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

Monday 12th May, 14:30pm – 16:30pm
Committee Room 18, The Palace

Chair: Andy MacNae MP

NOTES

Members and representatives in attendance:

- Andy MacNae MP
- Michelle Welsh MP
- Saqib Bhatti MP
- Tessa Munt MP

Speakers:

- Alicia Burnett, Black Baby Loss Awareness Week
- Rachel Burrell and Gina Reeves, Ebony Bonds Bereavement Support
- Mohamed Omer, Muslim Gardens of Peace
- Simon Riley and Waseema Shaikh, The Alder Centre
- Dr Celia Burrell and Midwifery Team, Barking, Havering and Redbridge University Hospitals NHS Trust
- Professor Judith Rankin and Professor Joht Singh Chandan, National Institute for Health Research Maternity Disparities Consortium

Guests attending in-person:

Maryan Ahmad	Barking, Havering and Redbridge University Hospitals NHS Trust
Jananie Aldridge	Royal College of Pathologists
Emily Cannon	Office of Michelle Welsh MP
Aimee Conroy	Luna's Fund
Kate Davies	Tommy's
Kate Davis	Department of Health and Social Care
Heidi Eldridge	MAMA Academy
Clea Harmer	Sands
Ebele Ijomoni	Cradling Culture CIC
Ryan Jackson	Lily Mae Foundation
Lily Le Go	Barking, Havering and Redbridge University Hospitals NHS Trust
Jasmine Leonce	NHS England
Emily Lewis	Royal College of Obstetricians and Gynaecologists
Sharon Luca	The Luca Foundation
Charles Mason	Guest
Victoria Morrell	Twins Trust
Jenny Mcneill	Queens University Belfast
Helena Morais	Maila's Present
Bea Morrison	NHS England
Paula Mothersole	Petals
Geeta Nayor	Irwin Mitchell/ South Asian Maternal Health Conference
Sian Ness	CuddleCot
Holly Osman	Sands
Pauline Okhamesan	Barking, Havering and Redbridge University Hospitals NHS Trust
Mehali Patel	Sands
Zeshan Qureshi	NHS
Jess Reeves	Sands
Peter Reeves	Ebony Bonds CIC and N.I.N.E
Owen Reily	Office of Andy MacNae MP

Emma Rose	Royal College of Midwives
Angela Rice	Midwife
Suzie Scofield	Footprints Baby Loss Twin Triplet Support
Leanne Turner	Aching Arms
Lucy Wakeley	BBK LLP
Jenny Ward	Lullaby Trust
Claire Waters	Barking, Havering and Redbridge University Hospitals NHS Trust
Gillian Weaver MBE	Co-founder; the Human Milk Foundation

1. Welcome & introductions

Andy opened the meeting and welcomed everyone attending.

2. APPG on Baby Loss Updates

Andy provided updates on several items of relevance to the group:

APPG on Baby Loss Change NHS Submission

Andy updated the group that following the APPG on Baby Loss meeting in February, the APPG on Baby Loss made a submission to the Change NHS consultation.

The submission can be found in the Minutes of the 3rd February meeting, which is on the APPG on Baby Loss webpage.

Joint APPG Letter to Rt Hon Wes Streeting MP

Andy informed the group that the APPG on Baby Loss, along with the Patient Safety APPG and Maternity APPG, are in the process of sending a letter to the Secretary of State for Health and social Care. The letter crystalizes the ambitions and current challenges in maternity and bereavement care, in addition to clearly stating what we need to see in the NHS 10-year plan. The letter will be shared, and further updates will be provided.

Action: The secretariat to share a copy of the joint letter when it is sent.

Bereavement leave following miscarriage

Andy updated the group that the Government has committed to legislating for bereavement leave for people affected by pre-24 week pregnancy loss.

Andy noted that the move marks a significant step forward in the *Leave for Every Loss* campaign, run by the Miscarriage Association and campaigning efforts by previous officer of this group and now Chair of the Women and Equalities Select Committee Sarah Owen MP and others.

Westminster Hall Debate on Black Maternal Health Week

Andy informed the group that Bell Ribeiro-Addy MP held a Westminster Hall debate on 29th April which highlighted the disparities in maternity care and outcomes for Black mothers.

