

## **Little Heartbeats – Written evidence (PRT0082)**

Little Heartbeats evidence, Little Heartbeats is a small non-profit charitable organisation, led by volunteers who have endured a PPRROM pregnancy. PPRROM stands for Preterm prelabour rupture of membranes. It is also known as when your waters break before 37 weeks of pregnancy.

1. I am sincerely grateful for the opportunity to submit this evidence. Although there are moments when I feel like a broken record, my dedication as a volunteer remains resolute. Over the past 14 years, I have been privileged to support thousands of women in the UK and around the world. This commitment was born out of a profound personal tragedy of the loss of my firstborn baby, Sinead, 14 years ago. In the wake of this devastating event, I made the decision to leave my career as a construction buyer and dedicate myself to raising awareness. Despite struggling with my PTSD, the constant flashbacks, my steadfast belief is that by investing in our work, we can prevent preterm birth and alleviate the emotional toll it takes on women.
2. My name is Ciara Curran and I am a patient advocate and the founder of Little Heartbeats - a patient group for women who have been through, or are going through, PPRROM. Since Little heartbeats was founded nearly 14 years ago it has helped thousands of women both in the UK and internationally. I would like to invite you to truly listen to the stories of women like me who have experienced PPRROM and think about how we can do better for women with this condition.
3. I am the woman who talks about her sleeping baby, I never got the chance to parent her. Nearly 14 years ago, I was pregnant for the first time and my waters broke. The doctor was going to send

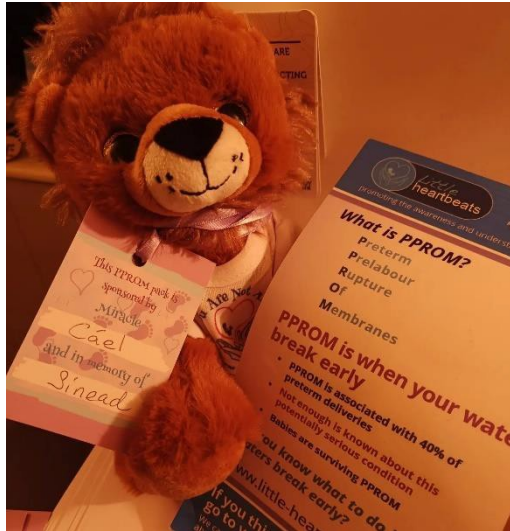
me home, so I fought to be kept in the hospital. But when I got to the maternity ward, I found that there was no protocol for PPRM. As a result, I was not given antibiotics, infection was missed, and I developed sepsis. A week after losing my waters, I birthed and lost my first-born baby Sinead. It was only when I got home that I first saw the term "PPROM" in my medical notes.

4. It was less than 24 weeks when my waters broke, and I was told my baby couldn't survive at that point. It made me feel that I was nobody's priority, I didn't feel listened to by the medical teams caring for me. I tried to raise my concerns after I lost my baby, with the hospital and beyond, which included the Ombudsman and NHS England, but they did not listen or understand PPRM. I vowed to change this by listening to other women. My last words to my daughter Sinead were "we will change things". So, I vowed to myself to take action and that is why I set up Little Heartbeats.
5. We at Little Heartbeats aim to raise awareness of PPRM to reach the women affected by the condition so they know they are not alone and to save babies lives. Through Little Heartbeats, we now know that given the correct medical care, PPRM mothers can bring home healthy babies, even after very early membrane rupture. At Little Heartbeats, we promote informed choice, and support mothers throughout and beyond their PPRM experience.
  - We aim to give women accurate evidence-based information to empower them to understand the condition, the risks and enable them to ask the right questions about their care.
  - We provide PPRM pregnancy care packs, baby loss packs and neonatal packs.
  - We aim to raise awareness among the general public and with healthcare professionals.
  - We advocate for high quality compassionate care.

