House of Commons
London SW1A OAA
All-Party Parliamentary Group on Baby Loss

Monday 3rd February, 15:00pm – 17:00pm
Committee Room 17, The Palace

Chair: Andy MacNae MP

NOTES

Members and representatives in attendance:

- Andy MacNae MP
- Michelle Welsh MP
- Saqib Bhatti MP
- Alice Macdonald MP
- Maya Ellis MP
- Julia Lopez MP
- Lizzi Collinge MP
- Mike Martin MP

Speaker:

- Rob Wilson, Head of Sands and Tommy's Joint Policy Unit
- Georgia Stevenson. Data and Evidence Lead, Sands and Tommy's Joint Policy Unit
- Katie Russell, Parent Speaker

Guests attending in-person:

Kath Abrahams	Tommy's
Rachel Burrell	Ebony Bonds Bereavement Support CIC

Emily Cannon	Office of Michelle Welsh MP
Kate Davis	Department of Health and Social Care
Clea Harmer	Sands
Ryan Jackson	Lily Mae Foundation
Beth McCleverty	Bliss
Victoria Morrell	Twins Trust
Hannah Putley	Department of Health and Social Care
Gina Reeves	Ebony Bonds Bereavement Support CIC
Jess Reeves	Sands
Jennifer Reid	Teddy's Wish
Owen Reily	Office of Andy MacNae MP
Angela Rice	Midwife
Mollie Ricketts	Sands
Zoe Russell	RCOG
Suzie Scofield	Footprints Baby Loss Twin Triplet Support
Tomasina Stacey	Kings College London
Celine Walters	Lewisham and Greenwich NHS Trust

1. **Welcome & introductions**

Andy opened the meeting and welcomed everyone attending in-person and online.

2. **APPG on Baby Loss Updates**

Andy provided a brief overview of the APPG on Baby Loss explaining that it is a group of MPs and members of the House of Lords from all parties fighting the corner for bereaved families and expectant parents in Parliament. He highlighted the purpose of the group is to raise awareness of what more can be done by the government, Parliament and other agencies to improve care for families after baby loss and to improve safety in maternity services and reduce the risks.

Andy set out that the group will focus on current issues around baby loss and maternity and neonatal care, but please do contact the Secretariat at Sands if there are any issues you feel we should consider as a group.

<u>Change NHS Consultation and 10-year health plan</u>

Andy informed the group that the Government has published a public consultation on the future of the NHS. **Andy** highlighted anyone can take part and contribute their views on how they think the NHS needs to change over the next 10 years.

Andy emphasised this is an important opportunity to make maternity safety, bereavement care and addressing inequalities in baby loss a priority in the reform of the NHS, and we will be looking at this later in the meeting.

Government response to the House of Lords inquiry into preterm birth

Andy updated the group that in January 2025, following the House of Lords preterm birth committee's inquiry and report on preterm birth (the single biggest cause of neonatal death and illness in the UK), the Government published their response. The report is to be welcomed, particularly recommendations for a focus on tackling the stark and unacceptable inequalities, in rates of preterm births that exist for Black and Asian women and babies, and women and babies from the most deprived backgrounds.

Andy noted the report is available on the Government's website.

Bereavement leave following miscarriage

Andy informed the group that the Miscarriage Association have launched a campaign entitled *Leave for Every Loss* calling on the Government to extend current parental bereavement leave to pre-24-week losses.

Andy added alongside this, a new report by the Women and Equalities Committee has called for changes in the law so that a period of paid leave is 'available to all women and partners who experience a pre-24-week pregnancy loss'. Such a law change would bring things in line with existing provision for baby loss after 24 weeks.

Andy noted Sarah Owen MP, Chair of the Women and Equalities Committee has tabled an amendment to the Employment Rights Bill on this which has now cleared Committee stage and will move to report stage where the amendments will be considered.

Andy encouraged any MPs in the room who wish to support the campaign and even add their name to the amendment to let the Secretariat know, who'll put them in touch with the Miscarriage Association.

3. **Sands & Tommy's Joint Policy Unit - Future maternity safety ambitions to save more babies' lives** (Rob Wilson and Georgia Stevenson)

Rob outlined that in 2022 Sands and Tommy's formed their Joint Policy Unit, which aims to drive policy change to save babies' lives by utilising data, insight, and evidence to influence government and health service policies.

