All-Party Parliamentary Group on Baby Loss

Written evidence submission to the National Maternity and Neonatal Investigation

March 2026

About the APPG on Baby Loss

The All-Party Parliamentary Group (APPG) on Baby Loss aims to raise awareness of what more can be done by the Government, Parliament and other agencies to improve care for families after pregnancy and baby loss, and to improve safety in maternity services to reduce the risks.

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About the evidence submission

The evidence submission was compiled following an APPG on Baby Loss meeting in March 2026, in which fifty-five attendees including MPs, bereaved parents and families, pregnancy and baby loss organisations, healthcare professionals, academics and legal representatives shared their views on the systemic and structural issues affecting pregnancy and baby loss during an open discussion session.

Minutes from the meeting are available here.

The APPG on Baby Loss also shared an online survey based on the discussion topics with our supporters, through which a further fifteen responses were received. The evidence submission below draws on the information shared with the APPG on Baby Loss through the meeting and survey.

The submission covers the following topics which relate directly to the terms of reference and methodology for the National Maternity and Neonatal Investigation:

1) National standards of maternity and neonatal care
2) Justice, compassion and accountability for bereaved parents
3) Tackling the impact of inequalities on maternity and neonatal care
4) Barriers to improvement of maternity and neonatal services.

The evidence reflects deep and persistent systemic failings across maternity and neonatal care in England, recurring over years despite multiple inquiries and investigations, with contributors describing failures in safety, communication, culture, accountability, and equity.

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Key recommendations

- Systemic change in maternity and neonatal services with a long-term funding plan to sustain this.
- Clear mandatory national guidance for delivering care in maternity and neonatal services with national oversight and local accountability, with interventions properly evaluated so services know what works.
- New national level ambitions to reduce rates of baby deaths and eliminate inequalities in outcomes.
- Compassionate and culturally sensitive communication and bereavement care to be core competencies for the maternity and neonatal workforce.
- A fundamental restructuring of the reviews and investigations processes following the death of a baby to centre bereaved families' needs and embed learning.
- Psychological support to be accessible for all bereaved parents who need it after baby loss.

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National standards of maternity and neonatal care

National guidance and standards of care

Consistent evidence based maternity and neonatal guidance overseen at a national level should be used in all hospitals to prevent misinterpretation or individual opinion influencing clinical guidance in Trusts. There is an urgent need for the Investigation to understand the drivers of local variation and to recommend clearer oversight.

Contributors shared that misinterpretation of NICE and RCOG guidance on conditions such as ICP, for example, are known to have negatively impacted care. Likewise, the use and recent ban of Intergrowth fetal charts demonstrates the avoidable perinatal deaths which can occur when Trusts deviate from unclear national guidelines.[1]

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[1] Corfield and Devlin (2025) Changes in the Choice of Fetal Growth Charts in England: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=5722522 and,
Merricks, Hugh and Gardosi (2025), Effect of INTERGROWTH-21st Charts on Identification of Small-for-Gestational Age Fetuses: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=5622033

Contributors highlighted how one of the key issues is that multiple agencies produce national guidance, creating confusion as to what guidance should be followed. Research from the Sands and Tommy's Joint Policy Unit highlights the perceived conflict between delivering care in line with national guidelines and personalisation/choice, which suggests that current guidelines do not offer sufficient flexibility or staff require more resources to support women and birthing people's choice. Analysis is needed to consider where local variation from national standards is justified.

Overall, contributors agree that clear and simplified mandatory national guidance is required, with sufficient flexibility to personalise care in response to local demographic needs. Staff need ringfenced time for training on guidance, as well as the resources to deliver them. Lastly, there is the need for strong national oversight to monitor adherence to guidance and the implementation of agreed standards, to hold organisations to account in meeting them.

Improving accountability at the Trust level

Contributors outlined that with no national capacity to provide oversight, monitoring or support, Trusts are currently left to their own devices. There are minimal systems to ensure that local guidance and delivery is in line with national standards. Local or regional clinicians interpret national guidance (much of which is not evidence based), resulting in significant variation in how national standards are translated into local policies.