- We also raise funds for research and collaborate with many research projects.
  - At Little Heartbeats, we not only advocate for informed choices but also provide unwavering support for mothers, guiding them through and beyond their PPRM experiences.
6. I just want to briefly highlight some of our achievements to date, as follows:
- We have raised thousands of funds to help support a study looking at resealing the membranes with University College London, and I am the lay person on the research project.
  - We have taken part in research videos to raise awareness with Dr Tina Chowdhury at Queen Mary University of London and Prof Anna David at UCLH.
  - I had an important role in the University of Liverpool and UK Obstetric Surveillance System PPRM prior to 23 weeks' prospective observational study that has recently been published in BMJ Medicine. I was also the lay person on the study steering committee.
  - We are collaborating with the research team at King's College London to investigate ways to improve patient information and psychological wellbeing of women with PPRM. This has led to two publications so far: one in BJOG "Googling PPRM" and one in the The Journal of Reproductive and Infant Psychology." Preterm premature rupture of the membranes (PPROM): a study of patient experiences and support needs"
  - We helped to reinstate the Royal College of Obstetricians and Gynaecologist (RCOG) Green Top Guideline on the management of PPRM > 24 weeks' gestation
  - Our website details are included in this RCOG PPRM clinical guideline and patient information leaflet. I am the lay author

on the RCOG's upcoming Scientific Impact Paper on PPROM prior to 24 weeks' gestation.

- Our website support page is included as a link on the Belfast NHS. RCOG PPROM patient leaflet.
  - We currently supply our care packages directly to women who apply for care packs via our website. We have also provided care packs to NHS Trusts, such as Warwick Hospital. Although we've received requests from hospitals in Birmingham, Surrey, and various other locations, we're currently unable to fulfil them due to insufficient funds. Our team is actively working to secure funding so we can extend our support to these hospitals as well.
7. In terms of our care packs, the below picture is an example of one. We have had so many positive comments about our care packs - here are just some:



- *"My pack arrived and most of my despair was relieved almost immediately. The pack informed me of what I needed in my care, what to expect in the situation and it gave me enormous hope. The colouring set allowed me to occupy my mind and*

*time on the ward, the teddy bear with my little one's heartbeat gave me comfort at my darkest moments.*

- *Without the pack and the group, I would have lost my hope and my sanity and would not have made it to the gestation I did.*
- *This empowered me for appointments so that I could ask the right questions and challenge anything that I was not happy with. I will always be grateful for the support received..."*

Furthermore, a mum sent me a video of herself with her baby at 1 year old. She gave birth at the later gestation, after she PPRM after 24 weeks. She told us because we sent her the care pack and read the leaflet on cord prolapse. This helped save his life, because she felt prepared and knew what to do, and was also lucky enough to be in hospital, where action could be taken immediately.

8. I have included a video of some of the mothers we have looked after discussing their experiences. This was compiled with their permission, and I would be grateful if you could take the time to watch it. (this is just for the panel to watch and not for the general public)

9. Below is a list of actions that we would like to see achieved, and we believe that your support would help us make this a reality:

- Compassionate care for all women with PPRM.
- That the concerns of women with PPRM are heard.
- That guidelines for PPRM at every stage of pregnancy are in place in every hospital in the UK.
- To raise awareness of PPRM and the effects it has on women and their families.
- To help women with PPRM find Little Heartbeats so they do not feel alone.
- To encourage research into PPRM to work out the best possible care so more women can take their baby's home.
- To ensure all relevant medical staff are informed of the latest evidence.
- To establish the correct time for delivery of women who experience PPRM at all gestations to prevent babies being lost to sepsis, placental abruption and cord prolapse, but also to minimise the long-term harm associated with preterm birth.
- To ensure that women with PPRM are primarily cared for by an obstetrician and gynaecologist, whose main area of expertise is obstetrics.
- For women not to be sent home without clear management plans and support.

10. Academic Papers

- Hall M, Challacombe F, Curran C, Shennan A, Story L. Googling preterm prelabour rupture of the membranes: A

systematic review of patient information available on the internet. BJOG. 2023; 130(11): 1298–1305. <https://doi.org/10.1111/1471-0528.17498>

- L Goodfellow, A Care, C Curran, D Roberts, M.A. Turner, M Knight, Z Alfirevic. Preterm Prelabour Rupture Of Membranes (PPROM) before 23 weeks gestation: A prospective observational study. medRxiv 2023.03.07.23286863; <https://doi.org/10.1101/2023.03.07.23286863>. Published in BMJ Medicine November 2023
- BJOG, Googling preterm prelabour rupture of the membranes: A systematic review of patient information available on the internet <https://doi.org/10.1111/1471-0528.17498> Megan Hall, Fiona Challacombe, Ciara Curran, Andrew Shennan, Lisa Story

The above work has been done as volunteers working with doctors who I have met during my journey of raising PPRM awareness after losing my first-born baby Sinead. It would be incredible to be supported on this, and gain acknowledgement of our work from the Prime minister and the House of Lords.

