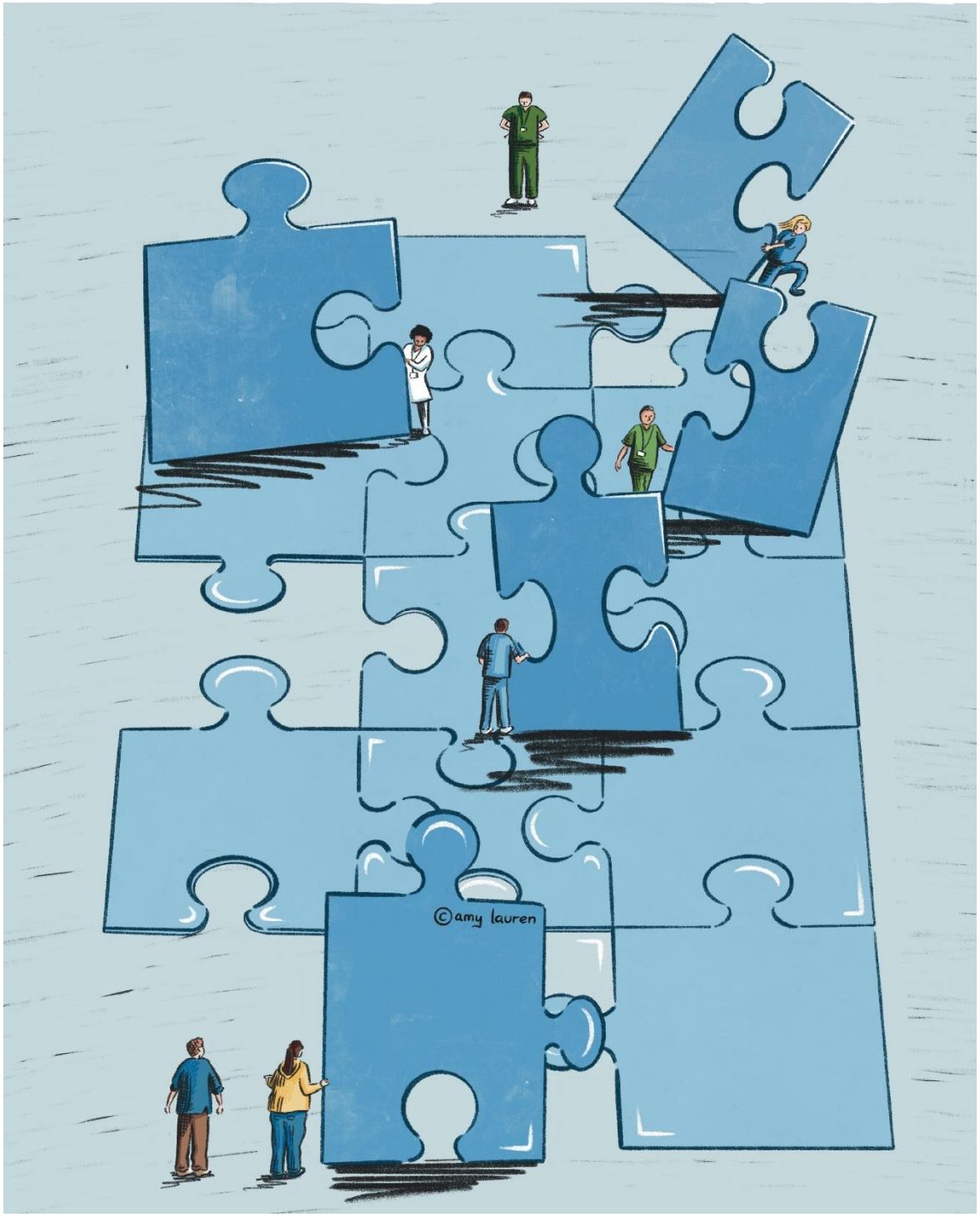
This '*Ending Preventable Baby Deaths'* action plan suggests a multi-level approach to perinatal death prevention, including public health initiatives and detailed clinical care pathways. To successfully implement this proposal, input and co-creation with interest holders from multiple disciplines is necessary. As such, this proposal should be viewed as an evolving proposal, adaptable to the changing needs of the health regions and healthcare system.