Georgia provided an overview of the stillbirth and neonatal mortality rates in England. The stillbirth rate has declined since 2010, with a target to halve the 2010 rate by 2025. However, while there has been a 30% reduction, a significant decline is still required to meet the goal of 2.6 per 1,000 births. Similarly, neonatal mortality rates showed initial progress but have risen in recent years, putting the 2025 target at risk.

Georgia stated a key focus was also on preterm birth rates, with a target to reduce rates from 8% to 6%. However, the latest data shows only marginal progress, with the most recent figure at 7.8%. **Georgia** highlighted stark inequalities in baby loss based on area-level deprivation and ethnicity, demonstrating the need for targeted interventions.

Georgia mentioned the Joint Policy Unit's newly launched data hub, which consolidates and presents critical statistics related to baby loss. This will be updated regularly as national data evolves.

Rob outlined future government commitments to reducing baby loss, recognising that current maternity safety ambitions will expire in 2025. **Rob** emphasised the importance of setting ambitious yet achievable targets and outcomes over a 10-year plan, aligning with the Government's broader health strategy. The proposal of commitments includes:

- A stillbirth rate of 2 per 1,000 total births, aligning with the best-performing European countries.
- A neonatal mortality rate of 0.5 per 1,000 live births.
- A re-commitment to reducing preterm births to 6% while improving data quality to better understand contributing factors.
- A strong focus on eliminating inequalities in baby loss based on ethnicity and deprivation.
- Improving data collection on losses before 24 weeks to better inform policy.
- Ensuring a UK-wide alignment of targets, as England is currently the only nation with explicit goals on baby loss.

Rob then discussed the JPU's submission to the consultation on the Government's 10-Year Health Plan. This included the need for stronger national leadership, improved oversight mechanisms to ensure the implementation of recommendations from maternity inquiries, and better evaluation of policy initiatives to ensure effectiveness. **Rob** stressed the need for stronger local leadership and accountability at the trust level, where oversight of maternity safety and quality of care is often inadequate.

Rob also addressed workforce challenges, emphasising that while increasing numbers of midwives is essential, there is also a need to assess broader staffing

requirements, such as perinatal pathologists. **Rob** further identified equitable access to maternity care as a critical factor in reducing inequalities in baby loss.

Andy thanked Rob and Georgia and stressed the importance of setting clear ambitions in line with the Government's emerging plans.

4. Q&A

Andy opened the floor to questions.

The Q&A session began with a discussion on the necessity of oversight in national healthcare policies. It was noted that while there have been multiple reviews and inquiries, the resulting oversight mechanisms have been fragmented, often leading to a dispersal of responsibilities across different groups with overlapping members. The need for a more cohesive and nationally led structure was emphasised, with an emphasis on the Department of Health and Social Care and NHS England taking a leadership role in ensuring effective oversight.

Concerns were also raised regarding the lack of implementation of recommendations following different maternity reviews. It was highlighted that without a clear strategic approach, these recommendations fail to align with a cohesive national healthcare strategy.

Lizzi Collinge MP, representing Morecambe and Lunesdale, raised concerns regarding cultural issues within maternity services, referencing Dr Bill Kirkup's inquiry and its findings on working practices and ideological influences within the health service. **Lizzi** enquired about the current state of cultural challenges in maternity care.

Lizzi also discussed a draft submission to the 10-Year Plan by the Patient Safety APPG, supported by James Titcombe. She outlined the key recommendations, including:

- The inclusion of human factors in safety considerations.
- The creation of a continuously updated National Patient Safety Dashboard
- The publication of a prioritised list of national patient safety recommendations.
- The commissioning of an independent review of the healthcare litigation system, recognising maternity care as a significant contributor to NHS litigation costs.
- Ensuring compliance with learning depth reviews.
- Establishing a director of patient safety on every hospital board.
- Setting a new national ambition for maternity safety by the end of 2025.

It was acknowledged that while multiple APPGs are engaged in similar work, there is a risk of fragmentation. The importance of collaboration between APPGs was highlighted to ensure unified submissions. The group expressed a strong commitment to working across different APPGs to develop cohesive, cross-endorsed submissions that carry greater weight and impact.

Action: the APPG on Baby Loss to work with other APPGs in the future.

Michelle Welsh MP, representing Sherwood Forest, began by providing full transparency regarding her personal experience with Nottingham University Hospital Trust. She shared that she and her son received inadequate care from the trust. She highlighted the ongoing investigation, which now involves over 2,700 families, two police investigations, and three CQC prosecutions, with the numbers continuing to rise.