Trust policies are often not openly available and only able to be obtained via Freedom of Information requests, which are often blocked. Boards often do not have the expertise or information to challenge deviations from national guidance, resulting in a lack of oversight. Regulators do little to monitor Trust level deviation from national standards in their own policies and often no action is taken when these are reported. Trusts are incentivised to avoid financial repercussions and reputational damage, and do not have sufficient capacity to thoroughly investigate internal failures.

These factors feed into a systemic lack of accountability for deaths at the Trust level. Guidance due to be published by the British Association of Perinatal Medicine indicates the pathways for reviewing a death, however, it is done within the clinical team involved and there is no obligation to report the deaths or statistics to a senior member of the Trust, meaning deficiencies in care can become ingrained into departments.

There should be clear lines of accountability in NHS Trusts and their Boards which should rest with the Chief Executive. Every hospital with a maternity or neonatal unit must review all cases where there has been harm or a baby death with mandatory external oversight and a commitment to appropriately investigate, review and change services to improve.

For example, respondents shared that a recent CQC inspection report for Sandwell and West Birmingham NHS Trust identified that of 19 PMRTs during the review period, found that none identified any issues that might have affected the outcome. However, the CQC review found growth restrictions detected but not acted upon, gestational diabetes tests not offered, neonatal resuscitation not carried out in line with guidelines, and lack of use of interpreter at antenatal appointments.

In their current form, regulators are not effective in helping to improve safety and quality performance at the Trust level, as they only examine high level issues and act punitively, rather than supporting improvement. Responses to concerns raised directly by families has been poor whilst a 3-year limitation to prosecutions mean action is rarely taken in time. There needs to be national capacity which clearly sets core safety and quality policies related to baby deaths based on the best available evidence.

Mandatory performance data monitoring and evaluating needs to occur at the national level overseen by DHSC, with a centralised system which flags when performance at Trusts drops below acceptable standards. Family experience data and parent input also needs to be integrated into monitoring and performance assessment. A consultant obstetrician who shared evidence recommended that the PMRT should consider having Regional Clinical Leads, so that regional trends can be identified more quickly and strategies put in place to improve safety and reduce mortalities.

While the new Maternity Outcomes Signal System (MOSS) is intended to enable early warning signals, effective intervention will rely on Trusts taking appropriate action. Boards must also be careful not to assume that the absence of MOSS alerts means their services are automatically safe.

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Justice, compassion and accountability for bereaved parents

Compassionate care and communication

A core theme throughout the evidence was poor interpersonal and organisational communication across every stage of care. Parents described being told incorrect information, and clinical staff dismissing their concerns about symptoms – including reduced fetal movements and severe pain. Contributors highlighted cases of staff failing to listen to parents or leaving them uninformed about next steps and escalation processes.

The impact of communication failures is profound. Contributors shared how poor communication had led to catastrophic delays in care and impacted the delivery of bereavement care, including memory making, follow up appointments, and the support received during subsequent pregnancies. There was often failure to flag that families had experienced a loss, with parents having to repeat their story because staff were unaware.

Contributors shared that where good, sensitive care was received, this often came from individual commitment and effort, rather than being supported by existing systems and structures in maternity and neonatal care, which can stand in the way of delivering compassionate care. This highlights the dedication of maternity staff but is not safe for their wellbeing. They must be supported to be able to deliver compassionate care within the system.

Communication skills are central to safety, compassion and trust. Contributors suggested adding training in communication to the midwifery curriculum, alongside mandatory and thorough training on bereavement care.

Midwifery students need to understand that handling bereavement is a core part of their profession. If staff do not wish to work with bereavement, then this may not be the correct career choice for them. This should be measured as part of core competencies to ensure staff qualifying into midwifery have the skills required.

Alongside core competencies, staff should be supported to access continual professional development in this area. Regular and ongoing bereavement care training must be available to all staff who may be providing care to bereaved families, including sonographers, ambulance staff etc. All staff need to be empowered to effectively support and advocate for bereaved families. This requires ongoing training in sensitive and effective communication to facilitate better care.

Transparency and the duty of candour

A cross-cutting theme was the entrenched culture of fear and avoidance within maternity services. Contributors repeatedly described a pattern where staff, departments, and trust leadership sought to avoid admitting mistakes, primarily to protect reputations, minimise legal exposure, or prevent regulatory and financial consequences. This included examples of staff being discouraged from speaking to families after the deaths of babies, details which could reflect poorly on the trust not being disclosed, clinical records downplaying concerns raised by parents, and staff fearing personal repercussions if they reported unsafe practice.

