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House of Commons

London SW1A 0AA

All-Party Parliamentary Group on Baby Loss

Monday 14th September 2020, 16:00 - 18:00, Via Zoom

MINUTES

Members in attendance:

- Rt Hon Jeremy Hunt MP (Chair – first hour)
- Cheryl yn Mackrory MP (Chair – second hour)
- Jess Faulkner, representing Sharon Hodgson MP

Other guests:

- | | |
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| • Aimee Middlemiss | University of Exeter |
| • Alex Mancini | Chelsea and Westminster Trust |
| • Alison Mintoft | UCLH |
| • Alyx Elliott | Petals |
| • Amneet Graham | Willow's Rainbow Box |
| • Ann Chalmers | Child Bereavement UK |
| • Belinda Champion | CRADLE |
| • Beth McCleverty | Bliss |
| • Beverley Radcliffe | The Coroners' Courts Support Service |
| • Charlotte Bevan | Sands |
| • Charlotte Wilson | RCM |
| • Christina Rolles | Lullaby Trust |
| • Clea Harmer | Sands |
| • Clotilde Rebecca Abe | FiveXMore |
| • Daniel Brett-Schnieder | Sands |
| • David Monteith | Grace in Action |
| • Donald Mbeutcha | Dope Black Dads |
| • Prof Elizabeth (Liz) Draper | MBRRACE-UK |
| • Emma Brooke | ONS |
| • Erin McCloskey | Canterbury University |
| • Fauzia Paize | Kings College |
| • Geoff Heaps | Lily Mae Foundation |
| • Gillian Weaver | The Hearts Milk Bank |
| • Hannah McConnell | ONS |
| • Harriet Jordan | University Hospitals of Leicester NHS Trust |

- Heidi Eldridge MAMA Academy
- Helen Graham Lullaby Trust
- Professor Jacqueline Dunkley-Bent OBE NHS England and NHS Improvement
- Jane Denton Multiple Births Foundation
- Jane Plumb Group B Strep Support
- Jenny Kurinczuk MBRRACE-UK
- Jenny Poirier Lullaby Trust
- Jenny Ward Lullaby Trust
- Jessica Read NHS England
- Jessica Reeves Sands
- Jo Carroll Lullaby Trust
- Jo Dickens University of Leicester
- Josie Anderson Bliss
- Julia Bueno
- Karen Burgess Petals
- Karen Luyt NCMD
- Karen Todd Department for Health and Social Care
- Kate Holmes Lullaby Trust
- Kate Mulley Sands
- Leanna Brace CRADLE
- Leanne Turner Aching Arms
- Louise Zeniou CRADLE
- Marc Harder Sands
- Marcia Jones Lullaby Trust
- Mel Scott Towards Tomorrow Together
- Michelle Kelly Belfast City Council
- Munira Oza Ectopic Pregnancy Trust
- Niamh Brookes NHS England
- Nikki Crowley RCPCH
- Oliver Plumb Group B Strep Support
- Paula Abramson Bereavement Training International
- Penny Kerry The Miscarriage Association
- Rachel McBryde Department for Health and Social Care
- Rejoice Absutsa Lullaby Trust
- Rich Boyd Twins Trust
- Roopal Shah Babyloss Support LLR
- Ruth Bender-Atik Miscarriage Association
- Ruth Matthews Leicester University
- Ryan Jackson The Lily Mae Foundation
- Sara Balmforth Forget Me Not Children's Hospice
- Sarah de Malplaquet Kit Tarka Foundation
- Sharon Darke Twins Trust
- Sophie Daniels Liberty's Mother
- Sophie Dodgeon Rainbow Trust Children's Charity
- Stephen Hall RCOG
- Steven Wibberley Cruse Bereavement Care

- Sylvia Stoianova NCMD
- Tara Arnold Nova Foundation
- Tinuke Awe FiveXMore
- Vicki Robinson Miscarriage Association
- Vicky Sleep NCMD
- Zoe Moulton RCOG

1: Welcome, introduction and updates (Jeremy Hunt MP, Co-Chair of APPG on Baby Loss)

Jeremy opened the meeting and welcomed everyone. He introduced herself as the new Co-Chair of the APPG alongside Cheryl Mackrory MP. Jeremy paid tribute to previous Chairs of the APPG, including Will Quince MP, Antoinette Sandbach and Victoria Prentis MP. He further thanked the APPG's Vice-Chairs, Sharon Hodgson MP and Patricia Gibson MP for their work in driving the group forward. He also thanked the many charities and bodies who support the work of the APPG. He noted that the APPG on Baby Loss is one of the most effective in the House of Commons.