The committee asked the following topics, and this is our answers,

11. Treatments and interventions that can assist in the prediction and prevention of preterm birth Predication
  - More research on the biomarker prediction tests to ensure they are more accurate, I was on the NICE committee for

this subject, see here: [6 Diagnostics advisory committee members and NICE project team | Biomarker tests to help diagnose preterm labour in women with intact membranes | Guidance | NICE](#)

- Enhance care for pregnant women during the 12 to 24 weeks gestation period.
- Offer fortnight cervical scans to take measurements, for women who have had any treatment to their cervix.

## 12. Prevention

- Implement routine urine laboratory testing (including screening for E. coli).
- Conduct regular laboratory examinations of vaginal discharge (to check for bacterial vaginosis, Group B streptococcus).
- Prioritize the management of bleeding episodes, including subchorionic hematoma (SCH), with increased attention and prompt intervention.

## 13. Treatments

- Offer regular cervical measurements as part of prenatal care.
- Ensure timely and increased availability of cervical stitches/TACs for women in need.
- Offer progesterone pessaries as part of the treatment plan.
- Provide regular cervical measurements as part of prenatal care.
- Offer antibiotics if they are required promptly.
- Offer women a passport into triage if they are experiencing a high risk pregnancy like PPROM, so she does not need to



repeat herself.

Identifying women at high risk presents a challenge. Similar to many first-time expectant mothers, I wasn't categorized as high risk. I was that first time mum who was not deemed high risk, yet I went into preterm birth. It's very concerning that women who have experienced preterm birth and baby loss don't automatically receive scheduled reviews or follow-ups. These appointments are incredibly helpful for women, providing insight into their experiences and aiding in understanding how to potentially prevent future preterm births. I would like to see this as an urgent protocol.

14. Intervention - Invest in research.

- Optimal timing of birth to be discussed with women.
- Antibiotics and steroids given.
- To ensure that all women who have experience preterm birth, including those who have experienced a second trimester loss, are placed in preterm birth clinics to help prevent preterm birth. If all women were cared for between 12 to 24 weeks, we believe many of these women would avoid preterm birth. If infection is caught earlier there is more chance of successful treatment and bleeding can be monitored.

15. Neonatal and longer-term care and support for babies born preterm

- Any woman who suffers with PPRM before 24 weeks should be referred to a level 3 neonatal unit

as soon as she reaches 21 weeks gestation.

- All women should be offered perinatal support and meet the neonatal team, and to have an open-minded plan in place for her birth. Magnesium sulphate. Steroids, antibiotics.
- Women (and if they have a husbands or partner), to be informed of the plan for baby, explain all the drugs that can be offered, nitric oxide for babies with mothers who have endured PPRM before 24 weeks ([Early Use of Inhaled Nitric Oxide in Preterm Infants: Is there a Rationale for Selective Approach? - PMC \(nih.gov\)](#))
- Enhance support for pregnant mothers in planning for their unborn future baby's care, by providing comprehensive information about available treatment options, including the use of nitric oxide for infants born to mothers who experienced PPRM before 24 weeks. A plan for those going home with babies on oxygen
- A plan for mothers who lose a baby, support, and care, including their husbands / partners
- To educate staff of the impact on mothers and fathers because the care for the mother will be different to the needs of a father or partner - see paper on the impact on PPRM
- Women should be offered a review of what happened in their pregnancies. Only a limited number of women are offered this.
- This should be standard protocol for women who lose babies, all departments including their GP's and health visitors, should be informed. This should also be the same for women who endure a preterm birth with surviving babies.