As shown in the Sands and Tommy's Joint Policy Unit's submission to the DHSC Duty of Candour review, multiple reports and reviews into the safety of maternity and neonatal services have found that staff do not consistently implement the statutory Duty of Candour and failures of transparency are a recurring theme.

The duty of candour exists within a system that does not incentivise staff to speak up or make them feel safe to do so. The 2023 NHS England staff survey found that a quarter (25%) of midwives do not feel secure raising concerns about unsafe clinical practice. The fear of litigation can create a toxic culture which ultimately makes the system less safe for families, with staff not feeling psychologically safe to share their concerns without potential prosecution, leading to a lack of honesty and trust.

Contributors described unsafe staffing levels, underfunded bereavement care, and pressures from senior leadership as core factors in deterring honesty and transparency. Capacity within governance teams, failure of hospital leadership to properly engage with these issues, and lack of external oversight further contribute to a culture which fails to embed learning and fulfil the duty of candour for bereaved parents and families.

Following the death of a baby, or any patient safety incident, hospitals must adopt a 'just culture', which prioritises learning and ensures both accountability and justice for families and for the NHS.

Investigations into the death of a baby

Contributors described investigation processes as fragmented, confusing, and inconsistent. Families often face delayed, multiple and overlapping investigations, none of which communicate effectively with one another. The investigation system operates in a way that undermines transparency, fuels mistrust, and leaves families without meaningful answers.

Although health care professionals have a legal and professional obligation to be open and transparent with bereaved parents, as determined by the Duty of Candour, this is not the reality experienced by many. Families reported missing or inaccurate notes, false information reported to regulators, and reviews which justified rather than explained sub-optimal care. These experiences point to an opaque and defensive system rather than one focused on learning, improvement and accountability.

Investigations need to be trauma-informed and timely. Bereaved parents want answers about why their baby died and, where relevant, for lessons to be learned to prevent other babies from dying in similar circumstance in the future. To achieve this, the current system for reviewing baby deaths needs to be fundamentally restructured to centre bereaved families' needs and embed learning.

Firstly, this requires simplifying and improving the review process to better enable parents to engage. The current systems for reviewing deaths are complex with unclear thresholds for local and national processes. Some deaths may go through multiple reviews (e.g. PMRT, MNSI) which are disjointed and do not share findings with each other. Reviews rely on clinical notes with limited opportunities for parents to attend review meetings, to feed in their perspectives or challenge findings.

A recommendation from contributors was the creation of a single portal where parents can view all the information and reports in relation to their case and upload their evidence. In Denmark, Danish Patient Compensation gathers all documents relevant to a case in one place and assigns an individual case worker, creating a single transparent process for all reviews and investigations.

Having centralised information and one point of contact could support families to understand the review processes, share their perspectives and challenge findings. An assigned case worker such as a Maternity and Neonatal Independent Senior Advocate (MNISA) could drive a more empathetic and human-centred approach and support parents with their right to challenge inaccurate information.

Learning and improvement following reviews

Learning from reviews must lead to improvements in service delivery. Reviews should focus on systemic issues and ensure that recommendations are informed by parental engagement, genuine and open reflection on what went wrong from staff, and independent scrutiny. Staff time must be ring-fenced to reflect on deaths in their maternity and neonatal services, implement recommendations and provide external oversight for other Trusts.

Current reviews suggest actions, but there is little oversight of their implementation. National, regional, Trust, and frontline services leadership must all play a role in a cohesive and joined up system to ensure accountability for implementation. Trust boards should take a more active role in monitoring the implementation of recommendations and understanding their impact.

Local Maternity and Neonatal Systems and national bodies should identify frequently occurring recommendations (regionally and nationally respectively), the level of implementation (or barriers to doing so), and the overall impact. Recommendations from investigations must be mandatory, urgent and be applied nationally, not just to the local Trust in which the investigation sits.

Contributors outlined that there must be a system for updating bereaved parents with the actions that have been taken following an investigation, supported by an evaluation of the outcomes and impact of these interventions.