Michelle emphasised the need for effective oversight of trusts, particularly in relation to board accountability. **Michelle** pointed out that the board at Nottingham University Hospital Trust was aware of systemic failures as early as 2014, yet no action was taken. She predicted that by 2024, the number of affected families could rise to 3,000 and stressed the importance of swift accountability.

Addressing the role of NHS England, **Michelle** expressed her disagreement with their suitability for overseeing maternity services. She stated that one of the fundamental issues in maternity care is the NHS's ability to scrutinise itself, which she believes is inadequate, particularly in cases involving neonatal deaths being misclassified as miscarriages. **Michelle** further suggested that an external body should be responsible for this scrutiny, rather than the NHS or the CQC.

Michelle acknowledged the importance of the NHS 10-Year Plan but stressed that there is an immediate opportunity to push for reform, particularly in light of the ongoing maternity scandal in Nottingham, which she noted as the largest in NHS history. She called for MPs to engage in public conversations about necessary changes, arguing that this would not only reinforce the long-term plan but also create a sense of urgency.

Michelle then addressed issues surrounding language in maternity care, referring to the Green Party manifesto's stance on reducing C-sections as problematic. She highlighted the prevalence of similar attitudes within maternity services and academic institutions, stressing that the only priority in childbirth should be ensuring a safe birth, regardless of the method.

Michelle also drew attention to cultural issues in maternity care, particularly regarding the disparities in treatment based on ethnicity and socio-economic

background. She referred to the findings of Donna Ockenden's maternity review, which found significant inequalities in pain management for women from different ethnic backgrounds.

Alice Macdonald MP, representing Norwich North, raised a query regarding women's health hubs, questioning whether there has been an assessment of existing support structures and best practices. **Alice** noted the importance of ensuring clear guidance and pathways for women navigating pregnancy-related information and care.

Alice further highlighted the broader impact of workplace quality and the necessity of addressing systemic inequalities. She suggested that MPs should engage with local trusts to inquire about their maternity care provisions and ensure adherence to best practices. She stressed that addressing maternity inequalities is a cross-departmental issue, not limited to health, and requires a multi-sectoral approach.

It was raised that the APPG on Patient Safety, noting that its first inquiry will focus on maternity care, which presents a significant opportunity for collaboration and alignment of objectives between groups working on patient safety and maternity care.

Discussion moved to the issue of NHS England's role in maternity care oversight. It was noted that while this was not an endorsement of NHS England's current performance, there is a need for strong national leadership with the authority to implement change. Concern was also raised that the current system is a set of groups with unclear responsibilities, which hinders progress.

The conversation then turned to cultural issues within maternity services. A review of 30 reports on maternity services across the UK revealed recurring issues, particularly the lack of a safety culture. This cultural challenge is difficult to address through policy intervention, as it requires effective measurement and sustained commitment.

The stagnation of progress in maternity care over recent years was noted, with a comparison between 2019 and 2023 highlighting a decline in outcomes despite the lifting of pandemic-related restrictions. There remains an opportunity to improve standards of care and ensure adherence to national guidance to achieve better outcomes.

Regarding local trust engagement, it was acknowledged that trust boards often receive excessive amounts of information, much of which is not easily interpretable. Many board reports lack clarity, with some even being illegible. Efforts should be made to provide trust boards with clear, consistent, and

meaningful metrics. Additionally, concerns were raised about the lack of follow-up on issues raised in meetings, highlighting the need for a structured approach to accountability.

A suggestion was made to develop briefing materials for MPs to support engagement with local trusts. It was agreed that MPs should be encouraged to reach out to their trusts with specific questions regarding maternity care standards and practices. While not all MPs will engage, providing structured guidance can encourage proactivity.

Action: APPG to develop briefing materials to support MPs engaging with local trusts.

The discussion then addressed systemic inequalities in maternity outcomes, particularly for Black and South Asian communities. The disproportionate rate of baby loss among these communities was identified as a pressing concern. It was emphasised that a dedicated focus on reducing these disparities is necessary, with a commitment to measurable improvements.

Rachel Burrell highlighted the deterioration of trust between Black communities and the NHS, noting that Black women frequently report being dismissed in maternity settings. **Rachel** stressed that outreach and engagement with Black and ethnic communities is essential to rebuilding trust and ensuring effective maternity care. The role of charities in filling gaps left by government services was also noted, underlining the need for the government's commitment to addressing these disparities.