10 Minute Rule Bill Maternity Units (Requirement for Bereavement Suite)

Andy informed the group Rosie Wrighting MP introduced a 10 Minute Rull Motion on 29th April requiring all new build hospitals to provide a bereavement room. The Bill will receive a second reading on 16th May.

Service Development Funding (SDF) for maternity services

Andy informed the group that the Government have recently announced changes to the SDF ringfenced funding for maternity services in 2025/26 from £95m in 2024/25 to £2m in 2025/26.

Andy highlighted how it will be important to ensure that the government ensures maternity and neonatal services are delivering improvements without this ringfenced funding.

Andy noted that there would be a slight change to the running order on the agenda.

3. **Insights from Ebony Bonds Bereavement Support** (Rachel Burrell and Gina Reeves)

Gina introduced that Ebony Bonds would be presenting on best practice in bereavement care for black families.

Gina explained that Ebony Bonds is a peer led bereavement support service which holds spaces for black families who have experienced baby loss. It was started in May 2024 by Rachel, Temi and Gina. This presentation is for all babies and parents who said they weren't heard.

Gina shared how for Black families, the loss of a baby is carried in silence in systems which don't always respond. Too many families leave hospitals without babies, and too few have had people ask how they are.

Gina highlighted that in some cultures; the loss of a baby is viewed as a shame. With some viewing the baby as a bad spirit or loss being treated as a punishment. Parents may be told to move on or be grateful for what they have. Sharing experiences may be discouraged.

As a result, other bereaved parents are only comfortable sharing with Ebony Bonds because they have so openly shared their own experiences.

Why cultural competence matters

Gina explained that in many black communities, grief may be spiritual, sacred or collective. It may show up in rituals, music, food story, telling or silence held in reverence.

There is no right way to grieve, and grief must be met not managed. It is important to honour traditions and must validate each family's unique experience of loss.

Gina explained that every word, gesture and silence matters. Black bereaved parents may experience insensitive care after loss, dismissive culture or cultural ignorance. They may have historical and personal trauma,

Trust gaps

Gina explained that mistrust in healthcare is built on generations of harm, from forced experimentation to not being listened to in the labour room. With examples such as 'You didn't look like you were in pain' heard too often.

Gina shared how she was not just grieving, but surviving trauma. As her pain didn't fit healthcare professionals' expectations she was left alone, resulting in her husband having to actively go looking for help twice.

Gina received no support and no dignity. On top of the trauma of the experience, the hospital response was that they wouldn't have done anything different. **Gina's** experience shows how Black women are failed in the moments when they most need to be held.

Gaps in bereavement care

Rachel explained how Black mothers cannot be supported by generic leaflets with no representation in them. This is paired with support workers who don't reflect their experiences or don't have much experience working with them personally.

Rachel highlighted that additionally there is a lack of access to culturally competent therapists, it is very rare for families to be able to access culturally competent therapists, meaning that families are either left in silence or with therapy which doesn't resonate with them.

Rachel also highlighted how language barriers may be an issue, and that access needs to be expanded.

Rachel shared how Black parent's experiences of loss are personal, but support groups are provided to the general population without regard to race, culture or lived experience. Black parents sit in groups where no one looks or speaks like them, no one there understands racial trauma can be isolating and the opposite of healing.

Best practice

Gina and **Rachel** highlighted how culturally competent care must recognise cultural identity, understand families cultural, religious and spiritual beliefs and must understand death, grief and loss around communities.

Inclusive language is important, assumptions must be avoided and terms which reflect the family's preferred way of referring to their baby, babies name, spiritual practices should be used.

Gina and **Rachel** highlighted that there needs to be diverse representation in healthcare. Materials, staff and those representing Black families need to be representative of the communities they work with for healing and to build trust.

Additionally, support must be trauma informed and anti-racist. Support must recognise systemic racism issues, understand medical racism and trauma experienced in loss and interactions with healthcare.

Gina and **Rachel** shared how Black families must feel safe to share without fear, judgement, tokenism or being silenced. It is important that there is validation of the unique pain experienced by Black families. It's important to enable culturally grounded healing. This may include rituals, language, food, music, storytelling all of which may be rooted in African and Caribbean traditions.