Furthermore, designing and implementing a robust evaluation framework will be critical to measure the proposal's impact on reducing perinatal death rates and improving perinatal outcomes across Ireland. This evaluation framework should include roll out in a number of sites, longitudinal studies and the establishment of key performance indicators such as stillbirth rates, changes in clinical practice, and observed behaviour change. Adequate resourcing across staffing, training, and IT Infrastructure will also be essential to deliver this action plan effectively and equitably.

Preventing perinatal deaths is not solely about reducing mortality. Many of the same interventions that reduce stillbirth and early neonatal death, including improved identification of fetal growth restriction, management of hypertensive disorders, optimisation of maternal health, and timely decision-making around birth, also reduce serious maternal and neonatal morbidity. These improvements have implications that extend beyond pregnancy, influencing long-term maternal cardiovascular health, child neurodevelopmental and metabolic outcomes, and future health service utilisation.

As such, investment in preventing baby deaths represents not only a moral and clinical imperative, but also a broader public health and economic strategy, with potential long-term benefits for women, babies, families, communities, the health system and society more broadly.

'Ending Preventable Baby Deaths' **is our call to action to start prioritising reductions in baby deaths in Ireland. By combining evidence-informed research and practices, multidisciplinary input and knowledge users' engagement in all units and nationally, we can improve pregnancy and perinatal outcomes.**



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Appendix 1. Working Group Members

Pregnancy Loss Research Group

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Glossary

A

ACHIEVE project: A research initiative in Ireland focused on involving bereaved parents in the review of stillbirths and neonatal deaths, to ensure the review process is more compassionate and leads to better care improvements. The project is led by the PLRG and funded by Féileacáin. More information: https://www.ucc.ie/en/pregnancyloss/researchprojects/achieve/

Antenatal: Refers to the period before birth, during pregnancy. For example, **antenatal care** means medical care received while a person is pregnant.

Antenatal corticosteroids: Medications given to a pregnant woman (usually before a preterm birth) to help speed up the baby's lung development. This treatment improves a premature baby's chance of breathing safely after birth.

Assisted reproductive technologies (ART): Fertility treatments that help people become pregnant. Examples include *in vitro* fertilisation (IVF) and other medical procedures used to assist conception.

C

Congenital anomalies: Birth defects or structural anomalies present from birth (for example, heart defects or chromosomal conditions like Down syndrome). These can sometimes be life-threatening for the baby.

Count the Kicks: A public awareness campaign urging expectant mothers to monitor their baby's movements in the womb. By "counting the kicks," women can notice reduced fetal movements early and seek medical advice promptly.

Coronial process: Refers to the procedures followed by a Coroner when a death is investigated. In Ireland, all stillbirths must be reported to the Coroner (as required by law). The Coroner's investigation typically involves a post-mortem examination (autopsy) and possibly an inquest to determine the cause of death. Improving coronial processes (for example, reducing delays in post-mortems and better communication of results) can lessen distress for bereaved families and ensure that findings are used to improve clinical care.

E

Experts by experience: People with expertise based on their lived experience, for example, of a condition, use of a service, or in a particular role. In the context of this action plan, it often refers to bereaved parents who share their experience of pregnancy or baby loss to inform and guide better policies, services and/or care. It also extends to people who may use maternity services and the public more generally.

F

Féileacáin: The Stillbirth and Neonatal Death Association of Ireland – a non-profit organisation that supports anyone affected by the death of a baby during or after pregnancy (feileacain.ie). Féileacáin (meaning "butterfly" in Irish) provides information, memory boxes, support meetings and bereavement resources for families. More information: www.feileacain.ie

Fetal growth restriction: A condition where an unborn baby is not growing as well as expected in the womb. Fetal growth restriction (also called intrauterine growth restriction) means the baby's weight or size is below normal for the stage of pregnancy, often due to problems with the placenta or other factors. This raises the risk of complications, so doctors will monitor and manage the pregnancy closely.