16. Existing clinical guidance relating to preterm birth, and how this is implemented

- The importance of reading the small print can matter in relation to women who PPRM and are told to get to 37 weeks to avoid preterm birth. This is not the case for all women, and we require more research to know the optimal timing of birth
- Listening and understanding a woman's pain and acting on it, especially in ethnic minorities, where it is known that pain symptoms are more likely to be dismissed or disregarded.
- Reward staff with awards for the best units and staff of the week, as this may encourage staff to do work more efficiently.

17. The ethnic and socioeconomic inequalities seen in relation to preterm birth, and how these could be reduced.

Addressing Ethnic Inequalities:

- Cultural Sensitivity: It's imperative to foster cultural competence by educating healthcare providers about different cultures and their specific needs. This includes ensuring that all patient information materials are translated into multiple languages and having trained interpreters available. Considering the potential benefits of translator apps, especially during times of staff shortages or high-stress situations like PPRM, it is recommended to have adequate IT support to integrate such apps into every

treatment room. However, it's acknowledged that not all units currently have this capability, which should be rectified universally.

- **Inclusive Diagnosis:** It's crucial to listen to and understand women from diverse cultural backgrounds, particularly during the diagnosis of conditions like PPRM. Cultural barriers can complicate the diagnostic process, and it's important to ensure that all women, regardless of their cultural background, receive timely and accurate diagnoses and care. PPRM does not discriminate against any culture, and healthcare providers must be equipped to address the unique needs of every patient. (I'm Ulster Irish, I was not heard, PPRM while it risks are high for maternal and baby deaths, because we do not have a PPRM protocol, PPRM does not discriminate regardless of our culture)
- **Awareness of Ehlers-Danlos Syndrome:** Women with Ehlers-Danlos syndrome often face disbelief or dismissal of their symptoms within the healthcare system. This underscores the need for increased awareness and understanding of this condition among healthcare professionals. By acknowledging and validating the experiences of women with Ehlers-Danlos syndrome, healthcare providers can ensure that they receive the appropriate care and support they need.
- **Amidst the COVID-19 pandemic,** many women we cared for were frequently mandated to attend hospitals unaccompanied, and some were even counselled to terminate their pregnancies. The complexities of these situations are significant. It is crucial to promptly reassess protocols for supporting women during such crises, particularly focusing on those who were screened solely for

COVID-19, neglecting potential sepsis screening. This is essential to guarantee comprehensive care and support for all affected individuals.

Socioeconomic inequalities: -

- Having funding in place where women who do not drive, have no one to drive them to hospital, have funding for the use of taxis to enable them to attend hospitals with those women threatening preterm birth.
- Funding support should be provided for travel expenses for mothers and their partners who have babies in NICUs located far from their homes.
- To liaise with hotel chains such as premier inn, to help provide accommodation for mothers and fathers moved in NICU in another town. There are only limited spaces at some units and it is a postcode lottery if they have any accommodation for women and their families. We currently have mothers who are having to spend a fortune with no government support though this crisis.
- Consider having a patient advocate like me, who can help navigate the support the mother requires on special conditions like PPRM.
- Allow nonprofits like Little Heartbeats, to be able to refer women to specialist obstetrician. when they feel they require a second opinion, also a system that allows us to contact health professionals when we are concerned for the physical and mental wellbeing of mothers, currently we are powerless to get women additional support. As the state relies on the women to go to a GP, by this time a woman physical and mental health deteriorates.

- Consider a method where women who do not have childcare, are supported in a way which does not prevent them from coming to hospital, where they are not afraid of being reported to social services for not having childcare.
- Women living rural areas often find themselves miles away from larger maternity units. It's crucial to establish plans and agreements with ambulance services to prioritize transporting women in urgent need, particularly those under 24 weeks gestation. Currently, these women may not be treated as priorities, despite the potential risks of sepsis and maternal mortality. This approach must change to ensure timely access to critical care.

