IN THE UK COVID-19 INQUIRY
MODULE 3

SUBMISSIONS ON BEHALF OF THE
PREGNANCY, PARENTING AND BABY ORGANISATIONS
FOR THE SECOND PRELIMINARY HEARING ON 27th SEPTEMBER 2023

A. INTRODUCTION

1. These submissions are made on behalf of 13 Pregnancy, Baby and Parent Organisations ('**the PBPOs'**). The PBPOs were collectively designated as a Core Participant ('**CP'**) for Module 3 of the Inquiry on 17th January 2023.

2. The PBPOs are (1) Aching Arms, (2) Baby Lifeline, (3) Bliss, (4) The Ectopic Pregnancy Trust, (5) Group B Strep Support, (6) ICP Support, (7) The Lullaby Trust, (8) The Miscarriage Association, (9) National Childbirth Trust, (10) Pelvic Partnership, (11) Pregnancy Sickness Support, (12) Tommy's and (13), Twins Trust. A detailed introduction to each of the PBPOs can be found in the PBPOs' submissions for the First Preliminary Hearing.[1]

3. The PBPOs are grateful to Counsel to the Inquiry ('**CTI**') for the helpful Note dated 29th August 2023, together with the Annexes. The PBPOs have some brief observations which are set out below.

B. SUBMISSIONS

(i) Non-Covid Conditions

4. The PBPOs are grateful to CTI for confirming at para. 21 of their Note that, in addition to the four identified non-Covid conditions to be examined in more detail, the Inquiry will also examine

[1] See: https://covid19.public-inquiry.uk/wp-content/uploads/2023/05/2023-02-21-13-Pregnancy-Baby-and-Parent-Organisations-Submissions-for-Module-3.pdf

"maternity and antenatal care including matters such as:

a. *the ability to maintain ante-natal care such as screening, scans and other appointments;*
b. *the use of technology to access maternity care and services;*
c. *the availability of staff and resources needed to provide maternity care;*
d. *guidance or advice for pregnant women; and*
e. *visitor restrictions."*

5. This reflects the Provisional List of Issues for Module 3 as follows:
   a. at para. 5cii: *"The impact of the pandemic on access to antenatal and postnatal care including impacts on the quality of maternity care and services."*
   b. at para. 8c: *"Visiting – (i) How visiting guidelines were created and updated during the pandemic; (ii) How potential negative effects of visitor restrictions to patient and staff well-being were weighed up against their intended effects, such as for infection prevention; (iii) whether the visiting guidance followed the scientific understanding of how the virus was transmitted and the risks of infection as the pandemic progressed".*

6. The PBPOs have extensive experience in these areas, from a range of perspectives, and are keen to offer the benefit of their expertise to assist in the Inquiry's ongoing distillation of these issues. The PBPOs acknowledge that the Provisional List of Issues and the examples included at para. 21a-e of CTI's Note are not exhaustive. In that light, the PBPOs make the following comments:

7. First, and overall, the PBPOs submit that the phrases *"maternity and antenatal care"* (para. 21 of CTI's Note) and *"antenatal and postnatal care"* (Provisional List of Issues) are too narrow. That language does not capture the range of issues which faced pregnant women and people in the healthcare system during their pregnancies, birth and post-birth care as a result of Covid-19, nor those experienced by non-birthing parents and babies (as highlighted in the draft Rule 9 evidence that will shortly be provided to the Inquiry for the PBPOs). For example, The Ectopic Pregnancy Trust and The Miscarriage Association both support women and pregnant people who suffer ectopic pregnancies, usually before 12 weeks' gestation, and whose care is through specialist early pregnancy units, rather than in maternity care; The Miscarriage Association also support those experiencing miscarriage

and molar pregnancy and also outside of maternity care; and Bliss supports babies born needing neonatal care, which is distinct from maternity care both in terms of its patient population and how it is commissioned and run.

8. Accordingly, the PBPOs submit that the following broader phrase should be used in the List of Issues at para 5(c)(ii): *"early pregnancy, pregnancy, maternity, antenatal, neonatal and postnatal care"*. It is also key that postnatal care is properly understood as extending beyond the hospital and into the community; it is typically understood to mean a minimum of six weeks' post-birth care. The PBPOs submit that it would be beneficial if the Inquiry clarified the intended scope of para. 5(c)(ii) in the List of Issues.

9. Second, the PBPOs submit that, in respect of the issues that the Inquiry has already indicated it will investigate, the Inquiry would also benefit from considering additional aspects of care, as follows:

   a. The matters set out in paragraph 21(a)-(c) of CTI's Note should all be expanded to include (beyond antenatal and maternity care) early pregnancy, neonatal and post-natal care, for the reason set out above;

   b. The reference to guidance or advice for pregnant women in para. 21(d) of CTI's Note should be expanded to also include "*pregnant people and new parents*", for reasons of inclusivity;

   c. While the PBPOs understand CTI's rationale for using the catch-all phrase *"visitor restrictions"* in para. 21(e) of the Note, in the context of maternity care, they submit that birthing partners of any kind (partners/mothers/friends) are much more than a mere *"visitor"*, and in fact are an essential part of the care-giving team for the pregnant woman or birthing person. In the PBPOs' experience, birthing partners provide essential care, such as helping to monitor the person giving birth, providing them with food and water, helping them to go to the toilet, etc. Family members and supporters who attend outpatient care or partners of women and people experiencing pregnancy loss at any stage of pregnancy are not simply visitors. Nor are non-birthing parents and carers in the context of neonatal care: they are primary caregivers, whose involvement in care delivery and decision-making is crucial to babies' short and long-term developmental

outcomes, as well as supporting good attachment and bonding. It is important that none of these categories are viewed as an optional extra, whose presence is only to keep the pregnant or birthing person company. The PBPOs therefore propose that the following phrase is used: *"Restrictions on visitors and other people supporting an individual's care"*.