Gina and **Rachel** spoke of the importance of support being provided flexibly. This may include 1:1 support, group support, online support and face to face support. The easiest way for this to be provided, is to work with existing services, partnerships with larger charities and specialist charities. It's important that organisations such as Ebony Bonds and N.I.N.E protect families from traumatisation in spaces which don't reflect them.

In closing, **Rachel** and **Gina** asked midwives, therapists, policy makers and organisations and everyone else to step up not with sympathy, but with action. For healthcare professionals, do not wait for training to be provided but offer culturally safe care. For allies, use your voice in rooms they aren't in. It's important to stop having conversations about ending inequalities without including organisation like Ebony Bonds. Institutions must acknowledge racial disparities and help to build trust by investing in long term change and not token gestures. Black grief deserves care, black babies deserve justice, black families deserve love. This is not about statistics, it is about humanity.

Gina and **Rachel** closed by stating “let us honour every life seen and unseen. Let us hold space for every family grieving and surviving. And let us continue this work together.”

Andy thanked **Gina** and **Rachel** for their clear call to action and powerful message, which was powerfully delivered. Through meetings like this we can turn words into actions, and this will be part of the APPGs mission going forward.

4. **Muslim Gardens of Peace** (Mohamed Omer)

Mohamed introduced himself and that he was here to share the Muslim prospective of pregnancy and baby loss. An in-depth presentation will be shared.

Mohamed shared that he was pleased to see diversity in the APPG meeting, he had been attending APPG meetings for a while, and we must have inclusion.

Mohamed noted that everything **Gina** and **Rachel** had said during their presentation resonated. As a Muslim community any loss is traumatic, but not a taboo subject. Life and death must be seen as a reality in life. However, those working with Muslim bereaved families may not understand what the culture and faith requirements are. They may not be given the training or try to educate themselves on what they should know to care for Muslim families. Muslim Gardens of Peace have reached out to organisations to try to provide training.

Mohamed explained that the Gardens of Peace is the largest Muslim cemetery in the entire Country. Possibly in the whole of Europe. With 50% of all the people who die from Muslim faith in London buried in the Cemetery.

Mohamed explained that when he started his work in 2002, he saw the high numbers of stillbirths and neonatal deaths. **Mohamed** reached out to Ministers, to ICBs, to Midwives to come and see this but they did not. **Mohamed** believes that if they did, they would have seen the inequality, and no one wanted to take responsibility for this. Which is unacceptable. Every mother and family irrespective of religion, or culture must be treated equally. Every child matters.

Mohamed explained that from a Muslim perspective miscarriage and stillbirth definitions do not correlate with NHS and UK definitions. In the Muslim faith any baby under 120 days gestation must be buried and cannot be incinerated. At 121 days of gestation the soul enters the body, requiring religious involvement. It is important to be aware of this to ensure specific culturally sensitive support can be provided to Muslim families.

Mohamed explained that when Gardens of Peace was founded, most pregnancy and baby losses under 24 weeks were incinerated by the hospital. As explained above, any baby under 120 days must be buried. They worked with the hospitals to make them aware of this requirement.

Mohamed explained that in both the Muslim and the Jewish faiths, burial must happen as quickly as possible. This means that mothers cannot always be present at the burial. Those working with bereaved parents must be aware of this. This again shows why it is so important to educate healthcare professionals.

Mohamed explained that there must also be sensitivity around the need for a postmortem to be completed. The fact that there are not enough paediatric pathologists in the UK, causing long waiting times for results, must be sensitively communicated to bereaved Muslim parents.

Mohamed explained how accessing support as a Muslim can be difficult. In other countries, you would find support from the wider community, but you do not have that support here. However, if you did go to secular community support systems, the community may ask why you discussed this with people outside the community. It's important that bereaved families can access support in their own community.

Mohamed reiterated, as raised by **Gina** and **Rachel**, there must be community support available. Government says that bereaved families should be at the centre of support, but it must be funded. Charities are providing the support, but they do not receive funding to provide bespoke support.