Psychological support for bereaved parents and families

A consistent thread across the evidence heard by the APPG was the need for specialist mental health support for bereaved parents and families. The Sands *Lost in the System* report found that 81% of bereaved parents wanted specialist psychological support after pregnancy or baby loss, however only 17% were able to access specialist support through the NHS.

High thresholds and restrictive criteria for specialist NHS services meant that many women and birthing people do not meet the criteria for support from maternal mental health services and/or face long wait times for talking therapies. Several parents described how trauma affected their subsequent pregnancies, relationships, family life, and ability to trust institutions, emphasising that access to specialist support is central to recovery.

Lack of clear national guidance on commissioning and no national oversight is leading to significant local variation in services. Charities providing counselling or peer support reported being overwhelmed by demand and often filling gaps left by statutory services. Most maternal mental health services in England do not commission any services for fathers and partners, and those who experience earlier pregnancy losses or the death of an older infant are also often excluded. Likewise, there is no support or resources available for siblings, or recognition of the impact of loss on the wider family.

Parents with experience of loss in other countries outlined receiving automatic access to counselling services commencing within a week and available indefinitely, demonstrating what good support can look like when mental health pathways for bereaved parents are fully embedded and resourced.

Contributors outlined that must be a whole system approach to ensuring all bereaved families can access mental health care at a time and place which is right for them. If these parents are referred to universal services, commissioners must ensure that waiting lists are not an access issue and that staff have been upskilled to support parental bereavement.

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Tackling the impact of inequalities on maternity and neonatal care

The impact of systemic racism on maternity and neonatal care

Contributors were clear that discussion of inequalities in maternity and neonatal care and the disparities in perinatal outcomes must explicitly acknowledge the impact of systemic racism. Black and Brown women and birthing people continue to face disproportionately high rates of stillbirth, maternal morbidity, and neonatal death, and systemic racism drives substandard and inequitable care across maternity and neonatal services from pre conception to bereavement care.

Systemic racism in maternity and neonatal care manifests both structurally, in pathways, training, triage decisions and risk management, and interpersonally, through communication, bias and assumptions. Respondents shared examples of racialised stereotypes influencing clinical decisions, national guidance being dismissed in relation to their care, and information around predisposed conditions such as pre-eclampsia being withheld.

Many parents stated that their babies would be alive if their concerns had been taken seriously, with others describing how their experiences were later misrepresented in investigations, with reports reframing events to shift blame onto women and families and portraying them as ‘refusing care’ despite evidence to the contrary.

Contributors shared further evidence which demonstrates that where end-of-life care has been needed on neonatal units, cultural bias, poor communication from staff[2], and a lack of

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[2] Clancy & Thomas (2025) Fostering cultural humility in perinatal palliative care. An interpretive qualitative study from the United Kingdom: https://www.tandfonline.com/doi/full/10.1080/13576275.2025.2483754#abstract

interpreters can exclude some parents from being involved in their baby's care and memory-making[3].

The APPG heard how midwifery training needs to include mandatory, structured training on racial inequalities and differences in clinical presentation by improving diversity in the curriculum, such as the way jaundice presents in darker skin tones for example. Little time is spent on cultural competence and training materials are based on a default white norm, leaving midwifery staff unprepared to provide equitable care.

Contributors outlined how staff must be supported to be 'culturally curious', by embedding this skill as a core competency across training and the delivery of maternity and neonatal services. They outlined that it cannot be left to charities or individuals to fill gaps in training and knowledge, and instead institutions and leaders need to name systemic racism, set measurable standards, and embed culturally safe models of care, including continuity and trauma-informed practice.

The APPG also heard how the National Maternity Safety Ambitions for England expired in 2025. The government needs to set new ambitions for reducing perinatal mortality and preterm births but crucially must expand these targets to eliminate disparities in stillbirths, neonatal deaths and rates of preterm births between ethnic groups by 2035. Alongside this, there needs to be a focus on eliminating inequalities by socio-economic deprivation.

Achieving these expanded ambitions requires transformative change with a whole-government approach to tackle wider inequalities in society and determinants of health. The Government must make ending inequalities in baby loss a priority and introduce a comprehensive, cross-government programme of work, supported by clear targets.

