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

Tuesday 9th January, 10.00am – 12.00pm
Chairs: Cherilyn Mackrory MP & Helen Morgan MP
Room C, 1 Parliament Street, Westminster

MINUTES

Members and representatives in attendance:

- Helen Morgan MP (Co-Chair) (HM)
- Cherilyn Mackrory (Co-Chair) (CM)
- Liliann Greenwood MP

Speaker:

- Professor Elizabeth Draper (ED), Lead Researcher, MBRRACE UK
- Mehali Patel (MP), Research Manager, Sands
- Minister Maria Caulfield MP
- Dr Christine Ekechi (CE), Co-Chair of the Race Equality Taskforce, RCOG
- Carolyn Jenkinson (CJ), Care Quality Commission
- Ciara Curran (CC), Founder of Little Heartbeats

Guests attending:

Jess Reeves	Sands
Clea Harmer	Sands
Mollie Ricketts	Sands
Kate Mulley	Sands
Celia Burrell	Barking, Havering and Redbridge NHS Trust
Amy Taylor	CMV Action
Victoria Morrell	Twins Trust
Caroline Brogan	Irwin Mitchell
Jake Poulton	NMC
Guy Forster	Irwin Mitchell
Hannah Putley	DHSC
Grace Palmer	DHSC
Millie McMillan	DHSC
Owen Cartey	Cherilyn Mackrory MP

Maninder Hayre	Child Bereavement UK
Josh Hartley	Sharon Hodgson MP
Iwona Przylecka	Lily Mae Foundation
Leila Hobart	Little Wings of Hope

1. **Welcome & introductions** (Cherilyn Mackrory MP)

Cherilyn opened the meeting and welcomed everyone attending in person.

MBRRACE UK Confidential Enquiries into Black and Asian Baby Deaths – The findings

Prof. Elizabeth Draper (ED) - MBRRACE UK

ED started the presentation by outlining the aims of the enquiries explaining the focus was to check whether the clinical guidelines and standards have been met throughout the care pathway. **ED** emphasised the importance of focusing on both good and poor-quality care to identify improvements, as well as evaluate whether improvements in care could have resulted in a different outcome for the baby and mother.

The enquiries took a random sample to ensure it was representative of Black, Asian and White women and reviewed 34 Asian, 36 Black and 35 White mother baby pairs between September 2021 to March 2023.

The overall grading was classified by:

1. Good care, no improvements identified
2. Improvements in care identified which would have made no difference to outcome
3. Improvements in care identified which may have made a difference to outcome

ED informed the group that the overall findings were very similar in the Asian and White mothers and similarly in the Black and White mothers for stillbirths and neonatal deaths.

ED identified four key themes from the enquiries:

1. Citizenship and Ethnicity
   - There was variation and inconsistency in the recoding of ethnicity, nationality and citizenship status
   - Recommendation: Develop national guidance and training for all health professionals to ensure accurate recording of ethnicity and citizenship status

2. Identification of language needs and interpreter provision
   - Responding to language needs was inadequate across all ethnic groups
   - Recommendation: Provide maternity staff with guidance and training to ensure accurate identification and recoding of language in order to provide personalised care

3. Identification of social risk factors
   - Social risks factors recorded less present for Asian women

- Recommendation: Develop a UK wide specification for identifying and recording the number and nature of social risk factors

4. Routine mental health screening and barriers to accessing specific aspects of care
    - Compared to White women, fewer Black women had evidence of routine mental health questions being asked
    - Black women were more likely to experience barriers to accessing specific aspects of care or advice
    - Recommendation: Ensure maternity services deliver personalised care, which include identifying and addressing the barriers to accessing specific care

ED further highlighted issues which were identified in the enquiries:

- Antenatal care: oral glucose tests were not offered to more eligible Asian and Black women and provision of information about reduced fetal movements was less common for Black women (47%) compared to White Women (58%)
- Labour and birth: where there was time, there was no evidence of partogram which was completed for almost twice as many Black women (64%) compared to White women (36%)
- Neonatal care: standard of neonatal care provision was similar for Asian, Black and Whie babies with suboptimal care identified in around 50% of all deaths in the enquiry
- Ongoing care: medication for lactation suppression was more likely to be offered and accepted by Asian and Black women than White women
- Pathology: Post-mortem was carried out for 18% of Asian, 67% of Black and 51% of White stillbirths and neonatal deaths.
- Follow-up appointment and letter: Following stillbirth, follow-up letters were more likely to be addressed to the GP (with a copy for the parents) for Asian parents (60%) than White parents (25%).