Mohamed explained how in recognising the gaps, they have created their own support service. This includes 36 volunteers headed by a doctor who give support free of charge. If there is a clinical need, they can refer parents.

Mohamed concluded by saying that this APPG is important, it can lead the way and can make sure change does happen. Everyone in this group wants change. But when you are making decisions or plans, please involve the people concerned. Representation in healthcare is very important.

Andy thanked **Mohamed** for the eloquent and clear questions and answers provided.

5. Simon Riley and Waseema Shaikh

Simon and **Waseema** explained that they work in the Alder Centre, which provides support for anyone affected by the death of a child. They are here today to share their recent experiences of childbirth in the last 10 weeks, where they saw firsthand the experiences of Black and Asian parents and felt it was important to share these.

Waseema explained that they gave birth to a baby boy in February, and she feels they would not be here today if things had gone how they seemed to be going. She believes it is pivotal to reducing preventable baby loss to share the treatment they witnessed.

Waseema shared that at the core of what they witnessed was racial disparities and attitudes. If you were Black or Asian, you would have to prove yourself to be

deserving of the care which you should automatically receive, whereas white counterparts were given the benefit of the doubt.

Waseema explained that their son was born with Jaundice. It was clear that you could see he was rebounding, and he was not feeding. When they raised concerns, every member of staff said, “that’s just your baby’s colour”. He had progressed so far it was lucky healthcare staff intervened when they did. In contrast, the couple next to them were white and a midwife came in and he was immediately checked (as procedure) because there was a slight yellow tinge. **Waseema** was calling out for help but feels that she was neglected.

Waseema also highlighted how important communication is. She saw 8 women who needed translation services during their stay. At one stage, she heard the staff say that it’s too much effort trying to translate, “we need to wrap this up”. **Waseema** felt that this meant critical medical information wasn’t being given to the woman about how to take care of herself and her baby postnatally. There was an expectation on family and friends to do this.

Waseema spoke about how breastfeeding is an essential part of taking care of your baby. However, every non-English speaking family was told they needed to go their own community or online to find support and advice on breastfeeding. In contrast, every white family on the ward were given access to specialists, pumps and bespoke services.

Additionally, **Waseema** witnessed white families being offered formula if they could not breastfeed. However, a Black Arabic speaking father was told he would need to go to the shop in the middle of the night to buy formula as they didn’t have any.

Waseema spoke about post c-section care and discharge, which she said was the catalyst for coming today and sharing their experiences. The standard practice for discharge following c-section is 3 days, as women need to hit certain markers to show it is safe for them to be discharged. However, **Waseema** witnessed non-white women being discharged within 24 hours, sometimes even within 3-4 hours.

Waseema witnessed healthcare staff saying, “don’t you want to be home with your family, with people you know.” She witnessed one woman clearly in pain being told to wait in a corridor to be collected by her partner. They did not use a language service to communicate with her. However, the mother could not even walk to the corridor which finally raised flags for the healthcare professionals, and they said they needed to run more tests before discharge. This was neglect. This was preventable.

Waseema shared she could give many more examples.

Waseema also highlighted differences in the way white women and non-white women were fed during hospital stays. Nutrition is important, to breastfeed you need to eat. However, all that was made available to **Waseema** everyday was a sandwich. There was a comprehensive list of foods, but **Waseema** shared she wasn’t allowed

to see the list. However, healthcare staff did give a list to **Simon** when they saw him first. **Waseema** witnessed one woman being told, “if you don’t speak English, they couldn’t get food”. This was explicit racism. Additionally, **Waseema** witnessed white fathers being given food, whilst non-white fathers were not.

Waseema concluded by highlighting invisibility and inconvenience. Families were made to feel an inconvenience for no reason other than they didn’t speak English well enough, they looked too different or weren’t integrated enough. This resulted in unequal systems. This is posing a risk to babies’ lives due to a lack of information.

Simon shared some recommendations:

1) Mandated training
2) Enforcing standardised care for everyone not just those who look the right way or can speak English
3) Ensuring translation apps are always used.
4) Clear accountability

Waseema highlighted how she was publicly shamed on the ward when she did share a concern and treated differently. There needs to be accountability for this behaviour. Visibility and Value = Safety. There must be equitable care which protects all mothers and babies. It needs to be recognised that there are changes which can be made now and they are not complicated to do.