Rob Wilson supported the argument that further reports are unnecessary, and that action must now take precedence. The Labour Party has committed to eliminating inequalities and discussion focused on how this ambition should translate into tangible actions to reduce baby loss disparities.

The discussion concluded with a commitment to prioritising practical solutions over additional data collection. It was agreed that the focus should now shift to implementing effective measures, ensuring accountability, and achieving meaningful progress in maternity care.

5. **Insights from a parent speaker** (Katie Russell)

Katie Russell shared her experience of maternity care failings in the UK, emphasising the devastating impact of preventable baby loss. **Katie** began by highlighting key statistics: more than one baby is lost every five hours, 1,000 die annually from preventable causes, and nearly 40% of maternity units are unsafe.

Katie recounted her personal story. In April 2021, she gave birth at Princess Royal Hospital, Telford, trusting it would be safe due to scrutiny following the Ockenden report. Despite expressing severe anxiety about childbirth and requesting a C-section, her concerns were dismissed. During labor, poor communication, inadequate monitoring, and a lack of urgency resulted in Poppy suffering from distress for over an hour and a half. She was eventually delivered by emergency C-section but had no brain activity. At 3:35 PM on April 11th, Poppy passed away in Katie's arms.

Katie shared that following Poppy's death, she discovered a cover-up attempt, with medical notes altered to shift blame onto her. Investigations by the HSIB and CQC failed to recognise systemic failings. At Poppy's inquest in October 2023, the coroner ruled her death preventable due to neglect, yet accountability remained lacking, and an apology was only received after multiple requests. A later meeting with the Trust revealed staff had tampered with her records, leading to an ongoing independent investigation.

Katie introduced and outlined *Poppy's Promise*, a five-stage initiative aimed at improving maternity care through early intervention, compassionate recruitment, better training, patient-centered care, and real-time feedback via an app. She is working with the Trust to implement these changes and called for wider support to prevent future tragedies.

Katie concluded by sharing how the fight for justice has overshadowed her ability to grieve and has deeply impacted her life. She urged immediate action to improve maternity care, ensuring no other parent suffers the same loss.

She ended with a tribute to her daughter:

"To my Poppy, I carried you for your entire life. I will love you for every second of mine."

Katie thanked attendees for listening.

6. Q&A

Andy expressed gratitude for Katie sharing her story, acknowledging the significance of sharing lived experiences to support bereaved parents. Katie then commended the speaker's resilience, highlighting the potential impact of Poppy's Promise.

Andy suggested increasing awareness among MPs and local trusts about Poppy's Promise and requested the APPG Secretariat to facilitate this.

It was stressed the importance of shaping policy based on real experiences rather than a top-down approach. The discussion reinforced the power of lived experiences in driving policy change.

Suzy Schofield, from Footprints Baby Loss, highlighted the need for a central mechanism to collect and utilise bereaved families' insights. The group agreed on the necessity of a structured approach to ensure these voices inform policy effectively.

The discussion then shifted to bereavement support, especially with regards to the randomness of available resources and the need for universal support. Many parents find themselves without guidance after leaving the hospital, often turning to grassroots organisations that are under-resourced but essential. The need for government recognition and funding for these organisations was highlighted.

The Q&A session concluded with reflections on the NHS consultation process and how lived experiences should shape future policy and support structures.

7. **Change NHS Consultation interactive session** (facilitated by the Chair)

Following on from the session, the APPG on Baby Loss submitted a response to the Change NHS Consultation.

Please find the submission attached here.

8. **AOB**

Angela Rice shared about her work writing to the Parliamentary and Health service Ombudsman and her Integrated Care Board about continued baby loss and poor care in East Kent Hospitals NHS Trust.

Kath Abrahams, the Tommy's Chief Executive, shared about the Stillbirth Priority Setting Partnership survey.

If you would like to participate in the survey, as well as share it, please use the link here.

Baby Loss and Pregnancy after Loss Art Exhibition

Willow's Rainbow Box, Abigail's Footsteps and The Worst Girl Gang Ever have come together to curate a baby loss and pregnancy after loss art exhibition taking place at St George's Art Centre in Gravesend.

Works have been submitted by bereaved families and some installations co-produced with local bereaved parents and a local artist. There also have been National and international contributions.

The full collection will be available to view 4th March-16th March. There will also be an open afternoon on 8th March 1-4pm if anyone would like to come down and view the works and meet the team.

9. **Close**

Andy thanked those who attended in-person and online. The Secretariat will be in touch about the next meeting in due course.