ED summarised by stressing the importance of training and resources for all maternity and neonatal staff, so that they can provide culturally and religiously sensitive care for all mothers and babies.

Lastly, **ED** emphasised the importance of parent engagement in the Perinatal Mortality Review Tool (PMRT). She concluded that it is essential that the existing PMRT guidance is developed further to ensure all women's and parent's voice are actively sought, and their questions are addressed.

Sands' Listening Project – The findings

Mehali Patel (MP) - Project Lead, Sands

MP opened her presentation by explaining the Listening Project heard a range of experiences spanning from pre-conception to postnatal and neonatal care. She highlighted that half of Black and Asian bereaved parents believed they received worse care or were treated differently because of their ethnicity.

MP noted they heard many different experiences both good and bad, and these have been presented under four key themes:

1. Being listened to and heard
2. Personalised, joined up care

3. Communication about safety and risk
4. Safety and learning

MP further explained that the Government has a duty to address wider social detriments of health, in addition to:

1. Setting out long-term, funded plans aimed at eliminating inequalities in pregnancy loss and baby deaths.
2. Ensuring that maternity services have the staff capacity, skills and resources required to assess and care for women and birthing people effectively, so that the risk factors affecting each individual are recognised and their impact reduced.
3. Initiating and funding a research programme to inform the development of effective interventions to address health inequalities and save babies' lives.
4. Taking steps to ensure that all maternity safety improvement schemes include a focus on tackling inequalities, with action, progress and impact monitored.

Women's Health Minister – Response to the three reports

Minister Maria Caulfield MP

Minster Caulfield began by stating that £183 million will be invested into maternity services this coming financial year. She acknowledged still more funding is needed. **Minister Caulfield** highlighted that the Government are recruiting more midwives and noted that they are starting to see a net gain in staffing numbers.

Minister Caulfield noted the Government are already working on recommendations Sands has put forward and outlined three main initiatives:

1. The Three-Year plan to improve Maternity Services. In March 2023, NHS England set out a three-year plan to improve maternity services, to be proactive rather than reactive when enquiries are published. **Minister Caulfield** shared that the three-year plan embodies similar themes which have been found at enquiries such as the Ockenden Review. These include safety, personalised care and how to better support staff. **Minister Caulfield** emphasised a key focus is to focus on listening to parents which was the main response from Women's Health Strategy survey.

2. Equity and Equality Guidance which is supported by £6.8 million of funding. **Minister Caulfield** outlined the aim of this is to tackle the root of inequalities some women are facing trying to access services, and ensuring these are positive experiences. The guidance is making sure staff are aware of differences between different groups of women and how women needs should be met.

3. The Maternity Disparities Taskforce which has been set up acknowledges there are poorer outcomes and inequalities for ethnic groups and minorities accessing services. **Minister Caulfield** stated pre-conception is the area which the Taskforce is focussing on as language, socio-economic, geographical, cultural needs to be tackled before a woman gets pregnant.

Minister Caulfield informed that the Government have been rolling out the 33 Maternal Medicine Network across England. These networks look after women's holistic health, in the hope that supporting women with their physical health will lead them to have healthier pregnancies.

Post-natal checks work is another measure the Government are implementing, which uses RCOG guidance for the six-to-eight-week checks and as a result provides guidance to the GP.

Minister Caulfield highlighted the importance of mental health support for new mums. She stated new mums, pregnant mums, post-natal mums are a priority group in the Suicide Prevention Strategy.

Minister Caulfield emphasised the role of Perinatal Pelvic Health checks which could potentially reduce the number of tears by about 20%, if the OAC bundle is used in hospitals.

Minister Caulfield drew attention to 2 to 3 years old data which is still being used and as a result means it's hard to measure the effect of these initiatives and what groups it is successfully helping. Maria reassured the group that more up-to-date data will be published this Spring.