Andy thanked **Simon** and **Waseeda** for sharing their story. **Andy** shared he had recently had a meeting with Bill Kirkup and Donna Ockenden and met with the new leadership of the CQC recently and this was top of the agenda in all these meetings.

Andy shared that it is helpful to be able to take these stories into those meetings. The message needs to be that these disparities must be eliminated. It is unacceptable and no excuse for lack of action.

6. **Black Baby Loss Awareness Week** (Alicia Burnett)

Alicia introduced Black Baby Loss Awareness Week and her background as a midwife. She qualified in 2021 and is currently working as a Tommy’s midwife on the helpline for Black and Mixed Black heritage women.

Alicia explained that before she became a midwife, she became a bereaved mother whilst training. At their 12-week scan, they were given devastating news. Her son was born in 2017 and lived for 6 months in intensive care. He died in May 2018 and Alicia went back to studies in September 2018 as she wanted to go back to helping families.

Alicia explained she has two angel babies; she experienced an ectopic pregnancy in 2019. Although a student midwife, training cannot teach you everything and she learnt a lot through her own experiences of baby loss and pregnancy after loss. Her

son is the reason she is here today. She would never have achieved what she did if he hadn't been here.

Alicia shared statistics on the increased rates of baby loss in Black mothers. She shared that she did not know this as a student midwife, despite living it, she knows this now through her work with Tommys. If she didn't know it, then her community won't know it. And through speaking with women on the helpline, she knows women do not receive the same excellent bereavement care she received. The excellent bereavement care she received allowed her to go back to her course.

Alicia explained the care and palliative care they received was excellent. What she would love to see for all black parents is for funding to be provided to the grassroots organisations providing support for bereaved black parents. Black parents are currently being failed by the system, whether the voluntary or private sector, and it is taking bereaved parents like **Alicia, Gina, Rachel** to provide peer support in their own time. If they were empowered with funding, they could achieve so much more. As things stand, there is a real risk of burnout and then what will happen to Black bereaved parents.

Alicia said that service providers must involve Black bereaved parents in the design of bereavement services. So many organisations want to provide care, but if you design it without including Black parents, it won't provide the care that is needed. There is a black baby loss community which is thriving, and they are in the room today. If you are designing services, look for them. When you lose a child, all you need is kindness and ways to grieve that are culturally and socially acceptable to you and if that means family visiting or playing certain music, bathing your child. These are things which you wouldn't know you need to provide if you don't speak to Black families when designing bereavement services.

Alicia introduced BBLAW. The first BBLAW was in February 2023 as she had heard that not all bereaved Black parents were able to access the care and support which she had received. When she started BBLAW she was confronted and challenged on why this was needed separately from BLAW and had to explain. **Alicia** had attended a remembrance event, where there were only two Black families. During that service the other child's name was pronounced incorrectly which deeply hurt **Alicia.** This is why BBLAW is needed. She explained the importance of names, and how her son's name so important.

Alicia concluded by talking through the agenda for the BBLAW this week, which includes events with **Rachel** and **Gina.**

Andy thanked **Alicia** for all the work she does, and for highlighting the importance of good bereavement care.

Action: the APPG to collate the experiences and recommendations from speakers with lived experiences presentations to ensure that these are

included in the joint action by the APPGs on Baby Loss, Maternity and Patient Safety to improve maternity safety in light of the upcoming 10-Year Plan.

7. Dr Celia Burrell and Midwifery Team, Barking, Havering and Redbridge University Hospitals NHS Trust

Celia introduced herself as a consultant obstetrician, alongside her colleagues **Tanwa Ogbara,** who works as a Senior Lead Midwife for Better Birth and Multi-Ethnic Empowerment and **Louise Butler** Specialist Midwife for Clinical Quality Improvement.

Celia explained the senior leadership were also with them today at the APPG and they work as a team.

Celia echoed comments already made, that she had been attending since 2018 and the diversity at this meeting was welcome.