G

Gestational diabetes: A form of diabetes that develops during pregnancy. It causes high blood sugar in the mother, which can lead to complications if untreated (such as a larger baby and difficult birth), but it usually goes away after the baby is born. Pregnant women with gestational diabetes are given dietary, exercise, or insulin treatment(s) to protect their health and the baby's health.

H

Health Service Executive (HSE): The public healthcare system in Ireland. The HSE is responsible for providing all of Ireland's health and social care services, including hospitals, community health services, and health promotion programmes.

Healthy Ireland: A Government-led national framework to improve the health and wellbeing of everyone living in Ireland. More information: https://www.gov.ie/en/healthy-ireland/campaigns/healthy-ireland/

HSElanD: The Health Service Executive's online Learning and Development portal. HSElanD provides e-learning courses and training modules for healthcare staff in Ireland (for example, modules on bereavement care and patient safety are available on this platform). More information: https://www.hseland.ie/

Hypoxic-ischaemic encephalopathy (HIE): A type of brain injury in a newborn baby caused by a lack of oxygen and blood flow around the time of birth. HIE can lead to serious neurological problems (it is a leading cause of neonatal seizures and long-term disability). Therapeutic cooling and supportive care are used to improve outcomes for babies with HIE.

Hypertension: High blood pressure. During pregnancy, hypertension can lead to complications such as pre-eclampsia (which threatens the health of mother and baby) if not managed. Blood pressure control and close monitoring help reduce risks associated with high blood pressure in pregnancy.

I

ICD-PM: Stands for *International Classification of Diseases – Perinatal Mortality*. It is a standardised system (developed by the World Health Organization) for classifying and recording causes of perinatal deaths (stillbirths and neonatal deaths). Using ICD-PM helps hospitals and researchers identify why babies die around the time of birth and compare data internationally to improve prevention efforts.

International Stillbirth Alliance (ISA): A global network of researchers, healthcare professionals, and parent advocates dedicated to stillbirth prevention and bereavement support. The ISA promotes research, awareness, and best practices to reduce stillbirth rates worldwide and improve care for affected families. More information: www.stillbirthalliance.org

M

Making Every Contact Count (MECC): A HSE programme that trains healthcare professionals to use routine appointments or contacts with people to offer brief advice on healthy behaviours. MECC focuses on health-related behaviours (like smoking cessation, healthy eating, alcohol use and physical activity) and in this context is being adapted to include pregnancy-specific advice on reducing risks to babies.

Maternal and Newborn Clinical Management System (MN-CMS): Ireland's electronic health record system for maternity and neonatal care. MN-CMS is used in maternity hospitals/units to record patient information, standardise care prompts (e.g. checklists for risk factors), and improve information sharing across hospitals/units.

Maternity and Children Quality Improvement Collaborative: An initiative in Scotland under the Scottish Patient Safety Programme to improve maternity and neonatal care quality. It implements evidence-informed practices in maternity hospitals – for example, improving how fetal growth issues are detected and managed – to make childbirth and newborn care as safe as possible.

MBRRACE-UK: Stands for *Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK*. MBRRACE-UK is a national programme that conducts systematic reviews of maternal and infant deaths in the UK to identify lessons and recommendations (twinstrust.org). It produces reports (such as the "Saving Lives, Improving Mothers' Care" report) and tools like the Perinatal Mortality Review Tool to help improve safety in maternity services.

Multiple pregnancy: A pregnancy in which a woman is carrying more than one baby (twins, triplets, etc.). Multiple pregnancies are higher risk, for example, they have greater chances of preterm birth and other complications, so they require extra monitoring and care.

N

National Health Service (NHS): The publicly funded healthcare system of the United Kingdom. In this document, the NHS is referenced in context with UK initiatives (such as the NHS's *Saving Babies' Lives* campaign). The NHS provides free health services to UK residents and is often cited in international comparisons of health strategies.