Jeremy went on to explain that during his time as Secretary of State for Health and Social Care, baby loss became an issue close to his heart. He reminded attendees of work that he did as Secretary of State, including introducing the National Ambition 'Halve It' campaign to reduce rates of stillbirth, neonatal and maternal deaths by 50% by 2025. He noted that it is still vital to continue doing everything possible to reduce baby loss and support families. He further explained that he is also Chair of the Health and Social Care Select Committee, which is holding an enquiry into maternity safety.

Jeremy explained that the meeting would focus on baby loss among BAME communities and include a panel discussion with expert speakers. It would further include an update on Baby Loss Awareness Week 2020.

Jeremy then updated attendees on actions from previous meetings of the APPG:

- 1) The MBRRACE-UK report on maternal deaths, discussed at August's meeting, has now been published and is available on their website.
- 2) The APPG has written to the Minister, Nadine Dorries MP, in relation to the National Ambition for reducing rates of stillbirths, neonatal and maternal deaths and brain injuries, and will report back once a reply has been received.
- 3) The APPG is now more active on social media as we have launched a Twitter account. All key documents continue to be published on the APPG's website.
- 4) The APPG has written to Lord Bethell, Health Minister, in relation to MBRRACE-UK and the national data opt-out, requesting a meeting to discuss this further. Jeremy explained that he also raised this issue with the Secretary of State, Matt Hancock, at a recent Health and Social Care Select Committee.
- 5) The APPG published a short report on baby loss and COVID-19 following the August informal meeting, which has also been sent directly to key stakeholders across NHS England and the Department of Health and Social Care.

Jeremy also provided updates on two policy issues of interest:

- 1) The Pregnancy Loss Review, set up to consider processes for pregnancy loss before 24 weeks, is expected to submit a report to Ministers by the end of 2020. At

January's APPG we heard that the report was expected in spring or summer 2020, so a short delay was noted.

- 2) The response to the consultation on coronial investigations of stillbirth is expected to be published 'soon' according to DHSC. At January's APPG we heard that the Government response was expected in spring or summer 2020, so again there has been a short delay.

2: Panel discussion: Baby loss among BAME communities

Jeremy introduced a panel discussion on baby loss among BAME communities. He noted that this is a pressing topic for the APPG, given known differences in rates and risk of pregnancy and baby loss between different communities. He expressed the APPG's thanks to the experts, both experts through training and experts through experience, who had joined the meeting to speak.

- Professor Liz Draper, MBRRACE-UK

Professor Draper presented data on rates of stillbirth and neonatal death in the UK. She explained that rates of stillbirth among Black and Asian populations are higher than among the white population, and that similar trends are seen for neonatal deaths. She went on to outline research into contributing factors for heightened risk of stillbirth, including ethnicity, deprivation (including income, education, crime levels locally, and local environment) and age.

Professor Draper noted that investigations into the causes of stillbirth and neonatal death, via post-mortem, are skewed due to low consent rates for mothers from deprived areas and mothers from Asian Pakistani and Asian Bangladeshi ethnicity. This means that the findings of investigations may not be giving the full picture. She explained that MBRRACE-UK are undertaking a confidential inquiry to assess the quality of care provision provided to the mothers of Black and/or Asian babies who are stillborn or who die in the neonatal period. MBRRACE-UK are keen to engage with a range of stakeholders to develop the inquiry.

- Dr Karen Luyt, National Child Mortality Database (NCMD)

Dr Luyt explained that the NCMD is funded by NHS England, and collects data on child mortality up to the age of 18. It began collecting data in 2019, and deaths must be reported to them within 48 hours of a child's death. The NCMD has played an important role in tracking child death during the COVID-19 pandemic. The database collects data on demographic details including ethnicity, suspected cause of death, and locality.

She went on to explain that infant mortality is understood as mortality up to the age of one year old. Two-thirds of all child deaths occur in the first year. Dr Luyt talked through data on death notifications to the database between 1st January and 30th June 2020, which have not yet been published. She noted that children from BAME populations were disproportionately represented in infant deaths, compared to children from white populations. She further explained that children from the most deprived quintile who died before one year of age were more likely to be from BAME populations than from white populations.