Celia introduced that BHRUT is the largest single site unit in North-East London and the third largest in the entire UK. They deliver over 7-8,000 babies a year.

Celia explained that at BHRUT they have been looking at the data around pregnancy and baby loss. They have been watching it nationally, but it is also important to see what is happening locally. Therefore, every year when MBRRACE-UK publish their report they look at it to see what is happening locally and how they can improve and reduce rates.

Celia explained that BHRUT is a very diverse area, covering four boroughs. There are differences in term of ethnicity, equality and deprivation. Only 40% of women are Caucasian, with 60% of the population not Caucasian. Having looked at the data, the Head of Midwifery was very proactive in seeing what was happening in the poorest postcodes (IG1 and RM10) and has adopted a targeted approach by looking at these two boroughs to see how they could help women in them.

Celia explained at BHRUT they have introduced:

- Bereavement Clinic
- Enhanced Continuity of Carer
- Ethnic Empowerment Lead
- Quality Assurance Lead

These are new roles which have been put in place to improve inequalities.

Celia highlighted how some Trusts do not look at their data, but at BHRUT they have annual audits. **Celia** has started a new bereavement clinic for women who have had an adverse outcome triggering an external review. The clinic is specifically focused on reporting back, alongside the PMRT lead midwife.

Celia also highlighted how they are holding a community event targeting postcodes where there are the highest inequalities. Local GP will also be in attendance.

Louise spoke about ongoing initiatives which the hospital is using to reduce inequalities. This includes real time trends analysis and action so that they can identify if there have been any increases in rates and look at what has happened. They have also introduced a first trimester screening programme for pre-eclampsia.

There is also a dietician who takes referrals and has produced a healthy eating leaflet recognising cultural needs.

Tanwa spoke about the enhanced continuity of care model, which ensures women receive consistent care from a dedicated team, which improves maternal and neonatal outcomes, reduces anxiety and increases patient satisfaction.

Tanwa explained that the model was implemented in 2023 at BHRUT, following thematic reviews of stillbirths which showed that they were higher in the two identified postcodes, as well as Black, Asian and Minority Ethnic groups.

Tanwa explained that BHRUT have launched 3 enhanced continuity of care teams in the two postcodes identified. They focus on delivering culturally competent care tailored in these two postcodes. This is integrated between midwives, obstetricians, and support services working together for holistic care.

Louise shared graphs showing the impact the commencement of enhanced continuity of care had on rates. In the last year, in the six-month periods there has only been one loss in each of the areas. When looking at data there has been a statistical drop in stillbirth and neonatal death rates from September 2024.

Louise explained that PMRTs had shown mothers were experiencing mismanagement of diabetes and hypertensive disorders. The data shows that since the introduction of these initiatives there have also been reductions in the mismanagement of diabetes and hypertensive disorders reviewed in PMRTs.

Tanwa highlighted that the healthcare professionals working within BHRUT are also very diverse, so women and birthing people are being cared for by healthcare professionals who look like them.

Andy thanked the speakers for sharing best practice. It is important to find ways to share best practice and what works. The officers of the APPG would be interested in visiting BHRUT to hear more about the work they are doing.

Action: The secretariat to contact APPG officers and BHRUT to see if it is possible to arrange a visit. As the hospital operates in the Secretary of State's constituency, an invite should also be extended to him.

Action: the APPG ensure that the services available at BHRUT are highlighted in the joint APPGs work to improve maternity safety.

8. National Institute for Health Research Maternity Disparities Consortium (Professor Judith Rankin, Senior Investigator in Public Health and Professor Joht Singh Chandan, Health Inequalities Lead)

Professor Judith Rankin thanked the APPG for the invitation and thanked all speakers sharing their personal stories which illustrates why we are all in this room. The Maternity Disparities Consortium is newly formed and funded through the NIHR. They hope it will contribute to the changes called for today.

Judith reiterated the evidence of the need for a maternity disparities consortium. Between 2017-2019 2020-2022 there was a 53% increase in the maternal death rates in the UK, an increase which is still present when excluding covid 19 deaths. The rates for Black mothers are the highest, with rates highest for those living in the most deprived areas. Stillbirths and Neonatal Deaths are higher for Black and Asian mothers. **Judith** also shared data showing that the care Black and Asian women receive is also far from where you would want it to be. Black and Asian women report maternity care that is poorer, for example first contact before 12 weeks is reduced.