National Healthcare Communication Programme (NHCP): An Irish Health Service Executive initiative designed to support healthcare staff in learning, developing and maintaining effective communication skills with patients. This programme helps staff communicate clearly and compassionately with patients, their families, and colleagues. In the context of maternity care, leveraging the National Healthcare Communication Programme's training and tools can improve how professionals discuss sensitive topics (like pregnancy risks and stillbirth prevention) with expectant parents. More information: https://www.nhcprogramme.ie/

National Office of Clinical Audit (NOCA): An organisation in Ireland that oversees national clinical audits across healthcare (for example, audits of surgical outcomes, maternity care, etc.). NOCA works to collect and report reliable data on healthcare performance, so that hospitals and the HSE can improve quality of care. NOCA collaborates with NPEC on perinatal mortality audits to ensure consistent national data on baby deaths. More information: www.noca.ie

National Perinatal Epidemiology Centre (NPEC): The NPEC is a centre based in Cork that collects data and conducts audits and research on pregnancy and newborn outcomes in Ireland. NPEC produces the *Perinatal Mortality Annual Reports* and other reports to understand why stillbirths and neonatal deaths occur, and to inform prevention strategies.

National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death: These are Ireland's national standards (first launched in 2016, updated in 2022) to ensure that families who experience a pregnancy loss or perinatal death receive high-quality, compassionate care. The standards outline, for example, how hospitals should support parents emotionally, involve them in decisions, create memories (like offering memory boxes), and train staff in bereavement care (the TEARDROP programme was developed in line with these standards). More information: https://www.ucc.ie/en/pregnancyloss/impact/nationalbereavementstandards/

National Women and Infants Health Programme (NWIHP): A programme established in 2017 within the HSE to oversee and improve maternity, gynaecology, and neonatal services nationally. NWIHP leads the implementation of Ireland's National Maternity Strategy and related initiatives – coordinating the rollout of new models of care, clinical guidelines, and quality improvements across all maternity hospitals/units. It plays a key role in driving the action plan's recommendations. More information: https://www.hse.ie/eng/about/who/acute-hospitals-division/woman-infants/

Neonatal death: The death of a live-born baby within the first 28 days of life. An **early neonatal death** means a baby died in the first 7 days after birth, and a **late neonatal death** means the baby died between 7 and 28 days old. Early neonatal deaths, together with stillbirths, make up the *perinatal* mortality statistics. Reducing neonatal deaths often involves improving newborn intensive care and preventing preterm birth.

P

Parity: The number of previous pregnancies a woman has carried to a viable gestational age (around 24 weeks or more). For example, a woman who has given birth once (at term or late pregnancy) has a parity of 1. Parity is considered in risk assessments – first-time mothers and women with many children can have different risk profiles in pregnancy.

Perinatal death: A broad term for baby deaths occurring around the time of birth. It usually includes **stillbirths** (death of a baby before birth, after a certain pregnancy age) and **early neonatal deaths** (death of a newborn in the first week of life). By tracking perinatal death rates, health services measure outcomes for pregnancies and newborns and aim to identify preventable cases.

Perinatal Mortality and Morbidity Review Tool (PMMERT): A standardised tool for collecting data and conducting structured reviews of perinatal deaths and severe newborn complications. PMMERT was developed in Ireland through a collaboration between NPEC and NWIHP to ensure that each stillbirth or neonatal death is evaluated in a consistent, thorough way. The ACHIEVE research project is currently evaluating and refining PMMERT to support objective, uniform reviews for all baby deaths and to include parents in the review process. Nationwide use of PMMERT is expected to help hospitals learn from every case and prevent future baby deaths.

Perinatal mortality rate: A statistical measure of how often babies die around the time of birth, typically expressed as the number of perinatal deaths (stillbirths plus early neonatal deaths) per 1,000 total births. This rate is used to track and compare outcomes across populations. Ireland's perinatal mortality rate has remained roughly unchanged in recent years, with over 300 babies dying around the time of birth each year.

Placental insufficiency: A pregnancy complication where the placenta is not working well enough to supply the baby with oxygen and nutrients. Placental insufficiency can lead to fetal growth restriction and distress, because the baby isn't getting what it needs to grow. It is one of the leading identified causes of stillbirth – doctors may recommend early delivery if this condition threatens the baby in the womb.