18. Priority areas for research to prevent preterm birth and improve care for mothers and babies.

- Invest into the studies like the resealing of the membranes project, see here, <https://www.ucl.ac.uk/news/2021/aug/new-evidence-foetal-membranes-can-repair-themselves-after-injury> (We have raised thousands for this project)
- Invest in the fluid replacement study – see Devender Robert's amnio infusion paper. [Amnioinfusion in preterm premature rupture of membranes \(AMIPROM\): a randomised controlled trial of amnioinfusion versus expectant management in very early preterm premature rupture of membranes--a pilot study - PubMed \(nih.gov\)](#)
- Better research on the Optimal timing of birth after women experiences PPRM
- Note for delivery, it states on the RCOG clinical paper 73, [Care of Women Presenting with Suspected Preterm Prelabour](#)

[Rupture of Membranes from 24+0 Weeks of Gestation - Thomson - 2019 - BJOG: An International Journal of Obstetrics & Gynaecology - Wiley Online Library](#) in the small print.

“The results and conclusions of the Cochrane review are influenced by those trials assessing ‘late’ PPRM (34<sup>+0</sup> to 36<sup>+6</sup> weeks’ gestation) such as the PPRMPT trial<sup>2</sup> and it is less clear whether expectant management to 37<sup>+0</sup> weeks’ gestation is appropriate for women who experience PPRM at earlier gestations. The Cochrane review acknowledges that research is required to determine which groups of women with PPRM would not benefit from expectant management, including gestational age at presentation”. However, most hospitals and doctors are not reading this part and instead they are informing women they must deliver at 37 weeks. They are not considering they PPRM before 34 weeks. We have lost many babies and especially at the later gestation of women experiencing PPRM between 28-33, and those who PPRM before 24 weeks who then get to 34 weeks. As a group, we have seen far too many babies die between the 33-37 weeks gestation due to their mothers not having individual care and being told of these risks. Women have lost babies within 24 hours of being sent home. There should be an urgent review on this matter. The research for timing of birth was carried out on women who were between 34 to 37 weeks and not women who PPRM before 34 weeks, yet it is coming standard practice to encourage women to term. In the paper release the RCOG did, when the top green paper 73 was published it stated “Babies not delivered at 34 weeks, mothers waters break” see here, [Babies should NOT be delivered before 37 weeks even if their mothers' waters break | Daily Mail Online](#) When we express disappointment in this headline, our voices were not heard clearly. Sadly, this misunderstanding on the optimal timing of birth, has costs babies lives and women have been in ICU due to this

misunderstanding of the optimal timing of birth. In our PPROM women's cases, they should be holding their babies, baby Rory and Ava should be in the arms of their mothers, instead they never got to come home due to the lack of understanding and training on PPROM. (One of Little Heartbeats goal's is to deliver this training with doctors, however due to a lack of money and lack of support from the government it will be a while before we can achieve this. This is one of the many reasons why we wanted an inquiry into PPROM in pregnancy, but this was turned down)

- Conduct research to optimize the utilization of urine testing methods (such as dipstick and laboratory testing) for detecting urinary tract infections in women experiencing PPROM. Prompt treatment of urinary tract infections with appropriate antibiotics has the potential to prevent preterm birth. Current Dipsticks have missed e-coli urine infections.
- Improve the link between maternity electronic patient notes and neonatal electronic patient notes (Badgernet), so that the neonatal and childhood outcomes of babies that have experiences PPROM can be appropriately investigated.
- Invest in a UKOSS survey, to see what is happening to women who PPROM over 24 weeks, and see what the outcomes are for women and their babies.
- Conduct research to understand the underlying causes of maternal deaths among women who have experienced PPROM, particularly focusing on why some develop sepsis and how these fatalities can be prevented. Additionally, investigate strategies to avoid severe illness among mothers at later gestational stages, who PPROM at the earlier gestation.



- Redress system to learn from cases which lead to loss of a baby or avoidable disability, we are not learning from the lawsuits; we must do better.
- How best to support mothers' mental health during and after PPROM/preterm birth
- Research into how to best care for women who experience PPROM under 24 weeks' gestation using existing care (including when to give antibiotics, when to trigger birth, optimal mode of birth, how to best communicate options after PPROM)
- Learn how best to support women and families who opt for termination for medical reasons after early PPROM- including method of termination/ medications and care during termination. (Note from UKOSS early PPROM these women had a 10% chance of sepsis and a 20% chance of surgery for removal of placental tissue)
- Learn more about placenta abruption after women experience PPROM, and learn when enough bleeding is enough to avoid full placenta abruption, currently there is no patient leaflets on this topic. The PPROM guidelines, do not cover the signs for this. We believe a patient leaflet on placenta abruption is needed.