The National Oversight Group has been set up to drive force the enquiry changes to every trust and maternity services, which includes members from CQC, NHS England and the DHSC. **Minister Caulfield** noted there has never been a capital programme for maternity units.

Minister Caulfield stressed the importance of staff training and retaining midwives. She added that midwives have never had access to apprenticeships in the same way nurses have. Therefore, the long-term workforce plan is currently creating apprenticeship routes in midwifery.

Minister Caulfield concluded that she wants to drive hard changes that makes biggest difference for ethnic groups.

Sands' Listening Project – Listening to the voices of Black and Asian Bereaved Families

MP - Project Lead, Sands

MP stated the Listening Project heard directly from 56 Black or Asian bereaved parents (47 mothers and 9 fathers).

1. Being Listened to and heard
   More than half of parents felt professionals didn't listen, some linked this to racism. This meant that important warning signs were missed or not escalated, as well as pain and distress was dismissed.

2. Personalised, joined up care
   Poorly co-ordinated care, involving many staff, led to delays and errors. This meant that information is missed, mis-documented or not communicated across teams.

3. Communication about safety and risks
   Many parents felt they were not given information needed about safety and risk, including relating to ethnicity. This meant that parents may not have the information they need to stay safe and raise concerns.

4. Safety and learning
   Most parents had negative experienced where reviews had taken place. This involved poor communication, delays and complex processes. This meant that opportunities to understand what went wrong are missed and not addressed.

Therefore, these practices are likely to be repeated contributing to unavoidable deaths.

MP concluded by emphasising the importance of this report for sharing the perspectives of Black and Asian parents and using this critical opportunity to learn more about how maternity and neonatal care can be made safer and more equitable at every stage.

Insights and Expertise from MBRRACE Stakeholders

Dr Christine Ekechi (CE)– Co-Chair of the Race Equality Taskforce, RCOG

CE began by explaining that the Race Equality Taskforce was set up at RCOG to address the inequalities amongst women's health. She highlighted that often missing from this discussion are the experiences of Obstetricians, Gynaecologists and trainee doctors working on labour wards. **CE** emphasised that there is so much clinicians do not know and understand, which makes it more challenging to close this gap.

CE noted poor care is universal irrespective of race. There is objective and subjective of poor care, but what is not without doubt is outcome.

CE explained that in situations where there have been errors, this has been usually down to the service not being robust. She emphasised it is crucial that we learn and improve to ensure that this does not happen again.

CE highlights three recurring themes:
1. Kown Risk factors
2. Poor Quality Care
3. Race

CE highlighted where a Black women need translation or mental health services, this needs to be divided out with acculturation. There are very discrete differences, but often there is the danger of stereotyping and grouping people together. **CE** states it is essential to look at granulation.

CE highlighted poor quality care can be because of a previous experience outside of maternity setting. She noted most risk factors are already embedded outside pregnancy. **CE** highlighted there is a lot of burn out at the moment. Therefore, support for midwives and trainees to make sure they feel empowered is paramount to allow for the best care to be delivered, especially since care given to mothers severely impacts peri and neonatal outcomes.

CE reemphasised that the best bereavement care is individualised care, but this needs good bereavement resources and bereavement midwives which can be challenging with rapid turnover. She emphasised the importance of a bereavement room to provide this care, but acknowledged not all services have these resources.

CE concluded by emphasising the need for more research to understand why some of these baby deaths occurs.

Finally, **CE** stated Saving Babies Lives Bundle One and Two are continually evolving. She informed that serial growth scans which were introduced in the pandemic for Black and Asian women as they are more likely to have stillbirths. The aim is to understand whether this is a useful tool to identify babies that may be at risk of loss earlier.

She explained the data take home:

1. Data qualification is dire: There is an electronic record system and the recoding of ethnicity is very poor.
2. Black and Asian women did not like having growth scans based purely on their race. They said race it is not direct cause of their baby's death and this is correct. They asked for more definitive reasoning as to why.
3. Implementing interventions can sometimes have negative unintentional consequences.
4. Most of black and Asian women have scan because of other risks factor, not just because of race.

