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

Wednesday 17th May, 10.00am – 12.00pm
Room B 1 Parliament Street

Chairs: Cherilyn Mackrory MP & Helen Morgan MP

MINUTES

Members in attendance:

- Cherilyn Mackrory MP (Co-Chair)
- Helen Morgan MP (Co-Chair)
- Theo Clarke MP
- Representative of Sharon Hodgson MP
- Representative of Luke Hall MP
- Representative of Lilian Greenwood MP
- Representative of Feryal Clark MP

Speakers:

- Stephen Anderson
- Jessica Read
- Rob Wilson
- Georgia Stevenson
- Dr Hemant Maraj
- Philippa Davies

Guests

Megan Ball	Sands, APPG on Baby Loss Secretariat
Jess Reeves	Sands
Alex Mancini	Chelsea & Westminster Hospital NHS Foundation Trust
Rosie Walworth	Royal College of Obstetricians and Gynaecologists
Abbie Aplin	Royal College of Midwives
Karen Burgess	Petals
Celia Burrell	Barking, Havering and Redbridge University Hospitals NHS Trust
Laura Bridle	SE London Helix Maternal Mental Health Service
Alicia Burnett	Black Baby Loss Awareness Week

Welcome & introductions (Cherilyn Mackrory MP)

Cherilyn opened the meeting and welcomed everyone attending in person.

APPG on Baby Loss updates (Cherilyn Mackrory MP)

Government response to the East Kent Review

The Government's initial response to the East Kent Maternity Review came the day after the last APPG meeting. The response set out some actions such as improving team working and culture and identifying problems at an early stage, however Cherilyn explained that much greater detail is required to outline the practical steps being taken to address the serious failings that were identified, both in the East Kent report and reviews of other maternity services.

Perinatal pathology triage policy

The APPG continues to work with the Royal College of Pathologists and hear updates about the work to bridge the gaps in the workforce. Concerns were raised at the last meeting on how the new

perinatal post-mortem triage policy is being communicated with bereaved parents and families. The group has written to NHS England about this and awaits a response.

Pregnancy Loss Review

The group has now heard from the Minister that the Pregnancy Loss Review will be published in the Summer to coincide with the first anniversary of the launch of the Women's Health Strategy.

Maternity Workforce

The Government's NHS Workforce Plan for England, which we hope will include measures committed to in last year's Autumn Statement (following our Safe Staffing campaign with the APPG on Maternity) , such as hiring an extra 2,000 midwives, and a long-term and independently verified plan for the maternity workforce, is due this Summer.

There are plans with the APPG on Maternity to follow up on the Government's staffing commitment ahead of summer recess. Cherilyn explained that Luke Hall MP is looking to reinstate the APPG for Premature and Sick Babies and will loop his office in the work too. Alex Mancini reiterated the need for neonatal workforces to be included in the workforce plan as well.

Theo Clarke MP introduced herself to the group. She explained that her particular interest lies in mental health, and a campaign in her constituency around re-opening the maternity unit. Cherilyn thanked her and welcomed her to the group as a new officer.

NHS England Maternity Transformation Programme Single Delivery Plan (Steve Anderson and Jess Read, NHS England)

Steve Anderson and Jess Read presented the three-year delivery plan for maternity and neonatal services. Steve outlined that the goals have not changed - the NHS still aims for safer, more personalised, and more equitable care. The Plan was formulated through over 50 events with families, clinicians, leaders, and stakeholders, where they spoke with over 1,000 people. As well as this, 2,128 responses were received from their online survey.

Safety was the key priority for all groups. Respondents outlined care should be personalised, support informed consent and choice, enable individuals to be listened to, and be joined up through maternity and neonatal care. This should be delivered by staff who feel supported and valued, are not delivering quality care under time constraints, work in a positive culture with adequate staff numbers, and have appropriate training and strong leadership.

Steve outlined the four themes and twelve objectives of the plan:

1) Listening to and working with women and families with compassion
    1. Care that is personalised
    2. Improve equity for mothers and babies
    3. Work with service users to improve care
2) Growing, retaining and supporting our workforce
    4. Grow our workforce
    5. Value and retain our workforce
    6. Invest in skills
3) Developing and sustaining a culture of safety, learning and support
    7. Develop a positive safety culture
    8. Learning and improving

9. Support and oversight

4) Standards and structures that underpin safer, more personalised, and more equitable care
    10. Standards to ensure best practise
    11. Data to inform learning
    12. Make better use of digital technology in maternity and neonatal services

Jess outlined the continued commitment to The National Maternity Safety Ambition to reduce deaths by 50% by 2025, and that they are looking into recent upticks in rates to get back on track. The priority remains to be listening to and working with women and parents with compassion, rolling out Personalised Care and Support Plans and working with Continuity of Carer schemes to implement them with women most in need.

Jess also highlighted the £5.9 million investment in bereavement services to ensure the availability of a seven day a week service by March 2024 and increasing specialised training provision. They are also working with the Bereavement Midwives and the National Neonatal Nurses in Palliative Care Forums to ensure their voices are heard.