Australia Antepartum Haemorrhage clinical guideline [King Edward Memorial Hospital - Obstetrics and Gynaecology Guidelines \(health.wa.gov.au\)](http://www.health.wa.gov.au/king-edward-memorial-hospital-obstetrics-and-gynaecology-guidelines)

UK clinical guideline [Antepartum Haemorrhage \(Green-top Guideline No. 63\) | RCOG](http://www.rcog.org.uk/guidelines/guideline.aspx?guidelineid=63)

- Cord prolapse why does this happen after PPROM, and which women are more at risk to this.
- Retained placenta, how best is this managed and can we

research if this can be avoided

- Research on Nitric Oxide for PPRM babies born prematurely, to see if the 44% of babies who were born alive via UKOSS study can all come home, as 26 % survived, can we research an intervention for this, targeting this subset may be beneficial in future trials of iNO.
  - [Early Use of Inhaled Nitric Oxide in Preterm Infants: Is there a Rationale for Selective Approach? - PMC \(nih.gov\)](#)
  - [Association between immediate oxygenation response and survival in preterm infants receiving rescue inhaled nitric oxide therapy for hypoxemia from pulmonary hypertension: A systematic review and meta-analysis - PubMed \(nih.gov\)](#)
  - Timing of giving Nitric oxide other treatments to give PPRM babies a better chance of survival, if we gave this soon after birth, has this helped and how many surviving babies received this. See above point.
19. We believe in awareness of all conditions which is associated with preterm birth, we used to have a book given to us when we fell pregnant, this was stopped. If we could have this book brought back to publication and have posters of awareness of complications which causes preterm birth, PPRM is a condition that impacts 18,000 women in the England and Wales alone (excludes Scotland) Northern Ireland provide this on a website, [The Pregnancy Book | HSC Public Health Agency \(hscni.net\)](#) it does not talk about PPRM or the complications which may happen. They talk about the risks of smoking but not complications of pregnancy conditions.
20. Awareness alone educates women about certain conditions and if women go to hospital as soon as they feel a gush or a leak, then

interventions and management can be put in place. A simple urine infection treated could prevent a woman from going into preterm birth, A woman with SCH bleeding, could be monitored and offered progesterone pessary / baby aspirin and put under obstetrician care, could make a difference to her mental wellbeing, and may just avoid preterm birth. I would appreciate if our website could be included with the list of other non-profit charitable causes, as you can see from the stories of the women we have helped, it really is a life saver support group. Link is here, [www.little-heartbeats.org.uk](http://www.little-heartbeats.org.uk)

21. Investing in specialised PPROM clinics, such as the one being established by Dr. L Story and Dr. M Hall at Kings College, could significantly benefit women facing this condition in the future. This investment would ensure that women receive care from doctors who are highly knowledgeable about PPROM and help empower women to make informed decisions about their healthcare. It would be particularly impactful to see similar clinics established in the North of England, like at Liverpool Women's Hospital, where doctors like Dr. L Goodfellow and Dr. A Care have conducted extensive research on this topic through the UKOSS study. This initiative is crucial for significantly improving the safety and well-being of women experiencing PPROM during pregnancy, especially considering the UKOSS study's confirmation of two maternal deaths. These efforts should be seen as essential measures for women's care, not optional.
22. Further to the above, more questions arise, other research required, we feel is important as follows: -
  - Antibiotics for all gestations – study into the best suited antibiotics for PPROM and when, regardless of gestation, when do this mask sepsis or can it avoid sepsis.
  - Placenta abruption and understanding it and its role in PPROM.