Insights and Expertise from Care Quality Commission

Carolyn Jenkinson (CJ) – Deputy Director of Secondary and Specialist Healthcare, CQC

CJ started her presentation by introducing the CQC's Maternity Inspection Programme. **CJ** explained these inspections make sure that there is an up-to-date rating across England. The inspections focus specifically within the safety and leadership domain. There are still 42 inspection reports to be published by mid-late March and in total 10% has been rated inadequate. **CJ** highlighted the inspections provide a good national perspective of the situation of maternity wards.

CJ outlined the findings of the inspection programme relate to the lack of assessment in risk, incident management and missed opportunities for learning. It is pointed out that there is a particular issue with categorisation of harm, as organisations possess very different grading systems of what they qualify as harm to women. In regards to inequalities for health, these are often an add on and not embedded into everyday practice. This includes lack of analysis of data for race.

CJ concluded by drawing attention to the women's pregnancy survey, which has not been sent to bereaved parents in the past but will now focus on listening to bereaved parents to hear about what the best way is to capture a women's experience. **CJ** expressed the hope that this will become an annual survey, especially since it provides an opportunity to hear nationally and understand the experiences of parents whose baby has died during pregnancy and childbirth.

Q & A with Panel

CM opened the floor to any questions.

CM asked with regards to the work with race and equality, how we separate out social deprivation and what trends we are seeing.

CE responded by stating race and equality shouldn't be separated out from social deprivation as it underpins the inequalities that have been discussed. She added it is important to be more granular as Black and Asian women are more likely to experience poor care and have poorer outcomes. Social deprivation underpins a huge majority of poorer outcomes. This occurs because Black and Asian women are overrepresented in lowest social economic groups. Therefore, it requires a combined approach across all agencies to improve this.

CM added in Cornwall there are huge pockets of social deprivation but little racial diversity, she asked how she ensures mothers receive the same help and attention through this work, even though it is not directly related to race.

CE responded by stating social and racial diversity can still occur, but it is important to acknowledge where race and racism play a role. This occurs when people make bias judgements and are not cognizant of the barriers Black and Asian women go through.

Minister Caulfield further added the Maternity Disparities Taskforce found the single biggest determent was socio-economic status. Those in the most deprived areas had the poorest outcomes and Black and Asian women are often overrepresented in these areas. The Taskforce is focussed on removing inequalities across the board. The Maternal Medicine approach will be available for all women with inequalities before their pregnancy in the hope it will improve their outcome.

ED countered this by stating MBRRACE's last perinatal surveyance report presented the difference between ethnicity using both the risk to do with ethnicity and the risk to do with social deprivation. The report found the most deprived white women had a lower risk of stillbirth and neonatal death, than the least deprived of very specific groups of Black and Asian women. **ED** highlighted this is why women shouldn't be put into the same category and that ethnicity has more of an impact than social deprivation.

CE added ethnicity is an additive. She stated a Black woman will automatically be presumed to be a lower economic group and this assumption immediately affects the care they receive.

Iwona Przylecka queried if there are plans to carry out more in-depth research relating to cultural differences and language barriers to allow for more separation to be done, and to help steer away from research focussing on just Black and Asian minorities. She added white ethnic minority groups are often forgotten.

Minister Caulfield responded by reassuring this work is being carried out but it is hard to give granulation. She stated the solution is good quality personalised care to ensure individual needs are being met. This is why it is so crucial maternity services are equipped with the right resources to do this and quality of care is prioritised.

HM asked when the CQC 2023 maternity survey findings will be published and what support will be put in place to help units who are struggling.

CJ stated the maternity survey is due to be published at the beginning of February. CJ added where services require improvement, CQC have been working with regional teams and most units will be placed on the maternity support programme. In addition to the CQC's commitment to visiting units again to follow up and ensure improvements are being made and maintained.

Minister Caulfield added the department has asked CQC to provide an honest review of units so that they are informed on the state of maternity services and support they need.

ED highlighted one of the problems when identifying inadequate units is that it affects moral and makes it more challenging to retain staff. She asked what measures are put in place to ensure morale is not affected.

CJ responded that a lot of staff have contacted CQC to thank them for the work they're doing. She noted this there can be backlash and criticism, but the majority of people are grateful for calling it out inadequate units.