- Amneet Graham, Willow's Rainbow Box

Amneet introduced herself as Founder and Chair of Willow's Rainbow Box, a charity supporting women who are pregnant after a loss. She is also Service User Chair of the Newcastle upon Tyne Maternity Voice Partnership. She explained that she is Indian, married to an English husband, with a half Indian daughter.

Amneet set out challenges relating to baby loss in South Asian communities. From her own experience she noted the taboo nature of baby loss, leading to keeping things personal and private. She went on to explain feedback from other women that there can be a preference towards male babies, a concept of blame for baby loss, and little support within the community. She noted that a lack of accessible support in different languages is especially important for older generations, who hold influence. She also noted inconsistency in cultural awareness in some health services, meaning that particular rituals or ceremonies around bereavement could not be carried out. Lastly, she explained that a lack of referral to perinatal mental health services was a concern.

Amneet went on to share stories from women and families from South Asian communities who have experienced pregnancy and baby loss. She set out a range of ways that services and professionals can help to support women and increase awareness and understanding. These included engaging communities where they are, for example via faith institutions or community radio stations. Other routes include providing a platform for different voices to be heard. She noted the importance of cultural awareness training for staff, and ensuring that support is accessible for those without English as a first language.

Amneet closed by highlighting research from Taraki into support routes for Punjabi communities, which found that support was most commonly accessed through friends, family and faith, and noted this should be kept in mind when planning services.

- David Monteith, Grace in Action

David spoke about the death of his daughter in the context of his experiences as a Black man. He set out the intrinsic and internalised biases he had noticed in himself and others against people of colour. He explained how these biases permeated through concepts of beauty, literature, even skin plasters where white was seen as default and desirable. He further explained how he worked to challenge these biases by learning about lesser known black culture and questioning his internalised biases.

David set out the data on perinatal deaths and disparities in outcome by ethnicity. He challenged responses to the data which ask about a genetic cause. He noted that this ignores diversity within Black communities. He further explained that disparities in outcomes are seen for marginalised communities in other countries, such as the USA. He highlighted how a medical student has taken it upon himself to develop resources for diagnostics for people with non-white skin, as this did not already exist.

David talked about the disproportionate level of disciplinary action against Black midwives, according to the Royal College of Midwives. He explained that we all hold intrinsic biases and need to recognise these, and that action in future needs to acknowledge this.

Jeremy thanked the speakers so far for their presentations, and handed over to Cherilyn to chair the second hour.

- Professor Jacqueline Dunkley-Bent, Chief Midwifery Officer at NHS England

Professor Dunkley-Bent outlined NHS England's approach to achieving equity of outcomes. The approach draws on 'proportionate universalism' to give every child the best start in life. A proportionate universalism approach takes universal action, but with a scale, pace and intensity that reflects the level of disadvantage. She set out some of the key equity interventions being taken to address baby loss by NHS England and Improvement, including continuity of carer, the Saving Babies Lives Care Bundles, Maternal outreach clinics, delivery of the NHS Long-Term Plan, and culturally appropriate genetic services.

Professor Dunkley-Bent explained the role that continuity of carer plays in preventing baby loss, with data suggesting a 16% reduction. 10,500 women (17%) are currently receiving continuity of carer, with an ambition to increase this. There is an aim to particularly increase the numbers of Black and Asian women, and those from the most deprived areas, who receive continuity of carer. Professor Dunkley-Bent went on to share stories from families who have experienced continuity of carer, and the impact it had on their experiences of care.

Professor Dunkley-Bent went on to talk about the Saving Babies Lives Care Bundles. She noted that they are key to the Halve It campaign. The first care bundle targets stillbirths, with four actions relating to reducing smoking, fetal growth restriction assessments, reduced fetal movement awareness and effective fetal monitoring during labour. While it is a universal offer, its impact will particularly impact on Black and Asian babies. The second care bundle focuses on reducing pre-term birth. The bundle includes specialist clinics, better risk assessment, medication and screening.

Professor Dunkley-Bent further spoke about the impact of COVID-19. She explained that Black and Asian pregnant women were more likely to be admitted to hospital with COVID-19. As a result, Local Maternity Systems were asked to take action including increasing support for pregnant BAME women, sharing tailored communications with pregnant BAME women, discussing vitamins and supplements, and ensuring risk factors are recorded. Information has been produced in a range of languages, and via animations. She further noted that fully reinstating treatment options and bereavement care for women was a priority during the COVID-19 recovery. She went on to discuss parental access to scans and hospital settings, noting that the expectation is that every service uses new guidance – including risk assessment – to facilitate greater access.