- SCH (subchorionic haematoma), what is the impact of these in PPRM, could the source of the SCH be detected and can anything be done to avoid it leading to PPRM.
- Infection, what are the bugs which are the ones for the concerns, which UTI (urinary tract infection) and discharge infections can be treated without risk to mum and baby. Why are the dipsticks missing picking up e-coli.
- Sepsis study, which women are more at risk to this, can it be avoided regardless of choices after PPRM occurs.
- In a new pregnancy after PPRM, who is at risk of all the complications.
- Fluid levels – chart needed in both ways to measure the fluids and having research to follow women in their pregnancies after PPRM if they chose to continue their pregnancy and does it make a difference in survival.
- Cord prolapse why does this happen after PPRM, and which women are more at risk

23. When addressing sex-based language in the House of Lords, I emphasised the importance of recognising the distinct experiences of women, particularly in maternal care. Our focus on saving babies' lives should not overshadow the well-being of pregnant women, as evidenced by the unfortunate deaths of two women in our study. Parenthood and infant care entail unique experiences for mothers and fathers, necessitating accurate sex disaggregation in research to ensure reliable findings. It's concerning that some researchers prefer the term "pregnant people" over "women," despite maintaining clarity in men's health discussions. This blurring of sex and gender undermines effective support for everyone and allocation of resources.

24. In terms of data collection, multiple ethnic teams have urged me to employ inclusive language. Each time, I've had to clarify why certain language choices are not appropriate. It's important to adhere to keep to the government "women's health strategy" regarding sex-based language and data collection to comprehend the factors contributing to preterm birth among women. Ensuring inclusivity by using the term "woman" is crucial for effective research in this area. Otherwise, we will not reduce preterm birth for women. (See <https://www.frontiersin.org/articles/10.3389/fgwh.2022.818856/full>)

I think it is vital that there should be a dedicated inquiry into sex-based language erasure, because there hasn't been enough consideration of its impact on the health of women and girls, or how distressing it can be for women. This topic merits deeper exploration and discussion).

25. I would like to highlight to the Lords, that unfortunately, Parliament MPs Jeremy Hunt and MP Theo Clarke rejected Little Heartbeats for inquiries into PPRM and birth trauma.

I was informed they did not feel PPRM needed an inquiry into PPRM, and because I had taken part in this preterm birth inquiry, we not thought to be important enough to be at the AGGP Birth trauma inquiry. I do not understand how you can improve care if we are selective on who gains a voice. Does complications of pregnancy such as PPRM not matter. It is now April, since I did my presentation at the APPG baby loss in Jan 2024, no MP who was at this meeting, has written back with a follow up meeting, My MP Robert Langan team still has not highlighted to the Prime Minister of our work. I am losing faith in parliament that anyone cares about our work and are not understanding the devastation left on our women and their families who endure this condition.

This was deeply disappointing for us, as we feel our voices aren't being heard to improve care for women like us. Personally, I've struggled with PTSD and depression from my birth experience, and it's distressing to see the women we mentor not receiving proper care. We hold an awareness month in September, I would appreciate it, if the Lords can help increased our voices.

26. We hope the Lords can take on board our evidence and take team Little Heartbeats more seriously, and the preterm birth inquiry team listens and take on board our comments and would kindly ask if the Lords could kindly scrutinise why the MP's are not taking our cause seriously enough and turned down from the other inquires just because we have been included in this preterm birth inquiry.
27. We've dedicated 14 years of our lives to this work. We are thankful for your patience on receiving our evidence. It is somewhat very emotional. I lost my baby on the 15th April, It be 14 years since my life was turned upside down. I feel greatly that our work is still not be recognised by this government and we are failing women by not listening to our grave concerns, meanwhile we are mentoring women in a system that has no protocols for PPRM and does not listen to improve care we must first listen, then action, and work with Little Heartbeats.
28. By providing our care packs, we have proven babies can survive PPRM and it has helped women to make informed choices and help them navigate their care, these are only a few of the thousands of women we have helped.
29. I've included testimonials and stories from the mothers we've assisted because firsthand accounts are incredibly impactful. PPRM is often misunderstood, so it's crucial to share their experiences to provide insight. Permission has been granted to use their details and names. When inquiries arise about preterm birth,

I want to ensure their voices are heard. It's essential that small non-profit charitable organisations like ours are given attention. Our team has played a significant role in saving babies' lives.

30. As a woman who volunteers her time to women who are threatening preterm birth, I have shown that even with little funding, lives can be saved. I hope you can join in saying thank you to the volunteers of Little Heartbeats, I hope one day our work is acknowledged and recognised by this House of Lords and houses of parliament.

*9 April 2024*