Placental pathology: The examination of the placenta for disease or abnormalities. Analysing the placenta after a baby's death can reveal issues such as clots, infection, or inadequate blood flow that may have caused or contributed to the loss. In fact, histopathological examination of the placenta is recommended to help determine the cause of stillbirth. Ongoing research into placental pathology is important for identifying preventable problems and improving pregnancy outcomes.

PLATFORM: A research project led by the PLRG, that brought together researchers, key civil society partners, experts by experience and other knowledge users. to enhance the translation of pregnancy loss research into policy and practice in Ireland. More information: https://www.ucc.ie/en/pregnancyloss/researchprojects/platform/

Pregnancy Loss Research Group (PLRG): A multidisciplinary clinical research team based at University College Cork that studies all types of pregnancy loss. They also engage in advocacy and education to improve care for those experiencing pregnancy loss.

Preterm birth: When a baby is born too early, before 37 completed weeks of pregnancy. Preterm (premature) babies may face health challenges because they are not fully developed, and preterm birth is a major cause of neonatal death and long-term disabilities. Preventing preterm birth (for instance, by treating maternal conditions or using progesterone and antenatal steroids in at-risk pregnancies) is a key part of reducing infant mortality.

Q

Quality Improvement (QI): In healthcare, this refers to systematic efforts to make services safer, more effective, and more patient centered. QI often involves using data to identify problems and then testing changes in practice to solve those problems. For example, a maternity hospital/unit might form a QI team to review every stillbirth and implement changes (like new training or protocols) to prevent future deaths where possible. In the document, "QI teams" are mentioned as local hospital teams that work on continuous improvement.

R

Reduced fetal movements: A condition where a baby in the womb is moving less than usual or the mother perceives a significant decrease in the baby's kicks. Reduced fetal movements can be an important warning sign of fetal distress or other issues, so healthcare providers urge women to seek prompt evaluation if this happens. Campaigns like *Count the Kicks* specifically aim to raise awareness of reduced fetal movements to prevent stillbirths.

RELEVANT project: A research project in Ireland focused on stillbirth prevention. The RELEVANT project has been building evidence to develop a behaviour-change intervention that raises awareness of modifiable risk factors for stillbirth and supports pregnant women in reducing those risks. In short, this project is working on practical ways (like educational tools or campaigns) to improve pregnancy outcomes. More information: https://www.ucc.ie/en/pregnancyloss/researchprojects/relevant/

Royal College of Physicians of Ireland (RCPI): The professional medical college in Ireland responsible for training and accrediting doctors in specialties like obstetrics and gynaecology. The RCPI, through its Institute of Obstetricians and Gynaecologists, oversees specialist education for maternity-care doctors. It is an Irish professional body dedicated to improving medical practice and sets standards through exams and guidelines. In the action plan, RCPI is noted as a partner for incorporating stillbirth prevention into medical training. More information: www.rcpi.ie

S

Safer Baby Bundle: An Australian initiative comprising a "bundle" of five evidence-informed interventions to reduce stillbirth. The *Safer Baby Bundle* includes actions like supporting pregnant women to quit smoking, better detecting and managing fetal growth problems, encouraging mothers to sleep on their side in late pregnancy, raising awareness about decreased fetal movement, and optimising the timing of birth. Implementation of this bundle in Australia led to a significant reduction in stillbirth rates. More information: https://www.stillbirthcre.org.au/about-us/our-work/the-safer-baby-bundle/

Sands (UK): A charity in the United Kingdom dedicated to supporting families who have lost a baby and to reducing the rates of stillbirth and neonatal death. **Sands** stands for the *Stillbirth and Neonatal Death Society* (though it is commonly just called "Sands"). They provide bereavement support services and also work with healthcare systems on research and prevention initiatives. More information: www.sands.org.uk