Judith explained that pregnancy and baby loss continues to be under researched, and those who experience those outcomes are least likely to be included in any research. There are persistent inequalities. This time last year the NIHR announced first challenge call. Desire to change things differently, bring together a diverse consortium of organisations, funders and researchers working in this space to increase the amount of research, increase evidence base to drive actions to reduce maternity inequalities and improve outcomes for women and babies. The consortium is also focused on developing the next generation of researchers.

Judith explained this is a really important initiative which wants to lead to change to improve outcomes, access to care and experiences of care for ethnic minority groups and those living in deprived areas.

Judith explained that there have been nine successful collaborations appointed to be part of the consortium, UK focus with partners in all nations of the UK.

Joht and **Judith** came into position at the end of October. They have worked with partners to undertake research prioritisation exercise to arrive at themes they want to drive forward. There are five research themes and two cross cutting work streams. Each theme and work streams have dedicated leadership and will have dedicated themes.

Judith explained the five research themes are:

- Access, Experience, Communication – seeking to ensure maternity services are welcoming, easy to navigate and culturally safe.
- Perinatal mental health and social wellbeing - prevent, identify and address perinatal mental illness
- Preconception and intra pregnancy health – aims to embed care and support between pregnancies.
- Maternal and Neonatal Health Risks Prevention and Recovery – Target modify drivers for maternal morbidity
- Intersectionality and tackling systemic racism – anti-racist interventions in community and clinical settings.

Judith explained the two workstreams are:

- Community engagement and co-production – grounded in lived experiences with service user as equal partners in research and governance
- Digital Data monitoring evaluation and implementation science workstream – provide the background

Judith explained that throughout it is important to develop the next generation of researchers and those working in healthcare– skilling up those who work across commissioning groups and health and public care research.

Judith concluded by saying that there are lots of opportunities through the maternity disparities consortium. This is a hugely important initiative which they hope will be supported by many in the room and it will contribute to the change we need.

Joht added that they want everyone in the room to engage and to be in this journey together. This is a value of the consortium. The focus is on tackling disparities, maternity service must be as good as possible but if we keep putting money in in a generic way we won't see the difference in inequalities. We need to do this together as an open consortium.

9. Q&A with panel

Andy opened the floor to questions.

- **Sharon Luca** shared her experience of setting up a charity in memory of her son and that at the time the hospital did not have a cuddle cot and her son went missing for 9 hours. **Sharon's** MP advised her to get in touch with the APPG as it is not possible to take matters relating to child loss to Court via exceptional cases (outside of procedures and guidance). This is usually only possible for cases relating to sexual abuse. **Sharon** asked whether there is

any research into how many parents become chronically ill following pregnancy and baby loss and legal matters.

Joht answered that the consortium is still in early stages planning for the next 5 years. **Joht** works in trauma informed care and highlighted that there is a lack of research and research usually doesn't allow voices to be heard especially when they have been through trauma. Additionally, trauma manifests as psychological and physical symptoms and we need to think about how the healthcare system is structured to hear parents' experiences and how it is linking into physical pain. **Joht** highlighted that sometimes healthcare professionals dismiss things quickly and there are inequalities in this. We don't currently have great research in this area but want to work together to think about it.

Andy highlighted that **Sharon's** MP can also contact Andy directly about this.

- **Zesham Qureshi** is a pediatrician taking a career break studying a PHD in this subject, he asked **Rachel and Gina** and **Mohammed** if it possible for all healthcare professionals to be trained to provide healthcare to all patients, or is it not possible for patients to receive the best quality care if it is not provided by healthcare professionals from the same cultural background?

  Rachel responded that it is clear education is very important and that it is not possible for patients to always be cared for by healthcare professionals from their own background. This is why education and training are so important. If you focus on saving black and minority ethnic babies' lives, then rates of stillbirth and neonatal deaths will reduce across the UK. If funding and focus is spent on bringing down rates, training and education is important as a part of that work.