The importance of data, monitoring and evaluation to tackling inequalities

To end inequalities in baby loss, contributors outlined the need for more comprehensive data on a range of social risk factors associated with pregnancy and baby loss. Improving the quality and collection of data can also help to target additional support for underserved groups. Whilst ethnicity data are routinely recorded, there are well documented concerns about the accuracy and completeness of these data.

This paired with limited data on social risk factors limits the ability to understand the health inequalities that exist, and what may be driving pregnancy and baby loss. Improving the collection of ethnicity data and developing UK-wide metrics to record the number and nature of social risk factors, will improve insight and support targeted action to tackle inequalities.

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[3] MBRRACE-UK (2024)The care of recent migrant women with language barriers who have experienced a stillbirth or neonatal death: https://www.hqip.org.uk/wp-content/uploads/2024/12/Ref.-501-MNI-CORP-Perinatal-CE-Report_FINAL.pdf

Contributors outlined that there is not a good understanding of how effective current approaches aimed at reducing inequalities are. In England, there is a requirement for Local Maternity and Neonatal Systems (LMNSs) to publish equity and equality action plans. But, as the Sands and Tommy's Joint Policy Unit highlighted, there is significant variation in the availability of resources to implement these plans and lack of understanding of their impact.

Any existing improvement projects that aim to tackle inequalities in maternity and neonatal care must be properly evaluated to measure impact and drive continuous improvements.

Improving the accessibility of services through translation and interpreting

Improving the accessibility of services must be a key focus for tackling inequalities. One recurring issue raised by contributors is the inadequate provision of translation and interpreting services, which research from the Maternity Consortium and the Sands and Tommy's Joint Policy Unit found was contributing to avoidable harm. The NHS should immediately commit to a comprehensive review of translation and interpreting services in maternity and neonatal care, with a view to ensuring consistent national provision.

Contributors outlined how existing telephone translation services are inappropriate for bereaved parents, with no access to transcripts after calls and no oversight or quality assurance, creating gaps in accountability when harm occurs. Hospital staff and family members should also not be used in place of professional translators.

The current system places responsibility for safety on bereaved parents and families, expecting them to be able to navigate complex pathways, know escalation routes and challenge clinical decisions. Due to the lack of translating and interpreting services, these issues disproportionately harm marginalised families and are a further example of structural inequalities in maternity and neonatal care.

The role of regulatory bodies in tackling inequalities

Regulatory bodies play a critical role in ensuring that maternity and neonatal services are safe, equitable, and centred around the experiences of families. However, evidence from the PMRT Annual Report and associated parent engagement materials shows persistent variation in review quality, parent involvement and multidisciplinary participation, issues that disproportionately affect marginalised women, birthing people and families.

For example, for parents whose babies died neonatally, contributors outlined that there is variation in quality of reviews in terms of which clinicians are involved. The PMRT annual report, for example, shows that for neonatal deaths reviewed in 2024, only 63% included a neonatal nurse as part of the multi-disciplinary review team, and only 87% a neonatologist.

Although NHS England guidance specifies that parents should have a named key contact to guide them through the review process, including explaining findings and maintaining communication, the implementation of this requirement varies significantly between Trusts.

Contributors outlined how families without strong support networks or health literacy, particularly those facing language or cultural barriers, are most disadvantaged by this inconsistency. Regulators must hold to account Trusts who fail to ensure that maternity and neonatal services and investigation and review processes, are accessible and equitable to all parents and families.

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Barriers to improvement of maternity and neonatal services

The failure to implement recommendations from previous reviews

Contributors noted that England has had decades of reports into maternity failings, many with similar findings. Despite this, learning is rarely translated into practice and unsafe cultures persist.

There is a lack of accountability for the implementation of previous recommendations and addressing known risks. At a local level, Trust boards should be responsible for ensuring safe care in their services. The Sands and Tommy's Joint Policy Unit's research raised questions about boards' ability to have a full understanding of the performance of maternity and neonatal units under their direction within the current system.

There must be greater support for frontline staff to improve the quality and consistency of reports shared with the board (including guidance on minimum metrics that should be included and examples of good practice), as well as support for board members to help them to contextualise and interpret the information that they receive. Boards must embed a culture of curiosity and learning rather than focusing on compliance and reputational management. A review of national initiatives, such as the Maternity Incentive Scheme, should evaluate whether they have delivered an increased focus on safety, or have had unintended consequences.