Saving Babies' Lives Care Bundle: A set of practices introduced by the NHS in England in a coordinated approach to reduce stillbirth rates. The *Saving Babies' Lives Care Bundle* includes measures like better screening for fetal growth problems, helping pregnant women stop smoking, raising awareness of reduced fetal movements, and encouraging women to sleep on their side in late pregnancy. This care bundle has been associated with about a 20% reduction in stillbirths where it was put into practice. More information: https://www.england.nhs.uk/publication/saving-babies-lives-version-three/

Second-trimester loss: A pregnancy loss that occurs during the second trimester (the middle phase of pregnancy). A second-trimester loss – sometimes called a "late miscarriage" – is typically defined as a miscarriage happening after 12 weeks and before 23 weeks' gestation. After 23 weeks of pregnancy, the death of a baby in the womb is classified as a stillbirth. Second-trimester losses can have various causes, such as cervical insufficiency, problems with the placenta, or fetal abnormalities.

Sláintecare: Ireland's national healthcare reform programme aimed at achieving universal health coverage and improving healthcare delivery. **Sláintecare** (*sláinte* means "health" in Irish) is a ten-year plan to make healthcare accessible to all, provided based on need rather than ability to pay. In the context of this document, coordinating with Sláintecare ensures that maternity and baby-health initiatives align with the broader health system improvements. More information: https://about.hse.ie/our-work/slaintecare-our-strategy-for-improving-irelands-healthcare-system/

Sleep on Side: A public health campaign message that encourages pregnant women, especially in the third trimester, to sleep on their side. Research has shown that going to sleep in a side position (rather than flat on the back) in late pregnancy can reduce the risk of stillbirth. *Sleep on Side* campaigns have run in several countries to spread this advice.

Social, Personal and Health Education (SPHE): A component of the school curriculum in Ireland that covers health and wellbeing topics for students. SPHE includes education on relationships and sexuality, emotional health, and personal development.

SPRING project: The *Supporting Pregnancy and Reproductive health INformation and Guidance* study – an Irish project that developed age-appropriate educational materials for teenagers about fertility, pregnancy, and pregnancy loss. SPRING worked with students and teachers to introduce topics like miscarriage and stillbirth into the classroom in a sensitive way. More information: https://www.ucc.ie/en/pregnancyloss/researchprojects/spring/

Still Six Lives: A stillbirth awareness campaign (originating in Australia) named to highlight that six babies are stillborn every day on average. The *Still Six Lives* campaign educated the public about actions to reduce stillbirth risk (such as not smoking in pregnancy, monitoring baby's movements, and sleeping on the side). It is an example of a focused campaign on stillbirth prevention mentioned alongside others like "Count the Kicks.". More information: https://preventstillbirth.org.au/about/

Stillbirth: In Ireland, a stillbirth is legally defined as a baby born with no signs of life at or after 23 weeks of pregnancy (threshold changed from 24 weeks in 2024) or weighing at least 400 grams. Stillbirth is a devastating outcome; prevention efforts focus on known risk factors (like fetal growth problems, maternal health conditions, etc.) and prompt intervention when warning signs appear.

Sudden Infant Death Syndrome (SIDS): The sudden, unexplained death of an apparently healthy baby less than one year old, usually occurring during sleep. It is sometimes called "cot death" or "crib death." Public health campaigns on safe sleep practices (like placing babies on their back to sleep, in a smoke-free environment, with no loose bedding) have successfully reduced SIDS rates.

T

Thyroid disorders: Medical conditions affecting the thyroid gland, such as hypothyroidism (underactive thyroid) or hyperthyroidism (overactive thyroid). In pregnancy, uncontrolled thyroid disorders can increase the risk of complications like miscarriage, preterm birth or stillbirth. Proper management – for example, taking thyroid hormone replacement if needed – can reduce these risks.

Tommy's: A UK charity that funds research into pregnancy loss and provides information to parents. Tommy's focuses on preventing miscarriage, stillbirth and premature birth, and funds research centres that study these issues. More information: www.tommys.org

Pregnancy Loss Research Group

NATIONAL PERINATAL EPIDEMIOLOGY CENTRE

Féileacáin
Stillbirth and Neonatal Death Support Ireland