On next steps, Steve outlined that the team will continue to engage with service users and the system to learn how the plan is working in practice. Infographics and a technical annexe are also being created to help communicate the plan and describe exact measures for monitoring. The Saving Babies Lives Care Bundle Version 3 and a revised Core Competency Framework will be published very soon.

NB: Saving Babies Lives Care Bundle Version 3 is now published and can be viewed here: https://www.england.nhs.uk/publication/saving-babies-lives-version-three/

Theo Clarke MP asked what are the challenges around the recruitment of midwives, what is being done to address this, and what plans there are around addressing perinatal mental health services. On staffing, Jess outlined 2,300 new midwifery posts have been created since March 2021. Over 500 internationally recruited midwives are in the country and work is being done to onboard them. A campaign is being run to encourage midwives who are on the Nursing and Midwifery Council Register but are not currently practising – there are 40,000 on this register – which has already seen some midwives complete a return to practice programme. Student midwife numbers are also increasing in line with Government programmes and at least 1,000 will come into training in the next couple of years.

On perinatal mental health, specialised services are increasing for women with moderate to severe needs, as well as the maternal mental health hubs. Both of these are part of the NHS Long Term Plan and due for completion at the close of the 2023/24 financial year.

Helen Morgan MP asked how the voices of bereaved parents are being included in these plans. Steve outlined that they expect Maternity and Neonatal Voice Partnerships to engage with bereaved parents, and are talking to the Care Quality Commission (CQC) about options to hear voices outside of the existing Maternity Survey.

Helen also asked about disparities in outcomes and how the NHS is prioritising those with the worst outcomes. Steve outlined Integrated Care Boards (ICBs) are making plans in local areas and National Maternity Voice Partnerships (MNVP) are doing outreach work. Enhanced Continuity of Carer for women from the most deprived areas will also support this work. Jess also shared that

Wendy Olayiwola, National Maternity Lead for Equality, is co-chairing the Maternity Disparities Taskforce.

Rob Wilson from the Sands and Tommy's Policy Unit asked how the NHS are supporting trusts to deliver the Plan's standards of care, as there is currently too much variation. Steve outlined that this is the responsibility of ICBs and that they should implement policies and procedures so that women moving between services receive good standards of care.

Alex Mancini, National Lead Nurse for Palliative Care, asked if the £5.9 million investment across neonatal and maternal services is ringfenced for training or if it funds staff roles, specifically those in neonatal. Steve outlined that this funding is specifically for bereavement care midwives and ensuring there is a 24/7 service, but would pick this up separately to ensure there is no gap.

Celia Burrell from Barking, Havering and Redbridge University Hospitals NHS Trust outlined challenges with training and onboarding international midwifery recruits with changes in policy resulting from Ockenden and East Kent, for example.

Sands & Tommy's Joint Policy Unit Saving Babies Lives Report (Rob Wilson and Georgia Stevenson, Sands & Tommy's Joint Policy Unit)

Rob and Georgia introduced the Saving Babies Lives Progress Report which pulls together existing data and research in one place to make pregnancy and baby loss the political priority that it deserves to be. The full report can be viewed at this link, the summary report at this link, and the infographic at this link.

Rob outlined that although there are overall reductions in stillbirths and neonatal deaths since 2010, we are currently off track to meet the 2025 ambition and there have been upticks in both rates between 2020-202, with neonatal mortality rates increasing in all four nations across the UK.

The report also outlines that rates of preterm birth have been hovering around 8% since 2010. The ambition is to reduce it to 6%. There is also no comprehensive data on miscarriages, and the report calls for a better process so we can understand the true impact of pregnancy loss.

Data around inequalities remain stark. Rates of stillbirth are lowest among white babies (3.17/1,000) and highest among Black and black British babies (6.41/1,000) who are over two times more likely to die. Similarly, neonatal death rates are lowest for white babies (1.51/1,000) and highest for Black and black British babies (2.71/1,000). Black and black British babies are over 1.7x more likely to die during the first 28 days compared to white babies. Inequalities remain prevalent according to a mother's social and economic circumstances. Stillbirth rates in the least deprived areas remain lowest (2.6/1,000 births) and increase as deprivation increases, up to 4.3/1,000 in the most deprived areas. For neonatal deaths, the data is broadly similar. Inequalities may also be connected to miscarriage risk. Georgia explained that data is more limited in this area, however, some research suggests people from black ethnic groups are at higher risk of miscarriage compared to white women.

As of July 2022, the Care Quality Commission (CQC) rated 32% of maternity services in England as 'requires improvement' and 6% as 'inadequate'. 23% of respondents in the 2022 CQC maternity survey also felt as though their concerns were not taken seriously during labour and birth, which has increased in recent years.