National oversight of implementation is also required as well as the resources to implement recommendations. The Sands and Tommy's Joint Policy Unit noted that despite the government committing to 'supporting trusts to make rapid improvements', NHSE funding cuts endangers this ambition. Contributors reported when, for example, specialist bereavement staff leave their roles funding is sometimes absorbed back into the general budget for the ward. Ring fenced funding and the commitment to monitoring improvements that can be funded are a vital step to ensure delivery of these needed improvements.

Hospitals are failing to resource and fund maternity, neonatal and bereavement services appropriately. Contributors emphasised severe staffing shortages, unmanageable workloads, and funding constraints that directly compromise safety. This included labour wards routinely operating below safe staffing levels, and staff redeployed from bereavement roles to general maternity areas or expected to cover entire hospitals with minimal capacity.

A long-term funding plan for maternity and neonatal services is vital to sustain meaningful change, as short term pots of money aimed at transforming specific services will not result in systemic change. Trusts also need to be held accountable for evidencing that money which is dedicated to maternity and neonatal services has been spent on those services, by ensuring that funding is ringfenced. For national standards and guidance to be implemented, this must be supported by funding.

Implementation of the National Maternity and Neonatal Investigation recommendations

Recommendations should be assigned to named organisations - whether national (DHSC), system level (LMNSs), or local (e.g. Trust boards) - who are responsible for their delivery. Contributors were clear that there is a need for national oversight to hold these organisations accountable for the delivery of recommendations and reporting of impact.

As outlined above, in 2025 the National Maternity Safety Ambitions for England expired. The Sands and Tommy's Joint Policy Unit believe that the government should set new ambitions for reducing perinatal mortality and preterm births – focussed on matching the best-performing countries in Europe. The proposed ambitions are outlined here, with a deadline of 2035 to align with the 10 Year Plan for the NHS in England.

For recommendations to improve neonatal care, contributors were clear that effective implementation relies on ensuring that those recommendations are evidence based, specific, and measurable, and crucially, that they meaningfully encompass bereavement care on neonatal units, not just maternity care.

They outlined how, too often, 'maternity and neonatal' recommendations translate into maternity only action in practice, leaving neonatal safety, bereavement support and the unique needs of families whose babies die on a neonatal unit overlooked. Similar issues apply across all hospital departments which provide perinatal care, such as gynaecology and emergency care.

For these families, high quality bereavement care, including timely communication, continuity of staff, memory making, and clear explanations of review processes, is essential, yet improvements in this area are frequently under monitored because neonatal care elements are not sufficiently embedded in national recommendations.

Priorities for improving neonatal care

To improve neonatal care, contributors working in neonatal care outlined that services should prioritise embedding Family Integrated Care (FICare) practice. The APPG heard how this model of care enables and empowers parents and caregivers to be partners in all aspects of their baby's care delivery and decision-making. This model has been associated with improved short-and-long term outcomes for babies, as well as improved mental health scores for parents. There are a myriad of barriers which prevent parental presence and involvement, meaning babies experience FICare practice inequitably.

When a baby dies in neonatal care, their neonatal journey can be viewed through the lens of memory making, and instances where parents were unable, or felt they were not allowed to provide care take on extra significance. Good FICare in neonatal settings is the starting point of good bereavement care.

Contributors also outlined that it is important to consider the breadth of neonatal death experiences which occur on the neonatal unit. Some babies will die soon after admission, having required intensive care and more limited opportunities for parents to provide care directly. Other babies will spend weeks or months receiving care before they die. Ensuring services have the resources and facilities to support all parents to participate in FICare practice is essential for ensuring all babies receive equitable care.

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Conclusion

The evidence received by the APPG on Baby Loss paints a clear picture of systemic failure across maternity and neonatal services:

- Investigations are inconsistent, inaccurate, and often traumatising.
- System culture encourages defensiveness, hierarchy, and concealment.
- Staff shortages and funding pressures make safe care impossible.
- Communication failures and lack of compassion deepen harm.
- Structural racism profoundly affects care and outcomes.
- Regulators lack integration, accountability, and coherence.

The National Maternity and Neonatal Investigation must deliver a full structural reform of maternity and neonatal care, cultural transformation, robust national accountability systems and properly funded services, to improve maternity and neonatal care for all.