Leila Hobart shared her experience of not being listened to by midwives as a pregnant woman in a very deprived community hospital in Hertfordshire. She explained she delivered her son at 23 weeks and upon receiving her MBRRACE PRMT, she found her ethnicity has been recorded wrong. Leila detailed how she has been supported by Petals Charity, but she

has waited over 6 months to receive NHS mental health support. This is an added challenge for Black and Asian minorities who also have to face systemic issues. **Leila** asked what work is being done to prioritise mental health support for bereaved women.

Minister Caulfield responded that in the recently published Pregnancy Loss Review, one of the recommendations is around bereavement support. There is now better capacity for mental health support with every part of the country having access to a mental health service. However, she acknowledged services are hard to access as they are in high demand. **Minister Caulfield** reassured this is key priority and noted improving suicide prevention support has a 2 ½ year deadline. She further added staffing is the issue, not funding, as they are trying to implement mental health services into schools, workplaces and maternity services.

CC raised why women who have been through and understand loss cannot be trained to provide bereavement support.

CM shared in her experience she received excellent care but there was no mental health support for her and her husband after her loss. She noted the importance of the National Bereavement Care Pathway and the need to ensure the model is operating to its full potential.

Spotlight Session

Ciara Curran (CC)– Founder of Little Heartbeats

CC began by stating PPROM occurs when the waters around the baby are lost prematurely, which affects 3% of all pregnancies and is associated with 30-40% of preterm births. **CC** explained the membranes form a protective barrier around the baby, and after these have broken, there is a risk of infection getting into the uterus (chorioamnionitis). This can cause early labour or sepsis for the mother or baby, which can be life threatening.

CC noted that PPROM management aims to prolong the pregnancy whilst monitoring for signs of infection. This is achieved through measures such as monitoring the mother's bloods temperature, amniotic fluid, colour and smell.

CC shared that she lost her baby Sinead a week after her waters broke at 20 weeks. **CC** stated her infection was missed and consequently she developed sepsis, which led to the loss of her baby. As a result, **CC** founded Little Heartbeats, to promote informed choices so that PPROM mothers can deliver healthy babies with the correct medical care.

CC highlighted that Little Heartbeats provide support and accurate information to women experiencing PPROM, as well as care packs to empower and inform mums to understand their condition. In addition to this, Little Heartbeats provides baby loss packs for families. Little Heartbeats has been involved in research, as well as fundraising to support a study looking at resealing membranes.

CC concluded the presentation by outlining what Little Heartbeats objectives:

1. Listen to women
2. Prevent baby loss and improve babies' health outcomes
3. Reduce these potential Risks to the pregnant woman
4. PPROM awareness
5. Invest and increase in research plans, to enable the best care to women
6. Ensure all women and medical staff are informed with the latest evidence to make decisions about their care

7. All women over vitality are aware of all the risks
8. All women under 24 weeks are not just sent home, but have management plans
9. Ensure women with pregnancies complicated by PPROM are cared for by obstetricians, who will care for the remainder of the pregnancy
10. The Government acknowledges the hard work of Little Heartbeats

CC expressed her disappointment that her local MP had not attended the APPG meeting.

HM thanked CC for sharing her story and assured her that MPs, as well as the Minister, are listening to her story.

Any other business

Celia Burrell highlighted that there is an absence in the midwifery training programme in the final year of teaching how students how to deal with women whose babies have died. Midwifery students need to be addressed, not just midwives.

CM queried who puts the midwifery courses together and was informed it is devised individually by each university, but the Nursing and Midwifery Council is best to contact regarding this.

MP stated Sands have been working with a researcher, Dr Julie Jones, who is creating a framework for training for undergraduate students which will be rolled out nationally and will be incorporated into post-graduate modules.

Jess Reeves pointed out Dr Julie Jones has spoken at the APPG previously on this work.
Action: Share details on the new midwifery training framework.

CC highlighted the need for more education about PPROM.
Action: Schedule a session on PPROM at an upcoming APPG meeting.

HM concluded the meeting by thanking everyone for attending.
Action: Share the APPG on Baby Loss Updates with the Minutes.