- Stephen Hall, Royal College of Obstetricians and Gynaecologists (RCOG)

Stephen set out the RCOG's work on a new Race Equality Taskforce. He explained that the taskforce has been set up in the context of the data on inequalities that had been explained by previous speakers. He noted that coronavirus has impacted on the College's understanding of inequality.

Stephen explained that before the pandemic, the RCOG held an event on International's Women Day setting this work in train. It culminated in a policy statement calling for Government action to examine and report on race inequality, end the gender and ethnicity data gaps in medical research, and establish a robust training programme in medical schools to eradicate racial bias and stereotypes. The College has been meeting with key stakeholders to share their calls.

The taskforce will include people with lived experience, clinicians and other key stakeholders. It will have three workstreams: women's health, RCOG products/functions, and workforce and careers. Its first meeting will be in October.

Stephen closed by highlighting the College's collaboration with Five X More, which will provide five tips for healthcare professionals who are working with pregnant BAME women.

3. Q&A and discussion (led by the Chair)

Cherilyn began a question and answer session, inviting attendees to ask speakers about their presentations.

Jane Plumb (Group B Strep Support) noted challenges in obtaining data by ethnicity of babies who develop Group B Strep. Guests from MBRRACE-UK and the NCMD responded to note that this data was available and agreed to contact Jane to progress this.

Munira Oza (Ectopic Pregnancy Trust) highlighted the lack of data on women who experience early pregnancy loss, including ethnicity data. She set out a plea to not forget women who experience this, and for stakeholders to collaborate to try to capture data on this group.

Tara Arnold (Nova Foundation) noted her personal experience of not being able to reflect her mixed race ethnicity in data capture. She further highlighted that mixed race itself is not a homogenous group, but very diverse and may include a range of outcomes. Cherilyn agreed that capturing as much data as possible is vital, and proposed contacting the ONS to explore this. Karen Luyt (NCMD) noted that a new census next year must take place which should collect the most detailed data as possible, using classification that is echoed across the health service and elsewhere.

Mel Scott (Towards Tomorrow Together) noted the restrictions on access for families to services currently and the impact of this, including access to mental health services.

Donald Mbeutcha (Dope Black Dads) highlighted the challenges of using BAME as a grouping, as it hides diverse experiences and outcomes. He also noted that the data on maternal outcomes and perinatal outcomes for Black women has been known for some time, and asked why action is being outlined now. Cherilyn agreed that data collection and groupings were a key issue which could prevent the granularity of data being properly reflected. Stephen Hall (RCOG) agreed that data on outcomes for Black women has been available for many years, including women's own stories.

4. Update on Baby Loss Awareness Week (Daniel Brett-Schneider, Sands)

Cherilyn introduced Daniel Brett-Schneider from Sands who provided an update on plans for Baby Loss Awareness Week 2020 (9-15 October). Daniel set out the purpose of BLAW which includes to enable people to commemorate their babies' lives and to raise awareness of baby loss.

Daniel went on to update attendees on the 2019 campaign, to ensure all parents who experience pregnancy and baby loss can access psychological support should they need it. In 2019 the Minister committed to taking action on this, via maternity outreach clinics although this has been delayed as a result of the pandemic.

Daniel explained that BLAW 2020 would focus on feelings of isolation around baby loss, particularly in light of COVID-19. The week aims to reduce isolation and enable people affected by baby loss to share their experiences. Each day during BLAW will highlight a different topic, such as partners, wider family, the workplace, BAME communities, and LGBTQ+ experiences. The week will culminate with the Wave of Light on Thursday 15th October. People can get involved by wearing a ribbon pin, turning buildings pink and blue, taking part in acts of remembrance, and by joining the Wave of Light on social media. Daniel signposted attendees to the BLAW website and social media channels.

In Westminster, BLAW activity will be less than usual, but an application is being made for a Backbench Business Debate. MPs are encouraged to contact Cherilyn's office if they would like to join the debate.

Cherilyn explained how she had been involved with BLAW last year, and her support for all the activity planned for 2020.

Sophie Daniels (Liberty's Mother) noted that videos of her performances from BLAW 2019 are available on YouTube for all to use during this year's activity.

5. Close of meeting

Cherilyn closed the meeting by thanking all the speakers and contributors. She noted that the next meeting of the APPG is planned for Monday 7 December, 16.00-18.00, via Zoom. The proposed focus of that meeting is learning from data.