  Mohammed said that they wouldn't advocate for patients to only be treated by healthcare professionals from the same background. But all healthcare professionals must be competent and aware of what requirements may be for different communities. All bereaved parents grieve differently. Healthcare professionals must explore how families can be supported to grieve culturally sensitively. Decision makers bringing in policies must speak with communities to help them formulate policies. **Mohamed** highlighted that because of inequalities people now are specifically avoiding certain hospitals because they are worried, they can't care for them adequately. **Mohamed** had previously invited the Secretary of State to visit to see this and extended an invite to the staff from BHRUT.

Andy highlighted that this is a forum to build links.

- **Leanne Turner** shared that her background is in education. She approached the local Community Voluntary Service who were promoting inequalities funding. **Leanne** wanted to improve the training they offer on cultural competency but was told the funding was only available for those who were doing face-to-face work with communities. As this training would have been for healthcare professionals they were not eligible. **Leanne** wanted to highlight that education is so important, teachers don't always reflect the students they are teaching but do very well at reflecting the needs of their students, so why can't the same happen in healthcare. Funding needs to be more flexible.

  Mohamed agreed that training needs to be adequately funded to ensure those working with families can access the training they need.

  Andy agreed that funding needs to be more flexible as it has historically been too prescriptive. **Andy** shared that he would like to think going forward funding will respond to need not predetermined outcomes.

As time was running tight, **Andy** asked if the next three questions could be taken together.

- **Angie Rice** introduced herself as a bereaved grandmother and midwife and asked for an update on paediatric pathology.

  Mohamed highlighted significant recruitments issues in paediatric pathology and that it has only recently come into one ministerial area which had meant previously it was difficult to find someone to take ownership of the issues. **Mohamed** highlighted how in Muslim and Jewish communities they do not want to permit invasive postmortems. Whilst there is no legal requirement for postmortem after stillbirth, it is a decision for the family. They are currently working with GOSH to explore options for minimally invasive postmortems.

  Andy highlighted that this would feed into the wider workforce planning tender for the Trust.

- **Ebele Ijomoni** asked if there was research around service users with language barriers.

  Judith shared that this would be looked at in the work on access to care and engagement. This research will be looking across lots of different areas, but baby loss will be included.

- **Helena Morais** asked if there could be better education for women about their risks which would enable them to know what symptoms to watch for and what they need to be aware of.

  Celia highlighted the new initiative they have introduced to screening for pre-eclampsia in the first trimester. There are also ways to explain the risks. Additionally at BHRUT ante-natal education classes are run bi-lingually.

  Celia also shared that they have a Lead on choice and personalisation who delivers mandatory training on the importance of discussing choices and personalisation of care. They also have a midwife who leads a culturally sensitive training update fortnightly.

10. AOB

Katie Davies shared that the Sands and Tommy's Joint Policy Unit Annual Saving Babies' Lives Progress Report will be published next week (week commencing 19th May) calling for new targets including a target to end inequalities in rates of baby deaths. There will be a webinar in June and please do get in touch with the Sands and Tommy's Joint Policy Unit if you would like to attend.

Gillian Weaver wanted to highlight that Monday 19th May will be recognised globally as the World Day of Human Milk Donation and on behalf of the Human Milk Foundation, Hearts Milk Bank and other milk banks nationally and globally pay tribute to the very many bereaved mothers and parents who donate breastmilk to human milk banks in support of preterm and sick babies being cared for on neonatal units and who are in need of human milk. Their generosity and their very precious gift are greatly valued by all who work in milk banks.

Heidi Eldridge highlighted MAMA Academy's wellbeing wallets to **Andy.**

Tessa Munt MP asked if future meetings could be published further in advance.

11. Close

Andy thanked those who attended the meeting and the speakers. **Andy** highlighted that there is a need to collate everything from today to share it with the Secretary of State.

Action: The secretariat to collate recommendations from this meeting, as well as previous meetings, to put together information which can be shared with the Secretary of State.

Andy confirmed that ending inequality is one of the highest points on the agenda across parties and across APPGs.

The Secretariat will be in touch about the next meeting in due course.