10. Third, the PBPOs submit that there are other issues which the Inquiry should fully investigate under the umbrella of maternity and antenatal care (assuming this phrase is interpreted widely, as suggested). While the PBPOs recognise that not all relevant issues and areas of investigation will be able to be highlighted in the List of Issues, they submit that the following are matters of importance for the Inquiry to consider in due course:

    a. Guidance and care for neonatal babies and their families;
    b. Provision and use of PPE in relation to babies and their families;
    c. Access to bereavement care services for losses at all stages of pregnancy, including mental health care;
    d. Access to treatment for women and pregnant people experiencing pregnancy complications and loss; and
    e. Maternal deaths from Covid-19.

(ii) Expert evidence

11. In relation to para. 29 of CTI's Note, the PBPOs note that the Inquiry has identified a number of potential experts to provide evidence in relation to the *"non-Covid conditions"*. It is unclear whether this will include an expert or experts to provide evidence in relation to antenatal, intrapartum and postnatal care during the pandemic.

12. The PBPOs submit that such an expert should be instructed by the Inquiry and propose two potential experts below.

13. First, **Professor Marian Knight**[2]. Professor Knight's research focuses on the care and prevention of severe complications of pregnancy and early life and addressing disparities in outcomes for women and babies from different population groups. The PBPOs anticipate

[2] Profile available at: https://www.npeu.ox.ac.uk/about/people/marian-knight-629

that her evidence would be of assistance to the Inquiry in considering maternity and antenatal care alongside the other four non-Covid conditions as a specific area of focus. In particular, Professor Knight leads efforts (co-ordinated by the National Perinatal Epidemiology Unit) via Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK **('MBRRACE-UK')** to conduct an annual investigation into the deaths of women during pregnancy, childbirth and the year after birth.

14. In particular, MBRRACE-UK, under Professor Knight, carried out important research and produced reports into maternal deaths during the relevant period for the Inquiry. The Confidential Enquiries into Maternal Deaths and Morbidity 2018-2020 Report[3], published in November 2022, covered one year of the pandemic and included (for example) details of avoidable ectopic pregnancy deaths during that time. Professor Knight will therefore be well-placed to assist the Inquiry with the impact of service changes on maternal health and care during this period and to place that in recent context. MBRRACE-UK also issued rapid reports on Covid-19 and associated maternal deaths in the UK including close reviews of the care provided during that period. The PBPOs anticipate that Professor Knight would add an academic, comparative perspective to the Inquiry's investigation of the matters in para 5(c)(iii) of the List of Issues, beyond the organisations identified at para 22 of CTI's Note.

15. Second, the PBPOs also submit that **Dr Helen Mactier** could offer useful expert evidence. Dr Mactier is a recently retired neonatologist based in Scotland who was President of the British Association of Perinatal Medicine (BAPM) during the pandemic (2019 – 2022). She has authored studies on the effect of Covid-19 on neonatal outcomes in the UK[4] and would be able to provide valuable insight into best practice in neonatal services, as well as evidence of BAPM's engagement with those services and the process of developing and implementing relevant guidance during the relevant period for the Inquiry. She may also be able to assist the Inquiry with a comparative perspective between Scotland and other devolved nations.

[3] This report is provided as an Annex to the draft Rule 9 evidence of the PBPOs, but can also be found at: https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2022/MBRRACE-UK_Maternal_MAIN_Report_2022_UPDATE.pdf

[4] See examples of her research at: https://eprints.gla.ac.uk/295026/

(iii) Key Lines of Enquiry for Every Story Matters

16. The PBPOs have considered the Overview of Module 3 Key Lines of Enquiry for Every Story Matters and make the following submissions:

17. The categories are evidently broadly drawn to cover a wide range of potentially affected persons. As above, in all categories identified, the PBPOs consider it will be important to ensure Every Story Matters draws out the experience of the wide range of people who needed to access early pregnancy, pregnancy, maternity, antenatal, neonatal and post-natal care during the relevant period.

18. In respect of bereavement, the PBPOs consider that it would be appropriate to add:

    a. A sub-paragraph addressing the "*Experiences of accessing bereavement support and the availability of bereavement support including mental health care*"
    b. Under the second bullet-point, a sub-paragraph addressing the "*Experiences of family members who were unable to be involved in decision-making and communication around end-of-life care or disposal of pregnancy remains*". This reflects the experience of PBPO members and constituents who were sometimes prevented from being at crucial discussions due to visitor restriction rules.

C. CONCLUSION

19. The PBPOs intend to make oral submissions at the Second Preliminary Hearing on 27th September 2023 and are available to discuss any issues arising from these submissions prior to the hearing if that would be of assistance.

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