The Saving Babies Lives Progress Report outlines 8 themes across recent reviews and investigations which are required to create change in services:

- Staffing levels and training
- Organisational leadership
- Data collection and usage
- Engagement with service users
- Culture of safety within organisations
- Personalisation of care and choice
- Learning from reviews and investigations
- Delivering care in line with best practice

The report also touches on the impact of pressurised working conditions on staff. The NHS Staff Survey data makes it clear that staff are under immense pressure, with midwives reporting some of the worst conditions (23.6% reporting they will leave the profession as soon as they can, 62.8% reporting illness due to stress).

Georgia outlined how improvements are required in understanding why babies are dying. The cause of 33% of stillbirths and 7% of neonatal deaths were unknown in 2022, and nearly 1 in 5 stillbirths are potentially avoidable if better care had been provided. The report found that two-thirds of action plans created following the death of a baby are rated as weak.

Finally, more research and evaluation are required to save babies' lives. For every £1 spent on maternity care, only 1p is spent on pregnancy research which is much lower than other conditions (7p on heart disease and 12p on cancer). Research is crucial in identifying new medical interventions and clinical approaches, but also evaluating what is working.

Laura Bridle from the South East London Maternal Mental Health Service praised the work of the report and called for greater financial support for rainbow clinics and bereavement nurses for women experiencing earlier losses. Laura also reiterated the importance of support for midwives, such as dedicated clinical supervision to enable them to process their trauma.

Dr Hemant Maraj from Betsi Cadwaladr University Health Board asked about research into different gestational ages for different ethnicities. Rob outlined that this was not in the scope of the current Saving Babies Lives Report however it is certainly something they could include in future iterations. Celia Burrell shared that NICE guidelines have tangentially approached this issue by encouraging the induction of women from BAME backgrounds at 40 weeks. Helen also highlighted the pregnancy risk assessment system that hasn’t been amended since the 1950s and how there is room for improvement in this area.

Rosie Walworth from RCOG asked what data collection around miscarriages looks like in practice. Rob explained that they propose data be drawn from Early Pregnancy Units, A&Es and GP surgeries, cleaned and then presented. He caveated that this still wouldn’t capture all cases, but would be much of an improvement and would improve consistency.

Jess Read reiterated the need to focus on midwifery retention, and Celia Burrell shared that, in her experience, childcare is a large issue in midwives staying in the profession.
Action: Helen stated that some written questions on this topic would be a good idea to increase attention.

Spotlight Session: SOS Babyloss (Philippa Davies & Dr Hemant Maraj, Our Sam)

Helen explained the new Spotlight Sessions at the end of APPG meetings, to allow speakers to share a short presentation on new projects, research or campaigns in the baby loss area. Helen introduced Philippa Davies, founder of the charity Our Sam, and Dr Hemant Maraj, Consultant Obstetrician and Gynaecologist in North Wales.

Philippa shared her and her daughter, Sam's story, who was stillborn on 23rd January 2012 at 33 weeks pregnancy after an antenatal diagnosis of Edward's Syndrome (Trisomy 18) at a 20-week anomaly scan. She also shared that she is a mum to four other babies, lost through miscarriages.

In her grief, Philippa looked for help but was not offered it automatically. Various healthcare professionals made attempts at offering support but these were not good enough, or the healthcare professionals themselves felt out of their depth or did not have the correct skills. 3 years following the loss of Sam, Philippa was completely isolated and struggling. Help came in the form of Hope House Hospice in North Wales, which provided support without belittling Philippa's loss or trying to make it better. They provided 3 years of support, which varied from being someone to talk to, to helping with everyday tasks.

After her loss and support from Hope House Hospice, Philippa wanted to ensure that no one was left to struggle alone and that everyone can get help, no matter when they need it and how they need it. Philippa wrote a play about her story which went on stage in North Wales and launched the charity, Our Sam. They then launched SOS Baby Loss, a comprehensive, one-stop, simple online signposting resource for anyone affected by, or working with people affected by baby loss following a miscarriage, termination for medical reasons (TFMR), stillbirth and neonatal death in the UK. This is an online search engine for services across the UK.

In the first year, one thousand searches were made through SOS Baby Loss, with 38% being for wellbeing and emotional support and 71% of searches coming from parents. SOS Baby Loss is being shared with healthcare professionals and advertised in hospitals and medical settings. Our Sam has also launched training sessions and podcasts.

SOS Baby Loss can be found at this link: https://sos.oursam.org.uk/

Dr Hemant Maraj spoke of how he learned from Philippa's story and the screening of her play. There are now plans to offer the play as free awareness training for healthcare workers and students during Baby Loss Awareness Week 2023. SOS Baby Loss offers an around-the-clock support service for healthcare professionals to provide adequate and appropriate information to patients. Effective and appropriate support makes a huge difference to mental health and quality of life after baby loss.

Laura Bridle asked if SOS Baby Loss had been shared with ambulance services. Philippa explained that she has presented to police, ambulance and fire services and is happy to expand this.

Any other business

There were no items of any other business. Helen closed the meeting and thanked all who spoke and attended. The next meeting will be in September.